THE UNIVERSITY OF HULL

Responses to dementia: A qualitative exploration of self and others

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Kirsty Michelle Patterson, BSc (Hons) Psychology

June 2015

Acknowledgements

Firstly, I would like to thank my participants, who welcomed me into their homes and shared their views and experiences with me. I am deeply grateful for their time and willingness to help, and have been inspired by their stories.

I would also like to thank my supervisors, Dr. Emma Wolverson and Dr. Chris Clarke, for their unwavering enthusiasm and support. They have helped me from the very beginning to look at dementia and aging from a different perspective, and I know that I will carry this with me wherever I go. My thanks go also to Dr. Tim Alexander and the rest of the department for their hard work in preparing us for the world of research and answering all of our questions!

I am grateful too for the support of the wonderful staff and group members who welcomed me to their meetings and helped me with recruitment. I was frequently inspired by the fantastic projects I saw happening within the community.

I would like to thank those close to me for their support and encouragement throughout. Thank you for being there with me to celebrate my successes and empathise with my struggles. A special thank you to my Mum and Dad, who have always been there for me, making sacrifices for me and supporting me in whatever I do, and finally for teaching me to 'always look on the bright side of life'.

Overview

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

Person-centred and social constructionist approaches to dementia have proposed that the experience of living with the condition is influenced by the responses of others towards the individual, and the personal response of the individual to dementia.

Part one is a systematic literature review that therefore critically evaluates and synthesizes the qualitative literature pertaining to the way in which people with dementia experience the responses of others towards them. The review aims to further our understanding of how people with dementia perceive the responses of others and the impact that these have upon them. This is deemed to be an important area to address given that theoretical understandings of dementia assign a critical role to the responses of others in influencing an individual's experience of dementia, and yet this aspect of subjective experience has been overlooked in previous reviews. Following a systematic search of the literature, 23 studies were suitable for review based on the inclusion criteria. A critical interpretative synthesis was conducted, leading to the development of four main themes to capture findings across the reviewed literature: 'Social outcasting – being treated as an other'; 'Social relegation – being treated as lesser'; 'The impact of others' responses'; and 'Strategies to manage the responses of others'. These themes and the subthemes within them are compared and contrasted to the themes developed by researchers in their original findings, paying attention to the discourses that may have been influencing their interpretation. The strength of the evidence is evaluated, and implications for clinical research and practice discussed.

Part two is an empirical paper investigating people's personal responses to dementia, focusing upon subjective experiences of growth in older people living with dementia. A qualitative methodology was utilised, using semi-structured interviews to investigate participants' experiences of positive and/or meaningful changes since living with dementia. Interviews were conducted with nine older people diagnosed with dementia living in the community. Interpretative phenomenological analysis was used to explore participants' subjective experiences and how they had made sense of these. From this, a theme of 'Moving Forward' was developed, containing five subthemes. A second theme of 'Living in the Now' was also developed, containing two further subthemes. The findings are discussed with consideration of the discourses we use to talk about dementia, and the implications of a growth discourse to clinical research and practice.

Part three consists of a set of appendices for both systematic literature review and empirical paper, including a reflective account of the research process and a statement of epistemology.

Total word count: 32,026 (including abstracts, tables, and appendices, excluding references)

Contents

List of tables

List of figures

Part one: Systematic Literature Review

The subjective experience of others' responses towards people with

dementia: A systematic literature review

Kirsty Patterson[1]*, Dr. Chris Clarke[1], & Dr. Emma Wolverson[1]

[1]Department of Psychological Health and Wellbeing,

University of Hull, Hull, United Kingdom, HU6 7RX

*Corresponding Author: Tel: +44 1482 464106, Fax: +44 1482 464093

Email Address: K.M.Patterson@2012.hull.ac.uk

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

International Psychogeriatrics

Please see Appendix A for the guidelines for contributors and Appendix B for

communication with the editor

Word count: 8,853 (excluding references & tables)

Abstract

Background

Social-psychological models of dementia suggest that the experience of dementia is affected by interpersonal factors, including the responses of others towards the person with dementia. This review aimed to synthesize findings that can provide an insight into how people with dementia perceive the responses of others towards them, and the subjective impact of these responses.

Method

A literature search was conducted using the electronic databases PsycINFO, MEDLINE, and CINAHL Complete. A critical interpretative synthesis was developed from the findings of included studies.

Results

The findings of 23 papers included in the review provide an insight into how people with dementia perceive the responses of others' towards them and the perceived impact of these responses. These perceptions were described by four main themes: 'Social outcasting – being treated as an other'; 'Social relegation – being treated as lesser'; 'The impact of others' responses'; and 'Strategies to manage the responses of others'. The findings indicate that people with dementia can feel outcast and relegated by others, but are also aware of positive responses from others. Both positive and negative responses impact upon the emotional and psychological well-being of people living with dementia.

Conclusion

Experiences such as loss and diminishing identity have previously been considered to be a direct result of dementia, with little consideration of interpersonal influences. The reviewed findings provide a basis for beginning to consider these experiences within an interpersonal context, and to understand how we might further improve the social conditions surrounding dementia.

Introduction

An emerging body of literature has begun to explore the experience of dementia within an interpersonal context. This research has often focused upon the impact of dementia upon relationships and how positive relationships are sustained in spite of dementia, in relation to family relationships (e.g. Ablitt et al., 2009; La Fontaine and Oyebode, 2013), friendship (e.g. Harris, 2012; 2013), and relationships within social care and support groups (e.g. Beard and Fox, 2008; Hochgraeber et al., 2013; Mason et al., 2005). This literature reminds us that people living with dementia inevitably do so within a social world, and indicates that the quality of people's social relationships is interwoven with their sense of identity (La Fontaine and Oyebode, 2013), and well-being (Ablitt et al., 2009).

Critically, the theoretical work of Kitwood (1990, 1997) and Sabat (2001, 2002) suggests that it is not just dementia that impacts upon social relationships, but that social relationships also impact upon the experience of dementia. Quantitative research has indicated that people with dementia present with better cognitive functioning when they are engaged in larger social networks (Bennett et al., 2006). Kitwood (1990, 1997) suggested that the qualities of these social relationships are also critical; he theorized that personhood and functioning can be undermined by malignant social processes such as stigmatization, labeling, and infantilization. Equally, they can be maintained and promoted by positive, person-centered interactions, such as attachment, comfort, and inclusion.

Sabat (2001, 2002) suggested that individuals with dementia are particularly vulnerable to being negatively *positioned* by others when there is a tendency to interpret a person's behavior on the basis of negative stereotypes and labels. When

others operate on the basis of such stereotypes they may remove the roles and responsibilities of people with dementia. This can lead to additional disability over and above that attributable to the direct cognitive effects of dementia. Observational case studies have demonstrated how negative positioning is conveyed within the communication patterns of family and professional caregivers in their interactions with persons with dementia (e.g. Sabat, 2004).

According to a social constructionist account of selfhood in dementia, an interplay exists between the way in which individuals are positioned or treated by others, and the way in which they view themselves. Sabat (2001) argued that the way in which an individual integrates dementia into his or her identity is shaped by (i) the individual's view of themselves and the impact of dementia; (ii) the reactions and positions directed towards them by others; and (iii) the way in which the individual responds to the responses of others. The perceptions and attitudes of others are therefore expected to influence the ability of the individual to construct a valued sense of self (MacRae, 2011). Theories of stigma have similarly suggested that the responses of others can mar a previously positive identity (Goffman, 1963), and that negative views about a condition can be internalized by an individual (Earnshaw and Quinn, 2012). Quantitative research has supported the idea that internalization of negative stereotypes by older people can have a negative impact, included reduced performance on cognitive tests (Levy, 1996).

These theoretical understandings all suggest that social interactions play a crucial role in the experience of dementia. Furthermore, the role of social interactions has been increasingly reflected in recent policies which aim to facilitate dementia friendly communities; free of stigma, and where people with dementia can feel valued, enabled, and understood by others (Department of Health, 2015).

However, what remains missing is a systematic review of the literature pertaining to social interactions and how these are experienced by people living with dementia.

Existing literature reviews have briefly documented experiences of stigma, isolation, and limitation, as well as the importance of positive social interactions to people living with dementia. However, the primary focus of these reviews has been upon the intrapersonal experience of dementia, and these social aspects have consequently been assigned a rather secondary focus; positioned as a supplemental part of the "impact" (de Boer et al., 2007, pp. 1026) or "transitional process" (Steeman et al., 2006, pp. 730) of dementia. Furthermore, whilst the body of research exploring social processes in dementia has continued to develop in the years following previous reviews, it has not yet been drawn together systematically. A systematic review would provide a more comprehensive understanding of people's experiences of living with dementia within a social world, and how we might facilitate a more helpful social environment for these individuals.

This review therefore aimed to synthesize the qualitative evidence pertaining to the latter two components of Sabat's (2001) understanding of dementia; (i) the reactions and positions directed towards people with dementia by others, and (ii) the way in which the person living with dementia responds to the responses of others. The overarching questions underpinning this review were therefore:

1. How do those living with dementia perceive others' responses towards them?

2. What is the perceived impact of others' responses upon people with dementia, and how do they respond to this?

Method

Search strategy

A systematic search of the literature was conducted using the electronic databases PsycINFO, MEDLINE, and CINAHL Complete. These databases were chosen to cover a broad range of disciplines that are likely to contribute to dementia research. Further data was sought through contact with relevant authors, scanning the reference lists of included papers, and hand-searching the journal Dementia.

The electronic search was carried out in December 2014. Based upon the contents of previous literature reviews, it was anticipated that literature pertaining solely to the perceived responses of others towards people with dementia would be relatively limited. Consequently, a broad search strategy was designed, utilizing a range of search terms derived from previous literature reviews relating to dementia (de Boer et al., 2007; Steeman et al., 2006) and relating to perceived responses to other mental and physical health conditions (Brohan et al., 2010; Jacoby et al., 2005; Ross and Goldner, 2009; Schomerus et al., 2012). Further search terms were added based upon the key words from retrieved papers. Search terms were generated in relation to three key strands:

- Terms relating to dementia: (Dementia OR Alzheimer*)
  (AND)
- Terms relating to social responses to dementia: Attitude* OR stigma* OR discourse* OR stereotyp* OR perception* OR perceive* OR reaction* OR prejudice* OR discriminat* OR view* Or social OR societ* Or public

(AND)

- Terms relating to qualitative approaches: Qualitative OR interview* OR subjective OR experience* OR narrative OR phenomenology OR "focus group"

Limiters were applied as follows:

- English language only

- Publication type: Journal article (to exclude other publications such as book chapters)

- Date range: 1989-present. The voices of individuals with dementia were typically missing in research up until this point (Lyman, 1989)

- Peer-reviewed journals only

- Search terms relating to dementia were also limited to the title only in order to reduce irrelevant papers.

Inclusion strategy

Papers were included if they met all of the following criteria:

- The study aimed to explore the social experiences of people with dementia. As the aims of qualitative research in dementia can be broad, both the aims of identified studies and any available interview schedules were searched to judge whether researchers had specifically intended to explore social experiences. Studies were included if either of these referred to 'social' factors/experiences (including specific social processes such as stigma), or if they referred to interpersonal 'interactions', or experiences within the 'relationships' of people with dementia (including marriage, friendship, and relationships with professionals)

- The study presented sufficient findings relating to the perceived responses of others towards people with dementia (at least two relevant quotes across two themes or at least 4 quotes within one theme). 'Others' was defined as people without dementia

- The majority, or all, of the study's findings represented the perspectives of people with dementia. If studies included more than just the perspectives of people with dementia, these needed to be clearly differentiated, or else needed to represent less than 10% of the sample

- The study employed a qualitative approach. This was necessary to ensure that papers captured the subjective experiences of social phenomena for people living with dementia

- The study was clearly empirical (i.e. not a literature review, commentary paper, or autobiographical account). To evidence empiricism, papers had to clearly state the use of an analytic procedure (e.g. thematic analysis, Interpretative Phenomenological Analysis (IPA))

- The study was written in the English language

- The study was published in a peer-reviewed journal, as an indicator of scientific rigor

Quality assessment

The methodological quality of the papers meeting the inclusion criteria was assessed according to the methodology checklist for qualitative studies developed by the National Institute for Health and Care Excellence (NICE, 2012) (see Appendix C). The quality assessment was utilized not as part of the inclusion strategy, but to critique the methods and underlying assumptions of the papers included, in order to contextualize findings and consider the strength of the

evidence overall (Dixon-Woods et al., 2006). Methodological quality was assessed by the first author, and a subset (5 of the 23 papers) was also checked by a peer researcher. Any differences of opinion were discussed and a final decision made by the first author.

Data synthesis

Data was synthesized using an approach based upon Dixon-Woods et al. (2006) critical interpretative synthesis methodology. Within this method, data is analyzed to produce a 'synthesizing argument'. This integrates findings from across the body of research to form a framework of concepts and connections between them. It goes beyond summarizing the body of findings, at times transforming original concepts from a study into something new. These newly synthesized concepts are still grounded in the original study findings, but are additionally considered in terms of the entire body of collated literature. In this way, aspects of a concept that may have appeared across several papers can be brought together and understood in terms of a synthesized concept. This approach was selected in favor of more descriptive methodologies due to the paucity of research directly investigating the questions of the review. It was anticipated that a more interpretative approach would be needed to make sense of findings gathered from a broad variety of papers.

The data synthesis process involved three key components, as proposed by Dixon-Woods et al. (2006):

- A detailed examination of retrieved studies, leading to the identification of common themes and a critique of the methodological quality and conceptual frameworks shaping the research.

- The development of synthesized themes that captured people's experiences across the literature, in line with the aims and questions underpinning the review. This was done by continuously comparing developing themes with original findings, and identifying the connections between concepts.

- An ongoing critique of the literature in relation to the ways in which researchers have understood their original findings, by drawing out possible assumptions and discourses that may have shaped these.

Results

Identification and classification of relevant studies

From the electronic database search, 19 papers met inclusion criteria, and a further 4 papers were added from hand searching of the journal Dementia and the scanning of reference lists, resulting in a final collection of 23 papers. This process of paper selection is outlined in Figure 1.
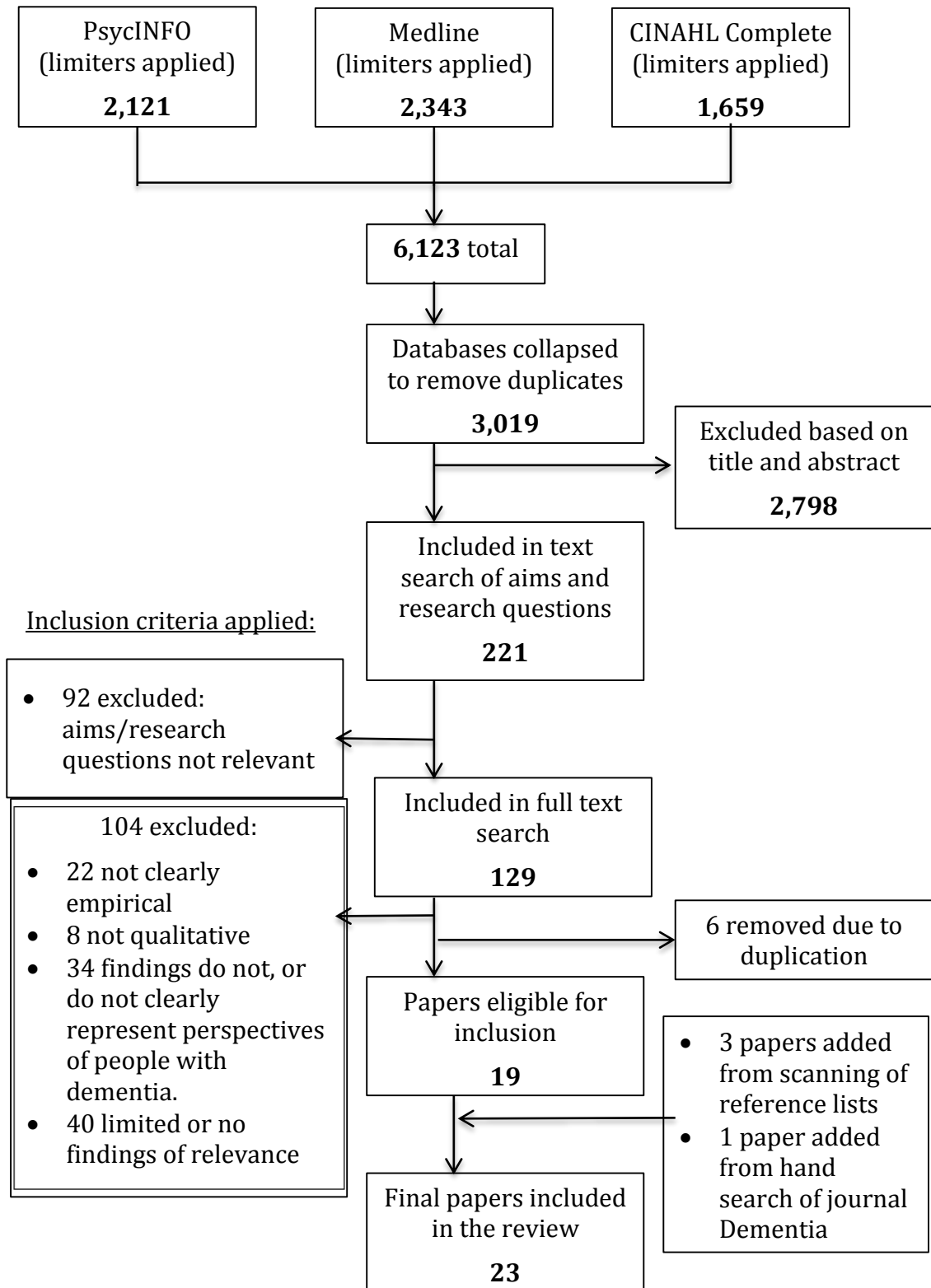
Figure 1: Flowchart depicting the paper selection process

Characteristics of included studies

Samples were mainly drawn from Western countries (UK, USA, Canada, Australia, and Sweden), with one study from China (Mok et al., 2007). The majority of studies focused solely, or mainly upon the experience of Alzheimer's type dementia but the type of dementia was not reported in seven studies. Sample sizes varied widely, from one single case study (O'Connor et al., 2010), to 114 participants (Powers et al., 2014), with a mean of 19 participants. Age range also varied widely, from 35 – 95 (mean = 70 years). Three studies specifically explored the experiences of people with young-onset dementia (Clemerson et al., 2014; Harris, 2004; Pipon-Young et al., 2012).

Four of the included studies also included participants with mild cognitive impairment (MCI) (Beard and Fox, 2008; Harris, 2004; Orulv, 2012; Powers et al., 2014) and four included the views of family or friends (Harris and Sterrin, 1999; Harris, 2013; O'Connor et al., 2010; O'Sullivan et al., 2014).

The majority of studies employed semi-structured interviews, or focus groups, but some additionally included observational data (Bartlett, 2014a, 2014b; Mason et al., 2005; O'Connor et al., 2010; Orulv, 2012), data from health and social care records (O'Connor et al., 2010), diary entries, and photographs (Bartlett, 2014a, 2014b). Analytic approaches included phenomenological (N=6), grounded theory (N=6), content (N=5), thematic (N=5), discursive (N=2), critical hermeneutic (N=1), and narrative (N=1), or were described more generally as having an inductive approach (N=1). Four studies drew on more than one analytic framework.

All papers reported at least one clear aim of exploring social aspects of living with dementia, or clearly explored social aspects within their data collection processes. However, only two studies specifically aimed to explore perceived responses of others to dementia (Langdon et al., 2007; MacRae, 2011). Further studies aimed to investigate the perceived impact of: social attitudes or oppression (Bartlett, 2014b; Katsuno, 2005; O'Sullivan et al., 2014), interactions in the social environment (Harris and Sterrin, 1999), socio-cultural factors (Mok et al., 2007; O'Connor et al., 2010), or friendship (Harris, 2012) upon the experience of dementia. In the remaining cases, information relevant to the review question arose from studies investigating other aspects of living with dementia. For example, MacQuarrie (2005) presented a study on awareness and coping within dementia, but from this, a theme depicting objectification by others emerged.

The main characteristics of the included studies are summarized in Table 1 and are grouped according to the aspect of subjective experiences in dementia that they seek to explore.

Table 1: Summary of the main characteristics of included studies

Author, date of publication, location	Study aims and relevant interview topics	Sample characteristics (AD= Alzheimer's Disease, MCI = mild cognitive impairment, VaD = Vascular Dementia, MID = multi-infarct dementia; FTD = frontotemporal dementia, HD = Huntington's dementia)	Methodological approach
Beard and Fox (2008) USA	Social processes within support groups To examine Alzheimer's Disease as a social experience, demonstrating how collective identity is formed through membership within support groups *Interview topic: views on social interaction*	Support group attendees aged 65+ (mean age 71) 28 men, 12 women 24 AD, 16 MCI	Semi-structured interviews conducted within focus groups (N=32) and individual interviews (N=8) Constant comparison method from grounded theory
Clare et al. (2008) UK	To further understanding of factors and effects involved in being part of a mutually supportive, self help movement *Interview topic: impact of self-help group on relationships*	Members of self-help group (DASNI), aged 48-66 (mean age 60) 2 men, 5 women Dementia type not reported	Semi-structured interviews conducted longitudinally via email (over two years) Interpretative Phenomenological Analysis (IPA)

Mason et al. (2005) UK	To examine mutual support processes, interactions, and experiences within support groups for people with dementia	Support group attendees, age 72-86 (mean age 79) 3 men, 8 women Dementia type not reported	Observational data from video recording and qualitative data from semi-structured interviews IPA (observational data handled quantitatively so not included)
Orulv (2012) Sweden	To explore how self-help group members construct a shared understanding of dementia, employing a citizenship perspective	Members of a local initiative self-help group, aged 63-83 (mean not reported) 2 men, 5 women 3 AD, 2 VaD, 2 cognitive disability due to vascular injuries (previously misdiagnosed as dementia)	Explorative case study, qualitative data gathered longitudinally through audio recordings of group sessions, field notes, and interviews with 3 participants Analysis of content, discursive patterns, lines of argument, and interactions between members
	Reactions of others to person with dementia		
Langdon et al. (2007) UK	To explore changes in participants' perceptions of their condition and understanding of others' reactions towards them, since dementia diagnosis. To explore what participants thought others understood by terms 'dementia' and 'Alzheimer's disease' *Interview topics: experiences of social responses to dementia diagnosis and ways of managing changes in relationships since dementia onset*	Participants recruited through Older Adult Mental Health Unit, aged 66-87 (mean age 79) 6 men, 6 women Dementia type not reported	Semi-structured interviews IPA

MacRae (2011) Canada	To examine how others' reactions to and treatment of people with dementia affect experience of dementia *Interview topics: relationships and interactions, perception of others' view and treatment of them*	Participants aged 60-85 (mean age 74) (recruitment sources varied – Memory Disability Clinic, advertisements, other professionals) 7 men, 2 women Dementia type not reported	Semi-structured interview Inductive analysis based on Coffey and Atkinson (1996), Lofland and Lofland (1995), and Taylor and Bogdan (1984), with symbolic interactionist framework
	<u>The impact of societal attitudes</u>		
O'Sullivan, Hocking, et al. (2014) New Zealand	To explore the experience of living with dementia and the influence of social attitudes	Participants recruited through community groups, 59-84 (mean not reported) 6 men, 5 women, and their caregivers 5 young onset, 6 older onset dementia	Semi-structured interviews with individuals and caregivers, followed by focus group discussion of findings Critical hermeneutic analysis within action research project
Katsuno, (2005)* US	To explore quality of life, people's experiences of dementia and the impact of negative public attitudes towards dementia *Interview topics: social support, quality of relationships, experiences of stigma and experiences of public's view of dementia*	Participants aged 66-91 (mean age 79) 4 male, 19 female 18 possible/probable AD, 3 MID, 2 dementia type undetermined	Mixed methods study: Quality of Life Scales and semi-structured interview Qualitative data analysis based on Miles and Huberman (1994) and Knafl and Webster (1988) (quantitative data not included in review)

	Friendship		
Harris (2012) USA	To examine whether remaining friendships impact on experience of dementia and what factors are critical to retaining friendship	Participants recruited from Alzheimer's Association, ages 59-85 (mean age 75) 8 women Majority (87%) AD	In-depth interviews, with follow-up interviews for N = 5 Grounded theory
Harris (2013) USA	To examine the quality and nature of friendships of people with dementia, and the effects of diagnosis upon relationships	10 people with dementia and 9 care partners from Alzheimer's Association (and four friends without dementia) Age 57-85 (mean age 72) 4 men, 6 women with dementia Majority (90%) AD	Focus group interviews Individual interviews with friends without dementia (not included in review) Phenomenological, inductive approach, also drawing on Spencer and Pahl (2006) conceptual framework of friendship
	Quality of life (QoL)		
Moyle et al. (2011) Australia	To understand factors that affect QoL for people living with dementia in long-term care, and how they perceive they are valued by others	Long term care residents, aged between 70 and 90+ (mean not reported) 10 men, 22 women Dementia type not reported	Semi-structured interviews Pragmatic, exploratory approach based on interpretative paradigm of Neuman (2000) Computer-assisted thematic concept-mapping
*(Katsuno, 2005, described above)			

	Younger-onset dementia as a unique experience		
Clemerson et al. (2014) UK	To explore subjective experience of young-onset AD, specifically personal, social, and psychological impact and adjustment/coping processes	Participants recruited from NHS services, aged 35-63 7 men, 1 woman Young-onset AD	Semi-structured interviews IPA
Harris (2004) USA	To explored lived experience of people with young onset dementia, specifically focusing on social dimension *Interview topics: family and social relationships, friends' responses, peer groups*	Participants from Alzheimer's Association and DASNI internet network Aged 43-68 (mean age 56) 10 men, 13 women Young-onset dementia, 14 AD, 6 FTD, 1 HD, 1 MCI, 1 'degenerative dementia'	Semi-structured interviews within focus groups and individual interviews (face-to-face and online) Analytic strategy based on Glaser and Strauss (1967)
Pipon-Young et al. (2012) UK	To further understanding of experiences of younger people with dementia (including difficulties encountered in relationships), and their experiences of support services	Participants recruited from NHS services, aged 60-67 years (mean not reported) 1 man, 7 women 7 AD, 1 mixed dementia	Semi-structured interviews Thematic analysis based on Boyatzis (1998) and Corbin and Strauss (2008) and concept mapping from action research interpretative method
	Service user experiences		
Gill et al. (2011) Australia	To understand how people with dementia perceive the interactions they experience from	Participants recruited from community care services, aged	Semi-structured interviews Thematic analysis based on Miles

	community care workers	80-92 (mean not reported) 8 men, 14 women Dementia type not reported	and Huberman (1994) and Spencer et al. (2004), and comparative textual analysis (Beattie et al., 2004)
	Socio-cultural influences		
Mok et al. (2007) China	To explore lived experience of people with dementia in China, and how culture and sociological factors impact on experience of dementia *Interview topic: Impact of forgetfulness on families*	Participants aged 56-80 (mean not reported 4 men and 11 women Dementia type not reported	Guided interviews Qualitative analysis based on Colaizzi (1978)
O'Connor et al. (2010) Canada	To add to literature focusing on how socio-cultural context can shape experience of dementia	1 participant aged 49 with atypical VaD Participant's daughter and partner also included	Longitudinal gathering of data from in-depth interviews, observations, telephone conversations, and health and social care records Narrative and discourse analysis
	Self-identity		
Harris and Sterin (1999) USA	To further understand how people with dementia define their sense of self, and to explore interactions within social psychological context that affirm or impair sense of self *Interview topics: reactions of others, impact of AD on relationships*	Participants recruited through Alzheimer's Association, aged 54-84 (mean age 70), and 15 caregivers 5 men, 12 women with AD	Semi-structured interviews Qualitative analysis based on Glaser and Strauss (1967)

Hedman et al. (2012) Sweden	To use Harre's (1998) social constructionist theory to describe how people with dementia express their sense of self *Interview topics: social situation, and 'self 3' within Harre's theory (how people position themselves and are positioned by others)*	Support group attendees, aged 65-80 (mean not reported) 7 men, 5 women with AD	Semi-structured interviews Content analysis using framework of Harre's (1998) theory of selfhood
Bartlett (2014a; 2014b) UK	<u>Activism and citizenship</u> Bartlett (2014a): To propose social movement theory as a framework for understanding dementia activism. To explore motivations behind people with dementia taking action and tactics used	Activists age 55-78 (mean age 64). 11 men, 5 women. Dementia type not reported.	Diary interview methodology and participant observation. Content and thematic analysis, techniques based on Richards (2005)
	Bartlett (2014b): To inform and advance debate about the psycho-emotional dimensions of disability by highlighting the oppression and barriers experienced by citizens with dementia who campaign for social change.	Activists aged 53-74 (mean age 64) 11 men, 5 women Dementia type not reported	Diary interview methodology and participant observation. Content and thematic analysis, techniques based on Richards (2005)
MacQuarrie (2005) Canada	<u>Awareness and coping</u> To find out how people in the early stages of AD experience their illness *Interview topics: Social questions around spousal, family and friend relationships, care and dependence*	Participants mainly recruited through dementia clinic. Ages 60-89 (mean 76.5) 9 men, 4 women with possible or probable AD	Semi-structured interviews Constant comparative analysis

	Stress Process Model for Individuals with Dementia		
Powers et al. (2014) USA	To use selected components of the Stress Process Model for Individuals with Dementia to further understanding of the illness experience (including family and role strain, and social support)	114 participants aged 50-95 (mean age 77) 46% men, 54% women 50% AD, remaining = mixed dementia, VaD, 'any type' or 'other'. 5.3% MCI	Interviews consisting of 5 open-ended questions Coding process based on Strauss (1987) and interpretation of themes per question

Methodological quality

Methodological quality ratings for each of the included papers are displayed in Table 2. Papers were assessed according to the methodology checklist for qualitative studies developed by NICE (2012), with an overall quality score applied to each as suggested by NICE (2007). No study attained the lowest quality score of **(−)**, where few or no criteria are fulfilled, or unfulfilled quality criteria are felt likely to alter the conclusions of the study. For a full overview of the quality assessment process, see Appendix C and D.

Table 2: Summary of the methodological quality of included studies based on NICE (2007; 2012) guidelines

Quality Rating	
(++): all or most criteria fulfilled. Those unfulfilled are very unlikely to alter conclusions	**(+)**: some criteria fulfilled. Those unfulfilled are unlikely to alter conclusions
Bartlett (2014a)	Beard and Fox (2008)
Bartlett (2014b)	Gill et al. (2011)
Clare et al. (2008)	Harris (2004)
Clemerson et al. (2014)	Katsuno (2005)
Harris and Sterrin (1999)	MacRae (2011)
Harris (2012)	Moyle et al. (2011)
Harris (2013)	O'Connor et al. (2010)
Hedman et al. (2012)	Orulv (2012)
Langdon et al. (2007)	Powers et al. (2014)
MacQuarrie (2005)	
Mason et al. (2005)	
Mok et al. (2007)	
O'Sullivan et al. (2014)	
Pipon-Young et al. (2012)	

In determining quality ratings, the first author gave least weight to the criteria of providing justification for methodological choices. This was because it was hypothesized that a lack of justification was more likely to reflect an absence in the reporting, rather than conduct, of the research. The first author gave more weight to the reliability of data coding, but was aware that the appropriateness of reliability checks for qualitative research is still debated in the field (Barbour, 2001), although NICE (2012) advises that coding should be completed or at least checked by a second researcher for purposes of reliability. Evidence of reflexivity was heavily weighted by the first author as a key component of qualitative research (Finlay, 2002). However, pragmatically, this had little effect upon quality ratings as there was little evidence of reflexivity across all included studies. The quality of the analysis and reporting of findings was given the most weight by the first author in judging methodological quality, as the reliability and validity of original findings would impact upon the reliability and validity of the synthesized themes. In some instances, interpretative themes appeared to be influenced by a priori research questions (MacRae, 2011; Powers et al., 2014), or seemed too broad to tie strongly with all of the data captured within them (Gill et al., 2011; Moyle et al., 2011). For example, in Moyle et al., (2011) the '*Things that influence quality of life'* included aspects of residents' experiences, reality, feelings about their situation, and feelings about how they were perceived. Researchers also did not always refer to discrepant results within their findings, giving the unlikely impression that all participants shared similar perspectives. However, these concerns were not determined to significantly undermine the validity of conclusions drawn as all papers had grounded their results within extracts of original data. As a result, no papers were excluded from the review based on

quality, as their findings held utility in understanding the phenomena in question when looking at the body of research as a whole (Dixon-Woods et al., 2006).

Nevertheless, their methodological limitations still need to be considered. The limited amount of reflexivity potentially impacts upon the reliability of the synthesized themes, as it is more difficult to judge the extent to which the researchers' values and assumptions may have influenced their original findings. It is also important to bear in mind that only a subset of studies directly aimed to investigate the perceived responses of others towards dementia or the perceived impact of social interactions.

Synthesis of findings

The synthesis resulted in 4 themes and 11 subthemes, as displayed in Table 3. The papers contributing to each subtheme are also displayed. An example of the synthesis process is provided in Appendix E.

Table 3: A table of themes and subthemes derived from the synthesis of findings

Themes	Subthemes	Papers (* denotes that paper was included because its findings contrasted with the majority experience of the subtheme)
Social outcasting – being treated as an other	*Stigma, labels, and misconceptions*	Bartlett, 2014a; Harris, 2013; Harris and Sterrin, 1999; Katsuno, 2005; Langdon et al., 2007; MacRae, 2011; Mason et al., 2005; Mok et al., 2007; O'Connor et al., 2007; Orulv, 2012; O'Sullivan et al., 2014; Pipon-Young et al., 2012.
	Social exclusion vs inclusion	Clemerson et al., 2014; Gill et al., 2011; Harris, 2004; Harris, 2012; Harris, 2013; Hedman et al., 2012; Katsuno, 2005; Langdon et al., 2007; Mason et al., 2005; Mok et al., 2007; Moyle et al., 2011; O'Sullivan et al., 2014; Powers et al., 2014.
Social relegation – being treated as lesser	*Disempowerment vs equal status*	Bartlett, 2014a; Bartlett, 2014b; Beard and Fox, 2008; Clare et al., 2008; Gill et al., 2011; Harris and Sterrin, 1999; Harris, 2012; Harris, 2013; Langdon et al., 2007; Mok et al., 2007; MacQuarrie, 2005; Moyle et al., 2011.
	Being treated as incompetent or having one's difficulties dismissed	Bartlett, 2014a; Bartlett, 2014b; Beard and Fox, 2008; Clare et al., 2008; Clemerson et al., 2014; Gill et al., 2011*; Harris, 2004; Harris, 2012*; Harris and Sterrin, 1999; Hedman et al., 2012; Katsuno, 2005; Langdon et al., 2007; MacQuarrie, 2005; MacRae, 2011*; O'Connor, et al., 2010; Orulv, 2012; O'Sullivan et al., 2014; Pipon-Young et al., 2012; Powers et al., 2012.
	Being restricted and limited	Beard and Fox, 2008; Harris and Sterrin, 1999; MacQuarrie, 2005; Mok et al., 2007; Moyle et al., 2011; Powers et al., 2014.
	No longer being asked or heard	Beard and Fox, 2008; Clare et al., 2008; Mason et al., 2005; Mok et al., 2007; Orulv, 2012; Powers et al., 2014.

The impact of others' responses	*Emotional impact*	Beard and Fox, 2008; Clare et al., 2008; Harris, 2004; Harris and Sterrin, 1999; Hedman et al., 2012; Katsuno, 2005; MacQuarrie, 2005; Mason et al., 2005; Mok et al., 2007; Moyle et al., 2011; O'Connor et al., 2010; Orulv, 2012; O'Sullivan et al., 2014; Powers et al., 2014.
	A jeopardized or supported sense of self	Beard and Fox, 2008; Clemerson et al., 2014; Harris, 2012; Harris, 2013; Harris and Sterrin, 1999; Hedman et al., 2012; MacQuarrie, 2005; Mok et al., 2007; Moyle et al., 2011; O'Sullivan, et al., 2014; Pipon-Young et al., 2012.
Strategies to manage the responses of others	*Choosing whom you pay attention to*	Beard and Fox, 2008; Langdon et al., 2007; MacRae, 2011; Mok et al., 2007; O'Sullivan et al., 2014.
Strategies to manage the responses of others	*Disclosing vs withholding*	Clemerson et al., 2014; Hedman et al., 2012; Katsuno, 2005; Langdon et al., 2007; Mok et al., 2007; Mason et al., 2005; O'Connor et al., 2010; Orulv, 2012; O'Sullivan et al., 2014; Pipon-Young et al., 2012.
	Assertions of power and agency	Bartlett, 2014a; Clare et al., 2008; Harris and Sterrin, 1999; MacQuarrie, 2005.

Whilst some studies found that people perceived little change in how others had responded to them since their diagnosis (Hedman et al., 2012; MacRae, 2011; Powers et al., 2014), and were not too concerned about the responses of others, a number of findings suggested that people with dementia perceived that they are treated differently from other people. Two dominant themes were of being outcast from, and relegated in, society.

Social outcasting – being treated as an other

Stigma, labels, and misconceptions

Studies commonly used stigma as a framework to describe the societal conditions surrounding people with dementia. The concerns that people with dementia raised about being categorized, excluded, and relegated were interpreted as perceptions of stigma in some studies (Bartlett, 2014a; Katsuno, 2005; Orulv, 2012). Several studies found that people with dementia were aware of the stigma attached to their condition, and two studies found that people were very conscious of stigma (Harris, 2013; O'Sullivan et al., 2014);

"It's got this stigma to it"
Theme: The pervasiveness of stigma (O'Sullivan et al., 2014, pp.488)

However, the pervasive stigma found by O'Sullivan et al., (2014) was not reflected in all studies. MacRae (2011) found that people with dementia were aware of a level of stigma but most were not concerned by it. Orulv (2012) found that whilst people felt that dementia was perceived by others as shameful, they saw no reason to be ashamed, and in two studies, people with dementia perceived that stigma related to dementia was beginning to reduce (Harris, 2013; MacRae, 2011).

The themes developed by researchers suggest that stigma was sometimes understood as a consequence of dementia (Harris, 2013 – *Impact of the disease*), and sometimes understood as a process within the surrounding social environment (Harris and Sterrin, 1999 – *Impact of the social psychological milieu on self-concept).*

Several studies also highlighted how people with dementia perceived that they risked being labeled by others. These studies found that people with dementia were aware of a labeling process where they were given the name of Alzheimer's disease (Katsuno, 2005) and felt that they were "carrying a sign" (Harris and Sterrin, 1999, pp.254). Some felt that others made assumptions and categorized them based upon the label of dementia (Orulv, 2012; O'Sullivan et al., 2014). Other studies found that people with dementia desired, or tried, to avoid being labeled by others (MacRae, 2011; Langdon et al., 2007; Mok et al., 2007; O'Connor et al., 2007).

The literature suggests that people with dementia perceived that the assumptions held by others about dementia were often incorrect. Two studies found that people with dementia worried that others would wrongly perceive them to be mentally ill (Mason et al., 2005; Mok et al., 2007), and in one study, people with dementia felt that being misperceived as crazy might be related to the language used by others to describe dementia (Langdon et al., 2007);

 "I don't like the word dementia because it means mindlessness"

Theme: Dementia' and Alzheimer's Disease' – fancy words or dreadful names?
(Langdon et al., 2007, pp.992)

In other studies, people with dementia felt that others misperceived dementia as contagious (Katsuno, 2005; Orulv, 2012), and held a misinformed attitude that people with dementia were no longer part of society (O'Sullivan et al., 2014), perhaps particularly because they associated dementia with the "*end stages*" of the condition (O'Sullivan et al., 2014; Pipon-Young et al. 2012, pp.605)*.* In some studies, people with dementia discussed how others did or did not treat them like they were "normal" (Harris, 2012; Langdon et al., 2007; Pipon-Young et al., 2012), suggesting that others could perceive them as abnormal.

One study highlighted that the assumptions that others held about dementia could lead to complicated experiences of stigmatization, where stigma was apparent when people with dementia conformed to stereotypes, but also apparent when they flouted these stereotypes;

Participant 1: "they say, 'Yeah, but I can't understand that there's something wrong with you', they say, 'You know, you take part in the conversation like the rest of us'".

...Participant 2: "...you should just *sit there*".

...Participant 1: "And just dribble or something".

Theme: *In-between trivialization and dismissal – facing double stigmatization*
(Orulv, 2012, pp.31)

The included studies therefore suggested that people with dementia were aware of the stigma and assumptions held by others about dementia and how these can impact upon the way in which others responded to them. People living with dementia perceived that these assumptions were likely driven by a lack of

understanding and education (Katsuno, 2005; Langdon et al., 2007; O'Connor et al., 2010; Pipon-Young et al., 2012).

Social exclusion vs. inclusion

Social exclusion was described by people with dementia across several studies. In the community, people perceived that some friends and family had reduced or ended contact with them since they had been living with dementia (Clemerson et al., 2014; Harris, 2004; Harris, 2013; Hedman et al., 2012; Katsuno, 2005; Langdon et al., 2007; Mason et al., 2005; Mok et al., 2007; O'Sullivan et al., 2014; Powers et al., 2014);

 "she never came to the house or anything. Ah well, excuses ... I didn't have your new address. They all don't check it ... all these friends that I'm talking about. There's a telephone book."

Theme: *Loss of friendship* (Katsuno, 2005, pp.207)

The cessation of social contact by others was framed by Katsuno (2005) as a *"loss of friendship"* and by Langdon et al. (2007) as a *"loss of social status and role"*, reflecting the dominant discourse of loss within the dementia literature. In Harris (2013), descriptions of the withdrawal of friends were captured within the theme "*Impact of the disease*", giving an impression that social exclusion is perhaps an inevitable consequence of the disease process.

However, several studies highlighted that people with dementia also perceived that many friends and family had stood by them (MacRae, 2011; Harris, 2012; 2013; Powers et al., 2014). In some cases, these friends had become more supportive or become closer (Harris, 2013; MacRae, 2011; Powers et al., 2014);

"Friends that I've had for 20, 30, 40 years are still my friends but we talk more. Reach out more often."

Theme: Nature of commitment (Harris, 2013, pp.152)

The themes generated by these studies highlighted the "*importance of relationships*" (Harris, 2012) and the "*significance of others and positive interactions*" (MacRae, 2011).

Two studies highlighted that services could also contribute to perceived experiences of social exclusion or inclusion. People with dementia accessing community support services described the friendly relationships fostered by their workers (Gill et al., 2011), whilst in long term care facilities, staff were perceived as too busy to talk to residents (Moyle et al., 2011). This latter study indicated how people with dementia could feel excluded even when others were around them, an experience shared by people with dementia in other studies (Katsuno, 2005; Mok et al., 2007);

"My children and daughters-in-law do not talk to me. When they come home, they do not talk, just say let's eat…they do not even greet me".

Theme: Problems in communicating with family members (Mok et al., 2007, pp.595).

Social relegation – being treated as lesser

Disempowerment vs equal status

Across several studies, people with dementia perceived that their status in society had been reduced. People described feeling that they had been "*socially demoted*" (Beard and Fox, 2008, pp.1517) and were now treated like second-class citizens (Bartlett, 2014a). They felt that they no longer had equal power within their

relationships (Harris and Sterrin, 1999), were looked down upon (Mok et al., 2007), and lacked dignity and respect from others (Barlett, 2014a; Clare et al., 2008). This change in social status was reported by two studies within a theme of loss (Langdon et al., 2007; Mok et al., 2007), whilst MacQuarrie (2005) reported that there was a "dialectical tension" between the agency of the individual and disempowerment by others;

"So I'd like to be asked by the Handi Dart drivers how well am I on my feet (rather than) have this 200 pounder pick me up like a bag of potatoes and help me in! That's not help!''

Theme: Dialectical tension between agency and objectification (MacQuarrie, 2005, pp.432)

Two studies of healthcare service experiences found that some people with dementia experienced services as controlling and disempowering (Moyle et al., 2011), and did not feel able to ask for things or speak up about service issues (Gill et al., 2011). However, other people with dementia appeared to feel a greater share of power, describing how care workers listened to their ideas and collaborated in providing appropriate care (Gill et al., 2011).

In a study of activism, Bartlett (2014a) found that this perceived social relegation motivated some to take action to improve the position of people with dementia in society. Some people felt able to use their identity as a dementia 'patient' to eke back some power (Bartlett, 2014a). However, even then, the responses of others could maintain a relegated position:

"I feel like others that we are 'wheeled out' when needed"

Theme: 'A high price to pay' (for activism) (Bartlett, 2014b, pp.1300)

Studies of friendship highlighted that people with dementia did not always feel relegated. Many maintained reciprocal relationships with friends (Harris, 2012), who did not see them as any lesser (Harris, 2013). In other studies, people with dementia described feeling valued and appreciated by others, mainly in response to the contributions they made through activism (Bartlett, 2014a; Clare et al., 2008).

Being treated as incompetent or having one's difficulties trivialized

In addition to being relegated in terms of power and status, a number of studies highlighted that people with dementia perceived that they were treated by others as if they were no longer cognitively or functionally capable (Bartlett, 2014a; Beard and Fox, 2008; Clemerson et al., 2014; Harris and Sterrin, 1999; Katsuno, 2005; Langdon et al., 2007; O'Sullivan et al., 2014; Powers et al., 2012). Some found that people with dementia experienced others as patronizing (Clemerson et al., 2014; O'Sullivan et al., 2014). Participants in included studies felt at times that others did too much for them (Harris and Sterrin, 1999; O'Sullivan et al., 2014), or checked unnecessarily as to whether they felt able to fulfill a task (Hedman et al., 2012; O'Sullivan et al., 2014);

"People are so kind to you. They say 'Are you alright? Now are you sure about this or can I help you with that? Let me do it'. This is the attitude. They wouldn't say that if it was you (person without dementia)."

Theme: The impact of patronizing attitudes (O'Sullivan et al., 2014, pp.489)

However, several studies found that people with dementia talked positively about the support received from others (Clemerson et al., 2014; Gill et al., 2011; Harris and Sterrin, 1999; Langdon et al., 2007; MacQuarrie, 2005; MacRae, 2011). One study highlighted that support felt appropriate when offered within the boundaries set by the person with dementia;

"I would rather a friend wait until I ask for help, then help me...I'm trying to hang on to what's left. My friend understands this."
Theme: *Recognition of a person's core values* (Harris, 2012, pp.310)

Whilst some people with dementia perceived that they were unfairly treated as being less competent than they were, another group of studies described a contrasting pattern of responses. Several studies found that people with dementia perceived that others did not always believe they had dementia and trivialized the difficulties associated with dementia (Bartlett, 2014b; Clare et al., 2008; Harris, 2004; O'Connor et al., 2010; Orulv, 2012; Pipon-Young et al., 2012).

"They're treating it as if it's a once-in-awhilers!... Yeah you have once-in-awhilers yeah, you screw up but it's only once in a while. Whereas for me it's an everyday occurrence!"

Theme: Being taken seriously – "it's not sometimers, it's ALLTIMERS!" (O'Connor, Phinney, et al., 2010, pp.35)

Two studies incorporated these findings within themes depicting the experience of "*Dementia Land*", which others could not understand (Clare et al., 2008), and the "*back stage*" "*effects of dementia*" (Bartlett, 2014b), which went unseen by others. Other studies incorporated them within themes highlighting "*others' reactions to*

dementia", which included not wanting to believe the diagnosis (Pipon-Young et al., 2012), and in the themes of "*in between trivialization and dismissal*" (Orulv, 2012) and "*being taken seriously*" (O'Connor et al., 2010), where participants' experiences of trivialization were understood to occur when their presentation deviated from the stereotypes that others associated with dementia.

Being restricted and limited

Across several studies, people with dementia perceived that others imposed unnecessary restrictions and limitations upon them. Some studies found that people with dementia perceived that others limited their activities (Mok et al., 2007), told them what they could or could not do without giving them a chance to prove themselves (Harris and Sterrin, 1999; MacQuarrie, 2005), and did not provide them with opportunities to be of value (Moyle et al., 2011). Other studies highlighted that people with dementia felt restricted when they perceived that they had to do what others wanted instead of what they wanted (Beard and Fox, 2008; Powers et al., 2014), when they were over-protected (MacQuarrie, 2005; Mok et al., 2007), kept indoors (MacQuarrie, 2005), or followed and observed by others (Beard and Fox, 2008; MacQuarrie, 2005);

"It restricts me on everything I'm exposed to…for example, I can't use my power tools when I am here by myself."

Theme: How memory loss affects daily routine (Powers et al., 2014, pp.6)

The way in which restrictions were put in place was also important for some:

"it wasn't the idea of what they did. It was not to have talked to me too!"

Theme: *Dialectical tension between agency and objectification* (MacQuarrie, 2005, pp.432)

In two studies, experiences of restriction and limitation were incorporated within themes describing how the autonomy and self concept of people with dementia could be undermined by the actions of others (Harris and Sterrin, 1999; MacQuarrie, 2005), and in another, limited opportunities for proving one's value was seen to influence quality of life (Moyle et al., 2011).

No longer being asked or heard

Several studies found that people with dementia perceived that their views were no longer sought by others or listened to. Others no longer asked them for advice, did not consult them in decision-making (Beard and Fox, 2008; Powers et al., 2014), and distrusted what they said (Beard and Fox, 2008; Mok et al., 2007). Some were left feeling that others did not care what they thought (Orulv, 2012, Powers et al., 2014), were not interested in hearing about their problems (Mason et al., 2005), or even no longer perceived them to have feelings and needs (Clare et al., 2008);

"The things that I say seem to be a lot more subject to question than they used to be. It's as if I can't possibly know anything anymore"

Theme: Strategies of management – Interactional tensions (Beard and Fox, 2008, pp.1516)

The impact of others' responses

Studies reported on how others' responses were perceived to affect the emotional and psychological well-being of people with dementia, and in two studies, this was

operationalized as impacting upon quality of life (Katsuno, 2005; Moyle et al., 2011).

Emotional impact

Several studies described participants' feelings of frustration, anger, and resentment at the way in which others responded to them (Beard and Fox, 2008; Harris and Sterrin, 1999; Hedman et al., 2012; Katsuno, 2005; MacQuarrie, 2005; O'Connor et al., 2010; Orulv, 2012; O'Sullivan et al., 2014). One study found that others' responses made people more scared about dementia itself (Katsuno, 2005). Feelings of pain and sadness were described (Beard and Fox, 2008; Harris and Sterrin, 1999; Harris, 2004; Katsuno, 2005; Mok et al., 2007), in addition to loneliness in response to social exclusion (Clare et al., 2008; Mason et al., 2005; Moyle et al., 2011; Powers et al., 2014);

"When I was first diagnosed...they all said 'Oh, what can I do?' I just asked them to remain being my friend; I don't know why they left. It hurts so badly."

Theme: Extreme social isolation (Harris, 2004, pp.29)

A jeopardized or supported sense of self

Several studies described how the identity of people with dementia was threatened by the responses of others. In some studies, the responses of others were seen to threaten people's sense of self as competent (Beard and Fox, 2008), or worthy (Mok et al., 2007; Moyle et al., 2011). In other studies, people with dementia described how the responses of others challenged their self-esteem (Harris and Sterrin, 1999), self-confidence (O'Sullivan et al., 2014) and even their sense of self as a human being;

"I'm told I can't do this and can't do that and it puts me on a negative feedback...of a situation where I am no longer a human being."

Theme: Impact of the social psychological milieu on self-concept (Harris and Sterrin, 1999, pp.254)

Moreover, Hedman et al., (2012). highlighted that people's social identities could also be threatened when others undermined their ability to perform previous roles.

In one study, the damaging influence of others upon identity was incorporated within themes depicting "threat to self" as a consequence of dementia (Clemerson et al., 2014) and "identity change" as a "consequence of diagnosis" (Beard and Fox, 2008). In contrast, the findings presented by Harris and Sterrin (1999) were captured within themes depicting the "*social psychological milieu*" surrounding people with dementia as a critical influence upon identity.

Across the studies, it was evident that positive responses from others could support a valued sense of self. Being accepted in the context of valued and reciprocal friendships could make people with dementia feel that they were still themselves and still important (Harris, 2013; Pipon-Young et al., 2012). Friends were also perceived to support people with dementia to maintain their activities (Harris, 2012; MacQuarrie, 2005) and support their values (Harris, 2012);

"Having somebody ring you and share their problems with you. A friend of mine did that yesterday and that was really good you know because it's like she's forgotten [Penny has dementia], and I'm still Penny."

Theme: Resilience (Pipon-Young et al., 2012, pp.608)

Strategies to manage the responses of others

In two studies, the responses of others were perceived to be an additional problem that people with dementia had to deal with on top of any difficulties associated with dementia itself (Beard and Fox, 2008; Orulv, 2012). The theme "*Being part of a bigger picture*" was used to capture this understanding that people's everyday difficulties were tied to their social environment and the behavior of others (Orulv, 2012);

"I think the disease itself is enough problem but the constrictions that they [family members, doctors, etc.] place around you…"

Theme: Resisting Relegation (Beard and Fox, 2008)

"*Strategies of management*" were therefore required in "*Handling relationships*" (Beard and Fox, 2008). Other studies similarly reported that people with dementia needed to develop ways of negotiating the social environment, with themes incorporating terms such as "*managing*" (Langdon et al., 2007) "*strategies*" (Mok et al., 2007), and *"(re)gaining respect*" (Bartlett, 2014a). These were all used to describe ways of handling the responses of others.

Choosing whom you pay attention to

In several studies, people with dementia were described as acutely "*sensitive*" and "*vigilant*" in attending to the responses of others towards them (Beard and Fox, 2008; Langdon et al., 2007; Mok et al., 2007; O'Sullivan et al., 2014). However, one study found that some people with dementia protected themselves by judging the negative opinions of others to be insignificant. They paid little notice to these, and focused instead upon those who responded normally or positively to them (MacRae, 2011);

"Oh, I have no doubt at all but what they probably think, oh poor Ernie Roberts, he's got a hell of a bad memory now. That's up to them. [So you don't let that bother you?] No, there's no point to it."

Theme: Concern about others' treatment of them (MacRae, 2011, pp.450)

Disclosing vs. withholding

A number of studies found that people with dementia made decisions about disclosing their diagnosis. Some found that those who experienced or expected negative responses from others managed this threat by keeping their diagnosis to themselves and trying to cover up any difficulties. Some studies reported these findings within themes emphasizing the active use of management strategies by people with dementia (Langdon et al., 2007 - "*Managing disclosure*"; Pipon-Young et al., 2012 - "*Saving face*"). In other studies, findings relating to withholding and covering up were incorporated within more passive themes pertaining to: "*stigma*" (Katsuno, 2005; Orulv, 2012; O'Sullivan et al., 2014), "*Losing status*" (Mok et al., 2007), "*threat to self*" (Clemerson et al., 2014) and exclusion ("*outside on your own*" – Mason et al., 2005).

"I'm trying to guard that...the reputation, you know...don't want to be looked down on ..."

Theme: Experience of stigma and devaluation (Katsuno, 2005, pp.206)

Contrastingly, studies found that some people with dementia actively chose to disclose their diagnosis to others. This could also be a way of "*saving face*" (Pipon-Young et al., 2012) by legitimizing any symptoms and eliciting understanding rather than negative assumptions (Hedman et al., 2012; O'Connor et al., 2010). It

could also be a way of challenging stigma (Orulv, 2012), or ensuring that one's difficulties were "*being taken seriously*" (O'Connor et al., 2010);

"And I don't want people to think I'm dumb or something. So it's easier if I explain it."

Theme: Being taken seriously - "it's not sometimers, it's ALLTIMERS!" (O'Connor et al., 2010, pp.35).

People with dementia shifted between the two strategies of withholding and disclosing depending upon the "others" in question. This was highlighted in the theme "*Managing levels of disclosure in the private and public worlds*" (Langdon et al., 2007). Three studies found that people with dementia were more likely to disclose to close family or friends (Harris, 2012) than to people in the public domain (Langdon et al., 2007; O'Sullivan et al., 2014). The theme "*You feel your way there*" (Hedman et al., 2012) highlighted the complexity of deciding to whom to disclose, and more widely depicted that socializing can be more complicated when one has memory problems.

Assertions of power and agency

Two studies found that people with dementia at times employed strategies to assert their agency in the face of restrictions and limitation (Harris and Sterrin, 1999; MacQuarrie, 2005). Sometimes this meant being clear to others about what level of support was acceptable, and sometimes it meant going against the restrictions put down by others. Themes reflected the importance of autonomy (Harris and Sterrin, 1999) and the tension between this and objectification by others;

"I stand up for myself more. Like when (spouse) says something about ''We'll do it another time. We don't need them right now'… I'd end up down at the store buying what I want anyway."

Theme: Dialectical tension between agency and objectification (MacQuarrie, 2005, pp433)

Studies described how people with dementia worked hard to be "*a valuable contributing member of society*" (Clare et al., 2008) and to "*(re)gain"* respect and power (Bartlett, 2014a). Some asked that others did not limit them and worked with them (Clare et al., 2008), whilst others used their identities as a 'patient' to stand up to others (Bartlett, 2014a).

In one study, it was apparent that not all people with dementia needed to assert their agency, as not all were concerned about being in a cared-for role. This was understood to reflect that people's need for "*autonomy*" has to be balanced against the "*importance of comfort and security*" (Harris and Sterrin, 1999).

Discussion

Overview of findings

This review aimed to collate and synthesize the subjective experiences of people with dementia in relation to the responses they encounter from others, the perceived impact of these responses, and the ways in which these responses and their impact are managed.

The findings reviewed suggest that people with dementia experience a range of responses from others, with overarching themes relating to being outcast and relegated in status within social interactions. These responses, across studies,

appear to impact negatively upon the emotional and psychological well-being of people with dementia, including their ability to conserve a valued sense of self. This then necessitates the use of management strategies to actively deal with the responses of others and maintain well-being.

The findings of this review are in line with theoretical concepts put forward by Kitwood (1990), who highlighted 25 years ago the malignant social environment that can surround people with dementia and undermine their personhood. Across these studies, the accounts provided by people with dementia depict a social environment that can still be malignant in its processes of stigmatization and labeling, exclusion, patronizing responses, and disempowerment. Accordingly, people with dementia across several studies described the ways in which they perceived their sense of self and well-being to be threatened by the perceived negative responses of others. The impact of others upon self-identity and well-being is also in line with theoretical notions proposed by Sabat (2001; 2002). Across the included studies, people with dementia showed an awareness of being negatively positioned by others when they were treated as an 'other' and treated as 'lesser' as a result of having dementia. Conversely, people perceived that their identity was supported by friends who engaged them in reciprocal interactions. People living with dementia appreciated the friends who viewed them as equals and valued their contributions to the relationship.

The findings of this review share similarities with findings relating to the social interactions of people with dementia identified in previous reviews (de Boer et al., 2007; Steeman et al., 2006), particularly subjective experiences of being ignored and isolated, limited, feeling unaccepted, and being concerned about disclosure, as well as the importance of positive relationships. However, within previous

reviews, such experiences have largely been understood as part of the '*impact*' and '*transitional process*' of dementia. Feelings of loneliness and inadequateness, losses in self-esteem and self-identity were seen to result directly from the disabilities caused by dementia (de Boer et al., 2007; Steeman et al., 2006). However, this review extends the understanding of negative emotional states and loss in the context of dementia, by demonstrating how some losses are perceived by people with dementia to result from the responses of others, rather than dementia itself. It also identifies how people with dementia may actively try to manage the negative responses of others. These findings contrast with the deterministic nature of early biomedical understandings, which viewed the experiences of people with dementia as a passive result of the disease process (Lyman, 1989).

This review also highlights some of the complexities and nuances across the social experiences of people living with dementia. For example, people with dementia may face difficulties not just when they are treated as incompetent, but conversely, when their difficulties are trivialized. In addition, it was clear across the studies that people living with dementia had idiosyncratic experiences of social relationships. Within two very similar studies conducted by Langdon et al. (2007) and MacRae (2011), one sample described a range of negative responses from others (Langdon et al., 2007), whilst another sample perceived that others seldom responded negatively towards them (MacRae, 2011). In two studies of friendship (Harris, 2012; 2013), people with dementia talked about the positive responses of their friends more often than they talked about negative responses.

These differences could be understood in several ways. Firstly, they may reflect individual differences in the way in which people with dementia perceive, experience, and manage others' responses. For example, people who have

internalized a perception of dementia as shameful may be more likely to perceive others' responses as stigmatizing. Secondly, they may reflect differences in methodology. For example, interviews that focused around experiences of friendship may tend to elicit more discussions around positive responses (Harris, 2012; 2013). Furthermore, it is possible that participants recruited from a mental health unit (Langdon et al., 2007) might be surrounded by less supportive 'others' than those recruited from memory clinics and charity organizations (MacRae, 2011; Harris, 2012; 2013). This relates to a third point, that different experiences of others' responses may reflect differences in the kinds of relationships surrounding individuals with dementia.

Across the literature, subtle differences also arose in the angle from which findings were presented. In some studies, the perceived negative responses of others were understood as part of the impact, threat, or losses associated with dementia; the implicit assumption may be that dementia directly causes malignant social processes. In other studies, it was others' responses that were understood to impact upon the experiences and well-being of people living with dementia, and were at times seen as an additional problem on top of the direct effects of dementia. The assumption within these studies appeared to be that the responses of others influence people's experience of living with dementia, although MacRae (2011) also suggested that the responses of the individual and responses of others are likely to interact. The positive interactions described in some studies support the notion that negative responses are not an inevitable part of dementia.

Limitations of the review

It should be remembered that synthesizing the findings of qualitative research presents somewhat of a 'triple hermeneutic' (Suri, 2014). The reviewer is, to an

extent, interpreting the findings of researchers who have interpreted the views of their participants (who have interpreted their own experiences). The first author took a social constructionist epistemological position in her approach to the review. Therefore, an underlying assumption was that no experience of dementia or others' responses is more or less true than any other, as multiple perspectives or 'realities' will exist (Berger and Luckmann, 1966). A further assumption was that subjective experiences are constructed within a social context (Schwandt, 2000). The synthesis therefore attempted to capture and embed the diversity of people's experiences within a useful framework depicting the social context of dementia. As the assumption is that 'realities' are *constructed* rather than simply existing, there are issues in drawing conclusions across studies that have constructed their findings using such a wide range of methodologies and epistemologies. Efforts have been made throughout to ground the findings of this review in the findings and data of the included studies, but it cannot be presumed that the process of synthesis was, or even can be, entirely objective.

There was a paucity of research directly investigating the perceived responses of others and their impact. Furthermore, due to the exploratory nature of qualitative research on dementia, social experiences were not often explicitly addressed within research aims or described in any significant detail within the findings. It is possible that some relevant findings were not identified based upon the chosen inclusion criteria.

Due to the limited subset of studies directly investigating the questions posed by the review, the reliability of the synthesized themes is likely to be strongest where there is coherence between synthesized themes and the original findings of this subset of studies. The three subthemes receiving the least support from this subset

were "*not being asked or heard*", "*being restricted and limited*", and "*assertions of power and agency*". The focus of the studies contributing to these subthemes varied more from the review questions, and their findings therefore required an increased level of interpretation in order to consider them in relation to the entire body of literature. However, an important aspect of an interpretative synthesis is at times to transform original concepts into something new (Dixon-Woods, et al., 2006).

Nine of the included studies did not report the use of reliability checks and/or had gathered data from one method only (see Appendix D), and evidence of reflexivity was lacking across the literature. These methodological limitations make it more difficult to judge whether the original findings of the included studies were reliable and credible, thus potentially impacting upon the reliability and credibility of the synthesis.

With the exception of one study (Mok et al., 2007), all of the included studies sampled their participants from Western countries. It cannot therefore be presumed that the findings will extend to the experiences of people with dementia across cultures. Nevertheless, it is noteworthy that many of the experiences present in Western studies were shared by the Chinese sample interviewed by Mok et al. (2007).

The majority of samples were likely to have included people with mild-moderate dementia. This was not always made explicit, but the in-depth interview methods typically used were likely to have been more suited to this population. The findings therefore may not extend to those with more advanced stages of dementia. The majority of participants were defined as having Alzheimer's Type Dementia,

although different subtypes were present across the literature. From the included studies, it was not possible to draw any conclusions about whether the responses of others towards people with dementia is affected by the subtype of dementia. The included samples varied widely in terms of age and recruitment sources. Whilst many experiences appeared to be shared across the age range and across different services and support groups, there are limitations when synthesizing the experiences of such a diverse range of people. As the average age of participants was 70, it is possible that the responses of others were influenced not just by a person's dementia, but also by their older age. In future research, it will be important to explore whether the responses of others differ depending upon the person's age and other demographics, and whether the social environment surrounding people with dementia differs across people recruited from healthcare services, for example, compared to community support groups. The perspectives of people accessing community and residential healthcare services were particularly limited in this review, and would require further investigation.

Implications for research and practice

The findings of this review remind us that it is not sufficient for us to consider dementia solely as an intrapersonal experience. Within our clinical research and practice, we need to consider that the social context surrounding a person will have a significant impact upon their subjective experience of dementia. Social environmental factors should be a key part of our assessments, and friends, family, and professionals should be assisted in learning how to support people in a way that maintains their social status and sense of identity. With a growing public policy emphasis on developing 'dementia friendly communities' (Department of Health, 2015), it is important that we reflect upon what we mean by 'dementia

friendly', and ensure that the societal changes we seek to make fit with the subjective views and needs of people with dementia themselves.

The evidence presented within this review pertains only to the subjective impact of others' responses upon well-being. Further work is warranted to bring together these findings with quantitative evidence, in order to gain a clearer picture of the subjective and objective impact of the social context upon the well-being and functioning of people with dementia.

Only a small number of studies directly aimed to explore people's perceptions of others' responses towards them. There were also rather contrasting findings amongst two of the studies that did. It would be recommended that further qualitative research seeks to directly elicit the views of people with dementia on this topic, to add to the current understandings presented here. Within this, further study is particularly required to represent the views of those who are missing or limited in the current review; specifically, people with more advanced stages of dementia, people accessing community and residential care services, and people from a wider range of cultural backgrounds. It would also be recommended that future research explores both experiences of both positive and negative responses from others.

Conclusion

Negative responses from others are likely to mean that people have more to adjust to than the direct effects of dementia; they have to adjust to and manage social interactions that potentially ostracize and relegate them. In respect of this, it would be all too easy to again take an intrapersonal approach, by exploring the resilience of those who do not appear to be concerned by these interactions, for

example, or supporting those who are concerned to adjust to their new social position. The more effective and ethical approach, however, would be a systemic one, which seeks to facilitate change within the social context itself. It seems essential that we carefully consider and address the social context surrounding people with dementia as we look for ways to support these individuals to live well.

Conflict of interest

None.

Description of authors' roles

K. Patterson designed the study, carried out the data collection and analysis, and wrote the paper. C.Clarke and E. Wolverson assisted in the formulation of the search strategy, supervised the data collection and analysis, and assisted in preparing the paper.

References

Ablitt, A., Jones, G. V., and Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, *13*, 497-511. doi: 10.1080/13607860902774436.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal*, *322*, 1115-1117. doi: http://dx.doi.org/10.1136/bmj.322.7294.1115.

*****Bartlett, R.** (2014a). The emergent modes of dementia activism. *Ageing and Society*, *34*, 623-644. doi: 10.1017/S0144686X12001158.

*****Bartlett, R.** (2014b). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, *29*, 1291-1304. doi: 10.1080/09687599.2014.924905.

*****Beard, R. L., and Fox, P. J.** (2008). Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss. *Social Science & Medicine*, *66*, 1509-1520. doi: 10.1016/j.socscimed.2007.12.024.

Bennett, D. A., Schneider, J. A., Tang, Y., Arnold, S. E., and Wilson, R. S. (2006). The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: A longitudinal cohort study. *The Lancet Neurology*, *5*, 406-412. doi: 10.1016/S1474-4422(06).

Berger, P. L., & Luckmann, T. T. (1966). *The social construction of reality.* New York, NY: Penguin Books.

Brohan, E., Slade, M., Clement, S., and Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: A review of measures. *BMC Health Services Research*, *10*, 80-90. doi:10.1186/1472-6963-10-80.

*Clare, L., Rowlands, J. M., and Quin, R. (2008). Collective strength: The impact of developing a shared social identity in early-stage dementia. *Dementia*, *7*, 9-30. doi: 10.1177/1471301207085365.

*Clemerson, G., Walsh, S., and Isaac, C. (2013). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia*, *13,* 451-466. doi: 10.1177/1471301212474149.

De Boer, M. E., Hertogh, C. M., Dröes, R. M., Riphagen, I. I., Jonker, C., and Eefsting, J. A. (2007). Suffering from dementia – the patient's perspective: A review of the literature. *International Psychogeriatrics*, *19*, 1021-1039. doi: 0.1017/S1041610207005765.

Department of Health (2015). *Prime Minister's challenge on dementia 2020.* London: Author.

Dixon-Woods, M., et al. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, *6*, 35-48. *BMC Medical Research Methodology*, *6*, 35-47. doi:10.1186/1471-2288-6-35.

Earnshaw, V. A., and Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology*, *17*, 157-168. doi: 10.1177/1359105311414952.

Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*, 209-230. doi: 10.1177/146879410200200205.

*Gill, L., White, L., and Cameron, I. D. (2011). Interaction in community-based

    aged healthcare: Perceptions of people with dementia. *Dementia*, *10*, 539-

    554. doi: 10.1177/1471301211409626.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* New

    Jersey: Prentice-Hall Inc.

*Harris, P. B. (2004). The perspective of younger people with dementia: Still an

    overlooked population. *Social Work in Mental Health*, *2*, 17-36. doi:

    10.1300/J200v02n04_02.

*Harris, P.B. (2012). Maintaining friendships in early stage dementia: Factors to

    consider. *Dementia*, *11*, 305-314. doi: 10.1177/1471301211421066.

*Harris, P. B. (2013). Dementia and friendship: The quality and nature of the

    relationships that remain. *The International Journal of Aging and Human

    Development*, *76*, 141-164. doi: 10.2190/AG.76.2.c.

*Harris, P.B., and Sterin, G. J. (1999). Insider's Perspective: Defining and

    Preserving the Self of Dementia. *Journal of Mental Health and Aging*, *5*, 241-

    256.

*Hedman, R., Hansebo, G., Ternestedt, B. M., Hellström, I., and Norberg, A.

    (2012). How people with Alzheimer's disease express their sense of self:

    Analysis using Rom Harré's theory of selfhood. *Dementia*, *12,* 713-733. doi

    10.1177/1471301212444053.

Hochgraeber, I., Riesner, C., and Schoppmann, S. (2013). The experience of

    people with dementia in a social care group: Case study. *Dementia*, *12*, 751-

    768. doi: 10.1177/1471301212444300.

Jacoby, A., Snape, D., and Baker, G. A. (2005). Epilepsy and social identity: The stigma of a chronic neurological disorder. *The Lancet Neurology, 4*, 171-178. doi:10.1016/S1474-4422(05)01014-8.

*Katsuno, T. (2005). Dementia from the inside: How people with early-stage dementia evaluate their quality of life. *Ageing and Society, 25*, 197-214. doi: 10.1017/S0144686X0400279X.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society, 10*, 177-196. doi: 10.1017/S0144686X00008060.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham: Open University Press.

La Fontaine, J., and Oyebode, J. R. (2014). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society, 34*, 1243-1272. doi: 10.1017/S0144686X13000056.

*Langdon, S. A., Eagle, A., and Warner, J. (2007). Making sense of dementia in the social world: A qualitative study. *Social Science & Medicine, 64*, 989-1000. doi:10.1016/j.socscimed.2006.10.029.

Levy, B. (1996). Improving memory in old age through implicit self-stereotyping. *Journal of Personality and Social Psychology, 71*, 1092-1107. doi: 10.1037/0022-3514.71.6.1092.

Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist, 29*, 597-605. doi: 10.1093/geront/29.5.597.

*MacRae, H. (2011). Self and other: The importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies*, *25*, 445-456. doi:10.1016/j.jaging.2011.06.001.

*Macquarrie, C. R. (2005). Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial. *Aging & Mental Health*, *9*, 430-441. doi: 10.1080/13607860500142853.

*Mason, E., Clare, L., and Pistrang, N. (2005). Processes and experiences of mutual support in professionally-led support groups for people with early-stage dementia. *Dementia*, *4*, 87-112. doi: 10.1177/1471301205049192.

*Mok, E., Lai, C. K., Wong, F. L., and Wan, P. (2007). Living with early-stage dementia: The perspective of older Chinese people. *Journal of Advanced Nursing*, *59*, 591-600. doi: 10.1111/j.1365-2648.2007.04368.x.

*Moyle, W. et al. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Aging & Mental Health*, *15*, 970-977. doi: 10.1080/13607863.2011.583620.

National Institute for Health and Care Excellence (NICE) (2007). *Clinical guideline development methods: The guidelines manual 2007.* London: Author. Retrieved from http://www.h2mw.eu/redactionmedicale/2011/07/NICE_GuidelinesManual AppendixH.PDF.

National Institute for Health and Care Excellence (NICE) (2012). *Clinical guideline development methods: The guidelines manual 2012.* London: Author. Retrieved from http://publications.nice.org.uk/pmg6b.

*O'Connor, D., Phinney, A., and Hulko, W.** (2010). Dementia at the intersections: A unique case study exploring social location. *Journal of Aging Studies*, *24*, 30-39. doi:10.1016/j.jaging.2008.08.001.

*Örulv, L.** (2012). Reframing dementia in Swedish self-help group conversations: Constructing citizenship. *International Journal of Self Help and Self Care*, *6*, 9-41. doi: http://dx.doi.org/10.2190/SH.6.1.c.

*O'Sullivan, G., Hocking, C., and Spence, D.** (2013). Dementia: The need for attitudinal change. *Dementia*, *13,* 483-497. doi: 10.1177/1471301213478241.

*Pipon-Young, F. E., Lee, K. M., Jones, F., and Guss, R.** (2011). 'I'm not all gone, I can still speak': The experiences of younger people with dementia. An action research study. *Dementia*, *11*, 597-616. doi: 10.1177/1471301211421087.

*Powers, S.M., Dawson, N.T., Krestar, M.L., Yarry, S.J., and Judge, K.S.** (2014). 'I wish they would remember that I forget': The effects of memory loss on the lives of individuals with mild-to-moderate dementia. *Dementia, 0,* 1-15. doi: 10.1177/1471301214553236.

Ross, C. A., and Goldner, E. M. (2009). Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: A review of the literature. *Journal of Psychiatric and Mental Health Nursing*, *16*, 558-567. doi: 10.1111/j.1365-2850.2009.01399.x.

Sabat, S.R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell Publishers.

Sabat, S.R. (2002) Selfhood and Alzheimer's Disease. In P.B. Harris (Ed.) *The person with Alzheimer's Disease: Pathways to understanding the experience* (pp.88-112). Baltimore: The Johns Hopkins University Press.

Sabat, S. R., Napolitano, L., and Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American journal of Alzheimer's disease and other dementias*, *19*, 177-185. doi: 10.1177/153331750401900311.

Schomerus, G., et al. (2012). Evolution of public attitudes about mental illness: A systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, *125*, 440-452. doi: 10.1111/j.1600-0447.2012.01826.x.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry: Interpretitivism, hermeneutics and social constructivism. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 189-214). Thousand Oaks, CA: Sage.

Steeman, E., Casterlé, D., Dierckx, B., Godderis, J., and Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal of Advanced Nursing*, *54*, 722-738. doi:10.1111/j.1365-2648.2006.03874.x.

Suri, H. (2014). *Towards methodologically inclusive research syntheses: Expanding possibilities.* Oxon: Routledge.

Part Two: Empirical Paper

Positive and Meaningful Changes: A Qualitative Exploration of Growth in

Older People's Lived Experiences of Dementia

Kirsty Patterson[1]*, Dr. Emma Wolverson[1], & Dr. Chris Clarke[1]

[1]Department of Psychological Health and Wellbeing,

University of Hull, Hull, United Kingdom, HU6 7RX

*Corresponding Author: Tel: +44 1482 464106, Fax: +44 1482 464093

Email Address: K.M.Patterson@2012.hull.ac.uk

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

Aging & Mental Health

Please see Appendix F for the guidelines for contributors

Word count: 5,999 (excluding references & tables)

Abstract

Objectives

The dominant discourse surrounding dementia is typically one of loss and decline. However, for people aging without dementia, or living with other illnesses, a discourse involving personal growth has developed. The concept of growth has not been previously explored in research investigating the subjective experience of dementia. A qualitative study was therefore conducted to explore the nature and extent of growth amongst older people living with dementia.

Method

Semi-structured interviews were carried out with nine older people living with dementia. Interpretative Phenomenological Analysis was used to explore and develop an interpretative account of participants' subjective experiences of dementia and growth.

Results

The analysis generated two major themes of 'Moving Forward' and 'Living in the Now'. 'Moving Forward' encapsulated participants' experiences of continuing to live and progress, feeling connected to life, and learning and evolving as people. 'Living in the Now' captured participants' experiences of living well in the present, where the future uncertainty of dementia was a background concern, but could also confer a greater sense of significance to living in the present. These themes were compared to theoretical concepts within existing models of growth.

Conclusions

The findings suggest that personal growth can be a possible and meaningful experience in the lives of people with dementia. The findings also raise questions about the societal discourses that may prevent older people from drawing upon growth narratives as they navigate life with dementia.

Introduction

The societal narratives surrounding dementia typically revolve around loss, suffering, and decline (Mitchell, Dupuis, & Kontos, 2013). However, there is a growing recognition that many individuals continue to live well in spite of dementia (Alzheimer's Society, 2014). Individuals have been shown to employ active coping strategies (Clare, 2002; Pearce, Clare, & Pistrang, 2002), and sustained spirituality (Dalby, Sperlinger, & Boddington, 2011; Katsuno, 2003; Snyder, 2003), positive relationships (Harris, 2012, 2013; Hellstrom, Nolan, & Lundh, 2007), and hope (Wolverson, Clarke, & Moniz-Cook, 2010) in the presence of dementia. Such work is stimulating a different narrative; that it is possible to *live well with*, and not just *suffer from*, dementia.

Looking beyond the literature base on dementia, however, further narrative options have been developed to help make meaning out of people's experiences. These include narratives of growth, which pertain to the concept that people might live well not just *in spite* of adverse circumstances, but *because* of them. The concept of growth has been studied in relation to aging (Tornstam, 1989), trauma (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004), and living with illness (Paterson, 2001). As we broaden and update the traditional discourses surrounding dementia, it is pertinent to examine whether, and to what extent, growth narratives are applicable to the experience of living with dementia.

Gerotranscendence

The theory of gerotranscendence posits that older people can naturally redefine themselves, their relationships, and develop existentially, as part of normative aging (Tornstam, 1989, 2005, 2011). In support of this, older adults have reported an increased appreciation for life, a stronger focus upon the quality of

relationships, and enhanced spirituality with age (Rempel, 2013). This theory complements other theories of positive aging, which suggest that older people can achieve more affective emotion regulation by increasingly devoting their resources to their most meaningful and pleasurable activities and relationships (Carstensen, 1992), and can attain a state of wisdom and contentment in older age (Erikson, 1963).

When we consider older people living with dementia, it may be easy to forget the positive transformations that can emerge with age. Empirical research has yet to demonstrate that dementia precludes growth through aging.

Post-traumatic growth (PTG)

Traumatic events can shatter people's assumptions about life, but through the restructuring of these assumptions, it is thought that people can be positively transformed (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). This has been defined as post-traumatic growth (PTG) and is commonly described in relation to growth of the self, interpersonal growth, and existential growth, for instance, re-evaluating one's priorities (Joseph & Linley, 2005). People living with physical illnesses have described experiences of growth across these domains, in addition to enhanced body awareness and healthier lifestyle choices (Hefferon, Grealy, & Mutrie, 2009).

Receiving a dementia diagnosis can be traumatic for some (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Steeman, Casterle, Dierckx, & Godderis, 2006; Werezak & Stewart, 2002). It is therefore possible that this event could stimulate PTG amongst some individuals, and PTG may even accelerate existing processes of

gerotranscendence (Weiss, 2014). Empirical research has not yet examined these possibilities.

Wellness within illness

Dementia may not always be experienced as a trauma. A number of individuals are not surprised, and even relieved, to receive a diagnosis of dementia (Aminzadeh et al., 2007; Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006; Jha, Tabet, & Orrell, 2001), which may mean that their assumptions are not shattered as suggested by theories of PTG (Tedeschi & Calhoun, 2004). However, growth may also occur through a more gradual process of navigating life with a chronic illness.

Moch (1989) suggested that illness can enhance a person's sense of meaning in life. A number of people living with a chronic illness have been found to relegate illness to the background of their experience, and live with 'wellness in the foreground' (Paterson, 2001, pp.24). From this perspective, illness is framed as an opportunity for meaningful change, often via an increased focus upon emotional, spiritual, and relational experiences.

It is possible that people may similarly frame dementia as an opportunity for growth. Again, no empirical research to date has explored this notion.

Growth in the current dementia literature

It is perhaps due to the negative discourses traditionally surrounding dementia that research has neglected to look for or recognise growth in people living with dementia. Accounts of positive experiences from people with dementia are often interpreted as a 'façade' or lack of awareness (Steeman, et al., 2007, pp.125) or might be overlooked by traditional approaches to outcome measurement in

dementia (Moniz-Cook et al., 2008). Furthermore, negative discourses may inhibit the experience of growth itself, as growth is thought to be facilitated by discourses around positive change (Paterson, 2001; Tedeschi & Calhoun, 2004), and hindered by stigma (Paterson, 2001) and negative attitudes to aging (Tornstam, 2005). The study of growth may also have been neglected due to the emphasis upon the role of cognitive processing in some models (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). It may be assumed that cognitive impairment will consequently impede growth, but some suggest that growth is not always a cognitive process (Bauer & Park, 2010).

However, a small body of research has explored growth amongst caregivers of people with dementia (Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991; Kramer, 1997; Leipold, Schacke, & Zank, 2008; Ott, Sanders, & Kelber, 2007; Peacock et al., 2010; Sanders, 2005). These studies have identified that whilst the caregiving experience can generate strains, it can also generate positive gains, for example, developing inner strength, and stimulating caregivers to re-evaluate their lives (Sanders, 2005).

To the authors' knowledge, only two studies have explicitly examined positive transformations in people with dementia. Kitwood (1995) and Fukushima (2005) documented positive changes such as increased warmth, appreciation and capacity for friendship, and enjoyment of the present, as observed by professional and family caregivers. In other studies, people with dementia have perceived positive transformations within themselves, despite the fact that these studies did not intend to study growth. Table 4 summarises the transformations reported by some participants within these studies.

Table 4: A summary of positive changes reported by participants in previous studies

Study	Positive changes reported
Clare (2002)	• Becoming a better Samaritan • Understanding and learning more about oneself
Dalby, Sperlinger, & Boddington (2011)	• Developing more understanding for others with difficulties and greater compassion
Hedman, Hansebo, Ternestedt, Hellstrom, & Norberg (2012)	• Becoming more humble, less prestige-seeking • Becoming more open • Lowering of ambitions and demands upon oneself, in order to focus on personal well-being • Enhanced appreciation of family relationships
Preston, Marshall, & Bucks (2007)	• Increased sensitivity towards others • Forming new relationships • Developing new interests • Finding new sources of meaning • Becoming more open • Becoming less worried about trivial things
Stuckey, Post, Ollerton, Fallcreek, & Whitehouse (2002)	• Becoming a better person • Slowing down to enjoy life and enjoy family relationships

These largely serendipitous findings have been conceptualised in relation to frameworks of acceptance (Stuckey et al. 2002), coping with dementia by fighting (Clare, 2002) or simply being positive (Preston et al. 2007). Without an explicit exploration of growth, potentially positive transformations in the lives of people with dementia may continue to go overlooked.

To fully understand the lived experience of dementia, we need to consider positive as well as negative experiences, rather than assume that these cannot co-exist (Aspinwall & Tedeschi, 2010). The positive psychology movement, which brings

empirical attention to positive experiences, traits, and virtues (Seligman & Csikszentmihalyi, 2000), has been criticised for failing to accept, understand, and validate negative experiences (Held, 2004). However, there is an equal risk and ethical concern if we fail to accept, understand, and validate positive experiences in dementia where they do occur.

An understanding of positive experiences is important if we are to effectively enable and empower people with dementia to live well. There is some evidence that growth may confer beneficial effects in mood and physical health (Helgeson, Reynolds, & Tomich, 2006; Sawyer, Ayers, & Field, 2010). It has been argued that these effects are not consistent, and that perceptions of growth are sometimes an illusion (Zoellner & Maercker, 2006). However, it is important to consider that the *subjective* experience of growth may be a positive outcome in its own right, regardless of whether it equates to objective change. It is also relevant to consider that whilst difficult experiences in dementia may not enhance hedonic well-being (i.e. feelings of happiness), they may contribute to eudaimonic well-being; an increased sense of meaning and living according to one's values (Ryff & Singer, 2008). In order to understand the nature of growth as experienced by people with dementia, it is essential to seek the perspectives of people with dementia themselves.

Aims

This study aimed to explore the subjective experience of growth amongst older people living with dementia. Due to the exploratory nature of this endeavour and the intention to elicit participants' personal, lived experiences, a qualitative methodology was employed. Specifically, the study aimed to explore: (i) in what

ways growth might be experienced in individuals living with dementia and (ii) how these individuals might make sense of growth experiences.

Method

Design

This was a qualitative study using semi-structured interviews to explore the concept of growth in older adults with dementia. Interview data was transcribed and analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009).

Sample

Purposive sampling was used to develop a sample that was sufficiently homogenous for in-depth analysis. Individuals were therefore only included if they were over the age of 65, living in the community, and were willing and able to consent to take part in a conversation about positive experiences and dementia (see Appendix G and H for information and consent procedures). Guidelines for the Rating of Awareness Deficits (GRAD) (Verhey, Roozendaal, Ponds, & Jolles, 1993) were used as a guide for assessing participants' awareness of their dementia diagnosis (see Appendix I). Participants were included if they were comfortable answering questions about living with dementia. Individuals were excluded if they had a co-existing learning disability and if they had received their dementia diagnosis less than three months previously; to allow for adjustment, and because couples have been found to increasingly focus upon remaining abilities, rather than limitations, after this time point (Derksen et al., 2006).

Participants were nine individuals with a clinical diagnosis of dementia. They were recruited from an NHS memory clinic in the North of England (N=4), charity-led community groups (N=1), and groups associated with the Dementia Engagement and Empowerment Project (DEEP; http://dementiavoices.org.uk) in the North of England and Scotland (N=4). The majority of participants (N=8) volunteered in response to verbal advertisements of the study at their relevant group. One volunteered after being informed about the study through a research mailing list. One participant was excluded for reasons of capacity, and the data of a further participant could not be included due to a failure of the recording device.

Participant demographics are presented in Table 5 (see Appendix J for further demographic details). Eight participants described themselves as white British and one as white Scottish. Eight out of nine participants lived with a spouse. There were a larger number of men (N=6) than women (N=3). Ages ranged from 65-81 years (mean= 74.5 years).

Table 5: Participant demographics

Pseudonym	Gender	Age	Dementia type (AD = Alzheimer's Disease, VaD = Vascular Dementia)	Time since diagnosis
Ruth	F	81	AD	18 months
George	M	72	VaD	5 months
David	M	81	AD	6 years
Edward	M	72	AD	7 months
Robert	M	77	AD	8 months
Susan	F	65	AD	11 years
Shirley	F	75	AD	4 years
Arthur	M	74	AD	2 years
Douglas	M	74	VaD	2 ½ years

Data collection

The study was reviewed and granted approval by a local Research Ethics Committee (see Appendix K).

Interviews were guided by a semi-structured interview schedule, which remained flexible to accommodate novel experiences. Participants were informed that the first author was interested in hearing about their experiences of living with dementia, any changes that had occurred, and particularly interested in any changes that had been positive or meaningful for them. The schedule was developed from qualitative and quantitative investigations of growth in other areas of the literature, with prompts relating to domains of (i) relationships, (ii)

personal attributes, (iii) activities and lifestyle, and (iv) beliefs and outlook on life (see Appendix L for details).

Interviews were tape-recorded and transcribed. Seven participants chose to have their spouse present, and spouses occasionally contributed to the conversation. However, due to the study's focus upon the subjective experiences of people with dementia, these contributions were not analysed. Interviews lasted between 35 and 112 minutes.

Data analysis

A social constructionist epistemology underpinned the research study. The method of Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) was selected to analyse the interview transcripts, as its phenomenological approach fit with the epistemological assumption that multiple, subjective 'realities' of growth within the context of dementia may exist (Berger & Luckmann, 1966). The principle of hermeneutics within IPA acknowledges the influence of a researcher's pre-conceived ideas upon the analysis (Smith et al., 2009), which according to social constructionism, are inevitably shaped by the social context (Schwandt, 2000). The first author's socio-cultural position meant that she was more likely to be in touch with the values held by and privileged to young, educated, white British adults. She was aware of her personal tendency, shaped through her upbringing, to draw out the positive aspects of people's narratives, but a professional tendency, shaped through her Clinical Psychology training, to also acknowledge and validate negative experiences. She therefore took a detailed approach to the analysis, considering positive and negative experiences, and looking for the meanings behind participants' words. (See Appendix O and P for a full discussion of epistemology and full reflective statement).

The analysis was an ongoing, reflexive process involving three broad stages:

1) Transcripts were read multiple times to become immersed in participants' experiences. A detailed line-by-line analysis generated descriptive codes to capture participants' experiences and understandings in their own words (see Appendix M for an example). To ensure that no meaningful data was missed, two full transcripts, and a subsection of each remaining transcript, were coded independently by a peer researcher. As a result, 40 additional descriptive codes were added to the next stage.

2) Content and linguistic aspects of descriptive codes were examined to arrive at an interpretative understanding. Codes were clustered into themes for each transcript based on the interpreted meaning.

3) Themes were compared and contrasted across all transcripts, and built into an overarching conceptual framework (see Appendix N for a table of themes and supporting quotes).

Results

The themes and subthemes developed from participants' accounts are presented in Figure 2. This Figure illustrates how participants' experiences of Moving Forward occurred within the context of normative processes of aging well, but their experiences of learning and evolving as people were additionally stimulated by the more atypical experience of dementia. The future threat of dementia was present, but a background concern, which could stimulate Living in the Now and enhance the significance of the present day.
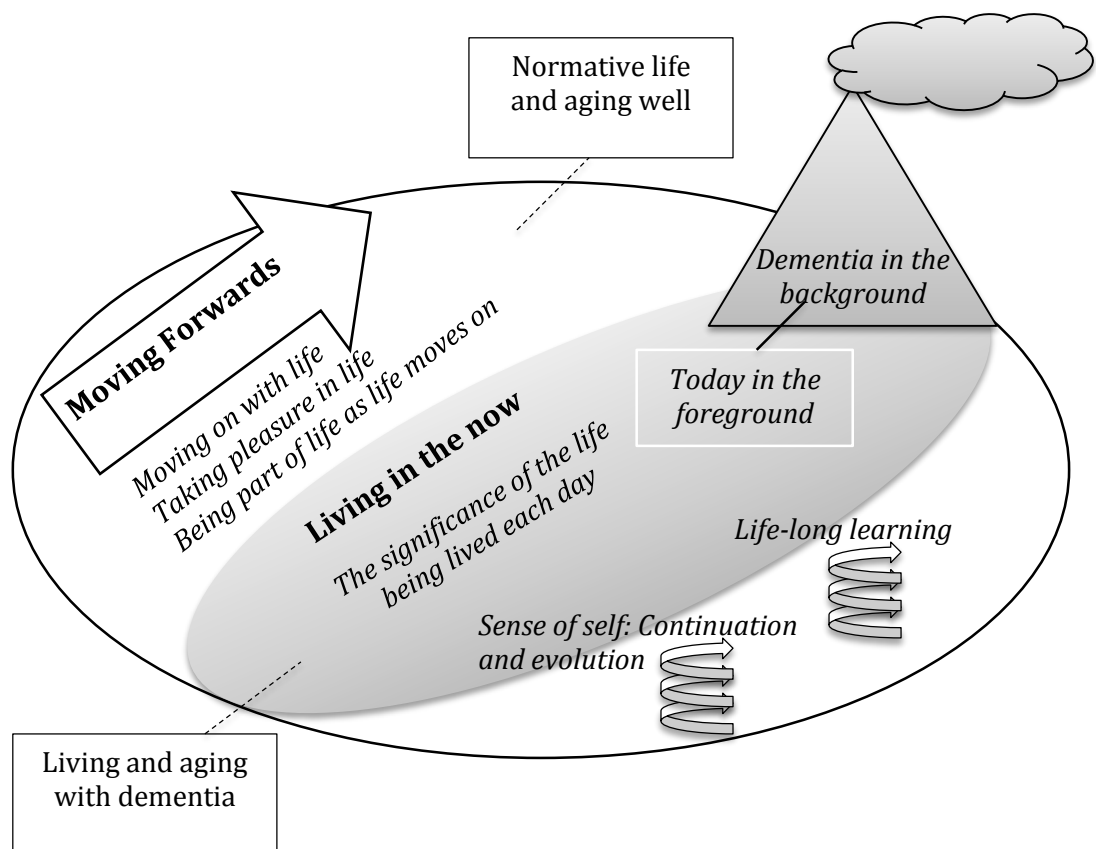
Figure 2: A pictorial depiction of themes

Moving Forwards

Moving on with life

Participants' accounts indicated that life did not stop because they had dementia.

As Douglas explained: '*It's not a death sentence'.* Part of participants' ability to

move forward related to their sense that the current effects of dementia could be

'*annoying', 'irritating', and 'frustrating'*, but not overwhelming;

'*Dementia hasn't been a burden. It's something that I've got to constantly live with,*

but it's not a burden.' (David)

Participants talked openly about the negative effects of dementia and aging.

However, they accepted, or were developing acceptance of these. Acceptance often

meant knowing that '*it's just the way it is*' (Arthur), and not wasting time '*wishing*' that things were different (Ruth, George);

 'You just accept it…Nothing you can do about it. If you could have a cup of tea and make it better, you'd have a cup of a tea!' (Robert)

Participants' acceptance of their situation allowed them to move forwards with life in spite of dementia. Moving forwards was expressed as common sense approach that just happened; reflected in pragmatic phrases such as '*you just get on*' and '*carry on*'. For some, moving forwards was a more conscious decision in response to dementia:

'You've got to think yes I am going to pull through and get on with life' (Susan)

Taking pleasure in life

Interviewer: 'What is it (that) *you like about it* (making journals)*?'*
Shirley: 'Everything. I want to see it, I want to go for it, I'm gonna pack it in'

As participants moved forwards with their lives, there was still much to be enjoyed in life. The words *'enjoyment', 'pleasure', 'interest', 'exciting',* and *'thrill'* suffused participants' narratives. Whilst participants described activities that they had given up or were less able to take part in, they also described a range of new hobbies and activities that they had begun.

Many participants described '*slowing down*' as they grew older with dementia, but several found enjoyment in living at a different pace. Ruth took pleasure in her '*supporting*' rather than '*organising*' events, as she could then go only if she *wanted* to; not because she *had* to. George was more able to take notice of what was

around him and enjoy his leisure activities, which he had been too tired to enjoy during his working life.

Focusing on the positive and pleasurable aspects of life was sometimes an active choice. Participants talked about '*thinking positive'* (Susan) and '*looking on the good side'* (Arthur). Ruth reflected that as she grew older;

'*You don't want to waste time on things you can't do anything about, and also you don't want to be unhappy too much*' (Ruth).

Enjoyment and positivity appeared to be a normative part of how participants moved forwards with their lives as they grew older.

Being part of life as life moves on

As participants moved on with their individual lives, life moved on in a wider sense, and participants were connected to this. Participants held valued social identities that were important in being part of a bigger picture in life. Despite altering her role within a community group, other members still sought Ruth out for advice and to reminisce; '*so you're still connected, you're not chopped off.'*

Participants also offered their wisdom to others and observed it being carried on by future generations. Arthur and Douglas explained that within their community groups, they supported each other to learn ways of living with dementia; '*we've taught each other really*' (Arthur)

Shirley's narrative suggested that her approach in life, to '*go where you've got to go*') was being carried on by her grandson, who was now going where he needed to go in life. Ruth understood this process as '*the normal course of things'*, and for

her and Douglas, it was important that they supported future generations by
'*pass*(ing) *on'* their respective knowledge:

'I want to make a difference for people who are coming at the back of me, people
(with dementia) *in the next ten years.'* (Douglas)

Life-long learning

Participants also remained engaged in a process of learning about themselves and
about life. Some learnt new ways of approaching life as they aged, such as saying
no to things that they did not want to do (Ruth) or learning to worry less (Arthur).
Dementia did not appear to stop this normative journey of life-long learning. For
some, living with dementia was an additional '*learning curve*' (Ruth), because as
Robert pointed out; '*I've never had it* (dementia) *before*'.

Participants learnt about dementia and ways to live with it, both practically and in
more philosophical ways. David explained what he had learnt about
communicating when you and those around you have dementia:

'You learn to talk to people, in a different way…there's more to learn from having
dementia than not'. (David)

Sense of self: Continuation and evolution

As participants moved forwards with life, so did their sense of self. There was a
strong sense of continuity in participants' identities, commonly conveyed in
statements beginning: *'I've always…'* and *'I still…'* Participants described how in
many ways: '*I don't feel any different!'* (George)

Other people were involved in maintaining the continuity of participants' lives and identities, via the continuing qualities of their relationships and by treating participants in much the same way as they always had.

Participants' sense of self also continued to evolve. They recognised the changes that occurred as they grew older with dementia, reporting '*I'm not as...*' or '*I'm more...*' or '*I can't do...*'. Yet they were able to update their own standards, expectations, and approach to tasks to adjust to these changes;

'*I can't do what I used to do, but I've just got to do what I can do, you know, and be happy with that' (George*)

This meant that a perceived continuity of self and an awareness of change could co-exist. Evolution also did not just refer to things that participants were less able to do. They continued to build upon life-long qualities and skills, or applied these in new ways – sometimes because of dementia. Arthur, who used to help older people in residential care, now helped to keep others positive at the community groups he attended for people with dementia. David had been developing his capacity for openness within his relationships throughout life, and continued to develop this whilst living with dementia. Age could also influence this evolution, for example, Edward perceived that '(as) *you get older, you become more tolerant.'*

Evolution was conveyed in the language used by participants to describe how processes had '*shifted*', '*open(ed)',* '*move(d)'* or been '*strengthened';* at times '*triggered'* by some '*catalyst'.* Dementia was the catalyst for some, stimulating participants to discover or develop new aspects of themselves. Susan had always been one to '*bottle things* (feelings) *up*' but since having dementia had started to

tell people if she was not happy with something they said. For Douglas, dementia had opened '*a new leaf*' in his book, for '*the new me*', where he felt more aware of people's difficulties and compassionate towards them. Edward explained how his focus in life had shifted since his diagnosis:

'I think that's because I realized that – what was really important…The relationships. That's what's important.' (Edward)

The evolution of self was often described as a process that '*just happened'.* At the same time, participants often appeared to have engaged in conscious processes of analysis and decision-making. Edward felt that receiving a diagnosis of dementia initially '*forces you'* to analyse, and Ruth found that she would '*suddenly realise*' the changes associated with aging and dementia. However, both then actively pursued this analysis, looking '*at the parts of me that…weren't too comfortable'* (Edward) and opening *'other little facets of things that you start looking at'* (Ruth).

Growth and development could therefore occur within the normative context of aging, but could also be stimulated within the landscape of dementia. As Douglas explained:

'That's how I look at my dementia…It's a volcano that's there, it's dangerous, but at the bottom of that, there's a fertile land, that you can grow and you can expand' (Douglas)

Living in the Now

Whilst participants moved forward, there was an equally important sense that they engaged with life in the present.

Today in the foreground, dementia in the background

Part of living in the now meant participants focused on today rather than dwelling on the future. The future concept of dementia was described in very different terms to their current '*irritating*' experiences; it was something uncertain, and at times, frightening. Participants were concerned about losing their sense of self, with language that conveyed a sense that this might *'suddenly happen', 'at any moment'.* This future threat seemed to loom in the '*back of* (the) *mind'* (Susan), like a volcano *'in the background, smoking away.'* (Douglas)

The future threat of dementia was therefore acknowledged by participants, but was in the background of their daily lives. Sometimes, this took a conscious effort; a case of '*try*(ing) *to forget'* (Arthur). However, participants chose to '*just look at today...not tomorrow*' (Arthur), had learnt to *'switch off'* (Robert), or chose not to '*dwell*' on it (Susan, Douglas), and to engage in enjoyed activities instead. Some just did not think much about the future threat of dementia:

 'I don't even think about it. (Laughs). I just come in here (art room) *and I'm here all day...I'll find something and do that'* (Shirley)

Participants therefore did not spend much time thinking about the future of dementia, whether this was effortless or a more conscious choice. For some, the ability to focus on the present also seemed to be aided by age-related changes, such as learning to worry less about the next day (Arthur). It was also aided by participants' perception that they were generally happy and satisfied with their current lives. Overall, participants felt very '*lucky*' in life;

'I'm a very happy, satisfied person. I've a lovely wife, good God, what else can I ask for?' (David)

The significance of the life being lived each day

For some, living with dementia added an extra sense of significance to their daily lives. For one participant, significance was enhanced by both dementia and some recent difficult life events. People compared themselves to others with dementia and felt lucky in comparison:

'(I'm) the lucky one, I've got the short term memory loss, which I think is quite brilliant, compared to other people' (Susan)

George, who had had several strokes leading up to his diagnosis of vascular dementia, felt that *'it learns you to enjoy things more'* and *'makes you realise…to be satisfied with what you've got'.* His strokes and dementia had enhanced his enjoyment and satisfaction with his present life.

For others, it was the *future* threat of dementia that conferred a greater level of significance to the present. Some explained that they did what they wanted to, or what was important to them *now*;

'I don't say well I could do that tomorrow. I do it now because I don't know what's going to happen to me when I wake up'. (Douglas)

Susan and Douglas explained that their previous approach in life had been *'happy go lucky'* and '*easy-weasy',* but starting a new day now was a more significant event. As Susan explained; '*now, I think well, yes, I've - I have woke up, I am the same, I am going to get on with life'.*

Discussion

Overview of findings

According to lifespan development theories, human beings adapt to circumstances and develop across their lives (Sigelman & Rider, 2009). In contrast, the experiences of people with dementia are often considered from a perspective of loss and regression (Grebe, Otto, & Zimmermann, 2013). Participants in this study, however, demonstrated that they were continuing to adapt, learn, and evolve as they grew older with dementia.

The collective experiences of participants strongly suggested that they continued to move forward with life. This was partly due to their continued sense of self, which has been previously identified as a key aspect of well-being (Pearce, et al., 2002; Preston et al., 2007; Steeman, et al., 2007; Werezak & Stewart, 2002). In previous studies, changes caused by dementia have also been understood to create discontinuity (Preston et al., 2007), resulting in attempts to *cope with* and *manage* changes and threats to identity (Clare, 2002; Clare, 2003; Clare, Roth, & Pratt, 2005; Werezak & Stewart, 2002). In contrast, perhaps, participants in this study experienced continuity of self alongside an awareness that some things had changed. This may be because they were able to integrate changes associated with dementia (Werezak & Stewart, 2002) and aging (Whitbourne & Sneed, 2002) into their identities.

Participants in this study were aware of the activities and relationships that they valued and enjoyed the most, and were motivated to seek out positive experiences. This approach has been evident in previous studies (Clare, 2002; Pearce et al., 2002; Preston et al., 2007), and interpreted largely as a way of coping with or

fighting dementia. However, within normative processes of successful aging, older people are suggested to select the activities and relationships that are most pleasurable and important to them, making compensations as necessary (Baltes & Baltes, 1990) to focus their time and energy upon them (Carstensen, 1992). The findings here suggest that these processes are not necessarily inhibited by dementia.

Tornstam (2005, 2011) suggested that older people experience transcendental and existential shifts as they take an increasingly collective approach to living in the world and perceive their lives as part of a connected whole. Similarly, participants in this study viewed their lives within a bigger picture, which included others around them and future generations. These processes again did not appear to be solely in response to dementia, but part of participants' journeys of aging well.

Participants' experiences of living with dementia suggested that they tended to live with 'wellness in the foreground' (Paterson, 2001). Participants' continued sense of self alongside their awareness of change may have reflected an ability to update appraisals of what is normal or feasible in the context of a chronic illness (Paterson, 2001). Participants' evolving sense of self included developments such as enhanced compassion and enhanced appreciation of life and relationships. Notably, such themes were described by Paterson (2001) in relation to how some individuals use illness as an opportunity for meaningful change.

People living with chronic illness are proposed to relegate illness to the background of their daily experience, in order to focus upon living well (Paterson, 2001). In some ways, living in the present was more desirable for participants than contemplating the future threat of dementia, which in previous studies, has been

interpreted as avoidance and a coping strategy (Clare et al., 2005). However, it seemed that these participants often elected to live well in the present rather than waste time and energy focusing upon difficulties or worrying about the future. These findings highlight the possibility that processes underpinning well-being and growth when living with a chronic illness are also applicable to living with dementia.

Participants' approaches to living with dementia were also reflective of the principles of mindfulness, where emphasis is placed upon experiential awareness in the present moment (Kabat-Zinn, 2003). A similar transformation was observed in people living with dementia in Japan (Fukushima, 2005). A truly mindful approach is to engage in present experiences regardless of whether they are deemed positive or negative (Kabat-Zinn, 2003). Whilst it was striking how participants in this study were motivated to seek out positive experiences, they were also accepting of the more negative aspects of living with dementia, as found previously (Werezak & Stewart, 2002). Due to the episodic memory problems often associated with dementia, it might be assumed that people with dementia are more engaged with past memories than present moments, but these findings suggest that this is not necessarily the case.

Participants appeared to continue to learn and grow as a part of the typical course of human development, but coupled with growth stimulated by more atypical experiences; commonly, dementia. Participants' experiences of enhanced compassion and appreciation of their lives and relationships are congruent with the serendipitous findings of previous research (Clare, 2002; Dalby et al., 2011; Hedman et al., 2012; Preston et al., 2007). They are also in line with theories of

PTG, as are the experiences of those participants who renegotiated what was important to them (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004).

In line with PTG theories, periods of cognitive processing appeared to have facilitated these developments, indicating that growth is still possible within conditions that affect cognitive abilities. Given that this particular sample were likely to be living with mild-moderate stages of dementia, it is possible that the cognitive aspects of growth are complicated by advanced stages of dementia. However, Bauer and Park (2010) suggest that many forms of growth in older people are experiential, rather than cognitive, where growth is a *felt* sense. Given the importance placed on cognitive capacity within Western society, it is important to remember that growth may not only occur via cognitive routes.

The experience of growth outlined in models of *post*-traumatic growth implies that trauma is located in the past. However, for some of these participants, growth was stimulated by experiences of living with dementia in the present, or anticipated experiences of dementia in the future. In this way, the nature of growth in dementia may differ somewhat from growth stimulated by other life events.

Atypical, and traumatic life events have the potential to stimulate PTG (Joseph & Linley, 2005; Tedeschi & Calhoun, 2004), and may accelerate gerotranscendence (Weiss, 2014). The findings of this study can be seen to reflect this potential interplay between age-related and post-traumatic growth. There was not always one singular 'catalyst' for growth amongst participants who were growing older, living with dementia, and experiencing other life events. It is never possible to know if participants would have experienced similar forms or levels of growth had they grown older without dementia. However, findings indicated that the presence

of dementia did not preclude experiences of growth, and some participants felt strongly that dementia had played a key role in this process. Both of these notions have been largely over-looked in previous research. This may reflect the negative discourses surrounding dementia, and perhaps a malignant tendency to dehumanise people with dementia (Kitwood, 1997), thus preventing us from considering that they too may be engaged in normal developmental and adaptive processes.

Limitations

Findings are limited by the small sample studied; participants' views are not intended to be representative of all people with dementia. Measuring the cognitive functioning of participants was beyond the scope and epistemological position of this study, however, it is likely that the included participants would be regarded clinically as living with 'mild-moderate' dementia. In future, more creative approaches may be needed to investigate whether subjective experiences of growth differ amongst individuals living with more advanced dementia. The majority of participants were White British, whose experiences may differ from individuals in other cultures. The general impression was that participants had positive relationships with family and friends, which may facilitate growth (Tedeschi & Calhoun, 2004). As an exploratory study, this research provides an initial idea of what growth might look like for a small set of individuals, but it will be important in future to extend this to a broader range of people.

Some have argued that growth can be a purely subjective experience, and at times a defensive mechanism (Zoellner & Maercker, 2006). This study does not intend to categorise participant's experiences into subjective or 'objective' changes. Moreover, it could be argued that feeling that one is growing as a person whilst

living with dementia is a hugely important outcome in its own right. The importance of the subjective perspectives of people living with dementia should not be minimised, as highlighted in principles of person-centred care (NICE, 2006). It will be important to further explore growth as a subjective experience, and additionally investigate how it might be associated with more 'objective' measures of quality of life and well-being in dementia.

Implications

Growth narratives are commonly used by older people to make meaning of their experiences (Bauer & Park, 2010), and yet have not previously been explored in older people living with dementia. This could be because older people with dementia do not always draw upon growth narratives, or because researchers do not ask them about these. In either case, we need to wonder about the underlying assumptions that may prevent people from considering growth in the context of dementia, and how these assumptions drive our clinical work and research. This is particularly important as both Paterson (2001) and Tornstam (2005) suggest that societal attitudes and discourses can impede people's capacities to grow.

One common assumption is that dementia is solely a loss-based experience, and based upon this, we may focus upon supporting people to maintain previous activities and adapt to losses. The current findings instead suggest that well-being may also be enhanced when people living with dementia are supported to try new activities and learn new skills. Another common assumption is that the ability to remember experiences is critical to people's happiness (Kahneman, 2010). However, we are reminded that happiness can be gained in one moment, regardless of whether the specifics of this are later remembered (ESRO, 2014). Activities that focus upon reminiscence and reviewing past events can be very

meaningful, however, the current findings also emphasise the meaning and enjoyment that can be gained when people with dementia are engaged in the present moment.

Conclusions

Throughout this research, the authors were aware of the dangers of creating yet another oppressive discourse for people with dementia. Each person's experience of dementia will be different, and the aim of this study is therefore not to suggest that *all* people with dementia *should* be turning their illness into a meaningful and life changing experience. The purpose of this study was to explore a previously over-looked discourse, and to offer it as an equally valid discourse to any other. The experiences of these participants suggested that whilst dementia presented current difficulties and future threats, it also created a fertile land in which they could continue to learn and grow as people. Perhaps for those navigating life with dementia, this will be a useful discourse for some.

References

Alzheimer's Society. (2014). *Dementia 2014: An opportunity for change*. London: Author.

Aminzadeh, F., Byszewski, A., Molnar, F. J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, *11*, 281-290. doi: 10.1080/13607860600963695.

Aspinwall, L. G., & Tedeschi, R. G. (2010). The value of positive psychology for health psychology: Progress and pitfalls in examining the relation of positive phenomena to health. *Annals of Behavioral Medicine*, *39*, 4-15. doi: 10.1007/s12160-009-9153-0.

Baltes, P.B., & Baltes, M, M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. Baltes, & M. Baltes (Eds.), *Successful aging*: *Perspectives from the behavioral sciences* (pp. 1–34). Cambridge: Cambridge University Press.

Bauer, J. J. & Park, S. W. (2010). Growth is not just for the young: Growth narratives, eudaimonic resilience, and the aging self. In P.S. Fry & C.L. Keyes (Eds.), *New frontiers in resilient aging: Life-strengths and well-being in late life* (pp. 60-89). New York, NY: Cambridge University Press.

Bellizzi, K. M., & Blank, T. O. (2006). Predicting posttraumatic growth in breast cancer survivors. *Health Psychology, 25*, 47-56. doi: 10.1037/0278-6133.25.1.47.

Berger, P. L., & Luckmann, T. T. (1966). *The social construction of reality.* New York, NY: Penguin Books.

Carstensen, L. L. (1992). Social and emotional patterns in adulthood: Support for

    socioemotional selectivity theory. *Psychology and Aging, 7,* 331-338. doi:

    10.1037/0882-7974.7.3.331.

Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of

    Alzheimer's disease. *Aging & Mental Health, 6*, 139-148. doi:

    10.1080/1360786022012682 6.

Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's

    disease. *Social Science & Medicine, 57*(6), 1017-1029. doi:10.1016/S0277-

    9536(02)00476-8.

Clare, L., Roth, I., & Pratt, R. (2005). Perceptions of change over time in early-stage

    Alzheimer's disease Implications for understanding awareness and coping

    style. *Dementia, 4,* 487-520. doi: 10.1177/1471301205058304.

Clare, L., Rowlands, J. M., & Quin, R. (2008). Collective strength: The impact of

    developing a shared social identity in early-stage dementia. *Dementia, 7*, 9-

    30. doi: 10.1177/1471301207085365.

Dalby, P., Sperlinger, D. J., & Boddington, S. (2011). The lived experience of

    spirituality and dementia in older people living with mild to moderate

    dementia. *Dementia, 11*, 75-94. doi: 10.1177/1471301211416608.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M., & Scheltens, P.

    (2006). Impact of diagnostic disclosure in dementia on patients and carers:

    Qualitative case series analysis. *Aging and Mental Health, 10*, 525-531. doi:

    10.1080/13607860600638024.

Erikson, E.H. (1963). *Childhood and Society. (2nd ed.).* New York, NY: W.W. Norton.

ESRO (2014). *A good life with dementia*. London: Author.

Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991).

    Finding meaning: An alternative paradigm for Alzheimer's disease family

    caregivers. *The Gerontologist, 31*, 483-489. doi: 10.1093/geront/31.4.483.

Fukushima, T., Nagahata, K., Ishibashi, N., Takahashi, Y., & Moriyama, M. (2005).

    Quality of life from the viewpoint of patients with dementia in Japan:

    nurturing through an acceptance of dementia by patients, their families and

    care professionals. *Health & Social Care in the Community*, *13*, 30-37.

    doi: 10.1111/j.1365-2524.2005.00534.x.

Grebe, H., Otto, W., & Zimmermann, H. (2013). "The journey into the land of

    forgetfulness". Metaphors of aging and dementia in the media. In U.

    Kriebernegg & R. Maierhofer (Eds.), *The ages of life: Living and aging in

    conflict?* (pp.89-144). Bielefeld: Transcript Verlag.

Harris, P.B. (2012). Maintaining friendships in early stage dementia: Factors to

    consider. *Dementia, 11*, 305-314. doi: 10.1177/1471301211421066.

Harris, P. B. (2013). Dementia and friendship: The quality and nature of the

    relationships that remain. *The International Journal of Aging and Human

    Development, 76,* 141-164. doi: 10.2190/AG.76.2.c.

Hedman, R., Hansebo, G., Ternestedt, B. M., Hellström, I., & Norberg, A. (2012). How

    people with Alzheimer's disease express their sense of self: Analysis using

    Rom Harré's theory of selfhood. *Dementia*, *12,* 713-733. doi

    10.1177/1471301212444053.

Hefferon, K., Grealy, M., & Mutrie, N. (2009). Post-traumatic growth and life

    threatening physical illness: A systematic review of the qualitative literature.

    British Journal of Health Psychology, 14, 343-378.

    doi:10.1348/135910708X332936.

Held, B. S. (2004). The negative side of positive psychology. *Journal of Humanistic Psychology, 44*, 9-46. doi: 10.1177/0022167803259645

Helgeson, V. S., Reynolds, K. A., & Tomich, P. L. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology, 74,* 797. doi: 10.1037/0022-006X.74.5.797.

Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia*. Dementia, 6*, 383-409. doi: 10.1177/1471301207081571.

Jha, A., Tabet, N., & Orrell, M. (2001). To tell or not to tell—comparison of older patients' reaction to their diagnosis of dementia and depression. *International Journal of Geriatric Psychiatry, 16*, 879-885. doi: 10.1002/gps.412.

Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology, 9,* 262-280. doi: 10.1037/1089-2680.9.3.262.

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical Psychology: Science and Practice, 10*, 144-156. doi: 10.1093/clipsy/bpg016.

Kahneman, D. (2010, February). The riddle of experience vs. memory [Video file]. Retreived from http://www.ted.com/talks/daniel_kahneman_the_riddle_of_experience_vs_memory?language=en.

Katsuno, T. (2003). Personal Spirituality of Persons with Early-Stage Dementia: Is it related to perceived quality of life? *Dementia, 2,* 315-335. doi: 10.1177/14713012030023003.

Kitwood, T. (1995). Positive long-term changes in dementia: Some preliminary

    observations. *Journal of Mental Health, 4*(2), 133-144.

    doi:10.1080/09638239550037677.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to

    Alzheimer's disease. *Ageing and Society, 10*, 177-196. doi:

    10.1017/S0144686X00008060.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham:

    Open University Press.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next?

    The Gerontologist, 37, 218-232. doi: 10.1093/geront/37.2.218.

Leipold, B., Schacke, C., & Zank, S. (2008). Personal growth and cognitive

    complexity in caregivers of patients with dementia. *European Journal of*

    Ageing, 5(3), 203-214. doi 10.1007/s10433-008-0090-8.

Mitchell, G. J., Dupuis, S. L., & Kontos, P. (2013). Dementia discourse: From imposed

    suffering to knowing other-wise. *Journal of Applied Hermeneutics.* Retrieved

    from

    http://jah.journalhosting.ucalgary.ca/jah/index.php/jah/article/view/41

Moch, S. D. (1998). Health-within-illness: Concept development through research

    and practice. *Journal of Advanced Nursing, 28,* 305-310. doi: 10.1046/j.1365-

    2648.1998.00790.x.

Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012).

    Functional analysis-based interventions for challenging behaviour in

    dementia. *The Cochrane Library, 2.* doi: 10.1002/14651858.CD006929.pub2.

National Institute for Health and Care Excellence (NICE) (2006). *Dementia:*

    Supporting people with dementia and their carers in health and social care.

NICE clinical guideline 42. London: Author. Retrieved from

    www.guidance.nice.org.uk/cg42.

Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience

    of spouses and adult-child caregivers of individuals with Alzheimer's disease

    and related dementias. *The Gerontologist, 47*, 798-809. doi:

    10.1093/geront/47.6.798.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of*

    Nursing Scholarship, 33, 21-26. doi: 10.1111/j.1547-5069.2001.00021.x.

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., ... &

    Henderson, S. R. (2009). The positive aspects of the caregiving journey with

    dementia: Using a strengths-based perspective to reveal opportunities.

    Journal of Applied Gerontology, 29, 640-659. doi:

    10.1177/0733464809341471.

Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: Coping in the

    early stages of Alzheimer's disease. *Dementia, 1*, 173-192. doi:

    10.1177/147130120200100205.

Preston, L., Marshall, A., & Bucks, R. S. (2007). Investigating the ways that older

    people cope with dementia: A qualitative study. *Aging & Mental health, 11,*

    131-143. doi: 10.1080/13607860600844572.

Rempel, A. R. (2013). Gerotranscendence and successful aging: The lived

    experience. (Unpublished Master of Social Work Clinical Research Paper). St.

    Catherine University: Minneapolis, MN.

Ryff, C. D., & Singer, B. H. (2008). Know thyself and become what you are: A

    eudaimonic approach to psychological well-being. *Journal of Happiness*

    Studies, 9, 13-39. doi: 10.1007/s10902-006-9019-0.

Sabat, S.R. (2001). *The experience of Alzheimer's disease: Life through a tangled* veil. Oxford, UK: Blackwell Publishers.

Sabat, S.R. (2002) Selfhood and Alzheimer's Disease. In P.B. Harris (Ed.), *The person with Alzheimer's Disease: Pathways to understanding the experience* (pp.88-112). Baltimore, MD: The Johns Hopkins University Press.

Sanders, S. (2005). Is the glass half empty or half full? Reflections on strain and gain in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care, 40*(3), 57-73. doi:10.1300/J010v40n03_04.

Sawyer, A., Ayers, S., & Field, A. P. (2010). Posttraumatic growth and adjustment among individuals with cancer or HIV/AIDS: A meta-analysis. *Clinical Psychology Review, 30*(4), 436-447. doi:10.1016/j.cpr.2010.02.004.

Schwandt, T. A. (2000). Three epistemological stances for qualitative Inquiry: Interpretitivism, hermeneutics and social constructivism. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 189-214). Thousand Oaks, CA: Sage.

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*, 5-14. doi: 10.1037/0003-066X.55.1.5.

Sigelman, C., & Rider, E. (2014). *Life-span human development (7th ed.).* Belmont, CA: Cengage Learning.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London, UK: Sage Publications.

Snyder, L. (2003). Satisfactions and challenges in spiritual faith and practice for persons with dementia. *Dementia, 2*, 299-313. doi: 10.1177/14713012030023002.

Steeman, E., Casterlé, D., Dierckx, B., Godderis, J., and Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal of Advanced Nursing, 54*, 722-738. doi:10.1111/j.1365-2648.2006.03874.x.

Steeman, E., Godderis, J., Grypdonck, M., De Bal, N., & De Casterlé, B. D. (2007). Living with dementia from the perspective of older people: is it a positive story? *Aging & Mental Health, 11*, 119-130. doi: 10.1080/13607860600963364.

Stuckey, J. C., Post, S. G., Ollerton, S., FallCreek, S. J., & Whitehouse, P. J. (2002). Alzheimer's disease, religion, and the ethics of respect for spirituality: A community dialogue. *Alzheimer's Care Today, 3,* 199-207. Retrieved from Ovid: 0130990-200203030-00004.

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15*, 1-18. doi:10.1207/s15327965pli1501_01.

Tornstam, L. (1989). Gero-transcendence: A reformulation of the disengagement theory. *Aging Clinical and Experimental Research, 1*(1), 55-63.

Tornstam, L. (2005). *Gerotranscendence: A developmental theory of positive aging*. New York, NY: Springer Publishing.

Tornstam, L. (2011). Maturing into gerotranscendence. *Journal of Transpersonal Psychology, 43,* 166-180. Retrieved from http://www.atpweb.org/jtparchive/trps-43-11-02-166.pdf

Verhey, F. R., Rozendaal, N., Ponds, R. W., & Jolles, J. (1993). Dementia, awareness and depression. *International Journal of Geriatric Psychiatry, 8,* 851-856. doi: 10.1002/gps.930081008.

Weiss, T. (2014). Personal transformation: Posttraumatic growth and

gerotranscendence. *Journal of Humanistic Psychology, 54*(2), 203-226. doi:

10.1177/0022167813492388.

Werezak, L., & Stewart, N. (2002). Learning to live with early dementia. *The*

Canadian Journal of Nursing Research, 34, 67-85. Retrieved from PsycInfo:

2002-15264-004.

Whitbourne, S.K., & Sneed, J.R. (2002). The paradox of well-being, identity

processes, and stereotype threat: Ageism and its potential relationships to

the self in later life In T.D. Nelson (Ed.), *Ageism: Stereotyping and prejudice*

against older persons (pp. 247-275). USA: MIT Press.

Wolverson, E. L., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early-

stage dementia: A qualitative study. *Aging & Mental Health, 14*, 450-460. doi:

10.1080/13607860903483110.

Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology—A

critical review and introduction of a two component model. *Clinical*

Psychology Review, 26, 626-653. doi:10.1016/j.cpr.2006.01.008.

Part three: Appendices

Appendix A: Manual preparation and submission instructions for authors of the journal *International Psychogeriatrics*

<u>Scope and contributions</u>

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, "for debate" articles, case reports, letters to the editor, book reviews and 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 (2013) is 1.892. 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

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. Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. 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 for protocol only papers should omit the third sub-heading (Results). Abstracts for case reports should have no sub-headings. 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. Any statistical procedures used should be outlined and their

use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

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. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ2).

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. 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: 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.

For a journal article: **Smith, J., Jones, W. I. and Doe, J. T.** (1996). *Psychogeriatrics for pleasure and profit: an expanding field*. International Journal of Unreproducible Results, 3, 240–242. doi:12.3456/S123456789.

For a book: **Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V.** (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter. **Park, K., Tiger, B. and Runn, F.** (1999). Psychogeriatrics in context. In G.Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.
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 come 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, but because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

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."

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

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.

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: Communication with the editor of journal *International Psychogeriatrics*

☆ **ipaj-ed** ⌄

To: Kirsty Patterson   Cc: Joan Mary Mould

    ipaj-ed@unimelb.edu.au

RE: Systematic literature review

9 February 2015 05:44

Inbox - Exchange 📁

Dear Kirsty Patterson,

thank you for your interest to publish your work in International Psychogeriatrics (IPG). Systematic reviews are popular with readers of IPG and reviewing the qualitative literature on how people with dementia experience responses by others to their illness is an interesting approach. I therefore encourage you to submit your review to IPG via ScholarOne. In your conclusions it would be helpful to put the discussion in the international context as IPG is an international journal.

kind regards
Nicola Lautenschlager
Editor-in-Chief, International Psychogeriatrics

Appendix C: NICE (2012) methodology checklist for qualitative studies

Study identification Include author, title, reference, year of publication		117
Guidance topic:	**Key research question/aim:** .	
Checklist completed by:		

	Circle or highlight one option for each question	
Section 1: theoretical approach		
<u>1.1</u> **Is a qualitative approach appropriate?** *For example:* • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings (in healthcare this would apply to how care is organised and patient experiences of care)? Or could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
<u>1.2</u> **Is the study clear in what it seeks to do?** *For example:* • Is the purpose of the study discussed – aims/objectives/research	Clear Unclear Mixed	Comments:

question(s)? • Are the values/assumptions/theory underpinning the purpose of the study discussed?		
Section 2: study design		
<u>2.1</u> **How defensible/rigorous is the research design/methodology?** *For example:* • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?	Defensible Not defensible Not sure	Comments:
Section 3: data collection		
<u>3.1</u> **How well was the data collection carried out?** *For example:* • Are the data collection methods clearly described? • Were the data collected appropriate to address the research question?	Appropriate Inappropriate Not sure/ inadequately reported	Comments:
Section 4: validity		
<u>4.1</u> **Is the context clearly described?** *For example:* • Are the characteristics of the participants and settings clearly defined? • Were observations made in a	Clear Unclear Not sure	Comments:

variety of circumstances and from a range of respondents? • Was context bias considered (that is, did the authors consider the influence of the setting where the study took place)?		
4.2 **Were the methods reliable?** *For example:* • Were data collected by more than one method? • Were other studies considered with discussion about similar/different results?	Reliable Unreliable Not sure	Comments:
Section 5: analysis		
5.1 **Are the data 'rich'?** *For example:* • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • Has the detail of the data that were collected been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
5.2 **Is the analysis reliable?** *For example:* • Did more than one researcher	Reliable	Comments:

theme and code transcripts/data? • If so, how were differences resolved? • Were negative/discrepant results addressed or ignored? • Is it clear how the themes and concepts were derived from the data?	Unreliable Not sure/not reported	
5.3 **Are the findings convincing?** *For example:* • Are the findings clearly presented? • Are the findings internally coherent (that is, are the results credible in relation to the study question)? • Are extracts from the original data included (for example, direct quotes from participants)? • Are the data appropriately referenced so that the sources of the extracts can be identified? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:
5.4 **Are the conclusions adequate?** *For example:* • How clear are the links between data, interpretation and conclusions?	Adequate Inadequate Not sure	Comments:

• Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Are the implications of the research clearly defined? • Is there adequate discussion of any limitations encountered?		
Section 6: ethics		
<u>6.1</u> **Was the study approved by an ethics committee?**	Yes No Not sure/not reported/not applicable	Comments:
<u>6.2</u> **Is the role of the researcher clearly described?** *For example:* • Has the relationship between the researcher and the participants been adequately described? • Is how the research was explained and presented to the participants described?	Clear Not clear Not sure/not reported	Comments:

Appendix D: Summary table of included studies based on NICE (2012) quality checklist

Study	Theoretical approach	Study design	Data collection	Validity & reliability	Analysis	Reflexivity	Overall quality rating
Bartlett (2014a)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear and reliable	Good	Lacking	++
Bartlett (2014b)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear and reliable	Good	Lacking	++
Beard and Fox (2008)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear and reliable	Adequate	Lacking	+
Clare et al. (2008)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear, reliability somewhat questionable	Very good	Lacking	++
Clemerson et al. (2014)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear, reliability	Very good	Lacking	++

				somewhat questionable			
Gill et al. (2011)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear, reliability somewhat questionable	Adequate	Lacking	+
Harris and Sterrin (1999)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear, reliability somewhat questionable	Good	Lacking	++
Harris (2004)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear, reliability somewhat questionable	Adequate	Lacking	+
Harris (2012)	Appropriate and clear	Appropriate but rationale not always clear	Appropriate	Clear and reliable	Very good	Lacking	++
Harris (2013)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Good	Lacking	++

Hedman et al. (2012)	Appropriate and clear	Appropriate but rationale not always clear	Appropriate	Clear, reliability somewhat questionable	Good	Lacking	++
Katsuno (2005)	Appropriate and clear	Appropriate but rationale not always clear	Appropriate	Clear and reliable	Adequate	Lacking	+
Langdon et al. (2007)	Appropriate and clear	Appropriate but rationale not always clear	Appropriate	Clear, reliability somewhat questionable	Very good	Lacking	++
MacQuarrie (2005)	Appropriate and clear	Appropriate but rationale not always clear	Appropriate	Clear and reliable	Good	Lacking	++
MacRae (2011)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear, reliability somewhat questionable	Adequate	Lacking	+

Mason et al. (2005)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Very good	Lacking	++
Mok et al. (2007)	Appropriate and clear	Appropriate although rationale not always clear	Appropriate	Clear and reliable	Very good	Lacking	++
Moyle et al. (2011)	Appropriate and clear	Appropriate, but rationale not always clear	Appropriate	Clear, reliability somewhat questionable	Adequate	Lacking	+
O'Connor et al. (2010)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Adequate	Lacking	+
O'Sullivan et al. (2014)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Good	Lacking	++
Orulv (2012)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Adequate	Lacking	+
Pipon-Young et al. (2012)	Appropriate and clear	Appropriate and defensible	Appropriate	Clear and reliable	Very good	Lacking	++

| Powers et al. (2014) | Appropriate and clear | Appropriate, but rationale not always clear | Appropriate | Clear, reliability somewhat questionable | Adequate | Lacking | + |

Appendix E: An example of synthesised themes

Subtheme: *Stigma, labels, and misconceptions* (a theme requiring a lower degree of interpretation)

Supporting studies: Example findings	Commentary	Synthesis
Bartlett (2014a, pp. 634) Theme: *(Re)gaining respect* "Clearly, these <u>participants were conscious</u> of how people with dementia are <u>stigmatised</u> and sought to (re) gain respect in an effort to change this"	People are conscious of stigma associated with dementia. (Stigma is linked to experiences of relegation)	*Subtheme: Stigma, labels, and misconceptions* The majority of these findings suggest that people with dementia are conscious of being stigmatized by others, although not all are concerned about this (MacRae, 2011). They also suggest that people with dementia are concerned about being labelled by others (often the label of being 'mental' or stupid). People with dementia feel that others hold misconceptions/
Harris (2013, pp. 154) Theme: *Impact of disease* Subtheme*: <u>Societal level: Felt stigma</u>* "All the people with dementia talked about having a diagnosis of dementia often made them feel <u>stigmatized</u>, a feeling of '<u>otherness'</u>, though as more people became aware and knowledgeable about AD, <u>public opinion is beginning to change</u>. This <u>stigma can affect friendship development</u>"	The impact of the disease on a societal level is an experience of stigma (caused by disease itself?) People feel stigmatized and like an 'other' due to diagnosis. Stigma can impact on relationships Stigma is beginning to change through awareness/education	
Harris & Sterrin (1999, pp.254) Theme: *Impact of the social psychological milieu on self-concept* "It's <u>like a stigma, like carrying a sign</u> that you are sort of demented, and you can't do this and you can't do that."	Dementia diagnosis can be like carrying a sign defining you and your abilities. People are aware of this labelling process and feel stigmatized as a result. Stigma is part of the social	

"(Participant) was able to verbalize aspects of this milieu delineated by Kitwood: disempowerment, labeling, stigmatization, and feelings of banishment. He is well aware of the labelling process"	psychological environment surrounding dementia	stereotypes about dementia – that it means that people are 'mental' or that it always affects
Katsuno (2005, pp.206) Theme: *Experiences of Stigma and Devaluation* "The emotional experience of having Alzheimer's disease is very complicated, since <u>the disease readily produces stigma</u> and the devaluation of the sufferer by others."	Experience of having dementia includes experience of stigma. The disease itself seems to be seen to produce this stigma	people as would be seen in the advanced stages of dementia. Orulv (2012) suggests that stigma is also reflected in the way that
Langdon, Eagle, et al. (2007, pp.992) Theme: '*Dementia' and Alzheimer's Disease' – fancy words or dreadful names?'* "Participants also used phrases such as 'short on top', 'a screw loose', 'a bit funny', 'gaga', 'crackers' and 'need to be locked up', amongst others, to describe what others might associate with the term. They felt the use of these terms reflected <u>common misconceptions held by those who did not understand dementia</u>".	People with dementia feel that others associate dementia and related terms with ideas around being mad or lacking in intelligence. They feel that these are misconceptions. Lack of understanding is again an issue.	people's difficulties are dismissed/not believed if they do not fit these stereotypes
MacRae (2011, pp.450) Theme: *Concern about other's treatment of them* "Although some acknowledged that there was <u>very likely stigma</u> associated with AD, most <u>did not seem to be very</u>	People with dementia are aware of stigma, but majority here are not concerned by it. Stigma can be associated with other's	

concerned about it. Only two participants expressed concern about stigma: "They immediately think of people who are more debilitated, that's the stigma."	perceptions that people with dementia are more debilitated
Mason, Clare, et al. (2005, pp.103) Theme: *Outside on your own* "Some were anxious about how others would react, not wanting to 'be labelled' and worried that people would think 'they were going off their heads' or were 'mental patients'."	Sense of separation from society reflected 'on your own' People with dementia are worried about being labelled, concerned about associations with being crazy/'mental'
Mok, Lai, et al. (2007) Theme: *Attribution of illness* Subtheme: *Do not want to be labeled as having a mental illness (stigmatized)* "I do not like people telling me I have mental problems. I do not have a mental problem, just forgetfulness"	People with dementia are concerned about labelling as having a stigmatizing illness. The concern again is about being labelled as 'mental'.
O'Connor, Phinney, et al. (2007, pp.35) Theme: Being taken seriously - "it's not sometimers, it's ALLTIMERS!" "To her, the diagnosis offers an explanation that prevents others from labelling her as stupid."	People with dementia perceive themselves as at risk of being labelled as 'stupid'
Orulv (2012, pp.31) Theme: *In-between trivialization and dismissal – facing*	Stigmatisation is seen to occur through negative categorisation.

double stigmatization	Perception is that others will
"On one hand, they risk having their problems trivialized,	categorise them as 'mental'
perhaps resulting in a lack of support and disbelief. On the	Stigmatisation is also understood to
other hand, they risk being dismissed as mentally deranged	occur when others do not fully
due to <u>negative categorization</u>. This may be referred to as	recognise the person's difficulties
double stigmatization; it is a two-front battle."	when they do not fit stereotypical
"In order to fit the image, Karin would have to just sit there,	images of dementia
dribbling"	
O'Sullivan, Hocking, et al. (2014, pp.487)	Stigma is seen to be pervasive, and
Theme: *The <u>pervasiveness of stigma</u>*	keeps arising. People are very
"When gathering data, <u>the notion of stigma came up in</u>	conscious of stigma
<u>almost every conversation</u>. Sometimes it was in response to	
a question and sometimes it was unintentionally	
provoked."	
Pipon-Young, Lee, et al. (2011, pp.605)	Other's reactions to dementia are
Theme: *Others' reactions to dementia*	linked to misconceptions about it.
"I think that probably they would look at dementia as more	Others associate dementia with the
<u>what happens at the end stages</u>. I think that's what most	more advanced stages of dementia.
<u>people's perception of what dementia</u> is."	
"<u>A number of misconceptions</u> were described regarding	
others' understanding of dementia."	

Subtheme: *Being restricted and limited* (a theme requiring a higher degree of interpretation)

Supporting studies: Example findings	Commentary	Synthesis
Beard & Fox (2008, pp.1513-1514) Theme: *Resisting <u>relegation</u>* Participants experienced a general <u>decrease in the activities and roles</u> of their daily lives since being diagnosed. Some cited important parts of their (past) lives that they were no longer able or <u>allowed to</u> perform: "I mean, before when I was <u>free</u> to go, I'd go take a walk around the block…<u>You can't get away from everybody now</u>. Your husband will go with you, and that doesn't do it. Your neigh- bors will stop and talk to you, just for a minute. Then they'll say, 'Well, I'll walk around with you'	People with dementia are relegated by others, which includes a reduction in the activities/roles they are allowed to perform. They do not have the same freedom as before, as others follow/accompany them	*Subtheme: Being restricted and limited* Findings suggest that people with dementia perceive that others restrict the activities and roles that they are allowed to perform. This is sometimes associated with over-protectiveness. This more generally means that people with dementia perceive that their freedom and independence has been restricted by others since having dementia (which can also occur when others observe/supervise). Others can also limit the opportunities that people with dementia might have to take part, take control, interact, and contribute. These factors affect the relationships, daily routine, quality of life, and emotional experiences of people with dementia.
Harris & Sterrin (1999, pp.246) Theme: *Emotional reactions linked to efforts to maintain sense of self*	Part of people's emotional experiences when living with dementia are linked to perceptions that others are removing	

"Anger was displaced or intentionally focused on <u>others who were perceived as trying to take away their independence</u>" "One man was extremely angry about the driving <u>restrictions placed on him</u>" "<u>I'm told I can't do this and I can't do that</u> and they don't know if you can or can't because <u>they don't give you a chance to try. This is the thing </u>that annoys me the most, <u>I feel like a prisoner</u> in my own home"	their independence and placing restrictions upon them. People are told what they can and cannot do – no opportunity to try first. Restrictions on freedom (prisoner)
MacQuarrie (2005, pp.432) Theme: *Dialectical tension between agency and objectification* "A tough thing to live with is the <u>overly protective</u>" "The burden on autonomy was not lessened by the fact the AD spouse understood the vigilance: 'annoying thing is she <u>keeps me under observation.</u> Probably a lot to do with household survival'"	There is a tension between people's desire and ability to act as independent agents and the over-protective behaviour of others. People with dementia perceive that others are vigilant over them and observe them

Mok, Lai, et al. (2007, pp.596)	One change within people's relationships is an increase in protective behaviour from others.
Theme: *Relationships with family and friends*	
"The most consistently identified change in the family relationship was a loss of intimacy and an increase in protective behaviour. Caregivers were often described as limiting activities that participants could continue to perform, especially if some modification was made to simplify the activity."	Others are seen to limit activities that people are still able to perform, and do not modify to facilitate performance
Moyle, Venturto, et al. (2011, pp.974-975)	Some aspects which impact upon the quality of life of people with dementia are factors within the social environment which hinder them and limit their opportunities to interact with others, take control, and make a contribution.
Theme: *People <u>influences on QoL</u>*	
"some residents found it difficult to make friends and they spoke of the <u>environment as hindering</u> this endeavour. For example, residents spoke about other residents being placed into bed early in the evening, leaving <u>little opportunity</u> for conversations."	
Theme: *Influence of things on QoL*	

"if only there was something I could do. Not a job made just for me, that would be silly, but I don't know what they want."

"Such statements demonstrate the perception of a <u>lack of opportunity</u> for decision-making and control. Furthermore, staff did <u>little to encourage a view that residents could contribute</u>"

Powers, Dawson, et al. (2014, pp.6) Theme: *How does your memory loss affect your daily routine?* "Makes it difficult. I don't have the <u>freedom</u> I used to have" "It <u>restricts me</u> on everything I'm exposed to. Your life is never the same after you experience this, for example, I can't use my power tools when I am here by myself"	People with dementia perceive that they are not granted the same freedom as before, and are more restricted in what they are allowed to do than before.

Appendix F: Manual preparation and submission instructions for authors of the journal *Aging & Mental Health*

<u>Manuscript preparation</u>

1. General guidelines

Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.

Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:

For single agency grants:

This work was supported by the <Funding Agency> under Grant <number xxxx>.

For multiple agency grants:

Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

Each manuscript should have 3 to 5 keywords.

Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here.

Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.

All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.

Biographical notes on contributors are not required for this journal.

Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.

For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.

Authors must adhere to SI units. Units are not italicized

When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

Authors must not embed equations or image files within their manuscript.

2. Style guidelines

Word templates are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.

References are cited in the text by the author's surname, the publication date of the work cited, and a page number if necessary. Full details are given in the reference list. Place them at the appropriate point in the text. If they appear within parenthetical material, put the year within commas. Within the same parantheses, order alphabetically and then by year for repeated authors, with in-press citations last. Separate references by different authors with a semi-colon. If name and year are in parentheses, include the year in subsequent citations.

With a quotation, citations should be presented as:

- This is the text, and Smith (2012) says "quoted text" (p. 1), which supports my argument.

- This is the text, and this is supported by "quoted text" (Smith, 2012, p. 1).

- This is a displayed quotation. (Smith, 2012, p. 1)

With two authors: Smith and Jones (2012) or (Smith & Jones, 2012)

At first mention: Smith, Jones, Khan, Patel, and Chen (2012) or (Smith, Jones, Khan, Patel, & Chen, 2012)

At subsequent mentions: Smith et al. (2012) or (Smith et al., 2012)

In cases where two or more references would shorten to the same form, retain all three names.

For six or more authors: Smith et al. (2012) (Smith et al., 2012)

Authors with two publications in the same year: Put a, b, c after the year (Chen, 2011a, 2011b, in press-a)

- When citing an entire website, it is sufficient just to give the address of the site in the text: The BBC (http://www.bbc.co.uk).

In reference list:

- Book: Author, A. A., & Author, B. B. (2012). *This is a book title: And subtitle*. Abingdon: Routledge.

- Organisation as author: American Psychological Association. (2003). *Book title: And subtitle*. Abingdon: Routledge.

- Chapter in a book: Author, A. A. (2012). This is a chapter. In J. J. Editor (Ed.), *Book title: And subtitle* (pp. 300–316). Abingdon: Routledge.

- Place of publication: Always list the city, and include the two-letter state abbreviation for US publishers. There is no need to include the country name: New York, NY: McGraw-Hill Washington, DC: Author

- Publishers: Give the name in as brief a form as possible. Omit terms such as 'Publishers', 'Co.', 'Inc.', but retain the words 'Books' and 'Press'. If two or more publishers are given, give the location listed first or the location of the publisher's home office. When the author and publisher are identical, use the word Author as the name of the publisher.

- Journal article: Author, A. A. (2011). Title of article. *Title of Journal, 22,* 123–231. doi:xx.xxxxxxxxxx

  Author, A. A., & Author, B. B. (2004). Title of article. *Title of Journal, 22*, 123–231. doi:xx.xxxxxxxxxx

- Provide the issue number ONLY if each issue of the journal begins on page 1. In such cases it goes in parentheses

- If there is no DOI and the reference was retrieved from an online database, give the database name and accession number or the database URL (no retrieval date is needed): Author, A. A. (2011). Title of article. *Title of Journal, 22*, 123–231. Retrieved from http://www.xxxxx

- If there is no DOI and the reference was retrieved from a journal homepage, give the full URL or site's homepage URL: Author, A. A. (2011). Title of article. *Title of Journal, 22*, 123–231. Retrieved from http://www.xxxxx

- Organisation as author: American Psychological Association. (2003). Title of article: And subtitle. *Title of Journal, 2*, 12–23. doi:xx.xxxxxxxxxx

- Thesis: Author, A. A. (2012). *Title of thesis* (Unpublished doctoral dissertation or master's thesis). Name of Institution, Location.

3. Figures

Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.

Figures must be saved separate to text. Please do not embed figures in the manuscript file.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).

All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).

Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly. The captions should include keys to symbols, and should make interpretation possible without reference to the text.

The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

4. Publication charges

Submission fee

There is no submission fee for *Aging & Mental Health*.

Page charges

There are no page charges for *Aging & Mental Health*.

5. Reproduction of copyright material

If you wish to include any material in your manuscript in which you do not hold copyright, you must obtain written permission from the copyright owner, prior to submission. Such material may be in the form of text, data, table, illustration, photograph, line drawing, audio clip, video clip, film still, and screenshot, and any supplemental material you propose to include. This applies to direct (verbatim or facsimile) reproduction as well as "derivative reproduction" (where you have created a new figure or table which derives substantially from a copyrighted source).

You must ensure appropriate acknowledgement is given to the permission granted to you for reuse by the copyright holder in each figure or table caption. You are solely responsible for any fees which the copyright holder may charge for reuse.

The reproduction of short extracts of text, excluding poetry and song lyrics, for the purposes of criticism may be possible without formal permission on the basis that the quotation is reproduced accurately and full attribution is given.

For further information and FAQs on the reproduction of copyright material, please consult our Guide.

6. Supplemental online material

Authors are encouraged to submit animations, movie files, sound files or any additional information for online publication.

<u>Manuscript submission</u>

All submissions should be made online at the *Aging & Mental Health* ScholarOne Manuscripts website. New users should first create an account. Once logged on to the site, submissions should be made via the Author Centre. Online user guides and access to a helpdesk are available on this website.

Manuscripts may be submitted in any standard editable format, including Word

and EndNote. These files will be automatically converted into a PDF file for the review process. LaTeX files should be converted to PDF prior to submission because ScholarOne Manuscripts is not able to convert LaTeX files into PDFs directly. All LaTeX source files should be uploaded alongside the PDF.

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author should be removed to allow the files to be sent anonymously to referees.

Copyright and authors' rights

To assure the integrity, dissemination, and protection against copyright infringement of published articles, you will be asked to assign us, via a Publishing Agreement, the copyright in your article. Your Article is defined as the final, definitive, and citable Version of Record, and includes: (a) the accepted manuscript in its final form, including the abstract, text, bibliography, and all accompanying tables, illustrations, data; and (b) any supplemental material hosted by Taylor & Francis. Our Publishing Agreement with you will constitute the entire agreement and the sole understanding between you and us; no amendment, addendum, or other communication will be taken into account when interpreting your and our rights and obligations under this Agreement.

Copyright policy is explained in detail here.

Appendix G: Participant information sheet

Participant Information Sheet

A study of positive experiences whilst living with dementia

We would like to invite you to take part in our research study. The study will explore people's thoughts about positive experiences whilst living with dementia. We would first like you to know why the research is being carried out, and what will happen if you take part. You may want to talk to other people before you decide if you want to take part. The researcher will also talk through the information with you, and answer any questions.

What is the purpose of the study?

We know that people can have positive experiences at any time of life. We also know that people can still have positive experiences after being diagnosed with an illness. Some of these people have even said that some things in their life have changed for the better. For example, they may be spending more time with family or friends, have developed new skills or friendships, or may have a new outlook on life.

We want to learn about people's positive experiences after being diagnosed with dementia. We want to know what people with dementia think about these experiences, and what it is like to talk about them.   We hope that this study will help us to understand more about living with dementia. We also hope that it will help us to work together with people with dementia to support positive experiences.

 Why have I been invited?

We have sent you this information if you gave us your contact details after seeing a poster or being told about our study. This may have been at places like a memory clinic, at local groups for people with dementia, or on a website.

Do I have to take part?

You do not have to take part if you do not want to. If you agree to take part, but later change your mind, you can ask to be taken out of the study. You do not

have to give a reason for this. Your decision will not affect your healthcare or legal rights.

However, we will not be able to take your data out of the study if more than 4 weeks have passed since your interview. This is because your data may have already been used to produce the study's results.

<u>What will happen if I want to take part?</u>

1. The researcher will have a brief talk with you to make sure that you meet all the criteria to take part in the study. If you do not meet all of the criteria, you unfortunately will not be able to take part.
2. The researcher will also need to speak briefly to one member of your family or a member of staff who knows you. This is because they need one other person to confirm how you were given your diagnosis.
3. The researcher will then arrange to meet with you. At this meeting, the researcher will make sure that you fully understand the study and are willing and able to take part. You will then be asked to sign a consent form.
4. You will be asked some short questions about yourself (for example, your age, your previous job)
5. You will then take part in an interview. This will involve having a conversation with the researcher about positive experiences. It will take around 45-60 minutes. The researcher will audiotape the conversation.
6. After the interview, you will not be contacted again unless:
   You would like to be sent a summary of your interview, or
   You would like to hear about opportunities to help the researcher talk to others about the study and its findings.

<u>What are the possible disadvantages and risks of taking part?</u>

- Meeting with the researcher will involve sitting and talking for about 90 minutes. This may be inconvenient or slightly tiring for some.
- Although we will be talking about positive experiences, the conversation may bring to mind some upsetting experiences since your diagnosis. If this happens, the researcher will support you during the conversation, and encourage you to seek support afterwards.

<u>What are the possible benefits of taking part?</u>

We cannot promise that you will directly benefit by taking part in the study. However, we hope that you will enjoy taking part and talking about positive experiences. We also hope that your information will help us to better understand and support other people with dementia.

<u>What if there is a problem?</u>

If you have a concern about the study, you can contact the researcher or the research supervisor. Both will do their best to respond to your concerns. However, if you are still unhappy and wish to make a complaint, you can contact the local NHS Complaints department. These contact details are provided on page 5.

<u>Will my taking part in this study be kept confidential?</u>

- All of your personal information will be kept strictly confidential, and only seen by the researcher.
- Your information will be stored under a code, not under your name or anything else that could identify you.
- After the research is finished, audio recordings and personal information will be destroyed. All other data will be stored securely, and destroyed after 10 years.
- **There is one situation in which your information could not be kept confidential**. This would be if you tell the researcher something that suggests that you or someone else may be at risk of serious harm. If this happens, the researcher would need to contact the appropriate organisations to make sure that people are kept safe. This is very unlikely however, and the researcher will talk to you about this before contacting anyone.

<u>What will happen to the results of the study?</u>

The results will be written into a report for a thesis, and submitted to an academic journal. They may be published. Some direct quotes from your interview may be used in the report, but these will be under a false name. No information which could identify you will be included. The researcher may give a talk about the results, for example, to local groups or at scientific conferences.

<u>Who is organising and funding the research?</u>

This study is part of a doctoral research project in Clinical Psychology. It is funded and regulated through the University of Hull.

<u>Who has reviewed the study?</u>

A Research Ethics Committee is an independent group of people who review research studies. They want to make sure that researchers protect the rights and well-being of people who take part in their study. This study has been reviewed by the HSC Rec B Proportionate Review Research Ethics Committee, and received a favourable opinion.

<u>What happens now?</u>

The researcher will telephone you to talk through the information with you. If you are interested in taking part, the researcher will ask a few questions to see if you might be suitable for the study.

If you would like further information in the meantime, you can contact the researcher, **Kirsty Patterson.**

If you would like to make a formal complaint about the research, you can do so by contacting:

The Chief Executive or the Complaints and PALS Manager
Humber NHS Foundation Trust
Willerby Hill
Beverley Road
Willerby
HU10 6ED

Tel: (01482) 303930

Appendix H: Participant consent form

Consent Form

Project: **A study of positive experiences whilst living with dementia**

Name of Researcher: **Kirsty Patterson**

Please initial all

boxes

1. I agree that I have read and understand the information sheet dated
   [18.03.14] (version **[3]**) for the above study. I have been able to
   consider this information and ask questions. I am satisfied that any
   questions I asked have been answered.

2. I understand that I am volunteering to take part in this study. I
   understand that I can ask to be taken out of the study at any point
   within the next 4 weeks. I understand that I do not need to give a
   reason for this, and that it will not affect my healthcare or legal rights.

3. I understand that my interview will be audio taped.

4. I agree that direct quotes from my interview may be used in
   presentations or published reports about the study. I understand that
   these quotes will be used under a false name so that I cannot be
   identified.

5. I agree to take part in this study

6. I would like to be contacted after the study to receive a summary of my
   interview and the results of the study (Optional)

7. I would like to be contacted after the study if there are
   opportunities for me to help the researcher to tell other people about
   the study (for example, at presentations) (Optional)

Name of Participant   Date   Signature

_____ _____ _____
Name of Person   Date   Signature
taking consent

Appendix I: Guidelines for the Rating of Awareness Deficits (GRAD) (Verhey, Roozendaal, Ponds, & Jolles, 1993)

1. Researcher asks the individual with dementia a question to elicit spontaneous information about their memory problems:

    Please tell me about the problems you are here for. Why did (name of person) refer you?

    (This was adapted depending on the circumstances of the individual, e.g: *Why did (name of person) suggest you attend this group? Or: What made you get involved with this particular organisation?*)

2. If the individual voices complaints that are not related to dementia, they are asked:

    Do you have any other complaints?

3. If the individual still voices no concerns about memory or cognitive functioning, they are directly asked about this:

    How is your memory functioning? Do you think you have a poor memory?

4. If the individual denies any memory difficulties:

    So there are no memory problems at all. Is everything going alright for you?

5. The complaints discussed by the individual are then explored further. The researcher tries to gain a better understanding of the nature and severity of cognitive problems as experienced by the individual, and asks for examples.

6. The individual is also asked to provide a brief history of how they obtained their diagnosis, which can be compared to that provided by the caregiver

Appendix J: Table of participant demographics

Pseudonym	Gender	Age	Dementia type	Time since diagnosis	Time in education	Previous occupation	Dementia relevant medication	Living situation	Dementia social/ support services?	Religion
Ruth	F	81	AD	18 months	11 years	Clerical	No	Retirement property with husband.	No	C of E
George	M	72	VD	5 months	10 years	Agricultural	No	Independent housing with wife and grandson	Yes – Psychosocial intervention group	C of E
David	M	81	AD	6 years	10 years	Construction/ engineering	Yes - Aricept	Independent housing with wife	Yes – social groups, some CMHT support	None
Edward	M	72	AD	7 months	12 years	Engineering	Yes - Aricept	Independent housing with wife	Yes – Psychosocial intervention group	None

Name	Sex	Age	Diagnosis	Time since diagnosis	Time in education	Occupation	Medication	Housing	Groups	Recruitment
Robert	M	77	AD	8 months	11 years	Engineering	Yes - Aricept	Independent housing with wife	Yes – Psychosocial intervention group	C of E
Susan	F	65	AD	11 years	11 years	Health & beauty	No	Warden-supported housing with husband	Yes – social and DEEP groups	C of E
Shirley	F	75	AD	4 years	4 years	Clerical	Yes - Aricept	Independent housing with husband	Yes – social and DEEP groups	C of E
Arthur	M	74	AD	2 years	10 years	Culinary	Yes - Galantamine	Independent with wife	Yes – DEEP group	None
Douglas	M	74	VD	2 ½ years	15 years (5 as mature student)	Mixed – manual and academic	No	Supported housing, lives alone	Yes – DEEP group	None

Appendix K: Documentation of Ethical Approval

(Removed for hard-binding)

(Removed for hard-binding)

(Removed for hard-binding)

Appendix L: Semi-structured interview schedule

The interview schedule was developed based upon:

- Theoretical models of growth (Joseph & Linley, 2005; Paterson, 2001; Tedeschi & Calhoun, 2004; Tornstam, 1989, 2005, 2011)

- Quantitative measures of growth (Abraído-Lanza, Guier, & Colon, 1998; Bride, Dunwoody, Lowe-Strong, & Kennedy, 2008; Joseph, Williams, & Rule, 1993; Joseph et al., 2012; McMillen & Fisher, 1998; Roesch, Rowley, & Vaughan, 2004; Ryff, 1989; Tedeschi & Calhoun, 1996; Tomich & Helgeson, 2004; Tornstam, 1997), and

- Qualitative explorations of growth (interview schedules were taken from published studies or gained through communication with authors) in illness (Danoff-Burg & Revenson, 2005; Gillen, 2005; Horgan, Holcombe, & Salmon, 2011; Petrie, Buick, Weinman, & Booth, 1999; Salick & Auerbach, 2006; Siegel & Schrimshaw, 2006; Sodergren & Hyland, 2000; Tartaro, et al., 2005; Towsley, Beck, & Watkins, 2007); caregiving for persons with dementia (Farran, et al., 1991; Kramer, 1997) and aging (Rempel, 2013).

Introduction to study: "When researchers ask questions of people living with illnesses such as cancer, they often ask them about the things that have been difficult or negative whilst living with cancer. However, they also often ask them if there are any ways in which life might have changed in a positive or important way. I wanted to ask similar questions to people with dementia to see what they had to say about this.

"In this interview, I'd be really interested to hear about your experiences of living with dementia. I'd like to hear about any thing that you feel has changed since

you've been living with dementia, and I'd be especially interested to hear about anything that you feel has changed in a positive or meaningful way"

What are the most positive or important things in your life right now?

- What makes these positive or meaningful to you?

- In what ways are the positive/important things similar or different to before you had dementia?

- Has anything changed in a positive or meaningful way since you've had dementia?

For any positive/meaningful changes discussed:

- What do you think/feel about this change?

- How did you first start to notice it?

- How did that change come about?

- What do you think supports or gets in the way of positive/meaningful changes?

Areas to prompt: in what ways have the following things changed or stayed the same since living with dementia:

- Your relationships with others?

- How you see yourself as a person?

- In your lifestyle (e.g. your activities or how you spend your time)

- Your outlook on life or how you approach things in life?

- Your beliefs?

To end interview:

- What has this conversation been like for you?

- How does it compare to the way you usually talk about dementia?

- Is there anything else you would like to add?

References

Abraído-Lanza, A. F., Guier, C., & Colón, R. M. (1998). Psychological thriving among

Latinas with chronic illness. *Journal of Social Issues*, *54*(2), 405-424. doi:

10.1111/j.1540-4560.1998.tb01227.x.

Bride, O. M., Dunwoody, L., Lowe-Strong, A., & Kennedy, S. M. (2008). Examining

adversarial growth in illness: The factor structure of the silver lining

questionnaire (SLQ-38). *Psychology and Health*, *23*(6), 661-678. doi:

10.1080/14768320701356540.

Danoff-Burg, S., & Revenson, T. A. (2005). Benefit-finding among patients with

rheumatoid arthritis: Positive effects on interpersonal relationships. *Journal

of Behavioral Medicine*, *28*(1), 91-103. doi: 10.1007/s10865-005-2720-3.

Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991).

Finding meaning: An alternative paradigm for Alzheimer's disease family

caregivers. *The Gerontologist*, 31, 483-489. doi: 10.1093/geront/31.4.483.

Gillen, G. (2005). Brief report—positive consequences of surviving a stroke.

American Journal of Occupational Therapy, 59, 346–350.

doi:10.5014/ajot.59.3.346.

Horgan, O., Holcombe, C., & Salmon, P. (2011). Experiencing positive change after a

diagnosis of breast cancer: A grounded theory analysis. *Psycho-Oncology*,

20(10), 1116-1125. doi: 10.1002/pon.1825.

Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An

organismic valuing theory of growth through adversity. *Review of General

Psychology*, 9, 262-280. doi: 10.1037/1089-2680.9.3.262.

Joseph, S., Maltby, J., Wood, A. M., Stockton, H., Hunt, N., & Regel, S. (2012). The

psychological well-being—post-traumatic changes questionnaire (PWB-

PTCQ): Reliability and validity. *Psychological Trauma: Theory, Research,

Practice, and Policy*, *4*(4), 420. doi: 10.1037/a0024740.

Joseph, S., Williams, R., & Yule, W. (1993). Changes in outlook following disaster:

The preliminary development of a measure to assess positive and negative

responses. *Journal of Traumatic Stress*, *6*(2), 271-279. doi:

10.1037/a0024740.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next?

The Gerontologist, 37, 218-232. doi: 10.1093/geront/37.2.218.

McMillen, J. C., & Fisher, R. H. (1998). The perceived benefit scales: Measuring

perceived positive life changes after negative events. *Social Work Research*,

22(3), 173-187. doi: 10.1093/swr/22.3.173.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of

Nursing Scholarship*, 33, 21-26. doi: 10.1111/j.1547-5069.2001.00021.x.

Petrie, K. J., Buick, D. L., Weinman, J., & Booth, R. J. (1999). Positive effects of illness

reported by myocardial infarction and breast cancer patients. *Journal of*

Psychosomatic Research, *47*(6), 537-543. doi: 10.1016/S0022-3999(99)00054-9.

Rempel, A. R. (2013). Gerotranscendence and successful aging: The lived experience. (Unpublished Master of Social Work Clinical Research Paper). St. Catherine University: Minneapolis, MN.

Roesch, S. C., Rowley, A. A., & Vaughn, A. A. (2004). On the dimensionality of the stress-related growth scale: One, three, or seven factors? *Journal of Personality Assessment*, *82*(3), 281-290. doi: 10.1207/s15327752jpa8203_04.

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, *57*(6), 1069. doi: 10.1037/0022-3514.57.6.1069.

Salick, E. C., & Auerbach, C. F. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research*, *16*(8), 1021-1037. doi: 10.1177/1049732306292166.

Siegel, K., & Schrimshaw, E. W. (2000). Perceiving benefits in adversity: Stress-related growth in women living with HIV/AIDS. *Social Science & Medicine*, *51*(10), 1543-1554. doi:10.1016/S0277-9536(00)00144-1.

Sodergren, S. C., & Hyland, M. E. (2000). What are the positive consequences of illness? *Psychology and Health*, *15*(1), 85-97. doi: 10.1080/08870440008400290.

Tartaro, J., Roberts, J., Nosarti, C., Crayford, T., Luecken, L., & David, A. (2006). Who benefits? Distress, adjustment and benefit-finding among breast cancer survivors. *Journal of Psychosocial Oncology*, *23*(2-3), 45-64. doi: 10.1300/J077v23n02_04.

Tedeschi, R. G. & Calhoun, L.G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3), 455-471.

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, 15, 1-18. doi:10.1207/s15327965pli1501_01.

Tomich, P. L., & Helgeson, V. S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology*, *23*(1), 16. doi: 10.1037/0278-6133.23.1.16.

Tornstam, L. (1989). Gero-transcendence: A reformulation of the disengagement theory. *Aging Clinical and Experimental Research*, 1(1), 55-63.

Tornstam, L. (1997). Gerotranscendence in a broad cross-sectional perspective. *Journal of Aging and Identity, 2*, 17-36.

Tornstam, L. (2005). *Gerotranscendence: A developmental theory of positive aging.* New York, NY: Springer Publishing.

Tornstam, L. (2011). Maturing into gerotranscendence. *Journal of Transpersonal Psychology*, 43, 166-180. Retrieved from http://www.atpweb.org/jtparchive/trps-43-11-02-166.pdf

Towsley, G. L., Beck, S. L., & Watkins, J. F. (2007). "Learning to live with it": coping with the transition to cancer survivorship in older adults. *Journal of Aging Studies*, *21*(2), 93-106. doi:10.1016/j.jaging.2006.08.003.

Appendix M: Worked example of descriptive coding and interpretative commentary

	Transcript	Descriptive codes	Interpretative commentary
Int	I was wondering, are there any good things about - about not having responsibility any more?		
P	Well yes, I think mentally you're a bit lighter. You've done it and then you don't - oh, I don't have to do that anymore.	Mentally lighter I don't have to anymore	A positive of relinquishing responsibility is that you feel mentally lighter ("Oh" was said like a pleased, relaxed sigh). Not *having* to do something anymore – less of a duty?
Int	Mm-hmm		
P	You know so - but I think that's a part of recognising the fact that you are getting older, and you just don't want to do it anymore. Because it's tiring. Both mentally draining and, physically tiring a lot of it. And the most - I think the thing which probably triggered me in many a thing is that you don't, bounce back, you don't recover as quickly. You know, you might have done a lot of tearing up and down these stairs for instance. Or, before we moved here, doing a lot of things. But, by the evening, you are	Recognising you're getting older It's tiring Triggered You don't bounce back/recover You are tired	You can recognise that you're getting older, you're aware of it Not *wanting* to do certain things anymore is part of the process of getting older You don't want to do things because they're tiring Noticing that she didn't bounce back was a trigger point - in noticing aging? or reducing responsibilities? She can compare herself to a year previously and notice the difference of aging Although talking about old age, still making reference to the future, and there is a sense of

	tired, which you were not tired probably in - a year previously. And that makes you realise that you are getting older. And you're not recovering as much, so you're not doing yourself any good for the future, if you're going to tire yourself beyond a certain, quick recovery stage	Makes you realise You're not doing yourself good for the future	wanting to protect yourself/keep yourself well for the future (linked later to threat of deterioration in the future)
Int	Mm-hmm. So does that change how you kind of approach things in life?		
P	...I don't know really...I think you think about it a lot. And you decide what you would like to do, what you - or rather, what you *can* do. And...slowly, you know, bring yourself down to what you can do, without - also without having to involve other people in having to help you.	You think about it a lot Decide what you would like to do What you can do You bring yourself down Without involving others	A sense of reflecting a lot upon how you approach things in life Thinking leads to decision making processes about what you would like to do (reflection and decision making sound active – you notice/realise first but then think about it?) What you *want* to do is important, but is qualified by what you can do – oscillation between these two? It is a gradual process <u>You</u> bring your activities down (it's an active process, they aren't just lost), to activities you can still do, independently. **Theme: Sense of self: Continuation and evolution**

Appendix N: Table of themes and supporting quotes

Themes	Subthemes	Example quotes
Moving Forwards	*Moving on with life*	Ruth: "I just get on with my life, and to me really, that therefore is a positive" George: "I just think, you know...just get on with your life and enjoy it as best you can" David: "l mean, I just know I've got dementia. And I – I live to the best of my ability" Edward: "I don't feel negative about it all that much. I'd rather not have it, of course, but I'm not too negative about it" Robert: "nothing you can do about it, is there? You've just got to accept it." Susan: "what is the point of sitting in a chair, doing nothing all day, when you could be getting on" Shirley: "we both say, you know, we just carry on" Arthur: "There's nothing you can do about it, so, what's the point? Douglas: "So dementia you can live with, even outside you can live with it. It's not a death sentence."
	Taking pleasure in life	Ruth: "I was still enjoying being there, but not having to be there for people to say, can I show this or where do I put this" George: "well it makes you slow down more and take notice of things more" David: "And very often, it might be a nice day and you think, shall we go out? No, it's nice and

		cuddly here"
		Edward: "I just enjoy – just enjoy their (grandchildren's) company, you know, and you just – it is – it yeh it is, you know – you can't be down with the little ones"
		Robert: "Well we both - we go for walks, we like walking"
		Susan: "I like doing my cards, where I can sit and concentrate – I mean, it might take me an hour to do a card, but, I know it's good when I've finished it"
		Shirley: "I do all sorts of things, so I was – I enjoy being outside"
		Arthur: "Oh I just liked it, you know, quite enjoyed it. Something to do"
		Douglas: "To me it's exciting to do it, I love it"
	Being part of life as life moves on	Ruth: "you pass it on to – to somebody else, which you know, is the norm – it's the normal course of things. You haven't blocked anything – in other words you've just stood back and let it happen"
		George: "everybody sort of talks to each other and...you know, you talk about your problems"
		David: There's no point in..."I like this little group", and – the world's too big for that sort of silliness...Not us and them. No, that's an idiot way of going through the world"
		Edward: "I've got a...five year old grandson and a seven and a half year old um, grand – um daughter, and uh, they're very important as well. I've got a thirty – nearly thirty year old grandson, um...he's important, but, his time's gone. When he was little, you know, he was important, but he's got his own life now"

	Robert: "Yeh but they're getting older now, so, days are gone when they used to stand on the trolley and I pushed them round Morrisons."
	Shirley: "And (grandson's name) is twelve now, and he's – he is going to a place that goes – for him going, to do things that he wants to do"
	Arthur: "talk about, um, people that trying to - trying to beat dementia. Not the ones that's got it, the people that can – people next year, year after. So, this is – dementia, we can't get it, we don't know what's happening, but we will do, and let's get – instead of – and let's help people to get to – to get to – in places where they can talk to each other"
	Douglas: "To make sure that the next ten years, we've got all these services on board, because you know as well as me, dementia in the next ten years is going to be the biggest thing out- it's going to be bigger than cancer"
Life-long learning	Ruth: "But you just don't know, it's a learning curve, everything is, we've not been through it before"
	David: "there's more to learn from having dementia than not"
	Edward: "I've learnt - I think we know what we like, don't we, over the years? I've been listening to it (music) since I was twenty"
	Robert: "I've never had it before. Never had dementia before"
	Arthur: "I've learnt to make myself - not happy, but happier. You know, not worried about things, all the time."

		Douglas: "It's the more I take on board, the more I learn about this, the more I can - to use the term - terminology, I can preach on the road to Damascus."
	Sense of self: Continuation and evolution	Ruth: "that sort of thing suddenly starts opening other little facets of things that you start looking at" George: "to be honest with you, I don't feel any different!" David: : "it opens… If you don't allow people to come into your life…how can you expect them to help…develop your mind better?" Edward: "So that – that part of me is less – is less important now. It's not – it's not defunct or anything, and I still like to keep it up at times" Robert: "We always hold hands, always have done. And um, (name removed) and (name removed), me daughter, saw us in town one day and she says, grandma and granddad are holding hands! They must love each other! And we said yeh, we do!" Susan: "I used to bottle things up, and when I saw Dr (name removed), I used to tell him this, and he'd say, don't bottle it up. Say to them that you don't like what they're doing. And, so after that, I did start doing it. And it does work, not bottling it up, you know, keeping it to yourself." Shirley: "I use all these things, and, I always have done" Arthur: "I just enjoyed it (old job), yeh, I enjoyed the people. I helped 'em… some of them are sitting in and fed up and stuff like that, and you know, just try make 'em feel a bit better (current life – dementia community group)

		Douglas: It's the new me. It's um, I've always been compassionate. Always. Never been anything else. But I've never expressed it"
Living in the Now	*Today in the foreground and dementia in the background*	Ruth: "it doesn't make any difference I suppose, it'll happen anyway, but you feel as if you're doing a little bit perhaps, to delay any sudden deterioration. But you don't know, you don't know anything really"
		George: "To have gone through it – how many times? Is it twice or -? At least twice, and got away with it, I think I'm very lucky"
		David: "I'm a very happy, satisfied person. I've a lovely wife, good God, what else can I ask for?"
		Edward: "I think I'm a bit nervous about the future"
		Robert: "It's not like having a broken arm and you know it's going to get better. So you just switch off from it I think"
		Susan: "I've got this feeling, you know, that, one of these days I'm going to wake up and I don't know who I am. You know, the illness is just going to jump and go off. I don't want that to happen. But, that's in my mind – at the back of my mind. And this is why I'm thinking now, live each day as it comes, and be thankful that I am ok"
		Shirley: "I don't even think about it. (Laughs). I just come in here (art room) and I'm here all day…I'll find something and do that"
		Arthur: "And there's people I've spoken to and they've said the sort of – sort of things, oh I think it will get worse next week or – just forget all of that, just – just look today, you know, not

tomorrow."

Douglas: "But there's always that thing in the background, smoking away there. And you can - it's going to blow it's top. And if you don't get out of the way, it's going to kill you"

The significance of the life being lived each day	Ruth: "And if you don't do it now, you're not going to be able to do it in a couple of years time"
	George: "Well it learns you to...enjoy things more - what you've got, you know"
	Edward: "I no longer can sit back and think oh I can do that tomorrow, I can be more open with people. Now I've got to do it."
	Susan: "I think it's more or less now, since I've got this illness that I live each day as it comes. Before I couldn't give a –a monkey's, you know, I used to just get up and...get on with life. But, I think about it more – more these days"
	Shirley: "I do the things that I want to do, you know. I don't want to miss gardening"
	Douglas: "I do things now. I don't procrastinate about them. I don't say well I could do that tomorrow, I could do that that day and there there there. I do it now because I don't know what's going to happen to me when I wake up in that - in my bedroom, the next day. I've no idea. And that is - in a way, it's not morbid. But it's just a fact of life"

Appendix O: Epistemological statement

The ontological assumptions underling a piece of research refer to the researcher's beliefs about the nature of reality, and what can be known about it (Ormston, Spencer, Barnard, & Snape, 2013). The epistemological stance of a piece of research is defined as the type of relationship that is assumed between the "knower or would be knower" and "what can be known" (Guba & Lincoln, 1994, pp. 108). Our approach to a research question and the methodological choices we make will always be based on these underlying assumptions about what reality is, what it is possible for us to know about 'reality', and how we can get to know it. This statement seeks to make transparent the epistemological assumptions of the empirical research described in this portfolio.

A positivist epistemological stance assumes that there is a truth to be found, which can be approximated through controlled research – generally through quantitative methodologies (Guba & Lincoln, 2005). With regards to the current study, this stance would therefore assume that the 'true' experience of growth could be approximated in a sample of older people living with dementia. There are problems with this for several reasons.

Firstly, whilst there are existing theoretical understandings of growth which have been developed into quantitative assessment tools, these understandings and tools have not before been studied in relation to older people with dementia. It was therefore not clear whether existing assessment tools would appropriately capture and approximate the 'true' experience of growth amongst people living with dementia.

Secondly, it has been suggested that dementia is a unique experience to each individual, based on a variety of neurological, psychological, and social factors

(Kitwood, 1990). It is difficult to imagine that there is a 'true' experience of growth to be found amongst people living with dementia, when the experience of dementia is likely to differ so vastly. Quantitative measures may again not be appropriate as they may not be able to capture the diverse range of ways in which people may experience dementia.

Thirdly, questions have been raised about whether growth is a subjective, rather than an objective experience, or whether it may be both (Zoellner & Maercker, 2006). Therefore the changes and experiences associated with growth may not always be clearly observable or easily measured, which again suggests that the 'truth' of growth may not be easily discoverable.

Given all of the considerations above, a positivist approach was rejected, as it seemed reductionist to search for growth as an objective truth when the subjectivity of this experience may be equally important. It also seemed reductionist to attempt to approximate the reality of growth in a population whose experiences of dementia may differ from the experiences previously studied in growth research, and whose experiences of dementia may vastly differ across individuals.

Instead, a social constructionist epistemology was considered more appropriate. The ontological assumption underlying this epistemology is that there is no independent reality; that reality is only constructed within the mind and importantly, within the social world (Ormston, Spencer, Barnard, & Snape, 2013). The social constructionist stance therefore assumes that experiences and meanings are subjective, and that multiple perspectives or 'realities' will exist (Berger & Luckmann, 1966). It also assumes that these 'realities' are co-created in the transactions between the research and the research participant (Guba &

Lincoln, 1994), and that these transactions are shaped by the social context in which these transactions take place (Schwandt, 2000).

The epistemological position will influence the chosen methodology of a study (Carter & Little, 2007). In line with this, a qualitative methodology was adopted, as this could take a much broader approach in capturing the subjective experiences of growth amongst people living with dementia. It could also acknowledge the interaction between the researcher, research participant, and social context, which is particularly important given that the researcher's enquiry revolved around a discourse that is not typically used to talk about people's experiences of dementia.

In selecting a specific qualitative methodology, grounded theory approaches were rejected in the first instance. Due to the paucity of research in this area, it did not seem appropriate to develop an explanatory account of growth in dementia from one initial study. Discursive methods were considered, but rejected, as the current study was interested in the *content* of participant's accounts of growth, and not just in the linguistic and discursive aspects of these. However, both content and linguistic aspects were still considered during analysis. Similarly, narrative methods were considered, but rejected, as the study was interested in people's experiences of growth, and not just in the way that they had 'storied' these experiences.

A phenomenological methodology - specifically, Interpretative Phenomenological Analysis (IPA; Smith, Larkins, & Flowers, 2009) - was selected because the phenomenological approach fit with the notion that it is the subjective experience of growth in dementia that is important; not the 'objective' experience or 'reality' of growth. The focus of IPA upon the idiographic, or the particular experience of a certain individual in a certain context (Smith, et al., 2009) was also relevant, given

171

that dementia is thought to be a unique experience to each person (Kitwood, 1990). The principle of hermeneutics, which is embedded within IPA, acknowledges the influence of the analyst's own experiences and assumptions on the interpretation of experience. This seemed particularly relevant to the current study, given the focus upon an under-utilised discourse in dementia, and given that it has been suggested that societal attitudes and interpersonal interactions can influence experiences of growth (Paterson, 2001; Tornstam, 2005) and experiences of dementia (Kitwood, 1990, 1997; Sabat, 2001, 2002).

References

Berger, P. L., & Luckmann, T. T. (1966). *The social construction of reality.* New York, NY: Penguin Books.

Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, *17*, 1316-1328. doi: 10.1177/1049732307306927.

Guba, E.G., & Lincoln, Y.S., (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.) *Handbook of qualitative research* (*1st ed.,* pp.105-117) Thousand Oaks: Sage.

Guba, E.G., & Lincoln, Y.S., (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.) *The sage handbook of qualitative research (3rd ed.,* pp.191-215) Thousand Oaks: Sage.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, *10*, 177-196. doi: 10.1017/S0144686X00008060.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham: Open University Press.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of nursing scholarship*, 33, 21-26. doi: 10.1111/j.1547-5069.2001.00021.x.

Ormston, R., Spencer, L., Barnard, M., & Snape, D. (2013). The foundations of qualitative research. In J. Ritchie, J. Lewis, C. Nicholls, & R. Ormston (Eds). *Qualitative research practice: A guide for social science students and researchers* (pp.1-26). London: Sage.

Sabat, S.R. (2001). *The Experience of Alzheimer's disease: Life through a tangled veil.* Oxford, UK: Blackwell Publishers.

Sabat, S.R. (2002) Selfhood and Alzheimer's Disease. In P.B. Harris (Ed.) *The person with Alzheimer's Disease: Pathways to understanding the experience* (pp.88-112). Baltimore, MD: The Johns Hopkins University Press.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, UK: Sage Publications.

Schwandt, T. A. (2000). Three epistemological stances for qualitative Inquiry: Interpretitivism, hermeneutics and social constructivism. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 189-214). Thousand Oaks, CA: Sage.

Tornstam, L. (2005). *Gerotranscendence: A developmental theory of positive aging.* New York, NY: Springer Publishing.

Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology—A critical review and introduction of a two component model. *Clinical Psychology Review,* 26, 626-653. doi:10.1016/j.cpr.2006.01.008.

Appendix P: Reflective statement

Through the development of this research portfolio, I have become aware of some of my own assumptions about dementia, and discovered some very new (to me) ways of thinking about dementia. My original assumptions have been challenged, and the new perspectives I began to develop were also challenged at times. By the end of this process, I feel that I have been able to build a more balanced and integrated understanding of what it means to grow older and to live with dementia – or at least, as much of an understanding as one can have without living through these experiences. I have no doubt that this understanding will continue to be challenged and shaped by the people and perspectives I come across in future.

During my undergraduate degree, I spent three years volunteering in day care and residential facilities with people living with dementia. I realise that one of the motivations for this was that I was really quite scared and uncertain about dementia, and thought that the best thing to do would be to approach one of the things that scared me the most. Following my undergraduate degree, I worked in a service for people with memory problems and dementia. In this service, I was introduced to the idea that the 'recovery' was a concept that could still be applied when working with people with dementia. This challenged my assumptions about recovery and dementia – that you do not have to be 'symptom' free to live well and that you can work towards living well even within a progressive condition. I was more on board with the idea that a person can have dementia and still have a reasonably good quality of life. However, looking back, I am aware that I still perceived dementia to be 'the worst thing you can get'.

At the Research Fair, I was introduced to the idea that people could have positive experiences and grow *because* they had dementia. I remember that my initial

reaction was that this was a step too far. Clearly, this idea was hitting upon my assumption that there was nothing positive to be gained from having dementia. I felt more comfortable sitting with the idea that people could live well *in spite* of dementia.

The assumption that nothing can be gained from dementia was challenged first by two main experiences. Firstly, I had to acknowledge that growth is talked about in illnesses such as cancer; an illness that previously was not even talked about because it was deemed too awful. The part of me that likes to champion the underdog was awoken; I started to feel that dementia might be unfairly left out of conversations about growth. Secondly, I began to read more closely around the lived experience of dementia. I began to notice the comments made by research participants about how they had come to appreciate aspects of their life more and change their approach to life as a result of having dementia. I read Christine Bryden's (2005) wonderful book, Dancing with Dementia, and Kitwood's (1997) Dementia Reconsidered, and began to consider that whilst a person's cognitive abilities may decline, this does not mean that their emotional, social, and spiritual capacities must follow suit. I began to notice the value I placed upon intellectual ability, and how this might be driving my assumption that a person cannot grow if a condition is affecting their cognitive abilities.

My reading and discussions in supervision also challenged the assumptions I held that are very relevant to my systematic literature review. Prior to this project, I had not given much thought to the interpersonal and societal context of dementia. My assumption was that what happens to a person with dementia is caused by an illness called dementia. I have come to believe that whilst 'dementia' almost certainly impacts upon the individual, another critical influence upon the

individual is the social environment in which they live. During the process of synthesis, I found that I was drawn to notice how researchers had understood the balance between these – whether difficulties were 'blamed' upon dementia or the social environment. I wrestled with my own thoughts about the balance between these; depending upon the perspectives I read or heard from people living with dementia. I also became aware of how difficult it becomes to ever disentangle the individual from their social context, and how important it is to view the findings of each research paper and research review as one 'piece of the picture'. I was struck by the paucity of research directly investigating perceptions about the social context surrounding dementia, and how this impacted upon people living with dementia. This necessitated a lot of thought about the search strategy and inclusion criteria, and later, about the process of data synthesis, as I tried to develop a helpful line of argument from a broad variety of studies.

The paucity of research was also apparent when I searched the literature for any previous explorations of growth amongst people living with dementia. It was clear that no one (in a published study) had really asked people living with dementia if they had grown from their experiences. Throughout the development of my interview schedule, and throughout the interview process, I continued to wrestle with the issue of how to ask people with dementia about growth. The original teaching I had received from my parents was to always look on the bright side and help other people to do the same. However, I noticed that I was very concerned about minimising the potential difficulties caused by dementia; a concern that was reinforced by some of the conversations I had with staff and caregivers, and even friends. I was aware that this concern had also been shaped by my Clinical Psychology training, where I had learnt the importance of validating difficult experiences. Furthermore, I became aware that one of my concerns about asking

176

people with dementia about growth, was that I might be inviting them to look for a positive experience, which may not be there. I realised that whilst this may be the case for some people living with dementia, this concern was mainly driven by a lingering assumption that there might not be any growth to be found in dementia. I had to think about the questions I chose to ask people, the assumptions that might be shaping these, and the concepts and narratives I might be withholding by refraining from asking about them. As the interviews progressed, I became more confident in my questioning approach, which was to not be afraid of asking about positive experiences, but still giving space for participants to talk about difficult experiences. These issues and assumptions were very relevant too during my analysis. From talking to participants throughout the research process, I had become more confident that growth experiences were possible in dementia. I had to balance this confidence against the importance of very carefully examining the words and meanings of participants; to look for the 'cloud' and the 'silver lining' simultaneously.

I feel that this has been a very important project for me personally, in bringing my assumptions into focus, and reminding me of all the parts of life outside of the narrow realms of cognitive ability, and outside of the narrow realms of the individual. It has rekindled my belief in the importance of exploring positive experiences, whilst respecting the challenges of negative experiences. It has brought me greater clarity in knowing how I wish to value the experiences and capacities of people (including myself), who have more to offer to society than just their intellectual function.