THE UNIVERSITY OF HULL

The experience of resilience in older people living with chronic illness

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

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June 2016
Acknowledgements

I would like to dedicate this thesis to the people who gave their time to participate in this research. Thank you for welcoming me into your homes and openly sharing your stories with me.

I am grateful to the staff at the many dementia support groups that I have visited. Thank you for being so helpful and encouraging, and thank you for seeing the value in this research.

I would particularly like to thank my research supervisors, Dr Emma Wolverson and Dr Chris Clarke, for helping me to consider an alternative story of ageing and ageing with dementia. You have believed in this research from the start, and have remained enthusiastic and supportive throughout the process. I am so grateful for the kindness and compassion that you have shown me. Thanks also to Dr Tim Alexander for preparing me for the highs and lows of conducting research and for helping me to gain confidence as a researcher.

Finally, I would like to thank my partner, close friends and family for their unconditional support throughout this journey. Particular thanks to Sarah and my fellow trainees for keeping me going. The most special thank you goes to my Mum, for teaching me about resilience a long time before I learnt the word for it.
A. Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical paper and a set of appendices.

Part one is a systematic literature review which synthesises the published qualitative literature investigating resilience in older people living with chronic illness. The review aims to explore the role that resilience plays in ageing with a chronic physical illness, and how resilience is experienced by this group of people. The synthesis resulted in eight sub-themes subsumed under three super-ordinate themes. Super-ordinate themes are ‘the resilient mindset’, ‘engaging with others’ and ‘continuity in life’. The strength of the empirical evidence is evaluated, and findings are discussed in terms of their implications for future research and clinical practice.

Part two is an empirical paper investigating narratives of resilience in older people who are living with a diagnosis of dementia. This qualitative study utilised a narrative approach to collect and analyse stories from eight older people around how they have responded to changes and challenges since receiving their dementia diagnosis. The stories contained a number of phases, and resilience emerged as an on-going process stimulated by people’s sense of identity, agency, connection and positive outlook on life. Clinical and research implications are discussed.

Part three consists of a set of appendices which relate to both the systematic literature review and the empirical paper. This also includes a reflective account of the research process and an epistemological statement.

Research portfolio total word count (excluding references): 27,377
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Part 1: Systematic Literature Review
Part 1: Systematic Literature Review

The experience of resilience in older people living with chronic illness: A systematic review of the qualitative literature

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This paper is written in the format for submission to International Psychogeriatrics.
See Appendix A for the Guidelines for Authors.

Total word count: 8051 (excluding references)
Journal word limit: N/A
Abstract

**Background:** There is evidence that resilience in later life is associated with positive outcomes, enabling people to overcome aging-related challenges, such as the increased likelihood of illness. However, there is debate around how resilience should be conceptualised. This review aimed to synthesise qualitative research findings that investigate older people’s subjective experiences of resilience in living with chronic illness.

**Method:** A systematic literature search was conducted across five electronic databases to identify studies. Included studies were subject to a methodological quality appraisal to assess the overall strength of the body of literature. A thematic synthesis was conducted across study findings.

**Results:** Fourteen studies were reviewed. Three higher-order themes were identified, each consisting of multiple sub-themes. The first higher-order theme was a resilient mindset, associated with a strong sense of personal agency, perseverance, a positive outlook and an ability to evaluate health through a wider lens than chronic illness. The second higher-order theme related to remaining engaged with others, highlighting the importance of mutual support. The third higher-order theme related to experiencing continuity in life, associated with spirituality and a stable sense of identity.

**Conclusions:** The review provides insight into the experience and role of resilience in older people living with chronic illness. Resilience emerged as a multi-dimensional concept, consisting of internal and external factors which interact fluidly to enable older people to live well with chronic illness.
Key words: Aging, Chronic illness, Experience, Resilience, Review, Qualitative,

Running title: Reviewing resilience in aging with chronic illness

Introduction

People across the world are experiencing increases in life expectancy (National Institute on Aging, 2011), meaning that more people are living for longer with chronic physical illnesses (World Health Organization; WHO, 2015). The majority of older people can expect to live with at least one chronic illness, with many experiencing multiple chronic conditions (WHO, 2015). Chronic illnesses have been defined as long-term conditions that can be treated through a variety of interventions, but not cured (Health Service Executive, 2008), thus the economic costs of chronic illness worldwide are profound. The 2015 WHO ‘World Report on Ageing and Health’ suggests that the management of chronic illness cannot purely focus on the biological processes of disease, emphasising the importance of developing interventions to help people become better at self-managing their illness (WHO, 2005), thus allowing people to enjoy an increased quality of life as well as an increased quantity (Lowe and McBride-Henry, 2012). Accordingly, the report also draws upon the concept of resilience, arguing that a key aim for older people living with chronic illnesses should be to build and maintain resilience, which will enable them to live well and thrive despite possible challenging circumstances. Resilience has been proposed as a useful alternative to existing models of successful aging (Harris, 2008; Wiles et al., 2012) which have defined success more narrowly as the absence of disease, disability and cognitive impairment (e.g. Rowe and Khan, 1997). Contrastingly, the concept of resilience enables us to acknowledge the reality that
many older people will live with a degree of disability or disease (Romo et al., 2012) whilst allowing us to take into account the wider strengths that people may have accrued over their lifespan which help them to adapt to any challenges which living with an illness may present.

There is debate surrounding the concept of resilience, with disagreement in the literature around how it should be defined, measured, and how it can be achieved (Purves et al., 2011). Resilience is commonly defined as a “process of successfully adapting” to stressful life events (Trivedi et al., 2011, p181). This definition has been interpreted in multiple ways, with some researchers viewing resilience as a ‘buffer’ against adversity, which enables people to maintain levels of physical and emotional functioning despite experiencing adversity (e.g. Ong et al., 2009). In contrast, others have viewed resilience as an ability to ‘bounce back’ after adversity to regain a previous level of functioning (e.g. Netuveli et al., 2008, p958).

Research exploring resilience has predominantly been conducted with children (Manning, 2014) from a developmental perspective (Luthar et al., 2000), with many researchers conceptualising it as an inherent internal trait which develops early in life (e.g. Garmezy, 1993). However, resilience has more recently been conceptualised as a process which can be developed at any life stage (Luthar et al., 2000), promoting research exploring resilience within the context of aging (Perkins, 2014). Within this literature, resilience has predominantly been viewed as a multi-dimensional concept, with Bergeman and Wallace’s (1999) model of resilience suggesting that it can be developed through a variety of internal factors (control, hardiness and self-concept) and external resources (family and community support), which together influence older peoples’ stress levels, coping, and ultimately their health outcomes (e.g. how they manage chronic illness). Resilience in later life has been linked to a number of
positive outcomes, including improved quality of life, higher sense of coherence, higher sense of purpose in life and increased self-transcendence (Netuveli and Blane, 2008; Nygren et al., 2005). It has also been suggested that resilience helps people to maintain levels of wellbeing and satisfaction in aging, despite the high number of losses they may encounter at this life stage (Jopp and Rott, 2006). In line with this, resilience appears to play an important protective role in later life (Staudinger et al., 2001).

Despite the aforementioned positive outcomes associated with resilience, little is known about the process through which resilience fosters such outcomes in relation to living with chronic illness in later life. The purpose of this review, therefore, was to conduct a systematic review and thematic synthesis of qualitative research that has investigated the subjective experience of resilience in older people living with chronic physical illnesses. The overarching questions that this review aimed to answer were:

1. How do older people living with chronic illnesses experience resilience?

2. What role does resilience play in the experience of living with a chronic illness?

3. Are there commonalities and divergences in how resilience is experienced in the context of later life and chronic illness?

**Method**

**Search strategy**

A systematic search of the literature was conducted across five electronic databases; CINAHL Complete, PsycARTICLES, Medline, Academic Search Premier and PsycINFO. These databases were chosen to enhance the breadth of the search, as it was considered that the topic being reviewed may have been researched across multiple disciplines. Further data was sought through relevant author contact and
hand searching the references of included studies. The final search was conducted in May 2016.

The search strategy consisted of four components designed to capture the key terms relevant to this review. These were; the (1) experience of (2) resilience in (3) older people with (4) chronic physical illness. Additional search terms were included for each component through a process of exploring relevant synonyms and examining abstracts from retrieved papers to find alternative words used for each component (see below). Component (4) initially included a variety of specific words relating to common chronic illnesses (e.g. pain, arthritis, cancer) but a final decision was made to keep this component broader (e.g. physical, ill*, health*) to reduce the risk of missing relevant papers that may have focussed on less prevalent chronic illnesses.

Components (1) and (4) had to be present in the Abstract of papers and component (3) had to be present in the Title of papers. This decision was made as part of an iterative approach to study selection, with the aim of obtaining a manageable dataset with increased relevance to the review topic. The limiter of ‘English Language’ was also applied prior to the search.

The final search string was:

1. (Abstract) Experience* OR Perspective* OR View* OR Thought* OR Opinion* OR Attitude* OR Philosoph*

   **AND**

2. Resilien* OR Bounc*

   **AND**

3. (Title) Old* OR Aged OR Aging OR Ageing OR Geriatric OR “Late Life” OR “Later Life” OR Elder*
**AND**

(4) *(Abstract)* Health* OR Ill* OR Physical OR Chronic OR Disease*

**Inclusion Strategy**

Papers were included if they met each of the following inclusion criteria;

- The study was published in a peer-reviewed journal, as an indicator of scientific rigor
- The study was written in English
- The study was a piece of empirical research (i.e. not a review article, commentary or book chapter)
- The study clearly explored the subjective lived experience of participants, as evidenced by the use of qualitative methodology which elicited first-hand accounts and direct participant quotations
- The study had a stated aim related to the concept of resilience or the results reported at least one theme or sub-theme titled ‘resilience’
- Participants were all living with at least one chronic illness (defined as a long-term condition which can be treated but not cured; Health Service Executive, 2008)
- Participants had a mean age of 60 years or older (although somewhat arbitrary, 60 years of age is a generally accepted cut-off for referring to the older population; WHO, 2016)

Papers were excluded if they met the following exclusion criterion;
• Participants were at the end of life: The dying process can include psychological, social and/or spiritual crises (Nakashima, 2007) and so may be associated with unique processes of resilience and warrant separate study to people living with long-term conditions who are not yet experiencing these final stages of life.

Quality assessment

There is debate around how best to assess the quality of qualitative research (Dixon-Woods et al., 2004), with various quality checklists available. The quality of research included in this review was assessed according to the quality appraisal checklist for qualitative research, as provided by the National Institute for Health and Care Excellence (NICE; 2012). This tool was chosen as it can be used to assess a variety of qualitative research methodologies and incorporates elements of previous checklists from a variety of sources, including the Public Health Resource Unit and the British Sociological Association (NICE, 2012).

The quality assessment was completed by the first author (SB) for each included paper. A sub-set of 4 papers were independently evaluated by a peer researcher to assess inter-rater reliability, enabling levels of agreement to be calculated and reported. If ratings differed, the first author re-read the relevant section(s) of the paper, compared each rater’s rationale for their quality rating, and used this information to make a final decision. Papers were not excluded on the basis of their quality ratings as the review aimed to consider the overall strength of the findings in terms of the methodological quality of the body of literature as a whole. Therefore, the quality assessment process was utilised as an opportunity to critique methodologies of included papers to enable consideration of the overall impact of the research evidence.
Data synthesis

Data was synthesised based upon the method of ‘thematic synthesis’ described by Thomas and Harden (2008). This method allows for the integration of findings from studies utilising different qualitative methodologies. Data synthesis was an iterative, inductive process which involved moving between analysing the data as a whole, and analysing the specific details within that whole (Zimmer, 2006). The process was underpinned by three overlapping stages:

- A detailed reading and re-reading of relevant study findings to enable line by line coding of findings. This analysis of the finer details led to the identification of common themes (i.e. ‘codes’).
- Development of broader descriptive themes through the re-interpretation and synthesis of these codes alongside direct participant quotations and original author interpretations, hence remaining close to each study’s original findings. This was firstly completed within each individual study and subsequently completed across studies to develop descriptive themes across the body of literature as a whole.
- Generation of analytical ‘higher-order’ themes, which involved a higher level of interpretation through examining descriptive themes in terms of the underlying aims and questions of the review (i.e. the subjective experience and role of resilience in older people with chronic illness). Following this, the first author was able to re-consider the descriptive themes and develop sub-themes relating to the higher-order analytical themes.

An example of the data analysis process can be found in Appendix B.
Results

Identification of studies

A total of 604 papers were found through the electronic database search. The process of selecting relevant studies from this dataset is outlined in Figure 1. The process culminated in a total of 14 papers being included for review. A reference search of the included papers found no additional relevant studies.
Search Terms

1. *Abstract*: (Experience* OR Perspective* OR View* OR Thought* OR Opinion* OR Attitude* OR Philosoph*) AND
2. (Resilien* OR Bounc*) AND
3. *Title*: (Old* OR Aged OR Aging OR Ageing OR Geriatric OR “Late Life” OR “Later Life” OR Elder*) AND
4. *Abstract*: (Health* OR Ill* OR Physical OR chronic OR disease*)

**Figure 1. Search Results**
Characteristics of included studies

A detailed overview of the characteristics of included studies can be found in Table 1. Most studies drew samples from a variety of Westernised countries, with half of the studies being conducted in the USA (N=7), four studies being conducted in Europe (Slovenia, Sweden, Norway and the U.K), one study from Australia, and one study from Canada. There was also one study from the Philippines.

Nine studies had aimed to explore the concept of resilience from the outset, whilst five studies had held broader aims of exploring illness experiences and wider health behaviours, with resilience arising serendipitously as a theme or sub-theme (Becker and Newsom, 2005; Harper et al., 2014; Hopp et al., 2012; Pentz, 2005; Ploughman et al., 2012). Within this latter set of studies, this review focussed purely on findings which related to resilience.

The total number of participants included across studies was 272, with sample sizes ranging from 2 (Harris, 2008) to 38 (Becker and Newsom, 2005). Most participants were recruited from the community (N=219), with the others being recruited from inpatient care facilities (Guzman et al., 2012; Haug et al., 2015; Browne-Yung et al., 2015). Participants mean ages, where stated, ranged from 66 years old (Harris, 2008) to 92 years old (Browne-Yung et al., 2015). Studies included participants with a wide variety of chronic health conditions, including cancer, osteoporosis, arthritis, stroke, and hypertension, and many participants lived with multiple chronic conditions (see Table 1).

All studies employed individual semi-structured or guided interviews as a method of collecting their data, with 6 studies employing additional data collection techniques, such as follow-up questionnaires and focus groups, to enable the subsequent analysis of multiple types of data. Various methods of data analysis were utilised across studies, with some studies conducting multiple analyses. Methods of analysis were described in varying levels of
detail across studies and included narrative analysis (N=2), content analysis (N=3), constant comparative methodology (N=1), grounded theory (N=3), phenomenology (N=1), case study analysis within a person-centred framework (N=1), framework analysis (N=2), and thematic analysis (N=4).
Table 1. Characteristics of included studies

<table>
<thead>
<tr>
<th>Source</th>
<th>Setting</th>
<th>Participant Health Condition(s)</th>
<th>Participant Characteristics</th>
<th>Study Aims</th>
<th>Data Collection</th>
<th>Analytic Approach</th>
<th>NICE Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Becker and Newsom (2005)</td>
<td>USA African Americans; Community</td>
<td>Various, including: Diabetes mellitus, Heart disease, Hypertension, Asthma, Arthritis, Stomach problems, Knee problems, (77% had multiple chronic illnesses)</td>
<td>38 participants (25 women, 13 men) Aged 65-91</td>
<td>“To examine older African Americans' philosophies about their chronic illnesses and how those philosophies affected chronic illness management” and “to explore how people lived with chronic illness on an everyday basis”</td>
<td>Semi-structured interviews</td>
<td>Content analysis &amp; Narrative analysis</td>
<td>++</td>
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<td>*Browne-Yung et al. (2015)</td>
<td>Australia; Community (85%) and aged care</td>
<td>Various, including: Cancer (N=4)</td>
<td>20 participants (13 women, 7 men)</td>
<td>“To identify aspects of late-life resilience and sense of self-identity and”</td>
<td>Semi-structured interviews</td>
<td>Narrative analysis</td>
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<tr>
<td><em>Domajnko and Pahor (2015)</em></td>
<td>Slovenia; Community</td>
<td>Various, including: Alzheimer’s disease</td>
<td>25 participants (22 women, 3 men)</td>
<td>“To identify the social conditions of resilient healthy ageing that could be promoted among elderly and at the wider societal level”</td>
<td>Semi-structured interviews</td>
<td>Content analysis</td>
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<td>facilities (15%)</td>
<td>Heart problems (N=6)</td>
<td>Diabetes (N=2)</td>
<td>Aged 88-98 years (mean 92)</td>
<td>locate them within a life narrative”</td>
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<td></td>
<td>Hypertension (N=9)</td>
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<td>High cholesterol (N=7)</td>
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<td>Osteoporosis (N=4)</td>
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<td>Asthma (N=4)</td>
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<td></td>
<td>Cataracts (N=2)</td>
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<td></td>
<td>Glaucoma (N=2)</td>
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<td>Study</td>
<td>Country/Setting</td>
<td>Sample Description</td>
<td>Participants</td>
<td>Research Question</td>
<td>Methodology</td>
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<tr>
<td><em>Ebrahimi et al. (2013)</em></td>
<td>Sweden; Community</td>
<td>Frailty (N=22) with one or more chronic diseases</td>
<td>22 participants (11 men, 11 women)</td>
<td>“To explore and identify influences on frail older adults’ experience of health”</td>
<td>Semi-structured interviews</td>
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<tr>
<td>Felten (2000)</td>
<td>USA; Community</td>
<td>Various, including: Chronic Pain, Sciatica, Stroke, Broken ankle (two screws and a plate), Congestive heart failure, Memory impairment</td>
<td>7 women Aged 85+ years (mean 88.6)</td>
<td>“To explore characteristics of resilience in community-dwelling women older than age 85”</td>
<td>Semi-structured interviews</td>
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<tr>
<td>Guzman et al. (2012)</td>
<td>Philippines; Aged care facility</td>
<td>Stroke with residual paralysis (100%)</td>
<td>9 participants (6 men, 3 women)</td>
<td>“To determine the essence of self-concept, disposition, and resilience of a select group of post stroke”</td>
<td>Robotfoto, semi-structured interviews and mask-painting</td>
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<tr>
<td>Study</td>
<td>Country</td>
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<td>Sample Description</td>
<td>Research Questions</td>
<td>Methodology</td>
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<tr>
<td>Harper <em>et al.</em> (2013)</td>
<td>USA; African Americans; Community</td>
<td>Colorectal Cancer</td>
<td>17 participants (9 men, 8 women) Aged 66-83 years (mean 74.1)</td>
<td>“To understand the relevance of general models of behavior change and culturally relevant beliefs to patterns of health behaviors in older African American CRC survivors”</td>
<td>Semi-structured telephone interviews (N=8) and two focus groups (N=4, 5)</td>
<td>Thematic Analysis ++</td>
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<tr>
<td>Harris (2008)</td>
<td>USA; Community</td>
<td>Early-stage Alzheimer’s Disease Dementia (N=2) Co-morbidities; Hypertension and Diabetes (N=1)</td>
<td>2 participants (1 African-American man, 1 Caucasian woman) Aged 61 years and 71 years</td>
<td>“To understand the role the resilience plays in the lives of these people with dementia who are ‘living with dementia, not dying with it’” and “to better understand the factors in the resilience process that contribute to a more positive dementia experience”</td>
<td>Semi-structured interviews (with and without caregiver) and field observations Case studies analysed within a person-centred resilience framework</td>
<td>-</td>
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<tr>
<td>Study</td>
<td>Location</td>
<td>Population</td>
<td>Methodology</td>
<td>Data Analysis</td>
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<tr>
<td>Haug <em>et al.</em> (2015)</td>
<td>Norway; Receiving somatic hospital care</td>
<td>Cancer: Colon (N=5), Prostate (N=4), Female breast (N=3), Lung (N=3), Lymph/Blood (N=3), Urinary tract (N=2), Skin (N=1), 1+ co-morbidity (N=13)</td>
<td>21 participants (12 men, 9 women) Aged 70-88 years</td>
<td>“Exploring how older people with incurable cancer experience the existential meaning-making function in daily living from a life-span perspective”</td>
<td>Semi-structured interviews Framework analysis (secondary analysis)</td>
<td></td>
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<tr>
<td>Hopp <em>et al.</em> (2012)</td>
<td>USA African Americans; Community Advanced heart failure</td>
<td>35 participants Aged 60-93 years (mean 74.3)</td>
<td>“To obtain qualitative, in-depth information about how African Americans with advanced heart failure experience their illness” and “To obtain qualitative, in-depth information on the strategies that older African Americans with advanced heart failure”</td>
<td>Four focus groups (N=13) and guided interviews (N=22) Thematic Analysis</td>
<td>++</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Setting</td>
<td>Illness Description</td>
<td>Participants</td>
<td>Study Objective</td>
<td>Methodology</td>
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<td>Pentz (2005)</td>
<td>USA; Community (11) and nursing homes (2)</td>
<td>Cancer (lung, prostate, pancreas, testicles, liver or bladder – 3 participants had cancer at 2 sites)</td>
<td>13 participants (10 men, 3 women) Aged 66-91 years (mean 77.1)</td>
<td>“To examine the psychosocial experience of older adults with cancer”</td>
<td>Guided interviews and field observations Grounded theory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pieters (2016)</td>
<td>USA; Community (N=18)</td>
<td>Breast cancer (N=18) At least one additional chronic condition (N=15)</td>
<td>18 women Aged 70 years+ (mean 76 years)</td>
<td>“To explore and describe the adaptational experiences of women ≥70 years, who recently completed treatment for early stage breast cancer from the perspective of the women themselves”</td>
<td>Semi-structured interviews Grounded theory ++</td>
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<td>Study</td>
<td>Country</td>
<td>Setting</td>
<td>Condition</td>
<td>Participants</td>
<td>Description</td>
<td>Methodology</td>
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<td>Ploughman et al. (2012)</td>
<td>Canada;</td>
<td>Community</td>
<td>Multiple Sclerosis</td>
<td>18</td>
<td>“To describe the factors influencing healthy aging from the perspective of the older person with MS”</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
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<td>Co-morbidities:</td>
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<td>Cancer (N=5)</td>
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<td>Osteoporosis (N=4)</td>
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<td>Stroke (N=1)</td>
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<td>Hypertension (N=2)</td>
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<td>Diabetes (N=2)</td>
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<td>High cholesterol (N=1)</td>
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<td>Aged 56-80 years</td>
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<td>(mean 66.5)</td>
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<tr>
<td>Richardson et al. (2014)</td>
<td>UK; Community</td>
<td>Community</td>
<td>Osteoarthritis (Moderate to severe chronic joint pain)</td>
<td>27</td>
<td>“Exploring wellness and resilience in older people with joint pain”</td>
<td>Semi-structured interviews followed by a monthly survey over 12 months</td>
<td>Thematic analysis</td>
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<td></td>
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<td>Some were living with multiple chronic conditions</td>
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<td>Aged 55-90 years</td>
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*Denotes studies where two researchers have completed the quality assessment*
**Methodological quality of included studies**

The methodological quality of included studies was assessed according to the quality appraisal checklist for qualitative research (NICE, 2012). This process culminated in each study being rated with one of three categorical quality ratings (++, +, or –). As outlined in the accompanying checklist guidelines (NICE, 2012), the highest quality rating (++) reflects that all or most of the checklist criteria have been fulfilled and that those unfulfilled are very unlikely to alter the study’s conclusions. The second quality rating (+) reflects that some of the criteria have been fulfilled and that those unfulfilled are unlikely to alter the study’s conclusions. The poorest quality rating (–) reflects that few or no criteria have been fulfilled, and that those unfulfilled are likely to alter the study’s conclusions.

As can be seen in Table 1, six of the included studies obtained the highest quality rating (++), seven studies obtained the middle quality rating (+) and one study obtained the poorest quality rating (–). Inter-rater reliability using the checklist was high, reaching a level of agreement of 92.9%. After assessing the divergent ratings (see Method), the first author decided to retain the original ratings.

Considering the quality of the literature as a whole, there is a lack of evidence of researcher reflexivity, with only one study (Hopp et al., 2012) being transparent in describing the relationship between the researcher and participants and the possible influence of this upon the findings. Other studies either made minimal and unclear reference to such processes (N=4) or failed to consider such processes altogether (N=9). Reflexivity is an important aspect of qualitative research (Finlay, 2002), although it should be noted that this apparent lack of reflexivity may be due to an absence in reporting rather than a genuine lack of reflexivity surrounding the research.
In comparing studies which achieved the highest quality rating (++) with studies achieving lower ratings (+ or -), key differences were found in how they presented their research design and analysis. All studies which obtained a ‘++’ rating were deemed to show transparency in their research design, often providing rationales for their sampling and data collection techniques, whilst also justifying the use of their chosen methodology. In comparison, only three out of eight studies with lower quality ratings fulfilled this criteria. Furthermore, all studies with a ‘++’ rating were deemed to have transparency and rigour in their process of data analysis, compared with only one study with a lower rating (Ploughman et al., 2012). The authors regard the quality of data analysis to be an important aspect of qualitative research, in line with recommendations from NICE (2012). Therefore, the uncertain quality of analysis in 7 of the studies was deemed a key weakness in 50% of the included studies.

In terms of findings and conclusions, the assessor deemed all studies to have relevant and convincing findings with internal coherence. The high quality of study findings was deemed particularly important with regards to the research questions underlying this review, which primarily required synthesis of study findings across the literature. Nonetheless, with a lack of transparency across studies we cannot evaluate how researchers’ assumptions influenced their interpretations. This lack of reflection sometimes extended to study conclusions, with half of authors failing to include any clear reflection around study limitations, alternative explanations and/or descriptions of clear links between data, interpretations and conclusions. This made it difficult to assess the transferability of some conclusions. However, as outlined, the overall quality ratings of nearly all studies (excluding Harris, 2008) suggest that the unfulfilled criteria are unlikely to alter study conclusions (NICE, 2012).
Further details regarding the quality appraisals can be found in Appendix D (Quality Appraisal Checklist, NICE, 2012) and Appendix E (Quality ratings for included studies).

**Synthesis of findings**

The thematic synthesis resulted in three higher-order themes and eight sub-themes. A summary of these findings, along with the relevant studies representing each sub-theme, can be found in Table 2. Sub-themes were represented by at least six studies.

**Table 2. Identified themes and relevant papers**

<table>
<thead>
<tr>
<th>Higher-order themes</th>
<th>Sub-themes and example quotes</th>
<th>Relevant papers</th>
</tr>
</thead>
</table>
### Personal agency

“*What I ain’t got, I’m gonna make some kind of way to get it*”

(Becker and Newsom, 2005, p219)

- Becker and Newsom (2005)
- Ebrahimi *et al.* (2013)
- Felten (2000)
- Guzman *et al.* (2012)
- Harper *et al.* (2013)
- Harris (2008)
- Pieters (2016)
- Ploughman *et al.* (2012)
- Richardson *et al.* (2014)

### Engaging with others

**Social support networks**

“*You have to go out, meet people*”

(Domajnko and Pahor, 2015, p192)

- Becker and Newsom (2005)
- Browne-Yung *et al.* (2015)
- Domajnko and Pahor (2015)
- Ebrahimi *et al.* (2013)
- Felten (2000)
- Harris (2008)
- Pentz (2005)

**Supporting others**

“*When you can’t help somebody else, you can’t help yourself*”

(Becker and Newsom, 2005, p218)

- Becker and Newsom (2005)
- Browne-Yung *et al.* (2015)
- Domajnko and Pahor (2015)
- Ebrahimi *et al.* (2013)
- Felten (2000)
- Harris (2008)
- Pentz (2005)

### Continuity in life

**Spirituality**

“*Reflecting by praying brings me peace and clarity*”

(Guzman *et al.*, 2012, p438)

- Becker and Newsom (2005)
- Browne-Yung *et al.* (2015)
- Felten (2000)
- Guzman *et al.* (2012)
- Harris (2008)
- Haug *et al.* (2015)
- Pentz (2005)

**Continued identity**

“*I’m still here*”

(Pieters, 2016, p25)

- Becker and Newsom (2005)
- Browne-Yung *et al.* (2015)
- Domajnko and Pahor (2015)
- Ebrahimi *et al.* (2013)
The resilient mindset

The first higher-order theme was evident in all studies and related to the importance that people placed upon their outlook on life and the way they think about and respond to their illnesses. Several characteristics of a resilient mindset emerged from the synthesis and were reflected in four sub-themes: ‘Health despite illness’, ‘A positive outlook’, ‘Perseverance’, and ‘Personal agency’.

Sub-theme: Health despite illness

Several studies found that participants subjectively perceived themselves as healthy with a good quality of life despite objectively living with a diagnosis of chronic illness;

“I feel healthy despite a diagnosis ... within this [these limitations] ... I live well ... and fully”

Theme: Well-being within limits (Domajnko and Pahor, 2015, p191)

In some studies, these perceptions of feeling well despite illness appeared to link to a person evaluating their health within the wider context of life and aging, rather than simply in terms of an absence of disease (Browne-Yung et al., 2015; Domajnko and Pahor, 2015; Ebrahimi et al., 2013; Felten, 2000; Richardson et al., 2014);
[Osteoarthritis] “I feel well, yes…so, my body is not as good as it was, I’m aware of that, but all in all, putting everything, you know, into perspective, being 80 next month, I feel pretty good.”

Theme: Severity and context of adversity (Richardson et al., 2014, p1387)

Across all representative studies, participants were able to acknowledge the restrictions that living with their chronic illnesses brought. At the same time, they were able to make adaptations to activities, hobbies and daily living to enhance their physical capabilities and engagement in life;

“That’s why I had to give it up [bowls] because I couldn’t bend. I ride the bike, I go on the treadmill, I go on the rowing machine. I can do all those things because I don’t have to bend down for those”

Theme: Adapting to aging-related physical changes (Browne-Yung et al., 2015, p4)

Ultimately, evaluating chronic illness within the wider context of life, whilst finding strategies to adapt to restrictions, reflected an important aspect of resilience in many older people living with chronic conditions.

Sub-theme: A positive outlook

A positive outlook on life was directly referred to as a component of resilience across several studies (Browne-Yung et al., 2015; Ebrahimi et al., 2013; Harris, 2008; Hopp et al., 2012; Pentz, 2005; Pieters, 2016; Ploughman et al., 2012). For some people, having a positive outlook was linked to feelings of optimism, hope, gratitude and humour (Ebrahimi et al., 2013; Pieters, 2016);
“And I thought that, my goodness, what I endure is a little scar and I’ve had 74 years (laughs) on this earth and what they’re doing is just amazing, and so I can take this scar”

Theme: Seeing the bright side (Pieters, 2016, p24)

A positive outlook was presented as a lifelong attribute across studies, with positivity being linked to a better health experience;

“If you go through life with a big old negative attitude, you know, it’s like having a heart problem...your blood pressure up, your heart going to beat fast. It’s going to be a worse condition. . .”

Theme: Life continuation (Hopp et al., 2012, p161)

A positive attitude appeared to help participants cope with days of poorer health;

“My heart is not really well and sometimes I don’t feel so good, and I just hope that tomorrow it will pass; and then the next day you feel better; then I’m happy, when you’ve gotten through it one more time”

Theme: Rein forcing a positive outlook (Ebrahimi et al., 2013, p292)

Having a positive outlook appeared to relate to a greater ability to cope with illness (Ebrahimi et al., 2013; Pentz, 2005; Pieters, 2016), meaning that after the initial shock of diagnosis, people were able to minimise the hardships they faced whilst maximising their ability to adapt.

Sub-theme: Perseverance
Several studies found that participants were determined to keep going and persevere in living a good life with chronic illness (Becker and Newsom, 2005; Felten, 2000; Guzman et al., 2012; Harper et al., 2013; Harris, 2008; Haug et al., 2015; Pieters, 2016; Richardson et al., 2014). Perseverance was seen as an important strategy to enhance resilience in later life;

“When you get to a certain age, you’re a senior citizen. You’re going to have health problems, but you overlook them. You just go on anyway because that’s what you have to do.”

Theme: Resilient philosophy (Becker and Newsom, 2005, p220)

Across all representative studies, perseverance was portrayed as a conscious decision to keep going, enabling people to adapt to illness through “doing what has to be done” (Pieters, 2016, p24);

“I just made up my mind to keep going, I guess.”

Theme: Determination (Felten, 2000, p110)

In three studies, perseverance was paired with combative language, such as having a “fighting spirit” (Harris, 2008, p56), not “giving up the fight” (Harper et al., 2013, p99) and reflecting a “refusal to be defeated” (Felten, 2000, p109). In others, it was described as a process of adaptation linked to future goal setting and finding new purpose in life (Becker and Newsom, 2005; Pieters, 2016). Across all studies, acting with perseverance appeared to require continued motivation, planning, and effort;

“I want to achieve something that is not out of sight but I can do. And I shall be persistent and consistent in it.”
Theme: Resilient philosophy (Becker and Newsom, 2005, p218)

Overall, perseverance was reflected in the behaviours that people showed, arising from making a conscious decision to keep going, which linked to a motivation to continue living and to continue living well with illness.

Sub-theme: Personal agency

A sense of personal agency was present across several studies, as evidenced by people’s abilities to make their own decisions, act with intentionality and work towards personal goals (Bandura, 2001). This sense of agency linked to feelings of control, and was conveyed through peoples’ confidence in their own abilities to adapt to their illnesses;

[Breast cancer] “I just knew that there wasn’t going to be anybody out there for me and I had to do it for me”

Theme: Being self-reliant (Pieters, 2016, p23)

Across all representative studies, this sense of agency related to feelings of self-competence. In some studies, this was discussed in terms of the participants’ problem solving skills and enhanced productivity (Harris, 2008; Ploughman et al., 2012), whereas other studies focussed on participant’s responsibility for self-care (Ebrahimi et al., 2013; Felten, 2000; Pieters, 2016). This component of resilience reflected people’s desire to maintain autonomy over aspects of life that they still have some control over. One participant’s sense of agency was so strong that he felt able to do as he wished, despite conflicting advice from professionals;
“They tell me not to go anywhere without a companion, which don’t mean too much to me. If I decide I want to go somewhere and a companion ain’t around, I’m on my way”

Theme: Independence (Becker and Newsom, 2005, p220)

Some studies portrayed this mindset of seeking personal agency and independence as a choice that could be made to enhance resilience (Felten, 2000; Harper et al., 2013; Richardson et al., 2014);

[Chronic pain, Osteoarthritis] “It’s a case of use it or lose it”

Theme: Use it or lose it (Richardson et al., 2014, p1391)

In contrast, others interpreted it as a way of thinking that is gradually learnt over time;

[Dementia] “This is the hand you were dealt with, so you learn tricks to help you cope with your problems.”

Theme: Coping strategies (Harris, 2008, p56)

Accordingly, this sense of personal agency often appeared to be associated with experiences from across the lifespan of successfully overcoming previous hardships (Browne-Yung et al., 2015; Felten, 2000; Guzman et al., 2012; Haug et al., 2015; Hopp et al., 2012; Richardson et al., 2014). For example, Hopp et al. (2012) found that older people with heart failure were able to face their illness with confidence after overcoming previous experiences of discrimination. Findings from these studies suggest that this aspect of resilience is something which can continue to develop over time;
“Now I have lived with incurable cancer for eight years. I handle things better than before, and I believe I have a strong resilience”

Theme: Life attitude (Haug et al., 2015, p7)

Engaging with others

The second higher-order theme related to aspects of the literature which suggest that resilience is associated with having mutually supportive relationships, as well as an ability to find a deeper sense of meaning and purpose in life through feeling socially connected. This incorporated two sub-themes: ‘Social support networks’ and ‘Supporting others’.

Sub-theme: Social support networks

A variety of social support systems were discussed across studies, including support from family (Domajnko and Pahor, 2015; Felten, 2000; Harris, 2008), friends and neighbours (Domajnko and Pahor, 2015; Pentz, 2005) the wider healthcare system (Browne-Yung et al., 2015; Domajnko and Pahor, 2015; Pentz, 2005) and the community (Felten, 2000; Harris, 2008). A strong family network appeared to be particularly meaningful in fostering resilience, with a sense that this support was unconditional and without limit;

“If I call [my daughter], I know she will drop everything and come to my aid”

Theme: Social support networks (Harris, 2008, p57)

Social support networks enabled people to feel connected, which was associated with a positive image of aging with chronic illness. Contrastingly, a lack of social support
was linked to negative stereotypes around late life loneliness and isolation (Domajnko and Pahor, 2015; Ebrahimi et al., 2013);

“The third life stage means to be active, not to enclose oneself in a room and contemplate only age and pain”

Theme: Socialising (Domajnko and Pahor, 2015, p192)

Some people appeared to actively reject conforming to these negative stereotypes of aging and evaluated their health in terms of the social connections they have (Domajnko and Pahor, 2015; Ebrahimi et al., 2013). Others shared their experiences of growth in their social support networks following illness (Pentz, 2005);

“Having cancer has really enlightened me on a lot of things. If it hadn’t been for this cancer, I wouldn’t have met a lot of people I really love”

Theme: Social Support (Pentz, 2005, p11)

Having a strong social network was presented as a positive component of resilience across studies, linked to feelings of happiness and security (Ebrahimi et al., 2013), optimism (Domajnko and Pahor, 2015) and finding meaning and value in life (Browne-Yung et al., 2015; Pentz, 2005).

Sub-theme: Supporting others

Many people also specifically discussed the importance of being able to give support to others. They talked about the immense personal benefits associated with helping others (Becker and Newsom, 2005; Domajnko and Pahor, 2015; Harris, 2008; Felten, 2000; Pentz, 2005);
“And my thanks to God is to keep busy and helping everybody. I feel that it does more for me then I do for them”

Theme: Care for others (Felten, 2000, p116)

Helping others appears to hold a deep level of meaning to people. It has been described as an aspect of spirituality, with one person reporting that helping others gave him;

[Cancer] “…a reason to live and keep on fighting”


Being able to support others appears to enhance other components of resilience, such as feelings of autonomy, wellbeing, spirituality, and finding meaning in life (Domajnko and Pahor, 2015; Felten, 2000; Pentz, 2005).

Continuity in life

The third higher-order theme related to how older people with chronic illness experienced continuity and growth in different aspects of their life. This incorporated two sub-themes: ‘Spirituality’ and ‘Continued identity’.

Sub-theme: Spirituality

Several studies reported spirituality to be an important source of strength and support for participants, enhancing their potential for resilience;

[Dementia] “God gives me strength. I never do anything on my own. God is always with me”
Theme: Religious beliefs (Harris, 2008, p56)

Some people found comfort from their belief in a greater power having control over their lives (Felten, 2000; Guzman et al., 2012; Haug et al., 2015);

[Cancer] “We cannot go anywhere, nor speak, walk, or think without God. If God will end my life, then it will be over”

Theme: A belief frame (Haug et al., 2015, p6)

Spirituality appeared to be a potential area for growth when living with chronic illness. One participant talked about experiencing a stronger sense of spirituality since living with chronic illness, and another talked about turning to God following their diagnosis (Becker and Newsom, 2005). Spirituality was linked to expressions of hope (Pentz, 2005), expressions of gratitude for the life lived (Pentz, 2005) and expressions of gratitude to God for His continued support (Becker and Newsom, 2005; Pentz, 2005);

“I thank God for the experience that I’ve had and I’m thankful that I was able to kind of look ahead...You keep on going. That’s the progress of growing.”

Theme: Religiosity (Becker and Newsom, 2005, p218)

Pentz (2005) suggests that feelings of gratitude may be a unique aspect of resilience in older adults specifically, with these expressions of gratitude helping people to cope with their illnesses.

Across studies, spirituality and faith in God was associated with a sense of wider connection to life. Participants were able to preserve their spirituality and draw upon their faith to enhance their resilience in living with chronic illness.
Continued identity

Within the representative studies, participants appeared to view their chronic illness as one aspect of their ‘normal life’ (Browne-Yung et al., 2015; Haug et al., 2015; Pieters, 2016), whilst retaining their core identity;

[Osteoarthritis] “There have been many obstacles in my life that I’ve had to overcome and I have done so. So this, in a way, is my latest challenge, you know”

Theme: Inner Strength (Richardson et al., 2014, p1389)

Many participants were actively maintaining a sense of identity through continuing previous hobbies (Becker and Newsom, 2005; Browne-Yung et al., 2015; Ebrahimi et al., 2013; Harris, 2008; Pieters, 2016, Richardson et al., 2014) continuing to learn new things (Becker and Newsom, 2005; Browne-Yung et al., 2015; Domajnko and Pahor, 2015; Ebrahimi et al., 2013; Ploughman et al., 2012) and pro-actively contributing to the wider community (Harris, 2008). This stable sense of identity enabled people to retain a sense of contentment and completeness with their past and present lives, as well as a sense of hope for their future;

“I have so many things that I like to do, or want to do that I still do. I haven’t had many unhappy times in my life, a few worries now and again but mostly I think life’s pretty good”

Theme: Continuity in Sense of Identity to Maintain Unity and Life’s Purpose

(Browne-Yung et al., 2015, p5-6)
Discussion

Overview of findings and clinical implications

This review aimed to synthesise the qualitative literature exploring subjective experiences of resilience in older people living with chronic physical illnesses. Resilience emerged as a multi-dimensional concept (Bergeman and Wallace, 1999) relating to having a resilient mindset, engaging with others, and experiencing a sense of continuity in life. These components of resilience interact fluidly as part of a dynamic process, meaning that although common themes emerged, people are actually able to draw upon different components as and when they have access to them. This is evident through different studies placing emphasis upon different aspects of resilience, such as the importance of spirituality and social support (Pentz, 2005) or the importance of a resilient mindset (Ploughman et al., 2012; Richardson et al., 2014). Resilience appears to play an important role in enabling older people to live well both in spite of, and in some cases because of, their chronic illnesses.

The first higher-order theme reflects how having a resilient mindset can help older people to experience subjective good health despite living with chronic illness. This fits with the ‘shifting perspectives’ model (Paterson, 2001) in which people living with chronic illnesses are able to focus on living well, whilst positioning their illness in the background. In focussing on life and living well, older people emphasised the importance of personal agency, perseverance and positivity. Accordingly, a key role for healthcare professionals will be to enable older people to have a level of autonomy in decision making about their healthcare, providing a space for people to develop their sense of personal agency. Through highlighting the important role that internal resources can have in living with chronic illness, healthcare professionals can also emphasise the level of personal control that people can have in terms of
their outlook on life and the ways in which they respond to their illness. Interventions which encourage older people to reflect upon their past successes may help them to develop a sense of positivity and agency.

The second higher order theme reflects the value of maintaining social engagement when aging with chronic illness. Resilience is linked to having mutually supportive, reciprocal relationships with family, friends and the wider community. Providing support to others gives meaning and purpose to life. This stands in contrast to common stereotypes of older people as primarily receivers of care (see WHO, 1999). The importance of social connection in stimulating resilience supports worldwide government and community initiatives aimed at reducing isolation and loneliness in later life (e.g. WHO, 2015). Healthcare professionals and community services can play an important role in encouraging older people to maintain meaningful relationships and to reflect upon the ways in which they are continuing to help others. Peer support groups may be particularly beneficial, given their emphasis on mutual support and everybody having something of value to offer.

The third higher order theme reflects the importance of experiencing continuity in life. Resilience is often associated with a strong sense of spirituality and links to expressions of contentment, hope and gratitude. This is consistent with theories of gero-transcendence (Tornstam, 2000), which suggest that older people develop a sense of wisdom as they continue to learn through experience, which enables them to eventually move their focus from materialistic goals to a focus on life’s deeper meaning. This theme is also consistent with the idea of successfully negotiating Erikson’s final psychosocial stage of ego integrity, whereby older people become
able to look beyond their present self and reflect upon their whole life, enabling them to retain a stable sense of identity and focus on a wider meaning and purpose in life (McLeod, 2013). Healthcare professionals can encourage older people to reflect upon their sense of identity and to consider the things that really matter to them. Life review and reminiscence may be useful clinical interventions in terms of facilitating this process of reflection (Hildon et al., 2008). Explicitly offering space for discussions around spirituality may also be useful (Rowe and Allen, 2004).

Overall, the findings support a definition of resilience as a process which can be developed at any life stage (Luthar et al., 2000), and which ultimately may be at its peak in later life due to the wealth of opportunities people have had to learn and grow from life experience. This suggests that many older people may naturally have a great potential for resilience, with healthcare professionals needing to take a supportive role in encouraging and stimulating the different aspects of resilience.

The findings also reflect the importance of healthcare professionals encouraging older people to evaluate their health and wellbeing from a wider context than an absence of illness. This supports a move away from narrow definitions of successful aging (Harris, 2008; Romo et al., 2012; Wiles et al., 2012) towards an understanding of chronic illness as one part of a complex, rich life story, reminding us of the need to explore people’s strengths and resources when evaluating what it means to age well.

Limitations

In terms of synthesising qualitative literature, there is controversy over whether findings from different epistemologies can be meaningfully compared, as epistemologies differ in terms of philosophical viewpoints and underlying principles.
(Walsh and Downe, 2005). However, the bringing together of separate islands of knowledge enables these studies to be considered as a whole, and so can also be viewed as a strength of the review.

In relation to the synthesis process itself, there is inevitably an additional layer of interpretation to data which has already been interpreted within original studies, which may mean that the review findings are further away from original participant experiences. In an attempt to reduce this discrepancy, the researcher remained close to the original findings throughout early stages of synthesis (Thomas and Harden, 2008).

In terms of the methodological quality of included studies, key limitations are evident in terms of a lack of general reflexivity across studies, and more specifically a lack of transparency regarding data analysis. This makes it harder to fully assess the credibility of the original findings, and future research within this area would benefit from ensuring transparency throughout the research process in order to support the validity of conclusions.

In terms of generalisability, with the exception of one study from the Philippines (Guzman et al., 2012) all samples were from Western countries, and so may not accurately reflect processes of resilience in Eastern countries, where a more collectivist culture may be present with different beliefs around the value of interpersonal support. However, findings from Guzman et al. (2012) were consistent with other studies. Crucially, this review does not claim to be representative of all older people living with chronic illness. It is acknowledged that studies asking about resilience and healthy aging are likely to attract a purposive sample of people who may believe they are adapting well and may hold different beliefs and attitudes to other older people living with chronic illnesses. The heterogeneity of the included
sample is also noteworthy, with participants living with a variety of chronic illnesses and having a high age range. Whilst many experiences appear to be shared, it is not possible to make conclusions around specific chronic conditions from the available literature. Processes of resilience may be affected in different ways by different health conditions, which can vary in their severity, level of threat, and the amount they impact upon our sense of identity and perceived control (e.g. living with incurable cancer may have a different impact to living with arthritis). Accordingly, useful next steps will be to research commonalities and divergences in resilience across health conditions in order to inform personalised packages of support.

Despite the outlined limitations, this review provides insight into the concept of resilience and its role in aging with chronic illness, leading us closer to understanding how to stimulate resilience in this population. The findings pave the way for future research to investigate the most effective interventions in helping to develop resilience in people aging with chronic illness.

Conclusions

This review provides insight into the role of resilience in aging with chronic illness. Resilience emerges as a multi-dimensional concept relating to a number of internal and external resources. The findings remind us that chronic illnesses exist as one part of an older person’s rich and complex life. A focus on resilience helps us to incorporate wider definitions of health and wellbeing, enabling older people to look beyond their illness and to draw upon their own strengths and resources in order to continue living well. A key role within clinical practice will be to support older people to draw upon these resources in order to stimulate their natural potential for resilience.
Conflict of interest

None.

Description of author’s roles

S. Buggins formulated the research questions, designed the study, conducted data collection and analysis, and wrote the article. Dr C. Clarke and Dr E. Wolverson supervised the research throughout, providing assistance and support during each stage of the process.

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*Indicates included studies for review
Part 2: Empirical paper
Part 2: Empirical Paper

Resilience in older people living with dementia – A narrative analysis

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This paper is written in the format for submission to the Journal of Dementia (see Appendix F for author guidelines)

Total word count: 5881

Journal word limit: 6000 (excluding references)
Abstract

Dominant discourses surrounding dementia focus on narratives of loss and decline. This limits the opportunity for alternative narratives of dementia to be shared and heard. This qualitative study utilised a narrative approach to analyse stories of resilience shared by eight older people living with dementia. Stories contained a number of phases and a variety of dynamic characters. Resilience emerged as an ongoing process stimulated by people’s sense of identity, agency, connection and positive outlook on life. Within their stories, participants weaved elements of loss with growth, passivity with proactivity, and fear with pleasure, telling a much richer story than that expressed by the dominant discourses surrounding dementia. The findings suggest that resilience is a relevant concept for older people living with dementia.

Keywords

Ageing, Dementia, Narratives, Resilience

Introduction

Discourses surrounding dementia have tended to be overwhelmingly negative, with many definitions of dementia originating from biomedical perspectives, emphasising its neurological basis and the losses and deficits seen to be directly caused by neurodegeneration (e.g. World Health Organization; WHO, 2016). This perspective prioritises the search for technical and pharmacological treatments capable of stopping or reversing this neurodegeneration. However, in the absence of an effective cure, this perspective has inadvertently fuelled discourses characterised by
hopelessness and nihilism, with these discourses being reflected in the stories told by, and about, people living with dementia (Bender, 2014).

Words hold significant power, with societal discourses shaping the way we act, our relationships with others, and the way that services, communities and policy makers respond (McTaggart & Kemmis, 1988). The dominant discourse of loss and pathology surrounding dementia increases stigma, with associated negative imagery restricting our ability to draw upon alternative frames relating to people’s qualities and strengths (Van Gorp & Vercruysse, 2012). This limits the stories that people are able to tell about their experiences of living with dementia (Mitchell, Dupuis, & Kontos, 2013), consequently limiting their ability to maintain selfhood (Sabat, 2002a, 2002b). Accordingly, there is an argument for embracing a new dementia narrative (Changing Aging, 2016) which incorporates aspects of positive psychology by focussing on mental health rather than mental ill-health (Seligman, 2002). In line with this, a small body of research has started to explore living well with dementia, enabling new stories of hope, growth and purpose in dementia to emerge (e.g. Wolverson, Clarke, & Moniz-Cook, 2010, 2015) alongside the dominant stories of fear, despair and loss.

There is a growing body of research exploring the concept of resilience in ageing (Perkins, 2014), and in ageing with chronic illness (Buggins, Clarke, & Wolverson, 2016). There is controversy around how to define and measure resilience (Purves, Savundranayagam, Kelson, Astell, & Phinney, 2011). Some researchers view resilience as a buffer against adversity (Ong, Bergeman, & Boker, 2009), whilst others view it as a process of ‘bouncing back’ (Netuveli, Wiggins, Montgomery, Hildon, & Blane, 2008, p958), but a commonality across definitions is that resilience is a capacity to successfully adapt to adversity (Luthar, Cicchetti, & Becker, 2000).
Resilience is thought to be a key process in responding to challenges associated with ageing, given that older adults have a wealth of experience to draw upon when adapting to adversity (Purves et al., 2011; Allen, Haley, Harris, Fowler, & Pruthi, 2011). Resilience has been associated with a number of positive factors in later life, including a greater sense of coherence, purpose in life, and self-transcendence (Nygren et al., 2005), in addition to better quality of life (Netuveli & Blane, 2008). Resilience has also been proposed as a meaningful alternative to models of successful ageing (Harris, 2008; Hochhalter, Smith, & Ory, 2011; Wiles, Wild, Kerse, & Allen, 2012) as it recognises people’s strengths and resources whilst also acknowledging the range of challenges that may surface in later life. Models of successful ageing have focussed on the importance of avoiding disease and disability (Baltes & Baltes, 1990; Rowe & Khan, 1997) and can be criticised in terms of whether they fit common realities of ageing (Romo et al., 2012), particularly when considering ageing with dementia. In contrast, rather than it being deemed necessary that a person be free of disease and disability, it is how a person manages such demands which is of interest when exploring resilience.

Little research to date has explored the subjective experiences of resilience in people living with dementia (Harris & Keady, 2008). This may be associated with the general lack of research exploring the voice of people living with dementia (Clarke, 2006), and may also relate to the dominant negative frames ascribed to people living with dementia in society, which focus particularly on loss of identity and autonomy (Van Gorp & Vercruysse, 2012). Having a strong sense of identity, a sense of control and an ability to remember past successes have emerged as factors associated with resilience in ageing (Bergeman & Wallace, 1999), and so the outlined dominant frames may lead to assumptions that resilience is not a concept worth studying in
relation to living with dementia. Harris (2008) conducted the only known study to date to explore subjective experiences of resilience in people living with dementia, utilising case studies to present data from two participants. Harris (2008) found evidence for resilience within the experiences of these older people living with dementia, associating resilience with access to personal and social resources that protect against threats to well-being. These findings suggest that resilience may be a relevant concept for this population, paving the way for further exploratory research.

This study used a narrative approach to explore stories of resilience from older people living with dementia. Stories are thought to provide insight into a person’s self-identity (Rosenthal, 1993; Randall, 2012), and there is evidence that autobiographical reasoning skills increase with age, enabling older people to integrate aspects of self within their stories (Pasupathi & Mansour, 2006). By collecting stories from people with dementia, they are given an important opportunity to be their own storyteller and shape their own narratives (Purves et al., 2011). In line with this, a social constructionist stance allows us to understand better the lived experience of dementia (Sabat, 2008), allowing for multiple stories and truths to exist within subjective experiences.

This research specifically asked:

- How do older people living with dementia talk about resilience?
- How are older people’s experiences of resilience in dementia expressed through their narratives?
- What key themes underpin their narratives?
Method

Design

A qualitative methodology was utilised to obtain resilience narratives from older people living with dementia. Data was collected through face-to-face interviews conducted by the first author, where participants were asked to share their story of how they have responded to living with dementia.

Inclusion criteria

Purposive sampling was used to recruit voluntary participants through charity organisations in the North East of England. Participants were invited to take part if they were 65 years of age or older and living with a diagnosis of dementia within the community. Participants were required to speak English with fluency. Participants needed to be aware of their diagnosis, as assessed through self-report, because the study was interested in people who perceived themselves to be living with dementia. Participants were excluded if they had received their diagnosis within the previous 12 weeks, as research suggests that key adjustment processes occur within 12 weeks post-diagnosis (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006) and this study was interested in the process of living with dementia rather than adjustment to diagnosis. Participants needed to have capacity to consent to participate in the research at the time of interview. This was evaluated by the researcher at the point of referral and at the time of interview, with this involving seeking advice from staff who knew the participants well at each recruitment site, utilizing principles of the Mental Capacity Act (2005), and following procedures
outlined by Warner, McCarney, Griffin, Hill, & Fisher (2008) on the assessment of capacity to consent to participation in dementia research.

**Participants**

The sample consisted of eight participants living with a diagnosis of 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 they all lived with a long-term heterosexual partner. Outside of their spousal relationships, all participants had regular social contact, seeing friends or family more than once a week. One additional participant was excluded after showing initial interest in participating as they denied having dementia. Further details about participants are displayed in Table 1. Pseudonyms are used to maintain anonymity.

**Table 1.** Participant demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Type of dementia</th>
<th>Time since diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brian</td>
<td>Male</td>
<td>69</td>
<td>Vascular &amp; Alzheimer’s disease</td>
<td>6 months</td>
</tr>
<tr>
<td>Henry</td>
<td>Male</td>
<td>79</td>
<td>Alzheimer’s disease</td>
<td>15 months</td>
</tr>
<tr>
<td>Julie</td>
<td>Female</td>
<td>71</td>
<td>Posterior cortical atrophy</td>
<td>4 years</td>
</tr>
<tr>
<td>Mary</td>
<td>Female</td>
<td>73</td>
<td>Alzheimer’s disease</td>
<td>8 months</td>
</tr>
<tr>
<td>Susan</td>
<td>Female</td>
<td>68</td>
<td>Alzheimer’s disease</td>
<td>2.5 years</td>
</tr>
<tr>
<td>David</td>
<td>Male</td>
<td>73</td>
<td>Lewy Body dementia</td>
<td>7 years</td>
</tr>
<tr>
<td>Robert</td>
<td>Male</td>
<td>82</td>
<td>Alzheimer’s disease</td>
<td>4 years</td>
</tr>
<tr>
<td>Leonard</td>
<td>Male</td>
<td>68</td>
<td>Alzheimer’s disease</td>
<td>5 years</td>
</tr>
</tbody>
</table>
**Procedure**

The study was granted Ethical Approval from the University’s research Ethics Committee (Appendix G). Posters and information sheets (Appendix H) were displayed at support groups organised through voluntary sector organisations for people with dementia. Where possible, the researcher attended these support groups to give people the chance to ask questions directly. Interested people were asked to provide their contact details and the researcher telephoned them on an agreed date to confirm participation. All participants remained willing to participate.

All interviews took place in participants’ homes. Prior to interviews, participants signed a written consent form (Appendix I) and completed a demographic information form (Appendix J). Participants were informed about their right to withdraw, and were assured that the dictaphone recording their interview could be stopped at any point. Participants were assured that there were no ‘wrong’ responses and no required length of time for the interview, as this would naturally depend on how long it took to share their story.

Due to the nature of narrative methodology, semi-structured questions were not set prior to interviews (Josselson, 2011). To start the interview, the researcher read an opening statement describing the study (see Interview schedule, Appendix K), and then used active listening skills and curious questioning to facilitate the sharing of participants’ stories of resilience.

Six participants had their spouse with them during the interview. The other two participants said that their spouse had been invited but could not attend due to other commitments. Each spouse contributed to their partner’s story at times, sometimes in response to an invitation to join from the storyteller, and sometimes choosing to join
themselves. These contributions were not analysed as the study focussed on the experiences of people living with dementia.

**Analysis**

There are many methods of narrative analysis, with each method having merits and limitations (Josselson, 2011). In this study, participants’ stories were subject to forms of structural, performative and thematic narrative analyses, based upon methods described by Riessman (2000, 2008) and the typology outlined by Phoenix, Smith, & Sparkes’ (2010) regarding narrative analysis in ageing studies. These methods were chosen in order to enable analysis of how narratives were constructed and what they were communicating. Analysis was guided by recommendations emphasising the importance of keeping the person with dementia “centre-stage” during narrative analysis (Angus & Bowen, 2011, p116).

The researcher adopted a social constructionist stance, considering each narrative to be a representation of one of many truths (Miller, 2006). The researcher also assumed that their role as interviewer, as well as the common presence of participants’ spouses during interviews, shaped narratives and lead to a co-constructed narrative between researcher, participant (Riessman, 2000, 2008), and in several instances the participant’s spouse. For further details regarding epistemology see Appendix L.

Each narrative was transcribed and listened to several times to enable the researcher to consider emotional expression, tone of voice and personal reflections. Typed transcripts were then re-read several times and each narrative was temporally ordered as the researcher highlighted significant events, emotions, characters and the relationships between these components (Smith & Sparkes, 2009; Phoenix et al.,
This process facilitated the unfolding of narrative plots reflecting the underlying narrative phases. These plots were then represented graphically in order to discover the narrative mood and overarching storylines (Frye, 1957; Riessman, 2008). Emerging themes were highlighted within each narrative and were, subsequently, analysed across narratives to find convergent themes. See Appendix M for a worked example of analysis.

**Results**

Participants’ stories lasted between 7 and 31 minutes, with an average story time of 18 minutes. Analysis revealed a number of structural phases, significant characters, and convergent themes present across narratives. Firstly, significant characters are introduced to provide context.

Participant quotes are used to illustrate 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 narratives (Smith & Sparkes, 2009; Stout, 2016). Participants were positioned as the main protagonist, playing dynamic characters with a variety of emotions, challenges, and roles. At times they played a passive role, awaiting for support from medical professionals and drugs companies, but mostly participants played an active role. Their spouses played the role of the sidekick, unconditionally loving and always at their side. The importance of this role was evident through participants frequently positioning themselves as a couple, repeatedly using the ‘we’ pronoun, and inviting their spouses to join as a
secondary storyteller. At times, this gave a sense of a shared identity between participants and spouses. However, participants also maintained a sense of self and portrayed their individual identity through using the “I” pronoun and positioning their spouses either next to or behind themselves at various points. Other characters included wider family and friends with supportive roles, medical professionals who were often positioned as antagonists, and charity organisations who were supportive protagonists. Dementia was positioned as a key antagonist, but played a dynamic role, with its presence, amount of control, and level of threat changing over time. Illustrations of characters are provided throughout the findings.

**Structural and thematic analysis**

Structural analysis revealed that although each person’s specific experiences differed, for seven participants the structural elements of their narratives reflected five common temporal phases; ‘The diagnosis’, ‘Initial tasks’, ‘The high point’, ‘Reflecting on limitations’, and ‘Focussing on today’ (Figure 1). For one participant, Leonard, the first two phases were not present. 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’.

Convergent themes and sub-themes emerged across narratives (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 described alongside the structural findings.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Example quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of self</td>
<td>Continued identity</td>
<td>‘I’m still here’ (David)</td>
</tr>
<tr>
<td></td>
<td>Evolving identity</td>
<td>‘I do know what it does to you later on’ (Mary)</td>
</tr>
<tr>
<td></td>
<td>Self-identity vs. shared identity</td>
<td>‘[My wife] will go with me, but I’m in the choir’ (Henry)</td>
</tr>
<tr>
<td>Being connected</td>
<td>Spousal relationship</td>
<td>‘if it wasn’t for [my wife] it would be a different story’ (Leonard)</td>
</tr>
<tr>
<td></td>
<td>Wider relationships</td>
<td>‘I’ve got good friends you see, so it’s alright’ (Mary)</td>
</tr>
<tr>
<td></td>
<td>Feeling supported</td>
<td>‘there’s a lot of good work being done by people…that makes a big difference’ (Mary)</td>
</tr>
<tr>
<td></td>
<td>Contributing to the community</td>
<td>‘I go out and I help other people’ (Julie)</td>
</tr>
<tr>
<td>Sense of agency</td>
<td>Seeking knowledge</td>
<td>‘I’ve asked a lot of questions. I’ve asked why, where, what and when’ (Brian)</td>
</tr>
<tr>
<td></td>
<td>Keeping busy</td>
<td>‘Once you do it, it makes you want to do more. And I do, I am doing as much as possible’ (Julie)</td>
</tr>
<tr>
<td></td>
<td>Aware of issues and making</td>
<td>‘I haven’t played since, not, not that, but now I’m playing croquet’ (Robert)</td>
</tr>
<tr>
<td></td>
<td>adjustments</td>
<td>‘...it’s like life, there’s always a challenge round the corner’ (Brian)</td>
</tr>
</tbody>
</table>
The narratives of the seven participants who described all five phases reflected an overarching storyline consistent with Frye’s (1957) tragic romance, characterised by underlying feelings of nostalgia, loss and fear, which were quickly absorbed into pleasure 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 a steady incline as the story closed (Frye, 1957).

<table>
<thead>
<tr>
<th>Phase</th>
<th>Humour</th>
<th>Focus on the present</th>
<th>Positive attitude</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial tasks</td>
<td>‘Another thirty year I might be calling might call myself an old age pensioner <em>laughs</em>** (Brian)</td>
<td>‘I go on now and just enjoy what I’ve got left’ (Julie)</td>
<td>‘So I’m just content quite honestly’ (Henry)</td>
</tr>
<tr>
<td>The high point</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reflecting on limitations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focussing on today</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outlook on life</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The narratives of the seven participants who described all five phases reflected an overarching storyline consistent with Frye’s (1957) tragic romance, characterised by underlying feelings of nostalgia, loss and fear, which were quickly absorbed into pleasure 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 a steady incline as the story closed (Frye, 1957).

**Figure 1.** Narrative plot of resilience
**Phase 1: The diagnosis.** The first phase, present for seven participants, described the events leading up to, and immediately following, receiving a dementia diagnosis. The phase was characterised by shock and confusion, with dementia positioned in the foreground. This phase represented the lowest point on the trajectory within all seven narratives, and participants were positioned in a passive role. Most participants began their story by describing how they noticed early changes in their abilities;

‘*I er kept forgetting things, leaving things on the train*’

*(Henry)*

Participants described the dementia assessments they completed in great detail, and recalled receiving their results. Participants particularly recalled the lack of support they received following diagnosis, with medical professionals playing key antagonists;

‘*...the di-diagnosis, which was a laugh in itself...you go to these people and they tell you straight to the face ‘sorry Julie but there’s nothing we can do for you’. And this went on and on, at all different places*’

*(Julie)*

For most participants, there was a great sense of feeling dismissed;

‘*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)

As Julie summarised;

‘It’s heart breaking, you have to live through all this, and you come to a point where you think, well, what’s it all about?’

(Julie)

**Phase 2: Initial tasks.** The second phase described the initial tasks carried out following the shock of diagnosis, and the trajectory began to incline as the narrative mood lightened. Some participants reached this phase almost instantly;

‘...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 involved 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 week’

(Brian)

This theme of agency was associated with proactivity and autonomy, and was reflected through a shift of positioning, as participants played more active roles;

‘Sod it, I’ll do it myself! *laughs*’

(Susan)

Charity organisations were introduced and played a protagonist role, being described as ‘marvellous’, ‘wonderful’ (Brian) and ‘very helpful’ (Mary), with Henry reporting their help ‘lifted me up’. Participants talked positively about starting to attend events organised by the various charities;

‘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 described 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. They talked about gaining new friends (Henry, Mary, David and Robert) and reconnecting with family (Brian). Several participants also described how they are 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, dementia was positioned in the background;

‘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 manage these. Dementia became somewhat more present in the narratives again;

‘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, and as in phase two a strong theme of agency was present;

‘...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)*

As reflected by Susan, there was a sense of having some control over dementia in this phase. 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)*

Participants reflected upon things which give them confidence in their abilities to overcome limitations. Spouses often played a prominent role as sidekick, and most
participants also 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 narratives, with participants emphasising the importance of positivity, gratitude, humour, and staying calm;

‘…you just laugh all the time…just keep laughing’

(Leonard)

Within this, participants portrayed a strong sense of self, emphasising the differences between themselves and others living with dementia who are not as resilient, talking about other people’s ‘lack of confidence’, ‘denial’ (Brian), how ‘they just sit at home and just don’t do anything’ (Henry), the belief that ‘a lot of people don’t want to join [things]’ (Mary), and how others may 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.** The final phase was characterised by a positive sense of focussing on the present, but within this was also a huge 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 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 portrayed a strong sense of self, emphasising their continued 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’ narratives ended with a positive mood, although the researcher also felt a sense of each narrative ending abruptly, which made it difficult to assess the final mood of the narrative although the general trend inclined (Figure 1). 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 others to ‘try and live it up as much as you can’.

Discussion

Overview of findings and implications

The stories shared support a definition of resilience as a process (Luthar et al., 2000). The narratives of resilience shared by these older people living with dementia weave elements of loss with growth, passivity with proactivity, and fear with pleasure, thereby telling a much richer story than is often expressed by the overwhelmingly negative dominant discourses surrounding dementia. Dominant discourses of loss, fear and pathology are present (Bender, 2014) along with narrative frames relating to searching for a medical cure and losing aspects of self-identity (Van Gorp & Vercruysse, 2012). However, each narrative primarily focusses on alternative frames reflecting people’s strengths and resources in ageing with dementia. Narratives emphasise processes of growth which occur both despite of and because of dementia, including new relationships that have formed, new activities which add meaning and value to life, an evolving sense of identity, and the continuing development of resilience through new experiences. Clinicians and researchers need to feel confident in encouraging and exploring these alternate narratives, as we can see that they are available to people if we ask questions which move the focus away from the dominant narratives of loss.

Characters

Through their stories, participants emerged as dynamic characters, positioning themselves in a passive role around the point of diagnosis, before becoming
increasingly active and autonomous. This fits with findings from the adjustment literature, which suggest that after receiving a dementia diagnosis people undergo a process of change, becoming more active as they develop new strategies to manage (Vernooij-Dassen et al., 2006). As resilience emerges, participants take on this more active role, and the positioning of dementia changes, moving from the foreground to the background. This fits with Paterson’s (2001) ‘shifting perspectives’ model, which suggests that people living with long-term illness are able to position their illness in the background in order to maintain wellbeing. The findings suggest that this is initially difficult, but becomes easier over time.

The resilience process is facilitated by supportive protagonists, including spouses, family, friends and the wider community, emphasising the importance of others in stimulating resilience. Spouses play a key role in co-constructing parts of the story for six participants, which supports the move towards relationship-centred approaches in dementia care and research (Nolan, Ryan, Enderby, & Reid, 2002), highlighting the importance of delivering interventions to dyads where possible, rather than focussing solely on individuals.

**Narrative structure**

There is a sense that participants need to start their stories by acknowledging the significant impact of initially receiving their dementia diagnosis before their narratives can lighten in mood and progress through the resilience process. Hence, this narrative structure supports the understanding of resilience as a process of ‘bouncing back’ (Netuveli et al., 2008, p958). Importantly, rather than solely relating to the impact of receiving the diagnosis itself, the low narrative mood is emphasised by participants’ strong feelings of being dismissed by medical professionals.
following diagnosis, suggesting there may be a post-diagnosis gap in dementia care (Martin, Turner, Wallace, Choudhry, & Bradbury, 2013). This highlights a key role for clinicians in providing continuing support for people following diagnosis, emphasising the importance of seeing the impact of diagnosis as a process of adjustment rather than a discrete event (Vernooij-Dassen et al., 2006).

Leonard’s narrative is the only one which does not contain the first two phases, instead starting at ‘the high point’. One interpretation of this is that Leonard, who was diagnosed with dementia five years ago, may have a greater level of memory impairment than others and cannot recall earlier parts of his story. Alternatively, an interpretation informed by resilience literature is that in Leonard’s experiences, resilience may primarily emerge as a protective buffer (Ong et al., 2009), as although Leonard moves on to acknowledge some limitations associated with dementia, he is able to minimise these to maintain a relatively high narrative mood throughout, suggesting he lives well with dementia and it has not posed a great challenge.

Leonard’s narrative questions an underlying assumption of resilience research, that resilience is associated with adversity. An assumption of this study was that initially a dementia diagnosis would inevitably bring challenges for participants. Through questioning this perspective, Leonard’s narrative reminds researchers and clinicians of the importance of hearing each person’s individual story (Angus & Bowen, 2011).

Towards the end of each narrative, participants emphasise the importance of focussing on today, with this focus on the present moment enabling participants to maintain wellbeing whilst simultaneously expressing fears of a threatening future. As narratives came to a close, the researcher felt a sense that they ended abruptly. This fits with the emergence of resilience as a process, with this process likely to be
on-going as people continue learning from experience.

**Themes**

The themes identified in this study were consistent with themes present in the literature on resilience in ageing (Bergeman & Wallace, 1999) and resilience in ageing with chronic illness (Buggins et al., 2016), suggesting that they may underpin core processes of resilience.

A strong sense of self emerges through participants’ emphasis on their continued identities, as they draw links between the past and present (Werezak & Stewart, 2002). Alongside this sense of continuity, participants also portray a sense that their identities continue to evolve (Pearce, Clare, & Pistrang, 2002), both in terms of loss associated with a progressing dementia, but also in terms of growth. Normative processes of growth in ageing are not disrupted by their dementia, with participants negotiating Erikson’s final stage of ego integrity (McLeod, 2013) through reflecting back across their lifespan and continuing to learn from experiences. A strong self-concept is acknowledged as important in other resilience research (Bergeman & Wallace, 1999), but is a particularly notable finding within this study as most research around dementia focusses on loss of identity or attempts to maintain aspects of identity (Caddell & Clare, 2010), rather than asking about experiences of growth.

The second theme, being connected, emphasises the importance of social relationships in living with dementia (Kitwood, 1997), highlighting the link between social connection and wellbeing. The importance of reciprocity in relationships to support wellbeing has been increasingly recognised (Vernooij-Dassen, Leatherman,
& Rikkert, 2011). Most measures of resilience are still primarily focussed on individuals (Windle, Bennett, & Noyes, 2011), but the importance of social connection in stimulating resilience supports the recent trend to consider resilience from a wider perspective than people’s internal traits (Purves et al., 2011). This finding supports models of couple resilience in later life (Yorgason, Piercy, & Piercy, 2007) and highlights the need for further research into processes of couple resilience in dementia.

The third theme, a sense of agency, highlights participants’ sense of self-confidence in their abilities to manage adversity. This is reflected through their proactivity and their focus on making adjustments to overcome limitations. Being able to reflect on past successes appears important in promoting agency, so life review interventions to encourage reflection on previous accomplishments may be helpful. This fits with how life review is currently being explored as an intervention to increase resilience in ageing (Allen et al., 2011). To promote agency, clinicians play an important role in enabling older people to have autonomy when making decisions about their dementia care and emphasising their level of control.

The fourth theme reflects the importance that participants attribute to their outlook on life in terms of living with dementia. Resilience is linked to an ability to focus on today. Previous literature suggests that focussing on the present may be an avoidant coping strategy used by people living with dementia (Clare, Roth, & Pratt, 2005), but in this study it emerges as a choice made by people to prioritise finding enjoyment in the present moment, whilst balancing an awareness of the future progression of dementia. Humour, gratitude and positivity are emphasised across narratives and play a role in enabling people to maintain this balance.
Limitations

The findings are not suggested to be generalizable to all older people living with dementia, but instead aim to provide insights into resilience in a small number of people, paving the way for future research to expand upon this. The small sample consisted of people who have strong social support networks and who attend at least one support group. Given the importance of social connection in stimulating resilience, processes of resilience may be different, and perhaps less available, to people living with dementia who are not as socially connected or as active within the community, and may warrant separate study. Additionally, all participants were white British, so findings may not reflect resilience narratives in other cultures whereby dominant societal discourses, and factors relating to resilience such as interpersonal support and values of independence and autonomy, may differ.

Cognitive ability was not assessed within this study, but it is likely that as dementia progresses verbal narratives may become more difficult to share. Finding creative ways to explore resilience in older people living with advanced stages of dementia may provide insight into the next part of the resilience stories that could not be captured within this study.

An issue faced during data collection was how most participants wanted spouses in their interviews and these contributions were not analysed. It is not known how joint interviews with spouses may have shaped people’s resilience narratives. Future research into couple resilience in dementia may provide helpful insights into spouses’ roles in stimulating resilience through their relationship. Whilst acknowledging the value of including spouses in research, a key strength of this research was how it enabled older people living with dementia to shape their own
narratives (Purves et al., 2011), giving them a voice that can often be lost within everybody else’s stories of dementia (Werezak & Stewart, 2009).

**Conclusions**

Resilience was experienced as an on-going process by these older people living with dementia, with this resilience process being stimulated by people’s sense of identity, agency, connection and positive outlook on life. Through asking people to tell their story, and through focussing this story on resilience, this study enabled people to have their own voice whilst also providing a space for an alternative dementia narrative; one primarily focussed on strength and resilience rather than fear and loss. The findings suggest that resilience is a relevant concept for older people living with dementia, and insights from the findings provide an initial focus for clinicians when assessing and attempting to stimulate resilience in their clients.

**Declaration of conflicting interests**

None declared.
References


Concepts, Research, and Outcomes (pp. 231-244). New York: Springer.


Part 3: Appendices
Appendix A

Journal of International Psychogeriatrics – Guidelines for authors

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are
not prepared in accordance with these guidelines will be returned to authors
unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching,
and research work with elderly people. It is the official journal of the International
Psychogeriatric Association (IPA) and is published by Cambridge University Press,
Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the
journal welcomes contributions from all concerned with the field of mental health
and aging. Original research papers are particularly sought. Contributions include
original research articles, reviews of the literature, brief reports, “for debate” articles,
case reports, letters to the editor, book reviews and guest editorials. Apart from
editorials, “for debate” articles and book reviews, which are commissioned,
contributions to International Psychogeriatrics are spontaneously written and
submitted by authors. Papers are reviewed by at least two expert reviewers selected
by the Editor-in-Chief. At present about half of the papers submitted are accepted for
publication in this journal which is published twelve times per annum. The journal’s
Science Citation Index Impact Factor (2014) is 1.934. Submission of a paper implies
that it is neither under consideration for publication elsewhere, nor previously
published in English. Manuscripts must be formatted double-spaced with ample
margins on all sides and the pages should be numbered. Please leave a spare line
between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. International Psychogeriatrics uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. International Psychogeriatrics has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (http://journals.cambridge.org/ipg) under the related links icon and the IPA website (http://www.ipa-online.org/).

Submission of manuscripts

Note: It is not acceptable to submit to the journal an article that has previously been published or submitted elsewhere. Authors are required to assert that they have not submitted their article elsewhere upon submission to International Psychogeriatrics.

Manuscripts should be submitted online via our manuscript submission and tracking site, http://mc.manuscriptcentral.com/ipg. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au

To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading
‘Submission of randomized clinical trials’ on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
2. That the authors have had full control of all the primary data.
3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final. The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors’ names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers’ names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer
form to sign after acceptance of the manuscript, consenting to publication of the paper in International Psychogeriatrics.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne, RMH Royal Park Campus, 34-54 Poplar Road, Parkville, Victoria 3052, Australia, Tel: +61 3 8387 2326, Fax: +61 3 8387 2667. Most authors can expect to receive an initial decision on the fate of their paper together with referees’ reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Each author must select only ONE country as their location. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author’s email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts for original research and reviews should be structured and incorporate 4 sub-headings: background, method(s), results, conclusion(s). Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.
Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long. Methods: Materials and procedures should be described in sufficient detail to enable replication. Results should not be included in the Method(s) section.

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, η², Cramers V, 95% confidence interval) should be reported in addition to p values.

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Any methodological weaknesses of the study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: This section must be completed. This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word “none” underneath it. For full details see below.
Description of authors’ roles: This section must be completed if the paper has 2 or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

References: For original research no more than 30 articles that have been published or are in press should be cited, and for brief reports no more than 15 references. If authors believe that more than 30 references are essential to an original research article this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. International Psychogeriatrics uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “et al.” should be employed, i.e., (Smith et al., 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith et al., 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.


Where an article or book chapter has more than six authors only the first author’s name should be given followed by the words “et al.”.

For further examples of reference style see papers in recent issues of International Psychogeriatrics.

Figures/Tables: The manuscript should contain no more than five figures or tables. The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data may be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Word limits: At present International Psychogeriatrics does not have a fixed word limit for articles. Because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Reviews of the Literature
International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of International Psychogeriatrics to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

**Conflict of Interest**

Conflict of interest occurs when authors have interests that might influence their judgement inappropriately, regardless of whether that judgement is influenced inappropriately or not. International Psychogeriatrics aims to conform to the policies of the World Association of Medical Editors in regard to conflict of interest. For full details please see the website http://www.wame.org/wamestmt.htm#fundres. To this end all authors must disclose potential conflicts of interest so that others may be aware of their possible effects. Specifically, under the heading conflict of interest, all articles must detail:

- The source(s) of financial support for the research (if none, write “none”).
- A description of any sponsor’s role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).
- Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by Bigpharma which directly competes with another drug made by Megadrug a declaration might say “Jane Smith
has received research support and speaker’s honoraria from Bigpharma and has received financial assistance from Megadrug to enable her attend conferences.”

General notes

Following acceptance of a manuscript the contact author should receive proofs within 1-12 weeks. They also will be required to complete and forward a copyright form and authors’ checklist both of which will be forwarded to the corresponding author by email when the article is accepted.

The average time from an article being accepted to being e-published ahead of print as a First View article is 35 days, provided authors return proofs promptly. E-publication generates a doi number and counts as full publication for citation purposes.

Editorials, “For Debate” articles and book reviews are commissioned by the editor. Reviewers who reviewed papers in the previous calendar year will be acknowledged in the journal each year. International Psychogeriatrics no longer publishes an annual index as modern computerised search techniques have rendered annual hard copy indices obsolete.

Contributors should refer to recent issues of the journal for examples of formatting (abstracts, headings, references, tables, etc.).
## Appendix B

### An example of the synthesis process for subtheme ‘Supporting others’

<table>
<thead>
<tr>
<th>Supporting studies</th>
<th>Study findings</th>
<th>Synthesis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Becker and Newsom (2005)</strong></td>
<td><strong>Theme: Independence</strong>&lt;br&gt;“To me, independence is that you do what you want to when you get ready. And when you can’t help somebody else, you can’t help yourself, or you don’t help yourself. You’ve got to share.”</td>
<td>Higher-order theme: Engaging with others Sub-theme: Supporting others Helping others appears to be a characteristic of resilience for these older people within these studies.</td>
</tr>
<tr>
<td></td>
<td>“And if you have someone around that you can teach and talk with, you may help them, but you also help yourself”</td>
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<tr>
<td><strong>Browne-Yung et al. (2015)</strong></td>
<td><strong>Theme: Changing social networks</strong>&lt;br&gt;“My friend I used to go [on holidays] with she’s in a home now. She can’t even get out of bed. It’s terrible really. I hate going down to see her but I have to go ‘cause she likes me to go”</td>
<td>Helping others appears to be linked to finding meaning and purpose in life – improved wellbeing, quality of life, and autonomy (linked to independence)</td>
</tr>
<tr>
<td><strong>Domajnko and Pahor (2015)</strong></td>
<td><strong>Theme: Intergenerational Solidarity</strong>&lt;br&gt;“I took care of grandchildren for some time. I babysat my first granddaughter for eight months, I came to them. Every day by bus. I took care of the second grandson a bit less, some four months … and that was a bit more for</td>
<td></td>
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</table>

102
myself, for my soul I say, for my soul”
“I feel well, am quite satisfied to have children, to have grandchildren … even more. Children are already … they are … but to have grandchildren, they come and we talk, still … I have to help them, with their learning”

The provision of social support was far from unidirectional. The participants reported many instances of giving social support…The experience of doing something for others (babysitting, helping with learning etc.) is an important social factor generating the feelings of coping autonomously and well with one’s life that further reflects in personal satisfaction
Giving social support, especially within intergenerational ties, could therefore be an effective proactive coping strategy

Pentz (2005) explicitly links helping others to a deeper level of spirituality, with this deeper level also appearing to be reflected in Domajnko and Pahor (2015) – ‘for my soul’.

Many of the extracts reflect the idea that helping others means that you are equally (or perhaps even more so?) helping yourself – the idea of giving and receiving → Mutual support and personal benefits – reciprocity. Helping others has been likened to a coping strategy and related to

Felten (2000) Theme: Care for others
“And my thanks to God is to keep busy and helping everybody. I feel that it does more for me then I do for them”
The participants also provided care for others, which they felt enhanced their own well-being. They felt doing for others gave them even more benefits than it did for the people they helped…Their active sharing lifestyles, despite the discomfort from aches and pains in everyday life, kept them more functional.

Harris (2008)  
**Theme: Social support networks**
[Daughter] “If I call her, I know she will drop everything and come to my aid. I watch her two daughters every day after school.”

Pentz (2005)  
**Theme: Spirituality-Faith- Helping Others**
…often stressed the meaning they found in helping others. Jack displayed meaning in being able to help others as a hospice volunteer. He said it gave him a reason to live and keep on fighting. “I like to help people”
## Appendix C

### Excluded references following full article review

<table>
<thead>
<tr>
<th>Reference</th>
<th>Reason for exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gosselink, C. A., &amp; Myllkangas, S. A. (2007). The leisure experiences of older U.S. women living with</td>
<td>Not focussed on resilience, no theme or</td>
</tr>
<tr>
<td>Title</td>
<td>Authors</td>
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<tr>
<td>HIV/AIDS. Health Care for Women International, 28, 3-20.</td>
<td></td>
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<tr>
<td>Author(s)</td>
<td>Title</td>
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<tr>
<td>Jopp, D., &amp; Rott, C.</td>
<td>Adaptation in very old age: Exploring the role of resources, beliefs and attitudes in for centenarian’s happiness.</td>
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<td>Authors</td>
<td>Title</td>
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<tr>
<td>Wiles, J. L., Wild, K., Kerse, N., &amp; Allen, R. E. S. (2012).</td>
<td>Resilience from the point of view of older people: There’s still life beyond a funny knee.</td>
</tr>
</tbody>
</table>
Appendix D
Quality Appraisal Checklist (NICE, 2012)

| Study identification: Include author, title, reference, year of publication |
| Guidance topic: Key research question/aim: |
| Checklist completed by: |

**Theoretical approach**

1. **Is a qualitative approach appropriate?**
   For example:
   - Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?
   - Could a quantitative approach better have addressed the research question?

<table>
<thead>
<tr>
<th>Appropriate</th>
<th>Inappropriate</th>
<th>Not sure</th>
<th>Comments:</th>
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</table>

2. **Is the study clear in what it seeks to do?**
   For example:
   - Is the purpose of the study discussed – aims/objectives/research question/s?
   - Is there adequate/appropriate reference to the literature?

<table>
<thead>
<tr>
<th>Clear</th>
<th>Unclear</th>
<th>Mixed</th>
<th>Comments:</th>
</tr>
</thead>
</table>
- Are underpinning values/assumptions/theory discussed?

**Study design**

**3. How defensible/rigorous is the research design/methodology?**

For example:

- Is the design appropriate to the research question?
- Is a rationale given for using a qualitative approach?
- Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?
- Is the selection of cases/sampling strategy theoretically justified?

<table>
<thead>
<tr>
<th>Study design</th>
<th>Defensible</th>
<th>Indefensible</th>
<th>Not sure</th>
<th>Comments:</th>
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</thead>
</table>

**Data collection**

**4. How well was the data collection carried out?**

For example:

- Are the data collection methods clearly described?

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Appropriately</th>
<th>Inappropriately</th>
<th>Comments:</th>
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</thead>
<tbody>
<tr>
<td>Question</td>
<td>Evaluation</td>
<td>Comments</td>
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<td>-------------------------------------------------------------------------</td>
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<tr>
<td>Were the appropriate data collected to address the research question?</td>
<td>Not sure/inadequately</td>
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<tr>
<td>Was the data collection and record keeping systematic?</td>
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**Trustworthiness**

5. **Is the role of the researcher clearly described?**

For example:

- Has the relationship between the researcher and the participants been adequately considered?
- Does the paper describe how the research was explained and presented to the participants?

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Clearly described</td>
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</tr>
<tr>
<td>Unclear</td>
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<tr>
<td>Not described</td>
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</table>

6. **Is the context clearly described?**

For example:

- Are the characteristics of the participants and settings clearly defined?
- Were observations made in a sufficient variety of circumstances
- Was context bias considered

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear</td>
<td></td>
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<tr>
<td>Unclear</td>
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<tr>
<td>Not sure</td>
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</table>
### 7. Were the methods reliable?

For example:

- Was data collected by more than 1 method?
- Is there justification for triangulation, or for not triangulating?
- Do the methods investigate what they claim to?

<table>
<thead>
<tr>
<th>Reliable</th>
<th>Unreliable</th>
<th>Not sure</th>
<th>Comments:</th>
</tr>
</thead>
</table>

### Analysis

### 8. Is the data analysis sufficiently rigorous?

For example:

- Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?
- How systematic is the analysis, is the procedure reliable/dependable?
- Is it clear how the themes and concepts were derived from the data?

<table>
<thead>
<tr>
<th>Rigorous</th>
<th>Not rigorous</th>
<th>Not sure/not reported</th>
<th>Comments:</th>
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### 9. Is the data 'rich'?

For example:

- How well are the contexts of the data described?

<table>
<thead>
<tr>
<th>Rich</th>
<th>Poor</th>
<th>Comments:</th>
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</table>
- Has the diversity of perspective and content been explored?
- How well has the detail and depth been demonstrated?
- Are responses compared and contrasted across groups/sites?

<table>
<thead>
<tr>
<th>10. Is the analysis reliable?</th>
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<tbody>
<tr>
<td>For example:</td>
</tr>
<tr>
<td>- Did more than 1 researcher theme and code transcripts/data?</td>
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<tr>
<td>- If so, how were differences resolved?</td>
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<tr>
<td>- Did participants feed back on the transcripts/data if possible and relevant?</td>
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<tr>
<td>- Were negative/discrepant results addressed or ignored?</td>
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<tr>
<td>Reliable</td>
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<tr>
<td>Not sure/not reported</td>
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<th>11. Are the findings convincing?</th>
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<tr>
<td>For example:</td>
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<tr>
<td>- Are the findings clearly presented?</td>
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<tr>
<td>Convincing</td>
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<tr>
<td>Not sure</td>
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</tbody>
</table>
- Are the findings internally coherent?
- Are extracts from the original data included?
- Are the data appropriately referenced?
- Is the reporting clear and coherent?

| 12. Are the findings relevant to the aims of the study? | Relevant | Comments:
|-------------------------------------------------------|---------|----------------
|                                                       | Irrelevant |               |
|                                                       | Partially relevant |               |

| 13. Conclusions | Adequate | Comments:
|-----------------|----------|----------------
| For example:    | Inadequate |               |
|                 | Not sure |               |
| - How clear are the links between data, interpretation and conclusions? | |
| - Are the conclusions plausible and coherent? | |
| - Have alternative explanations been explored and discounted? | |
| - Does this enhance understanding of the research topic? | |
- Are the implications of the research clearly defined?

**Is there adequate discussion of any limitations encountered?**

### Ethics

14. **How clear and coherent is the reporting of ethics?**

For example:

- Have ethical issues been taken into consideration?

- Are they adequately discussed e.g. do they address consent and anonymity?

- Have the consequences of the research been considered i.e. raising expectations, changing behaviour?

- Was the study approved by an ethics committee?

### Overall assessment

**As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)**

++ , +, −

**Comments:**
## Appendix E

### Quality ratings for included studies

<table>
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<tr>
<th>NICE quality rating item</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<th>13</th>
<th>14</th>
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<tbody>
<tr>
<td><em>Becker &amp; Newsom (2005)</em></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>11++</td>
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<td><em>Browne-Yung et al. (2015)</em></td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
<td>12++</td>
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<td>13++</td>
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<td>X</td>
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<td>X</td>
<td>?</td>
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<tr>
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<td>X</td>
<td>9+</td>
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</table>

*Denotes studies where two researchers have completed the quality assessment*
Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

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

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

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

1.1 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student’s dissertation or thesis.

2. Article types

_Dementia_ welcomes original research or original contributions to the existing literature on social research and dementia. _Dementia_ also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words. The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

_Dementia_ is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission
guidelines below, and then simply visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the 'Online Help' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

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retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author’s institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under
this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the SAGE Journal Author Gateway.

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at http://icmje.org. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.
Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (http://www.wma.net) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (http://www.cioms.ch). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

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

All contributors who do not meet the criteria for authorship should be listed in an ‘Acknowledgements’ section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose
whether they had any writing assistance and identify the entity that paid for this assistance.

### 7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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### 9. Manuscript style

#### 9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.
9.2 Journal Style

*Dementia* conforms to the SAGE house style. Lengthy quotations (over 40 words) should be displayed and indented in the text.

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

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

9.3 Reference Style

*Dementia* adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: *Helping readers find your article online*
The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE’s Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online. The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

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

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

9.4.4 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the
article. For more information please refer to SAGE’s Guidelines for Authors on Supplemental Files.

9.4.5 English Language Editing services

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit English Language Editing Services for further information.
Appendix G

Confirmation of ethical approval

Removed for hardbinding
Appendix H

Participant information sheet

Title of the study: Resilience in older people living with dementia

We would like to invite you to take part in our research study, which is looking at stories of resilience from people living with dementia in the community. Before you decide whether you would like to take part in this study, we would like to explain why we are researching this area, and what it will involve if you decide to take part. We are happy to answer any questions that you may have. Please take time to read through this information sheet and consider your decision.

What is the purpose of the study?

This study aims to explore how older people living with dementia share stories of resilience. By this, we mean what helps you to keep going and how you have faced any challenges. A lot of stories that we hear about dementia in the media are extremely negative, only talking about loss and disability. This study is interested in the factors that help people to live well with dementia. It is hoped that this focus will help to reduce the stigma that people living with dementia can face in our society, and that as a result of this wellbeing may increase. This study is interested in people’s stories around how they have responded to challenges of dementia.

Why have I been invited?

This information is being given to people who are 65 years or older and are living in the community with a diagnosis of dementia.
Do I have to take part?

No, participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. You are free to withdraw from the study up to the point that the study results are written up, and you do not have to give a reason for withdrawing. Your decision will not affect your legal rights or your care.

What will happen if I decide to take part?

If you decide to take part please telephone the researcher on the telephone number provided at the bottom of this information sheet. The researcher will be able to answer any questions you may have and may ask a few questions to check that you are able to participate. We can then arrange a meeting with you at a convenient place and time. When you meet the researcher, they will give you the chance to ask any questions you may have and ask you to sign your written consent to take part. After this, they will ask you to answer some short questions such as your gender and age. The interview will involve talking about your day to day life since your diagnosis in as much detail as possible, particularly how you have responded to changes and challenges since your dementia diagnosis. The interview will be expected to last about one hour and will be recorded on a Dictaphone. There are no right or wrong answers, as this is your story to tell.

What are the possible disadvantages and risks of taking part?

The interview with the researcher will take about an hour of your time, which may be inconvenient for you. The interview will involve talking about a potentially upsetting and sensitive topic, and some people may become upset when they talk about their experiences of responding to any changes or challenges relating to dementia. If you do become upset, you can take a break from the interview at any
point or can stop the interview – this is completely up to you, and the researcher will remind you that you are free to withdraw at any point.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is possible that telling your story will be enjoyable and that the experience of sharing it may be positive for you. It is also hoped that the information you give us will help us to understand more about experiences of resilience and how people respond to dementia, which will help to counteract the overwhelming number of negative stories about dementia in our society.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study at any point before the results are analysed. You do not need to give any reason for withdrawing. This will not affect your legal rights or care.

What if there is a problem?

If you have any concerns or questions about the study you can contact the researcher or one of their supervisors. They will do their best to answer your questions.

Will my taking part in this study be kept confidential?

Yes, all the personal information that you provide will be kept confidential in line with strict research confidentiality guidelines. The recording from your interview, and other information that you provide, will be kept in the research supervisors office in a locked cabinet, and only the researcher and their two supervisors will have access to this data. When the study is written up, any information that could be used to identify you will not be used, and your name will be changed to protect your
anonymity. The only time that information cannot be kept confidential is if you disclose something that suggests that you or somebody else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you beforehand.

What will happen to the results of the study?

After the study is completed, the results will be written up and submitted to an academic journal. You will be asked at your interview if you would like to receive the results from the study, and if so you will receive written feedback through the post once the study is complete.

Some direct quotes from your interview may be used in the write up, but identifiable information will be removed.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant sections of data collected during the study which are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an independent organisation which is called a Research Ethics Committee at The University of Hull. The Research Ethics Committee protects the interest of people who participate in research.
If you have any further questions, comments or queries, please do not hesitate to contact the researcher, Sarah Buggins. Thank you for taking the time to read this information.

Yours Sincerely,  

Sarah Buggins  
Trainee Clinical Psychologist

Supervised by,  

Dr Emma Wolverson  
Clinical Psychologist

Dr Chris Clarke  
Clinical Psychologist

Further information and contact details

Researcher:  
Sarah Buggins  
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Supervisors:  
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E-mail Chris: c.clarke@hull.ac.uk

Thank you very much for your interest!
Appendix I

Consent form

Title of the study: Resilience in older people living with dementia

Name of Researcher: Sarah Buggins

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point of write up. I understand that I do not need to give any reason for withdrawing, and that withdrawing will not affect my legal rights or care.

3. I agree to take part in the interview and understand that my interview will be audiotaped.

4. I confirm that direct quotes from my interview may be used in future publications and understand that they will be anonymised.

5. I understand that my data will remain confidential, unless the researcher has serious concerns of risk to me or to somebody else, in which case they will be obliged to share this risk with appropriate professionals.

6. I wish to receive a summary of the final results once the study is complete.

7. I wish to be invited to any events where the studies findings are shared.

________________________  ____________________  ____________________
Name of participant          Date                      Signature

________________________  ____________________  ____________________
Name of person taking consent Date                      Signature

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

Demographic information form

Title of the study: Resilience in older people living with dementia

Name of Researcher: Sarah Buggins

Participant number:

I would like to start by asking you some questions about yourself, but do not worry if you are unsure of the answer.

1. What is your age in years?

........................................................................................................................................

2. What is your gender? Please circle the one that applies to you.

Male / Female / Other

3. What is your ethnic background? Please circle the one that applies to you.

White British

Other White Background (please specify)..............................................................

Multiple Ethnic Background (please specify)..........................................................
Asian

Asian British

African/Caribbean

African British/Caribbean British

Other Ethnic Group (please specify) ........................................................................

4. Roughly when were you diagnosed with dementia?
.............................................................................................................................

5. What type of dementia were you diagnosed with?
.............................................................................................................................

6. Who do you live with?
.............................................................................................................................

7. Do you receive any support? If yes, what kind of support?
.............................................................................................................................

8. How regularly do you see family or friends?
.............................................................................................................................

Thank you very much for taking the time to answer these questions!
Appendix K

Interview schedule

This interview schedule will not be strictly followed in sequence, but will be used to guide questions and the general direction of the interview.

Opening statement:

This study is about resilience. I would like to ask you to tell me your 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 the challenge of living with dementia.

Prompts:

Active listening

What did you do?

Why?

How did you do it?

What helped?
Appendix L

Epistemological statement

The aim of this statement is to outline the epistemological position underpinning the empirical research contained within this portfolio. I believe that my underlying assumptions about the nature of reality will have inevitably influenced the ways in which I have approached this research, affecting the methodological choices I made.

In contrast to many quantitative approaches, which are often positivist in nature and aim to find an objective truth, my research was underpinned by a social constructionist stance. This fitted with my qualitative research aim to explore the subjective experiences of resilience in older people living with dementia (Sabat, 2008), allowing for multiple stories and truths to exist within each person’s subjective experiences.

I initially wanted to use Interpretive Phenomenological Analysis, which would enable me to explore people’s lived experiences (Smith, Flowers & Larkin, 2009). However, my final research proposal talked a lot about people’s stories and dementia narratives in our society. Over time, I realised that a narrative approach would fit better with my research questions. Whilst still enabling me to explore subjective experiences, a narrative approach would also allow me to look beyond the content and the themes in order to examine how people describe the processes that they have been through. Taking the position of story analyst (Phoenix, Smith & Sparkes, 2010), I would be collecting stories of resilience with which I could then analyse in a
number of ways.

During my time exploring narrative methodologies, I realised that there were many types of narrative analysis (Josselson, 2011), which were based on different theoretical perspectives and epistemological positions. A paper which helped me to think about my epistemological stance in relation to narrative approaches was Robert and Shenhav’s (2014) article outlining the fundamental assumptions across different narrative research methods. This helped me to realise that, to me, it makes sense to view narratives as a representational device and a tool of communication (Robert & Shenhav, 2014), whereby each narrative is a constructed representation of one of many truths (also acknowledged by Miller, 2006).

I approached the participant interviews with this mindset, accepting each narrative (or ‘story’) as a representation of that person’s constructed reality at that point in time. Within this perspective, I assumed that my role as an interviewer (and the common presence of participants’ spouses) would inevitably lead to co-constructed narratives (Riessman, 2000; 2008), as our verbal and non-verbal prompts, as well as the context surrounding the interview, would influence what each participant shared. Furthermore, I believed that the process of collecting and analysing stories meant that I would be interpreting people’s interpretations (Riessman, 2000). Broadening this way of thinking further, I acknowledged that narratives would inevitably be shaped by the wider cultural and societal discourses of loss surrounding dementia (Bender, 2014). Given this belief, it was my hope to provide a space for people to share any alternative narratives through this research. This was not about trying to emphasise that alternative ways of thinking are ‘right’ or the ‘truth’, but more about highlighting how alternative stories can exist.
I started to spend time reading around different narrative methodologies, and was drawn to Riessman’s (2000; 2008) work. I came across a typology for using narrative methodology in ageing studies which was written by Phoenix et al. (2010) and was influenced by the earlier work of Riessman (2008). This literature made me realise that in order to best answer my research questions, I wanted to use both structural and thematic forms of analysis, as I wanted to understand both ‘the what’ and ‘the how’ within peoples stories (Phoenix et al., 2010). These methods fit with my underlying epistemological position, describing the primary research aim as a quest to understand how participants find meaning in their subjective experiences rather than as a search for one truth (Riessman, 2000).

I started to search for research which had explored dementia and ageing through both structural and thematic narrative methods, as I wanted to ensure that these methods were feasible for my research. I found a helpful paper by Angus and Bowen (2011) which had drawn upon methods described by Riessman and the Phoenix et al. (2010) typology, with the authors conducting both a structural and thematic analysis. The Angus and Bowen (2011) paper also highlighted the importance of ensuring that the person living with dementia remains at the centre of the research process. I felt that this incorporated my desire to hear participants’ personal narratives and to enable them to have a voice. It reminded me to allow participants to take the lead in interviews, so that although stories would inevitably be co-constructed, their voice could hopefully be the strongest.
References


**Appendix M**

**Worked example of analysis**

<table>
<thead>
<tr>
<th>Participant (‘Brian’) quotations</th>
<th>Commentary</th>
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<tr>
<td><strong>Phase 1: The diagnosis</strong></td>
<td><strong>Phase 1 - Author’s reflections</strong></td>
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<tr>
<td>“Well, before this I was err very very active”</td>
<td>The lowest point on the trajectory</td>
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<td>“I started to do silly things like you know try to get out of bed and all and I climbed over the side”</td>
<td>Characterised by uncertainty</td>
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<td>“…but later on I was err getting very suspicious about it and I err we went we went to the doctors”</td>
<td>Low emotional tone</td>
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<td>“the memory clinic did all the tests there was hours and hours of tests and err different things”</td>
<td>Event – Before diagnosis</td>
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<tr>
<td>“Right. Ok. So, you want the err results. I thought <em>closes eyes slowly, looks down</em>…I said yes please. Right. I’m very sorry to tell you that you’ve got Alzheimer’s”</td>
<td>Sense of self – positive past identity</td>
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<td>Event – testing</td>
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<td></td>
<td>Describing the diagnostic tests</td>
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<td></td>
<td>Storyteller - positioned in a passive role</td>
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<td></td>
<td>here – sense of being ‘done to’</td>
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<td></td>
<td>Event – receiving a dementia diagnosis</td>
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<tr>
<td></td>
<td>Describing the results in detail</td>
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<tr>
<td></td>
<td>Emotional tone very low</td>
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<tr>
<td></td>
<td>Language: “I’m very sorry”</td>
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| | Non-verbal behaviours – closing eyes and looking down (a sense of a strong...
“it was mind blowing and I got up, he said where you going? I said I don’t know, I said I just wanna go, he said okay then. So, I went, and ten minutes later I went back and said I’m sorry about that”

Event – immediately following diagnosis:
Initial reactions following diagnosis of dementia
Lowest point, confusion
Language: “mind blowing”

“…we got home we just cried and laughed and cried and said what now?”

Use of “we” pronoun – in it together with spouse, shared identity, shared experience

Character role of spouse – positioned as the sidekick, sense of togetherness

“What now?” – BRIDGE TO NEXT PHASE – this phrase moves phase 1 (characterised by uncertainty, shock, confusion, very low emotional tone) on to phase 2.

<table>
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<tr>
<th>Phase 2: Initial tasks</th>
<th>Phase 2 - Author’s reflections</th>
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<tr>
<td></td>
<td>Characterised by the initial tasks – aware of the emotional tone starting to incline</td>
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<td></td>
<td>Strong theme of agency, autonomy emerges</td>
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“…we got home we just cried and laughed and cried and said what now?”

What now?
The first thing we had to do was phone the err the relatives. Err, I think we phoned about 15 relatives

The following morning we started ringing round different err different places. We rang errm different organisations

and then we rang the Alzheimer’s Association, so they was absolutely marvellous, and err you know we was put in touch with quite a lot of people

I’ve asked a lot of questions. I’ve asked why, where, what and when. Err, why, why has it happened, what err is it to do? Why have I got to do it? And you know, you can get all the answers if you sit and listen to people, mmm

and you know everything was sorted financially and securely within 6 week. Absolutely wonderful. They’ve err been to see if we needed any any help with the adjustments to the house and everything, you know to make me safe

Time – really quick move from the initial shock to “what now?”
Quick adjustment? Clear change to narrative tone following this

Event: Contacting family
Proactive
Connection to family

Event: Contacting organisations
New character is introduced: Charity organisations – described as “marvellous”
Character role → protagonist, supportive
Sense of gratitude from participant

Seeking knowledge
Reflects an emerging theme relating to a sense of personal agency/ autonomy – characterised by proactivity/ seeking/ striving towards goals – but with help from others – asking and also listening

Getting things sorted
Again, a sense of agency and a level of control – things being “sorted”
Language: “securely”
Charity organisations are described as “wonderful” → repeated sense of
gratitude, repeated his positive view of these organisations (repetition → sense
that they are an important character here)
Appendix N

Reflective statement

In this section, I aim to reflect upon some of my learning experiences from this research journey. I have kept a reflective diary throughout the process and have just re-read it before sitting down to write this statement. It is safe to say that it has been a research journey of highs, lows and all kinds of emotion. This section of the portfolio provides a space for me to share some of these experiences.

Research area

My research focusses on the concept of resilience in chronic health conditions. Resilience is a concept which holds a huge amount of meaning within my family. I grew up with both parents living with chronic illnesses and I learnt a lot about resilience in these years, although I did not fully realise this until later. Given my early experiences, I was aware of the potential emotional impact of researching this area. I was also aware that my experiences would have influenced my early assumptions and beliefs around what resilience looks like. These concerns were quite accurate, and on a couple of occasions during the research process I did put my work to one side until I had processed my feelings and felt ready to return to it. However, I also think this personal link made the research truly feel like ‘my own’, and made it so much more rewarding as I continued to develop my understanding in this area.

In terms of the empirical project, at the research fair my supervisor Emma had been talking about dementia, and more specifically considering dementia from a positive psychology perspective. She was clearly enthusiastic about the area, and made me want to find out more. I had a little bit of experience of working with people with
dementia from undergraduate, when I had volunteered at several care homes. I remember being struck by how quiet many of these people were, often appearing to be half-heartedly watching television. After a while I bought some activities for a reminiscence group, and I noticed how this would sometimes lead to people starting to talk, sharing memories and funny stories. I do think that this experience played a role in my early decision to focus my research on hearing the voices of people with dementia. Whilst I still view this as a very important endeavour, I also wonder whether I missed out on an important source of information by excluding participants’ partners from my research. After I started reading work from people like Kitwood and Sabat, I started to realise the importance of acknowledging the interpersonal context of dementia, and I wonder whether my early views were overly individualistic. The research findings themselves also reflect the importance of the spousal relationship, with many of the participants’ narratives being shaped by input from their spouses. The interpersonal context of dementia is definitely something that I would recommend future researchers in this area to consider.

Method

Given my desire to explore people’s lived experiences, qualitative research felt like the right ‘fit’ from the start. However, I held some reservations. Teaching from my undergraduate degree had favoured quantitative methods and I had very little experience of qualitative methods. I wondered whether qualitative research would be as ‘good’ or as publishable. These early concerns were soon challenged by my researchers, and given the exploratory nature of the research, along with my desire to ‘get out there and speak to people’ we decided to look into IPA. I soon became attached to IPA and started to write my final research proposal. During this time I was having research meetings with my supervisors, and they started to talk about
seeing links between my research proposal and narrative methods. I wanted to continue with IPA as I felt more confident with this, plus most of my peers were using IPA, so it took me a while to seriously consider narrative methods. Once I started looking into narrative methods I had two strong reactions; ‘this is perfect, I can capture the essence of people’s stories beyond the themes to really hear their voices’ but also ‘I don’t understand any of it’. I got to a point where although I did not understand everything, I felt that I knew enough to start planning for a narrative study. In future research, I will spend more time at the beginning considering different methodologies so that I can properly assess from the start which methods fit best with the research questions and my hopes for the research.

Recruitment

Once I got to the stage of recruitment I started to feel genuinely excited. I was finally about to start my favourite part – meeting people! I had spoken to a few members of staff at local charity groups and had asked if I could attend some of the groups for recruitment. This was difficult to fit in around placement and teaching, but after a month of not hearing anything from staff I realised that if I wanted to recruit I needed to be there in person, showing my face and sharing my enthusiasm. My first experience at one of these groups was not what I had expected. I was encouraged to attend as a volunteer for a few sessions before advertising my research, and one of the first things I was asked by a member of staff was ‘can you make dumplings?’ They didn’t turn out great, but at least I had started to meet people and started talking. Attending these groups became the highlight of my research journey. Not only was I starting to recruit interested people, I was having so much fun joining in the music groups and card games in brilliant company. I remember attending one particular karaoke event and singing along for an hour before realising that I hadn’t
even got my advertisement posters out of my bag! I did have some difficult conversations during this time which made me question my study. I had recruited two people and a volunteer came up to talk to me and said that I could do my interviews but ‘they can’t tell real stories’. I wondered what that meant, but later realised that it didn’t matter in terms of the study. The underlying epistemological stance of the research meant that I would be taking each story as that person’s reality, and that person’s truth in the moment.

**Interviews**

The interviews were associated with a lot of varied emotions. I was so excited to get started and it was amazing how each participant and their partners welcomed me into their home. Something which had been highlighted by a supervisor in my ethics application was the possibility that participants might feel pressured to ‘tell a good story’. To try to reduce this, I spent time talking to people before starting the recorded interviews to help them (and me!) settle in and start to feel more comfortable. I took time to assure people that there were no wrong answers, and no required length of time for their interview to last, as this would naturally depend on their personal story and the things they wanted to share. Something which I had not been prepared for was my own anxiety around this, and the pressure I put on myself to collect a ‘good’ story. Despite my reassurances to participants, I found myself worrying whether I should have asked further questions to extend stories, particularly when people started to come to the end of their stories and would seem to end them abruptly. I spoke about this concern in supervision and raised it in the qualitative research methods group. These discussions helped a lot, as we spoke about the pressure that researchers can feel to collect ‘good quality data’. We talked about the importance of allowing people to finish their stories when they naturally
I want to, rather than continuing to probe them. I reminded myself of the importance of allowing people to shape their own stories as much as possible, and I started to feel more relaxed during interviews, learning to trust the process and the narrative methodology.

Analysis and findings

I enjoyed the process of transcribing and analysing the stories more than I had initially expected. I had expected it to be really difficult to bring the different stories together, as the specific experiences that people had shared had been so varied. However, the narrative analysis enabled me to move beyond the content and I was surprised at the similarities in the underlying processes that people were describing and moving through in their stories. It was fascinating to see the strong links between stories, with these links being particularly clear at the level of character analysis. An example of this is the significant role that people’s partners have within the stories. In fact, in six of the stories partners physically shaped the stories through their interjections. I struggled with this in analysis, as I knew that I could not include the partners’ comments, but thought that it would have been interesting to analyse their input and their influence in guiding the story.

The main difficulty I encountered in relation to the findings was how to report them, as I honestly felt that I could have written a full results section on the structural analysis alone. I felt the same way about the themes that emerged from the data. I could even imagine writing a paper on the analysis of characters within the narratives! Deciding how to structure and report the findings took so much time. I re-wrote my results several times, not sure how to capture everything within the journal word limit. I looked into how other researchers using similar narrative methods had
managed this dilemma, and was surprised to find that they would sometimes publish their findings across multiple papers. It was a difficult process trying to decide which findings I believed were ‘key’ to include, and I had to accept that there would be pros and cons relating to any final decisions.

Choosing journals

I chose to write my systematic literature review for the journal of ‘International Psychogeriatrics’. This is a respected peer-reviewed journal and literature reviews are regularly published. I was initially wondering whether to submit the review to a health journal, but in the end realised that I wanted to retain the focus on later-life, with the hope that International Psychogeriatrics would attract the target audience. Choosing a journal for my empirical paper was difficult in terms of deciding whether to submit to a journal on general ageing or one focussed on dementia. I eventually decided to submit to the peer-reviewed international journal of ‘Dementia’, which focusses on research related to improving quality of life for people with dementia and their families. A search through previous editions of this journal showed that they have published papers on similar topics, and given their focus on research exploring lived experiences of dementia it felt like a good decision.

Final reflections

Despite finding parts of this research journey challenging, when I look back I can appreciate the opportunity that I have had to develop my research skills whilst also learning so much about topics that I am really interested in, both on a personal level and also in my clinical work. I have learnt so much from my two incredibly knowledgeable and enthusiastic research supervisors and I will now feel more
confident in taking on future research projects in my career as a qualified Clinical Psychologist.