

# Living positively with dementia: a systematic review and synthesis of the qualitative literature

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## Abstract

**Objective:** Little is known about how and to what extent people with dementia live positively with their condition. This study aimed to review and carry out a synthesis of qualitative studies where accounts of the subjective experiences of people with dementia contained evidence of positive states, experiences or attributes.

**Methods:** A meta-synthesis was undertaken to generate an integrated and interpretive account of the ability of people with dementia to have positive experiences. A methodological quality assessment was undertaken to maximize the reliability and validity of this synthesis and to contextualize the findings with regard to methodological constraints and epistemological concepts.

**Findings:** Twenty-seven papers were included. Three super-ordinate themes relating to positive experiences and attributes were identified, each with varying and complementing sub-themes. The first super-ordinate theme related to the experience of engaging with life in ageing rather than explicitly to living with dementia. The second theme related to engaging with dementia itself and comprised the strengths that people can utilize in facing and fighting the condition. The third theme captured how people with dementia might transcend the condition and seek ways to maintain identity and even achieve personal growth.

**Conclusions:** This review provides a first step towards understanding what conceptual domains might be important in defining positive outcomes for people who live with dementia. Highlighting the potential for people to have positive experiences in spite of or even because of their dementia has important implications for de-stigmatizing dementia and will enhance person-centred approaches to care.

**Keywords:** dementia; Alzheimer's disease; positive psychology; lived experience; systematic review

*No one should be criticized for not finding positive aspects of this disease [Alzheimer's Disease], but no one should be overlooked who has found gifts amid such loss*

(Stucky, Post, Ollerton, FallCreek, & Whitehouse, 2002, p. 206)

## 1. Introduction

Discourses around dementia can involve fear (Laforce & McLean, 2005; Moniz-Cook et al., 2006), stigma (Garand, Lingler, Connor, & Dew, 2009; Moniz-Cook & Manthorpe 2009), negative media representations (Kirkman, 2006) and pessimistic attitudes on the part of professionals (Clarke, Heyman, Pearson, & Watson, 1993; Keightley & Mitchell, 2004; Moore & Cahill, 2013; Snyder, 1999). However, whether personal experiences of the

condition involve anticipated levels of suffering is actually unclear (de Boer et al., 2007). Equally, while psychosocial interventions such as group cognitive stimulation (Spector et al., 2003) and cognitive rehabilitation (Clare & Woods, 2004) can improve quality of life, little is known about how this is achieved and what contribution, if any, is made by the person themselves to the outcome of such interventions.

While some accounts of positive lived experiences in dementia have emerged (Bryden, 2008; Phinney, 2008) their full range has yet to be investigated. Whether people with dementia can retain the capacity to experience positive states actively has been questioned (Schreiner, Yamamoto, & Shiotani, 2005). Positive narratives described by a group of people living with dementia are acknowledged and highlighted by Steeman et al. (2007) but these are framed conceptually in terms of a coping strategy that functions to help the person avoid negative social positioning as they actively attempt to maintain a sense of personal value. As such, loss, threat and a struggle to cope are seen as the only context within which positive experiences and narratives can be interpreted. Such assertions may reflect the dominance of negative narratives relating to living with dementia and its bio-medical construction as a universally 'devastating disease' (Henderson, 2002), factors that potentially obfuscate the documentation and interpretation of the positive subjective experiences of people living with dementia. The extent to which accounts of the experience of dementia might be constrained within negative discourses and also subject to factors such as privilege and marginalization has recently begun to be examined (e.g. Hulko, 2009).

Fully understanding the positive experiences, strengths and capabilities that people with dementia might retain has important implications for enhancing conceptual accounts of well-being and quality of life and for the development of positive outcome measures in person-centred dementia care (Moniz-Cook, Vernooij-Dassen, Woods, & Orrell, 2011).

Conceptual frameworks and constructs developed and researched from the perspective of positive psychology (Peterson & Seligman, 2004) are relevant to this effort. Positive psychology refers to scientifically informed perspectives on aspects of the human condition that can lead to happiness and fulfilment (Carr, 2011) and the study of conditions and processes that contribute to 'the flourishing or optimal functioning of people, groups, and institutions' (Gable & Haidt, 2005, p. 104). There is increasing evidence that positive psychological constructs such as hope, optimism, reciprocity, benefit-finding and personal growth are linked with positive adjustment to chronic physical health problems (Aspinwall & Tedeschi, 2010) and such constructs are beginning to be applied to understanding adjustment to dementia (Duggleby, Williams, Wright, & Bollinger, 2009; Vernooij-Dassen, Leatherman, & OldeRikkert, 2011; Wolverson, Clarke & Moniz-Cook, 2010). Person-centred care, it may be argued, is intrinsically concerned with promoting positive well-being and optimal functioning for people living with dementia.

The present review was grounded in the subjective experiences of people with dementia. We aimed to document and provide a synthesis of the positive experiences and attributes reported or demonstrated by people with dementia in order to inform knowledge and the measurement of outcomes associated with 'living well' with the condition.

## **2. Methods**

### **2.1. Search and inclusion strategy**

Previous reviews and syntheses indicate that the lived experiences of people with dementia are highly individual journeys involving myriad negative feelings emerging in the context of a struggle to maintain identity and find ways to adjust to losses, change and uncertainty (De

Boer et al., 2007; Steeman, de Casterle, Godderis, and Grypdonck, 2006). As valuable as these syntheses are, we were mindful of the biomedical and deficit-orientated context (cf. Portacolone, Berridge, Johnson, & Schickltanz, 2014; Sabat, 2001) within which previous research into subjective experiences in dementia is likely to have been conducted.

In contrast to previous reviews, we therefore deliberately sought studies which contained any possible evidence of positive states, experiences or attributes in people with dementia irrespective of whether studies aimed to examine such phenomena explicitly or specifically. Our methodological approach thus had a purposive component in relation to the selection of relevant articles, data extraction and the (re)interpretation of primary themes and quotes. The need to adopt such an approach in circumstances where new insights are being sought across a diverse literature base to improve the knowledge base is not without precedent (see e.g. Paterson, Thorne, Canam, & Jillings, 2001). Moreover, we selected only qualitative research in this field given that the study was focused on the subjective lived experience and the meanings that individuals construct about their personal experiences and social contexts (Miles & Huberman, 1994).

A systematic search was completed in March 2015 and utilized three computerized databases: MEDLINE, CINAHL and PsychINFO. Nesbit's CINAHL evidence based filter for qualitative research was also used. Key search terms were: 'dementia' and 'Alzheimer's' combined with:

- (1) Terms selected to access the lived experience literature in dementia. These were 'experience', 'perspective', 'well-being' 'adjustment', 'coping', 'meaning' and 'lived experience'.
- (2) Terms selected to represent a range of possible positive experiences and personal attributes that might be present in the experience of dementia. These included; 'happiness', 'wisdom', 'hope', 'optimism', 'resilience' and 'faith' (Peterson & Seligman, 2004).

Truncation of search terms was used where appropriate (e.g. dement) to ensure flexibility and breadth of data capture. To help ensure a full search, manual searches were conducted of the reference lists of all included articles and a hand search of the Journal of Dementia was also conducted.

Studies were included only if they clearly explored the subjective, lived experiences of people with dementia using first-hand accounts. Lyman (1989) issued an influential call for researchers to investigate the subjective perspectives of those with dementia and papers were therefore only included if they were published in peer-reviewed journals between January 1990 and March 2015 (inclusive). All qualitative methodologies were considered. Since the aim of the review was to explore the existence and nature of positive experiences in living with dementia as a broad-spectrum biopsychosocial condition, all types of dementia were considered. Studies were only included if they had used well-established criteria to confirm the existence of dementia in their participants (e.g. ICD-10; WHO, 1992. DSM IV; APA, 2000), regardless of severity. Once these preliminary inclusion criteria had been met, studies were only included if, in addition, they contained evidence of positive lived experiences, positive states, attributes or capabilities. This was achieved in three stages. First, retrieved papers were reviewed by title, to select for lived experience studies. Abstracts were then screened to ensure that the studies contained subjective accounts and that participants were people with a diagnosis of dementia, rather than caregivers. Finally, full text papers were screened. In particular, a detailed, qualitative examination of results sections was conducted to look for evidence of positive lived experiences and capabilities.

Articles were not included if they:

- (1) Were published in a language other than English.
- (2) Were biographical or auto-biographical accounts of living with dementia from the perspective of a single person with dementia.
- (3) Lacked an empirical basis, i.e. absence of a discernible research methodology.
- (4) Were reviews of the literature on lived experiences in dementia. We sought to examine primary and reliable sources of evidence pertaining to the extent to which positive strengths and experiences are present in dementia and to synthesize this evidence interpretively.
- (5) Related exclusively to young-onset dementia as the needs and experiences of people with young onset dementia are likely to be distinct and divergent from those of older people and therefore deserve attention in their own right (see e.g. Clemerson, Walsh, & Isaac, 2013).
- (6) Prioritized the views of family or professional care-givers over those of people with dementia. Some studies include accounts given by caregivers but these are used to contextualize and triangulate themes that emerge from primary accounts given by people with dementia (e.g. Clare, Roth, & Pratt, 2005).
- (7) Only explored circumscribed experiences in dementia (such as receiving a diagnosis) rather than ongoing lived experiences.
- (8) Did not report any aspect of positive lived experiences in dementia anywhere in the study.
- (9) Lacked evidence of adequate methodological quality, following a systematic evaluation of quality of methods and validity of findings (see below).

## **2.2. Quality assessment**

We followed approaches used by Steeman et al. (2006) and Thomas and Harden (2008) for the systematic assessment of methodological quality of qualitative studies, in order to maximize the validity and reliability of the review's findings. We evaluated the quality of each included study using a pre-established, structured rating instrument (Methodology Checklist: Qualitative Studies National Institute for Health and Clinical Excellence [NICE], 2009) that focused on five key areas: (1) clarity of reported aims; (2) study design; (3) methods (data collection, ethical issues and researcher reflexivity); (4) rigour of data analyses; (5) validity, relevance and critique of findings. We paid particular attention to the adequacy of sampling techniques and the apparent rigor of data analyses to ensure that any identified accounts and themes relating to positive experiences and/or attributes were derived from a transparent analytic strategy and that presented themes were credible in representing the personal experiences of participants living with dementia. Ratings of methodological quality were conducted by the first two authors and moderated by the third, with no significant disagreements arising.

Studies were given categorical ratings to reflect the extent to which the validity of their findings was likely to be threatened by their methodological quality (Table 1). In accordance with the quality checklist that we employed (NICE, 2009), studies were assigned 'category A' ratings if they fulfilled all stated criteria or if any unfulfilled criteria were judged very unlikely to alter their findings and conclusions. Studies were assigned to 'category B' if they fulfilled most key criteria (more than 50%) on the checklist, showed clear evidence of rigour in data analysis and if, overall, any unfulfilled criteria were judged unlikely to alter their findings and conclusions. Studies assigned to 'category C' were those for which key methodological criteria (adequacy of reported sampling techniques, data collection and/or rigour in data

analysis) were unfulfilled and where the validity/relevance of findings were therefore unclear. Studies in this category were excluded from the synthesis if, in addition, data analyses were deemed to lack any clear rigour and there was insufficient evidence that bias had been controlled.

### **2.3. Analysis and synthesis**

The method of 'thematic synthesis' described by Thomas & Harden (2008) was used as a basis for the analysis and synthesis of accounts of positive experiences evident in identified studies. We also drew on the method for metadata analysis described by Paterson et al. (2001) and on concepts discussed by Zimmer (2006). An iterative, inductive analysis was undertaken by the first two authors, firstly in isolation and later in collaboration. This initially involved the line-by-line reading and re-reading of the results sections of each article in order to isolate and extract any positive experiences/states and related themes that were presented by each study. These themes, along with related primary quotations, were then themselves (re)interpreted and coded into broader descriptive themes, within and then across articles. These descriptive themes formed the basis for the next interpretative level of synthesis in which higher level themes pertaining to the nature of positive experiences and attributes in dementia were generated. Following this, descriptive themes were developed into sub-themes relevant to each higher order analytical theme, with the aim of constructing an initial conceptual account of positive experiences in dementia.

## **3. Results**

### **3.1. Identification and classification of relevant studies**

The preliminary database searches yielded 424 qualitative articles. Sixty-three articles were deemed to be relevant on the basis of their title and so the abstracts of these studies were retrieved. Following abstract screening, 23 studies were excluded because they had not focused on the continuous experience of living with dementia but looked at specific elements of people's experience such as activity preferences, the experience of receiving a diagnosis or experiences of services. Four further studies were excluded because they had interviewed caregivers alongside people with dementia but it was not possible to separate the analysis to explore the views just of people living with dementia. Two studies were excluded because they examined the experiences of living with young onset dementia. Three studies were excluded because they were not found to contain any positive reports.

**Table 1 Studies containing positive reports of lived experience in dementia; aims, methods, key findings and methodological quality**

<b>Author and Year</b>	<b>Aim and Methods</b>	<b>Participants*</b>	<b>Setting</b>	<b>Identified Themes Relating to Positive Experiences and / or Capabilities</b>	<b>Example Quotation</b>	<b>Methodological Quality Rating **</b>
<b>Beard (2004)</b>	<p>Aim: To examine the impact of early AD on identity construction</p> <p>Methods: Grounded theory approach comprising observation, focus group and individual interviews.</p>	<p>13 people diagnosed with early stage AD</p> <p>70% were male.</p> <p>MMSE scores ranged from 22-26.</p>	Community (US)	<p>Defining moments</p> <p>Preservation</p>	<p>'When I did get told about this (dementia) I instantly felt that I'm gonna go day by day if I can and just make the best of it'</p> <p>'I don't think we should let the AD eat us up. If you like to play checkers, play them!'</p>	B
<b>Caddell &amp; Clare (2011)</b>	<p>Aim: To explore participants perceptions of the impact of dementia on their identity.</p> <p>Methods: Phenomenological Study – semi structured interviews transcribed and subjected to Interpretive Phenomenological</p>	<p>10 participants (5 women and 5 men) with diagnosis of AD or VaD.</p> <p>Aged 65-88 years.</p>	Community sample – memory clinic outpatients (UK)	<p>I'm still the same person</p> <p>Tensions between 'I'm still the same person' and 'I'm different to what I used to be'</p>	<p>'The same as its always been...to enjoy life, be nice to people and love my wife, and daughter-and do things about the house...all that's not changes at all. It's just that I've got a bad memory!'</p> <p>'I'm just an ordinary mum, you know, and grandmother...I think I haven't changed.</p>	B

	Analysis (IPA)	MMSE scores 22-28.		Life is much the same  Always that connection versus its not just me	'I still carry on as if nothing happened as such, 'cause nothing major has happened...I'm taking it all in my stride at the moment'  'I've got a good wife you see, she's brilliant, she always helps me...a wonderful daughter and lots of good friends, you know-what more could i wish for really?'  'You've come together haven't you, to understand each other, that's what we mean by love'	
<b>Clare (2002)</b>	Aim: To explore the process of adjusting to the changes experienced in early-stage AD.  Methods: Phenomenological Study – semi structured interviews transcribed and subjected to Interpretive Phenomenological Analysis (IPA)	12 people with probable AD (9 men, 3 women). Partners also interviewed.  Aged 57-83 (mean = 71).  MMSE scores ranged	Community – memory clinic outpatients. (UK)	Holding on Developing a fighting spirit	'It's also me facing up to things and making an effort'  'Then you decide, well ok, we'll fight it as long as we can.'	B

		from 19-29.				
<b>Clare, Goater and Woods (2006)</b>	<p>Aim: To explore how people with dementia conceptualize their condition and its implications.</p> <p>Methods: Qualitative Exploratory Study, using content analysis</p>	<p>22 people diagnosed with early-stage AD or mixed dementia (10 female and 12 male)</p> <p>Aged 57-87 (mean = 73.9)</p> <p>MMSE scores ranged from 16-29.</p>	Community caseload and memory clinic outpatients. (UK)	<p>Take things as they come</p> <p>Learned from it / positive aspects</p>	<p>'I'll just cope. I don't worry about that'.</p> <p>'I've learned an awful lot in this curious reaction thing...you understand about yourself...in some ways I could be grateful for what's happened'</p>	A
<b>Clare, Roth and Pratt (2005)</b>	<p>Aim: to explore participant's experiences over time and consider the implications for coping and awareness in early-stage AD.</p> <p>Methods: Phenomenological study - semi-structured interviews transcribed and subjected to IPA.</p>	<p>As for Clare (2002): 12 people with probable AD (9 men, 3 women). Partners also interviewed.</p> <p>Aged 57-83 (mean = 71).</p> <p>MMSE scores ranged from 19-29.</p>	Memory clinic outpatients - community. (UK)	<p>Making a contribution</p> <p>Still doing things</p> <p>Can't complain</p> <p>Coping as best you can</p>	<p>'There's this kind of research...I managed to make a contribution...it's something positive'</p> <p>'Still enjoy walking and reading in particular... and I still enjoy listening to music'</p> <p>'I think I've had a good life...I've got a good family. I've got nothing to grumble about'</p> <p>'I cope you know'</p>	A



<p><b>Clare, Rowlands, Bruce, Surr &amp; Downs (2008)</b></p>	<p>Aim: To explore the subjective experience of life with dementia in residential care.</p> <p>Methods: Phenomenological study - transcripts of unstructured conversations subjected to IPA.</p>	<p>81 people with moderate to severe dementia living in residential care.</p> <p>Aged 59-96 (mean=83.4).</p> <p>MMSE scores ranged from 0-20.</p>	<p>Residential care homes (10). (UK)</p>	<p>I'm alright, I'll manage</p> <p>I still am somebody</p> <p>It drives me mad</p>	<p>'All the while I'm well enough to keep going I'll keep going. And that's it'</p> <p>'I'm thankful for what I can do...I won't give in'</p> <p>'I still am somebody'</p>	<p>B</p>
<p><b>Dalby, Sperlinger &amp; Boddington (2011)</b></p>	<p>Aim: To build an understanding of experiences of spirituality, religion or faith for people living with dementia</p> <p>Methods: Phenomenological study – semi-structured interviews transcribed and subjected to IPA.</p>	<p>6 participants (1 male &amp; 5 female) diagnosed with AD, VaD or mixed dementia.</p>	<p>Range settings recruited through Alzheimer's society, religious communities and NHS mental health trust (UK)</p>	<p>Searching for meaning in dementia</p> <p>Staying intact</p> <p>Current pathways to spiritual</p>	<p>'And I've had to go through this, I think so that i have a better understanding and develop compassion, I haven't got much so what's happened very recently is seeing why I had to have this in the life plan so i could develop more'</p> <p>'Well if I've got Alzheimer's there's nothing I can do about it is there? Just make the best of it. I just go along with it, you know, whatever it is'</p> <p>I keep thinking that I'm lucky in that, you know, big plan, I</p>	<p>B</p>

				<p>connection and expression</p> <p>Connections with people</p>	<p>can't help but see it every now and again. And if gives reinforcement and hope'.</p> <p>'But then I've had so many blessings you see. I've got a nice home and a lovely family and you can't help getting old. And when you see the sunshine its lovely to see it and say thank you for the sun, thank you for the rain also, without the rain the flowers wouldn't grow'</p> <p>'And what's lovely, it's the people like me are retiring and getting Alzheimer's and all the rest, at home. All these other people are queuing up and waiting to go. So it's a big cycle'</p>	
<b>Gillies (2000)</b>	Aim: To explore accounts of living through dementia of people advanced into their dementia experience.	20 people (11 men, 9 women) diagnosed with dementia (10 diagnosed with AD, 10 diagnosed with multi-infarct dementia or 'unclassified' dementia), the majority of whom lived in the	Community based, recruited through health and social services. (UK)	Comparing self with former abilities and with others		B

	Methods: Qualitative Exploratory Study using semi-structured interviews and thematic analysis.	community. Aged 64-89 years		Coping with a failing memory  Coping on an emotional level	'I will make the best of what I've got'.  'I'm trying to control it. Trying to improve on things that I forgot about'  'Well, I just accept things as they are. I don't see what else you can do'	
<b>Graneheim and Jansson (2006)</b>	Aim: To explore the meaning of living with dementia and disturbing behavior.  Methods: Phenomenological study – informal interviews transcribed and subjected to IPA.	3 people (2 men, 1 woman)  Participants were aged 73-79 and had diagnoses of AD and VasD.  MMSE scores ranged from 16-20.	Residential home. (Sweden)	Being Included-  Needed and appreciated  Accepted	'Sometimes they ask for my knowledge and I enjoy giving information'  'It's easier now....you may be yourself. Just an ordinary man'	B
<b>Harman and Clare (2006)</b>	Aim: To explore the illness representations of people with early-stage dementia following diagnosis.	9 people with early stage dementia (defined as 1 or less on CDR). 4 male and 5 female. Diagnoses included AD (n=5), FTD (n=2), VasD (n=1) and 'dementia' (n=1).	Community – recruited through Alzheimer's Society Ad. (UK)	Finding ways to cope	'I'll stand me ground and fight it at the moment, in my own way on my own'	A

	Methods: Phenomenological study: semi-structured interviews transcribed and subjected to IPA.	Mean age = 65 (58-76).  Seven participants scored on CDR, 2 had a score of 0.5				
<b>Harris (2006)</b>	Aim: To explore what is it like to live alone with memory loss.  Methods: Exploratory and qualitative approach based on grounded theory.	15 people (13 women, 2 men) diagnosed with early stage AD or MCI (mean number of years since diagnosis = 2.3 years) and living alone in the community.  Mean age = 75.4 (62-87)	Community – recruited through Alzheimer’s Association and outreach department of senior citizen’s retirement center. (US)	Making it on my own  With a little help from my friends  Meaningful activities	‘I don’t want to give up the fight, but I know there will be a time when I might have to’  ‘you know what you can’t change, it’s smart to accept’  ‘That’s one of the fundamentals in terms of a living a good life, its accepting that you cannot control what happens to you’	C
<b>Hulko (2009)</b>	Aims: To explore the relationships between the experiences of	8 community dwelling people with dementia (5 women	Community – accessed through a hospital outreach	From not a big deal to hellish	‘It’s not something I’m ashamed of or anything like that. I don’t really think it	B

	<p>older people with dementia and the intersections of race, ethnicity, class and gender.</p> <p>Methods: Grounded Theory approach – data generated through interviews, participant observations and focus groups.</p>	<p>and 3 men).</p> <p>Participants recruited and grouped according to ‘... the relative amounts of privilege and oppression to which they were subject ...’</p> <p>4 participants described as having ‘mild’ degree of dementia, 3 ‘moderate’ and 1 ‘severe’.</p> <p>Average age = 77 (74-87)</p>	<p>program for older people and a local Alzheimer Society. (Canada)</p>	<p>Instrumental preoccupations</p>	<p>matters’.</p> <p>‘I remember what I want to remember...I eat, I sleep. Listen dear, I’m 75 years old. Life’s not the same when you’re older.’</p>	
<p><b>Jonas-Simpson and Mitchell (2005)</b></p>	<p>Aim: To give voice to the expressions of QoL for people with dementia in long-term care.</p> <p>Methods: Qualitative descriptive study utilizing individual and</p>	<p>17 people with diagnosed dementia (AD, VaSD, MID, FLD, Parkinson’s dementia).</p> <p>‘Six participants with moderate impairment, 6 with</p>	<p>Residents of long-term care facilities. (Canada)</p>	<p>Feeling content</p> <p>Importance of relationships</p>	<p>‘Oh my life is about as good as I ever enjoyed it’</p> <p>‘These people who I consider important...they have inspired me with confidence’</p>	<p>B</p>

	group interviews where music and art were used as 'mediums' for expression of aspects of QoL.	severe impairment, 3 with moderate/severe impairment and 2 with mild impairment.'		Choosing an attitude for living on Feeling worthy	'Look on the positive side of life' 'Believe in yourself'	
<b>Langdon, Eagle and Warner (2007)</b>	Aim: To explore participant's perception of their condition and their experiences of others' reactions to them.  Methods: Phenomenological study: semi-structured interviews transcribed and subjected to IPA.	12 people diagnosed with dementia (AD=4, VaSD=6, LBD=1, FTD=1).  Six women and six men.  Mean age = 79 (66-87)  MMSE scores ranged from 19 to 30/30	Outpatients/community based sample - recruited through Older Adult Mental Health Unit (UK)	Normal vs. abnormal memory loss-putting it into context	'I've got into the habit of making a joke about it otherwise it would take over my life'	A
<b>Macquarrie (2005)</b>	Aim: Explore how people in the early-stages of AD experience their illness.  Methods: Longitudinal, qualitative study. Semi-structured	13 people diagnosed with possible or probable early stage AD, and their spouses.  People with dementia: 4 women and 9 men.	Community – recruited through clinic and Alzheimer's Society. (Canada)	Constructing agency- All that I am: pride and enjoyment	'...I'm in complete control of my own, whatever I want, intend to do. I get it done and if I don't want to do it, I don't do it and so on.' 'I do all the cleaning of the house. That keeps me going.' 'I'm alive and I'm going to live life to the best I can'.	B

	interview (Transition Interview for Persons with Alzheimer's Disease) administered twice, 6months apart. Hermeneutic methodology used to derive key themes in transcribed interviews.	Average age = 76.5 (range 60-89 years).  Mean MMSE score = 22.4 (range 17-26)				'You've got to really focus on your abilities.. you appreciate you've got some assets. It's not all negative'. I've had a tremendous life. I wouldn't trade it with anyone. And when it ends, you know, I'm just grateful for all I've had, and I'm hoping to enjoy every minute I've got left.	
<b>MacRae (2010)</b>	Aim: To examine how people with AD 'interpret and respond to the impact of the disease on the self.'  Methods:	9 people diagnosed with early-stage AD; 7 men and 2 women.  Time since diagnosis	Majority community based, 1 participant lived in senior residence, 1 in a convent. Recruited through memory clinic, seniors publication, word of mouth referrals and Alzheimer's Society. (Canada)	Perceived change in self  Maintaining		'I'm still the same person'	B

	Transcriptions of face-to-face, semi-structured interviews subjected to an inductive thematic analysis, informed by phenomenology and symbolic interactionism.	varied from 2 months to more than 3 years.		identity  Normalizing Life Review		
<b>Menne, Kinney and Morhardt (2002)</b>	<p>Aim: To explore how people with dementia make sense of their day-to-day experiences.</p> <p>Methods: Qualitative exploratory study involving face-to-face, semi-structured interviews. Transcriptions thematically coded.</p>	<p>6 people diagnosed with dementia; 4 with AD, 1 with FTD, 1 unspecified diagnosis.</p> <p>3 women and 3 men. All attended a 'memory loss support group'.</p> <p>Mean age= 71.6, range= 57-88.</p> <p>MMSE scores ranged from 13-27.</p>	Community based sample – recruited through memory loss support group. (US)	<p>Lifestyle continuity</p> <p>Helping</p>	<p>'It's very important for an AD patient to do what they can do'</p> <p>'I certainly would like to help people who can be helped'</p>	B
<b>Mok, Lai, Wong and Wan (2007)</b>	Aim: To describe the lived experience of Chinese people with early-stage dementia	15 people diagnosed with early-stage dementia; types of dementia not	Community outpatients – referred by physicians. (China)	Continuing Living:	'I spend most of my time reading the newspapers ... Gradually, I will remember.'	B



	<p>and their ways of coping with the illness.</p> <p>Methods: Phenomenological study; transcriptions of semi-structured interviews subject to thematic analysis, based on Colaizzi (1978)</p>	<p>specified.</p> <p>4 men and 11 women. All lived at home with family.</p> <p>Age range: 60-84.</p> <p>Further clinical information not reported.</p>		<p>Keeping an active mind</p> <p>Live each day as it comes</p> <p>Letting go</p>	<p>'...I found that it is no use worrying... I only wish I can continue to live each day as it comes'</p> <p>'Be optimistic; I will comfort myself; I have to face the facts. I am not doing anything about them, but I am facing them'</p>	
<b>Nygaard and Borell (1998)</b>	<p>Aim: To describe the illness experiences of 2 people with dementia over 3 years, as expressed in their everyday lives.</p> <p>Methods: Phenomenological Study; Field notes from informal, conversational interviews and participant</p>	<p>2 women diagnosed with AD, both living alone at home. Both in their 50's when the study commenced.</p> <p>Further demographic and clinical information not reported.</p>	<p>Community based sample – recruited through diagnostic unit for investigating memory deficits. (Sweden)</p>	<p>Resistance and the management of threat; seeking valued occupations</p> <p>The meaning of experiencing and resisting the threat</p>	<p>'Yes, when I look in my art books, then I feel much better.'</p> <p>'I do what I want to do and I don't feel restricted by the disease or anything else'</p>	C

	observations were analysed for meaning using Empirical Phenomenological, Psychological method					
<b>Ostwald, Duggelby and Hepburn (2002)</b>	<p>Aim: To express the experiences of people with dementia; their losses, feelings; and attempts to cope.</p> <p>Methods: Qualitative descriptive study involving thematic analysis of short speech samples.</p>	<p>56 people diagnosed with dementia and living in the community.</p> <p>30 men and 26 women.</p> <p>Mean age= 77.6 (range; 47-97).</p> <p>MMSE scores ranged from &lt;15 to 24-30.</p>	<p>Community – recruited through a range of clinics, Alzheimer’s Association and health and social services agency. (US)</p>	<p>Management Strategies: Cognitive management strategies</p> <p>Feelings: Love / appreciation</p>	<p>‘What’s going to happen is going to happen ... I’m pretty much a realist anyway.’</p> <p>‘We have a good relationship with our family. That makes us all feel good’</p>	C
<b>Parse (1999)</b>	<p>Aim: To understand the meaning of the experience of QoL for people with AD.</p>	<p>20 women and 5 men diagnosed with ‘beginning or moderate’ AD.</p>	<p>Mixed. Most interviews took place in participants’ private rooms within a multi level car facility. 2 interviewed in their own home. (US)</p>	<p>Smooth-troublesome</p>	<p>‘Life is a humdrum, it’s very exciting’</p>	B

	Methods: Descriptive-exploratory study. Transcripts of semi-structured interviews analysed using the Descriptive Explanatory Method	Further demographic and clinical information not reported.		Opportunities - limitations  Close to -apart from	'I really love life, but I accept whatever is, for all of us. Right now, well I'm in my 90's and I expect I'm not going to live a long time, but I'm not going to dwelling on it'  'I worship that son of mine'	
<b>Roger (2006)</b>	Aim: To examine social changes as experienced by participants living with with AD and HD.  Methods: Cross sectional descriptive-exploratory design based on grounded theory. Individual interviews and focus groups used to gather data.	6 men and 14 women. 17 had a diagnosis of AD and 5 had Huntington's Chorea.  Mean age (AD group) = 78.4 (range; 58-94).	Mixed - Most participants referred through local day hospital affiliated with a long-term care home, some through Alzheimer's Society, others through Huntingdon's community-based organization. (Canada)	The new social addition (group for people with dementia)  Interactions with friends & family	'Everyday has it ups and downs. More now than before. The support group is great, I look around and I am still doing better than the rest of them....I have always thrived on competition'  'I've accepted it, you know just do the best you can and that's all you can do'  'If my husband wasn't here,	B

					my daughter's there, and if she wasn't, her husband would be there, you know what I mean? ...'	
<b>Sorensen, Waldorff &amp; Waldmar (2008)</b>	<p>Aim: To analyse how patients with mild AD cope with the challenges in everyday life and social relationships.</p> <p>Methods: Grounded Theory approach utilizing face to face interviews.</p>	<p>11 people with dementia living at home with spouse / partner. Participants diagnosed with AD, mixed dementia or DLB.</p> <p>6 men and 5 women.</p> <p>Mean age= 74.1 (range; 65-82).</p> <p>MMSE scores ranged from 22 to 27.</p>	Community based sample (Denmark)	<p>Well-being and worries</p> <p>Coping strategies (recounting life story)</p> <p>Everyday Life</p> <p>Social Relationships</p>	<p>'I help my wife to get dressed ....It is natural because we have always helped each other and we both enjoy it'.</p> <p>'I have had a lovely life and I feel satisfied...'</p> <p>'Daily life has changed and I have to accept that. It's no use feeling sorry about it ... there are still many books I want to read'</p> <p>'We have and we have had a happy marriage'</p>	B
Steeman, Tournoy, Grypdonck, Godderis and Direckx De Casterle	Aim: exploring changes in the experience of dementia over time and the dynamics of being valued.	17 participants interviewed all three time points; 2 men and 15 women.	Community – recruited through five memory clinics (Belgium)	Being valued for who you are	'Being with people, I love with people'	B

(2013)	Methods: longitudinal study over three years with an adapted grounded theory approach	Mean age: 78 (72-91)  Family members also interviewed.		Shift from being valued from being valued to what you do to who you are	'I believe I still have sound wisdom'  'I don't mope about it. I don't do that. What happens, happens. And until now. I can't complain. I have always been pretty good a doing things independently , and still do' 'The three of us are happy'	
<b>Van Dijkhuizen, Clare and Pearce (2006)</b>	Aim: To examine appraisal and coping in women with early-stage AD.  Methods: Phenomenological study: semi-structured interviews transcribed and subjected to IPA.	9 women diagnosed with 'probable AD'. Partners or family members also interviewed.  Mean age= 77.8 (range; 70-86).  MMSE scores ranged from 20 to 29. Mean MMSE score = 23.1.	Community – recruited through mental health trust psychology services. (UK)	Acceptance  Normalizing  Problem solving (engaging in activity)	'You put up with it and you get on the way best you can'  'I'm alright; I'm luckier than a lot of people'  'I like the programmes where they ask questions and like that, to see if I can answer 'em ...'	A
<b>Werezak and Stewart (2002)</b>	Aim: To explore and conceptualize the process of learning to live with memory loss	3 men and 3 women diagnosed with early-stage dementia (5 with AD and 1	Community (Canada)	Seeing self as the same person	'You've lost your memory but you haven't lost your mind. And you're still the same person'	B

	<p>in early-stage dementia.</p> <p>Methods: Grounded Theory approach involving face to face, semi-structured interviews conducted at two time points, 1-3 months apart.</p>	<p>with VasD).</p> <p>Age range: 61-79.</p> <p>3MS scores ranged from 79-91/100.</p>		<p>Acceptance</p>	<p>'I think I am very fortunate. I have really managed to accept it and to say that I'm luckier than a lot of others'</p>	
<p><b>Wolverson, Clarke &amp; Moniz-Cook (2010)</b></p>	<p>Aim: To explore the concept of hope in people living with early stage dementia.</p> <p>Methods: Phenomenological study: semi-structured interviews transcribed and subjected to IPA.</p>	<p>10 people diagnosed with dementia (5 AD, 5 VasD) 3 men and 7 women.</p> <p>Mean age = 81.1 (range: 72-87).</p> <p>MMSE scores ranged from 19-28 (mean MMSE score 23.2).</p>	<p>Community (UK)</p>	<p>Legacy of hope</p> <p>Self activating hope</p> <p>Positive coping</p>	<p>'It's natural to have hope, I suppose there is something in the brain that has been persevered and hasn't been destroyed'</p> <p>'If at first you don't succeed, there is no use giving up – if you don't hope for things you don't get them'</p> <p>'You just take each day at a time'</p>	<p>B</p>

Notes AD: Alzheimer's disease, HD – Huntington's Disease, QoL: quality of life: DLB Dementia with Lewy bodies: VasD – Vascular dementia: MMSE – Mini mental state examination (Folstein, Folstein & McHugh, 1975) 3MS – Modified mini mental state examination (Teng & Chui 1987)}

\*Description of participation based on that presented in each study. Not all studies reported full range of demographic and clinical characteristics of their sample.

\*\* Methodological quality ratings:

A: Any unfulfilled criteria very unlikely to affect validity of findings and conclusions

B: Some criteria fulfilled those not probably unlikely to alter findings/conclusions.

C: Few or no criteria fulfilled. The conclusions of the study are thought likely or very likely to alter.

### 3.2. Characteristics of included studies

Of the 31 articles meeting inclusion criteria, 4 were excluded following methodological quality assessment. The majority of participants sampled by the final pool of 27 included studies (see Table 1) lived in the community, with 20 studies recruiting from a community sample. Three studies recruited from residential care (Clare et al., 2008; Graneheim & Jansson, 2006; Jonas-Simpson & Mitchell, 2005) and four studies included participants living in a mixture of settings (Dalby, Sperlinger, & Boddington, 2011; MacRae, 2010; Parse, 1996; Roger, 2006). Geographically, samples were drawn from a variety of countries including, Canada, China, Denmark, Sweden, UK and USA. All participants had a diagnosis of dementia, the most common subtype being Alzheimer's disease (AD) (with seven studies exclusively involving people with AD). Other dementia subtypes examined in the studies were vascular dementia, frontal temporal dementia, mixed dementia, Parkinson's disease, Huntington's disease and dementia not specified/ undetermined. Four studies noted the presence of dementia in participants but did not specify subtype (Clare, et al., 2008; Graneheim & Jansson, 2006; Hulko, 2009; Ostwald et al., 2002). The sample sizes ranged from 2 to 81, totalling 439 people with dementia. Two studies did not report gender (Clare et al., 2008; Jonas-Simpson & Mitchell, 2005) but of those that did, 151 were male and 169 female. Five studies did not report participant ages (Beard, 2004; Dalby et al., 2011; Jonas-Simpson & Mitchell, 2005; MacRae, 2010; Parse, 1996), but for those that did, ages ranged from 50's (Nygard & Borell, 1998) to 96 (Clare et al., 2008). Two studies reported data from the same sample of participants (Clare, 2002; Clare, Roth & Pratt, 2005).

Studies were diverse in relation to their methodological and theoretical perspectives. Of those that explicitly claimed a methodological orientation, 6 used grounded theory and 13 were phenomenological in approach (10 interpretive and 3 descriptive). Another four used less prominent methods such as narrative analysis or discourse analysis. The remainder (Gillies, 2000; Jonas-Simpson & Mitchell, 2005; Meene, Kinney, & Morhardt, 2002; Ostwald et al., 2002) used less well-specified qualitative methodological approaches. For example, Gillies (2000) reports an exploratory study using thematic analysis. Most studies were cross-sectional with the exception of four longitudinal studies (Clare Roth & Pratt, 2005; Macquarrie, 2005; Nygard & Borell, 1998; Steeman et al., 2013). The disciplinary orientation of authors was varied and included clinical psychologists, nurses and social workers.

### 3.3. Methodological quality

Five studies were assigned a 'category A' status following methodological quality assessment (see Table 1) but the majority of included studies (n = 19) were assigned a 'category B' status, implying adequate rather than strong methodological quality overall. The most common reason for studies failing to earn category A status was lack of clarity in reporting around sampling and/or data collection methods. Three included studies were assigned a category C status on the basis of our methodological assessment (Harris, 2006; Nygard & Borell, 1998; Ostwald et al., 2002). In all three, while there was some lack of clarity regarding the validity of findings, this was primarily linked to inadequate reporting of recruitment and sampling strategies. Additionally, in all three there was evidence of sufficient rigour in the analysis of qualitative data with no clear evidence of potential biases.

Although all studies showed at least some evidence of rigour in data analysis and validity/relevance of findings, they varied in the extent to which they fulfilled other methodological criteria in each of the key areas addressed by the quality appraisal checklist employed. Variation was most evident in the clarity with which sampling techniques and data collection methods were reported. Only eleven of the articles clearly reported the roles of the named researchers with regard to data collection, analysis and write up. The remainder either lacked clarity on this or did not report researchers' roles. Only half of the papers

(13/27) adequately described how ethical issues in the study were addressed. With the exception of Graneheim and Jansson (2006) and Sorensen et al. (2008) all articles clearly reported the implications of their findings but eleven did not present an adequate methodological critique of their studies or findings.

### 3.4. Thematic synthesis - key themes in positive accounts of experiences in dementia

Three higher order themes and nine sub-themes emerged from the thematic synthesis. Each of these themes were represented in at least one study and many studies covered multiple themes (Table 2). We interpreted these themes as overlapping rather than mutually exclusive but we made no assumptions about causal relationships between them. However, the higher order themes varied in relative 'size', i.e. the extent to which they were represented in the results of the included papers and we therefore sought to integrate this observation into our interpretive synthesis.

**Table 2: Overview of Thematic Synthesis with Supporting Studies**

Higher-order theme	Sub-theme	Representative Studies
Engaging with life in ageing	Seeking Pleasure & Enjoyment	Clare, Roth & Pratt, (2005); Jonas-Simpson & Mitchell, (2005); Macquarrie 2005; Menne et al., 2002; Mok et al. (2007); Nygard & Borrell, (1998); Van DijkHuizen, Clare & Pearce, (2006)
	Keeping going	Clare, Rowlands, Bruce, Surr & Downs, (2008); Gillies, (2000); Jonas-Simpson & Mitchell, (2005). Macquaire, (2005); Mok et al, (2007), Steeman et al (2013)
	Love and Support	Caddell & Clare, (2011); Jonas-Simpson & Mitchell, (2005); Ostwald, Duggelby & Hepburn, (2002); Parse, (1999); Roger, (2006)
Engaging with dementia	Facing it, Fighting It	Caddell & Clare, (2011); Clare, 2002; Gilles, (2000); Harman & Clare, (2006); Mok, Lai, Wong & Wan, (2007); Nygard & Borell, (1998); Parse, (1999); Roger, (2006); Sorensen, Waldorff & Waldmar, (2008); Wolverson, Clarke & Moniz-Cook, (2012)
	Humour	Langdon, Eagle and Warner, (2007); Van Dijkhuizen, Clare and Pearce, (2006)
	Hope	Dalby, Sperlinger & Boddington, (2011); Gillies, (2000); Jonas-Simpson & Mitchell, (2005); Macquarrie, (2005); MacRae, (2010); Mok, Lai, Wong and Wan, (2007); Nygard and Borell, (1998); Ostwald, Duggleby & Hepburn, (2002); Wolverson, Clarke & Moniz-Cook, (2010)
Identity and Growth	Giving Thanks	Clare, Roth & Pratt, (2005); Clare, McRae, (2010); Rowlands, Bruce, Surr & Downs, (2008); Sorensen, Waldorff & Waldmar, (2008)



	Still being me	Clare et al, (2008); Harman and Clare, (2006); Graneheim & Jansson, (2006);  Jonas-Simpson & Mitchell, (2005); McRae, (2010); Werezak & Stewart, (2002)
	Growing & Transcending	Clare, Goater and Woods, (2006); Clare, Roth & Pratt, (2005); Dalby, Sperlinger & Boddington, (2011); Graneheim & Jansson, (2006); Menne, Kinney & Mordaht, (2002); Parse, (1999); Sorenson et al, (2008)

### 3.5. Engaging with life in ageing

This first higher order theme describes aspects of the literature associated with general positive experiences of ageing well. A pervasive theme within this was a sense of agency amongst older people living with dementia; a sense of actively engaging with and appreciating life despite challenges and limitations. Three specific subthemes appeared linked to this higher order theme of active engagement with later life: seeking pleasure and enjoyment, keeping going and love and support.

#### 3.5.1. Seeking pleasure and enjoyment

Several studies report expressions of pleasure and enjoyment in later life. In some cases, a general satisfaction and contentment with present life is expressed by people with dementia:

*Oh, my life is about as good as ever I enjoyed it.*

(From the theme 'Feeling Content'; Jonas-Simpson & Mitchell, 2005, p. 4)

However, many participants in included studies report taking active steps to enjoy particular activities and derive real pleasure from doing so (Clare, Roth & Pratt, 2005; Menne et al., 2002; Macquarrie 2005; Mok, Lai, Wong, & Wan 2007; Nygard & Borell, 1998). Maintaining engagement with previously valued occupations as well as seeking new challenges seemed important:

*I do all the cleaning of the house...that keeps me going.*

(From the theme 'Pride and Enjoyment'; Macquarrie, 2005, p. 437)

*I like the programmes where they ask questions and like that, to see if I can answer 'em...*

(From the theme 'Problem solving - engaging in activity'); Van DijkHuizen, Clare, & Pearce, 2006, p. 87)

Specific examples of valued activities that bring pleasure and enjoyment include walking, music, reading, games, housework and art (e.g. Beard, 2004; Clare, Roth, & Pratt, 2005; Nygard & Borell, 1998). Overall, what emerged here was evidence not only that people with dementia have the capacity to experience enjoyment but they actively take steps to engage positively with ageing and they seek meaningful and pleasurable activities as part of this effort.

### 3.5.2. Keeping going

For some participants, life is reportedly 'much the same' as it had always been (Gillies, 2000; Jonas-Simpson & Mitchell, 2005), suggesting that people with dementia can experience a continuity of life pre- and post-diagnosis. However, ensuring that life remains the same appears to require purpose, persistence and energy and this also involves a conscious decision to 'keep going' (e.g. Clare et al., 2008; Macquarrie, 2005; Steeman et al., 2013). Several studies make reference to the notion that this 'keeping going' requires strong agency on the part of the person with dementia:

*All the while I'm well enough to keep going I'll keep going. And that's it.*

(From the theme 'I'm alright, I'll manage'; Clare et al., 2008, p. 716)

A significant part of this effort appears related to a potential shift in time focus; across several studies participants make references to focusing on the present rather than planning for the future and this appears related to positive coping (see Wolverson et al., 2010) rather than passive resignation:

*I've found it is no use worrying, I can only wish to live each day as it comes.*

(From the theme 'Living each day as it comes'; Mok et al., 2007, p. 597)

In addition, some studies make references to the notion that people with dementia retain, and place value on, having an explicit sense of control, as part of their effort to 'keep going':

*...I'm in complete control of my own, whatever I want, intend to do. I get it done and if I don't want to do it, I don't do it and so on.*

(From the theme 'Constructing agency All that I am'; Macquarrie, 2005, p. 437)

Overall, this literature suggests that people with dementia are able to communicate their desire to maintain both their sense of agency and a feeling of continuity in life by turning toward the present as a means of achieving this.

### 3.5.3. Love and support

Positive experiences of loving relationships with others are strongly present in the findings of several studies (Caddell & Clare, 2011; Jonas-Simpson & Mitchell, 2005; Ostwald et al., 2002; Parse, 1996; Steeman et al., 2013):

*I've got a good wife you see, she's brilliant, she always helps me...a wonderful daughter and lots of good friends, you know-what more could I wish for really?*

(From the theme 'Always that connection versus it's not just me'; Caddell & Clare, 2011, p. 392)

Participants conveyed the ability to maintain an appreciation of relationships and regard their relationships as a source of strength and inspiration (e.g. 'Importance of relationships'; Jonas-Simpson & Mitchell, 2005). In other accounts there are indications that people can retain positive feelings about their close relationships and even positive expectations about the availability of support:

*If my husband wasn't here, my daughter's there, and if she wasn't, her husband would be there, you know what I mean?...*

(From the theme 'Interactions with friends and family'; Roger, 2006, p. 189)

Together, these accounts demonstrate how, despite ageing and dementia, people strive to maintain connections as they engage with their everyday lives; they are able to continue to appreciate and feel satisfied with their close relationships, and can actively draw on these for inspiration and support:

*Being with people. I love being with people.*

(From the theme 'Being valued for who you are', Steeman et al., 2013, p. 226)

### **3.6. Engaging with dementia**

This second higher order theme captures how, in addition to engaging actively with life in the context of ageing, people with dementia actively engage with life and their dementia. Thus, they report positive experiences in the context of living with the symptoms and challenges associated with the condition. It is apparent that some of the processes and personal and social resources outlined above in relation to engaging with life in ageing are also used by people in dealing with their dementia, sometimes in modified ways. In particular, the notion of 'keeping going' (i.e. active perseverance through resilience) in spite of dementia is a consistent theme. Engaging with dementia actively and positively seems to be underpinned by a process of 'facing' and accepting the condition. For some, this seems to lead on to actively fighting dementia while for others hoping and using humour represent positive coping strategies.

#### **3.6.1. Facing it and fighting it**

Living positively despite dementia appears to be a conscious decision involving active acceptance of dementia and choosing to 'make the best' of what is retained:

*I've accepted it, you know, just do the best you can and that's all you can do.*

(From the theme 'Interactions with friends and family'; Roger, 2006, p. 189)

Rather than being resigned to a diagnosis and fate, acceptance in some form or other such as 'facing facts' (Mok et al., 2007) is for some part of moving forward (Parse, 1996; Sorensen et al., 2008) and is an active component of maintaining well-being. For example, Gillies (2000) reports an account of acceptance as 'coping on an emotional level'. For some, the decision to 'face' a diagnosis is accompanied by a sense that the effects of dementia are not as far reaching or devastating in the context of day-to-day life as we might traditionally assume:

*I still carry on as if nothing happened as such, 'cause nothing major has happened...I'm taking it all in my stride at the moment.*

(From the theme 'Life is much the same'. Caddell & Clare, 2011, p. 389)

In several other accounts, perhaps rather than being associated with carrying on as before, acceptance is instead connected with a decision to actively 'fight' against dementia, perhaps as part of attempts to maintain continuity as the illness progresses:

*Then you decide, well OK, we'll fight it as long as we can.*

(From the theme 'Developing a fighting spirit'; Clare, 2002, p. 144)

In such accounts, dementia is framed as a challenge to be taken up, which in doing so appears to spur or maintain a sense of agency (Roger, 2006) and a determination (Wolverson et al., 2010) to live life to the full in spite of a diagnosis of dementia (Clare, 2002; Gillies, 2000; Harman & Clare, 2006; Nygard & Borell, 1998). Fighting dementia appears to allow some people to gain a sense of control (Gillies, 2000) and mastery (Nygard & Borell, 1998). Again this appears to be an active 'decision' taken by the individual with dementia to fight the dementia for as long as possible (Clare, 2002), to 'fight it at the moment, in my own way, on my own' (Harman & Clare, 2006).

### **3.6.2. Humour**

The literature demonstrates that people with dementia are able to enjoy humour and laughter and also value making others laugh (Langon, Eagle, & Warner, 2007). For some, humour appears to be associated with coping via taking a positive perspective which in turn de-emphasizes the position and the power of dementia in the context of their everyday lives:

*I've got into the habit of making a joke about it otherwise it would take over my life.*

(From the theme 'Normal vs. abnormal memory loss-putting it into context'; Langon et al., 2007, p. 995)

Humour might be associated with an attempt to maintain well-being as it helps people to minimize dementia and feel more 'normal':

*I'm alright; I'm luckier than a lot of people.*

(From the theme 'Normalizing: Minimisation (humour)'; Van Dijkhuizen, Clare, & Pearce, 2006, p. 86)

This particular quote and theme seems also to suggest that social comparisons are linked to this process of putting dementia in context and thus being able to engage in humour.

### **3.6.3. Hope**

General accounts of expecting the best and maintaining a positive outlook on life and the future (Gillies, 2000; MacRae, 2010; Mok et al., 2007) emerged:

*Life cannot be a bed of roses, but you can make it pretty good if you think in the right way.*

(From the theme 'Choosing an attitude for living on'; Jonas-Simpson & Mitchell, 2005, p. 57)

In particular, the experiencing of hope is both readily identified by people with dementia and is seen as a natural process not affected by the condition (Wolverson et al., 2010). Rather than describing hope as a cognitive process or expressing specific goals, hope is referred to as a more generalized motivational force (Dalby et al., 2011; Macquarrie, 2005; Nygard & Borell, 1998; Wolverson et al., 2010), associated with a sense of agency and determination that aids living well. Crucially, reference is made in one paper to the notion that hope in dementia requires personal effort and agency;

*If at first you don't succeed, there is no use giving up – if you don't hope for things you don't get them.*

(From the theme 'Self activating hope'; Wolverson et al., 2010, p. 454)

While small in number, reports of experiencing hope and optimism are present in this literature thus highlighting the potential that people with dementia have, for retaining these qualities and drawing on them in an ongoing effort to maintain well-being in the face of the condition.

### **3.7. Identity and growth**

A final higher order theme relates to how people with dementia actively preserve continuity in their sense of identity and that this can be connected to re-evaluating meaning and even growing as a human being. A significant component of is the experience and expression of feelings of gratitude that have been established through a process of active and positive life review. This theme is derived from a smaller literature base suggesting that concepts such as gratitude, wisdom and personal growth are phenomena that do exist and reflect new areas of potential enquiry in the context of having dementia. We therefore report aspects of the theme here with the intention of drawing attention to the potential significance of these experiences in the lives of people with dementia and their consequent relevance to ongoing clinical and research endeavours.

#### **3.7.1. Giving thanks**

Several references to a sense of gratitude for a life well lived were noted. In many cases this was linked to a process of positive life review on the part of the person with dementia (Clare, Roth, & Pratt, 2005; Clare et al., 2008). In particular, MacRae (2010) draws attention explicitly to this process in the theme 'life review' whereby participants actively look back in making sense of their lives and use this to counter-balance other experiences they have in the present. The gratitude that is expressed by participants across several studies also appears associated with feelings of satisfaction and integrity;

*I've had a lovely life and I feel satisfied.*

(From the theme 'Coping strategies - recounting the life story'; Sorensen et al., 2008, p. 294)

There is also a suggestion that this in turn may engender hope and agency in actively engaging with the rest of life that is available;

*I've had a tremendous life. I wouldn't trade it with anyone, and when it ends, you know, I'm just grateful for all I've had, and I'm hoping to enjoy every minute I've got left'.*

(From the theme 'Life Review'; MacRae, 2010, p. 300)

#### **3.7.2. Still being me**

Many included papers present accounts of how experiencing dementia relates to the preservation of identity and sense of self. Across studies, the importance of maintaining a sense of identity in general was highlighted as a strong concern for people with dementia (e.g. Clare et al., 2008; Harman & Clare, 2006; Steeman et al., 2013). In tandem, the need to feel of worth and 'believe in yourself' was highlighted (e.g. Jonas-Simpson & Mitchell, 2005). While dementia has clear potential to threaten a person's sense of self, what emerged here as a consistent theme was that people with dementia can also retain the perception that their identity is stable:

*I'm still the same person.*

(From the theme 'Perceived change in self'; MacRae, 2010, p. 297)

*You've lost your memory but you haven't lost your mind. And you're still the same person.*

(From the theme 'Seeing self as the same person'; Werzak & Stewart, 2002, p. 81)

Furthermore, that for some people, that process of adjusting to a diagnosis of dementia may result in a shift in core values relating to identity (Steeman et al., 2013) potentially allowing for, the preservation of a positive sense of identity:

*It's easier now....you may be yourself. Just an ordinary man.*

(From the theme 'Accepted'; Graneheim & Jansson, 2006, p. 1401)

### **3.7.3. Growing and transcending**

Some report positive experiences as a result of living with dementia, where, for example, the diagnosis of dementia enhanced life by allowing new opportunities for self understanding:

*I've learned an awful lot in this curious reaction thing... you understand about yourself...in some ways I could be grateful for what's happened.*

(From the theme 'Learned from it/positive aspects'; Clare, Goater, & Woods, 2006, p. 756)

*For others, there is a clear value attached to being able to contribute and therefore help other people from the position of having dementia:*

*There's this kind of research...I managed to make a contribution... it's something positive.*

(From the theme 'Making a contribution'; Clare, Roth, & Pratt, 2005, p. 504)

Other accounts of positive experiences related to sharing knowledge and experiences with others (Sorensen et al., 2008; Graneheim & Jansson, 2006; Meene et al., 2002), demonstrating the capacity of people with dementia to accept and transcend the condition (Parse, 1996). This ability to take a broader view of life and of dementia appears again to allow some people to put dementia in context and thereby minimize its impact on their life and their identity. For some this involves recognizing that life inevitably contains difficulty and tribulation; 'without the rain the flowers wouldn't grow' (Dalby et al., 2011, p. 13). Some other accounts demonstrate an almost spiritual wisdom surrounding a connectedness with humanity at a deeper level, but within the context of having dementia:

*And what's lovely ... people like me are retiring and getting Alzheimer's disease and all the rest, at home. All these other people are queuing up and waiting to go. So it's a big cycle.*

(From the theme 'Connections with people'; Dalby et al., 2011, p. 89).

## **4. Discussion**

A key aim of a person-centred approach to dementia is to maximize the potential of the individual (Edvardsson, Winblad, & Sandman, 2008). Valuing and understanding the strengths and resources that people bring to living with dementia, in order to ensure holistic and meaningful evaluations of quality of life, is therefore crucial. Accordingly, this review and synthesis was purposive in documenting positive lived experiences in dementia and the personal strengths and resources potentially connected with these experiences. We drew on the perspective of positive psychology to inform this, as an alternative conceptual

framework to the loss-deficit paradigm (see Sabat, 2001) that has arguably underpinned much dementia research to date.

The influence of a loss-deficit paradigm in dementia extends to the lived experience research included in this review and also to interpretations made by previous researchers. Notably, we only found two studies that explicitly examined the positive strengths or resources of people with dementia (Wolverson et al., 2010; Dalby et al., 2011). While positive subjective experiences in dementia have been reported elsewhere they are invariably interpreted as a struggle against the threats and losses that the condition brings, such as 'fighting spirit' (Clare, 2002), 'perseverance' (Beard, 2004), 'staying intact' (Dalby et al., 2011) and 'resisting the threat' (Nygard & Borell, 1998). Elsewhere, accounts of positive experiences have been interpreted as forms of denial or 'positive illusion' (Taylor, 1989). Consequently, it can be argued that this narrow paradigm has neglected the notion of a fulfilled individual who can retain choices, preferences, and strengths or the person who is capable of agency, mastery and growth even in the face of chronic illness (Aspinwall & Tedeschi, 2010). Thus, the potential for positive human experiences in dementia to co-occur with those that are difficult has been overlooked.

Previous reviews exploring subjective experiences (De Boer et al., 2007; Steeman et al., 2006) recognize that, in an attempt to actively adjust to and cope with dementia, relationships, acceptance, continuation and contentment appear vital issues but, consistent with an underlying loss-deficit paradigm, these have been placed within a social context of grief, loss, change and uncertainty. By contrast, the findings of this review capture a preserved sense of agency (Macquarrie, 2005) where people can actively seek pleasure and enjoyment, love and support and report experiences of hope, humour, and personal growth. Our findings therefore provide a first step towards understanding the conceptual domains that might underpin positive adjustment in people living with dementia.

The first of our higher order themes challenges the notion that living with dementia is the solely negative experience that might be expected (cf. de Boer et al., 2007). This theme suggests that, for some, dementia remains in the background of people's experiences while actively striving to age well is in the foreground. This is consistent with the 'shifting perspectives' account of living with a chronic condition (Paterson, 2001). Furthermore, the sub-themes of 'seeking pleasure and enjoyment', 'keeping going' and 'love and support' closely mirror key psycho-social dimensions of successful ageing such as positive coping, personal agency and social engagement (Baltes & Baltes, 1990). The notion that people with dementia can age successfully has, to date, been constrained both by narrow conceptualizations of dementia and biomedically focused, unidimensional models of ageing, but these can be challenged by subjective accounts (see Cosco et al., 2014). Broader conceptualizations of successful ageing, as well as related constructs such as gero-transcendence (Tornstam, 1996) could therefore be of value to future research into positive subjective experiences in dementia. Equally, the extent to which positive experiences in living with dementia are related to the preservation of adaptive personality traits such as positive affectivity, extraversion and openness to experience (see Kolanowski, Litaker, & Buettner, 2005) bears further empirical investigation.

The second higher order theme to emerge from our synthesis reflects how people actively manage the consequences of dementia. Consistent with a loss-deficit paradigm we note that people with dementia are regarded as actively coping, by accepting and 'fighting' against the condition in order to maintain a positive self-concept in the face of losses and threats (e.g. Clare, 2002). However, a positive psychology perspective invites a re-appraisal of people's experiences beyond common discourses of 'coping' (Clare, 2002), 'maintaining' (MacRae, 2010) or 'preserving' (Harris & Sterin, 1999) by providing new insights into the personal strengths and virtues (Peterson & Seligman, 2004) that may also exist in people with

dementia. These include the capacity for perspective (having the wisdom to 'look beyond' the dementia in accepting it - Clare, Goater, & Woods 2006), bravery (having the courage to face challenges, threats and difficulties - Harman & Clare, 2006), persistence (persevering despite the challenges and obstacles of dementia - Caddell & Clare, 2011) and vitality (approaching life with enthusiasm and energy in spite of dementia - Wolverson et al., 2010), all of which we noted within our review. Hope and humour deserve particular consideration as potentially key personal resources that help people with dementia to live well. Indeed, both are well documented as strong predictors of well-being and adjustment in a range of other chronic health conditions (see Lefcourt, 2002; Rand & Cheavens, 2009). They might therefore be considered positive outcomes in their own right in the context of dementia or may facilitate other positive outcomes and quality of life generally and further research could explore these issues. Humour may serve the function of maintaining and strengthening close social bonds and may therefore take on extra significance in the lives of older people living with dementia (Stevens, 2012). The nature and function of hope may alter for people living with dementia (see Wolverson et al., 2010) and the possibility that hope in dementia relates to a process of active acceptance, as described within the theme Facing it and Fighting it, is a valuable question that further qualitative work should investigate.

The notion that people living with dementia can retain such resources and that they might operate to help in transcending their condition and maintaining supportive relationships stands in contrast to a dominant biomedical model of deficit and inexorable decline. Extending the notion of living well in spite of dementia, our third higher order theme hints at the possibility of living well because of having dementia. The nature of gratitude, growth and transcendence have yet to be fully examined in people who live with dementia. It should not be presumed that growth is prompted only by traumatic circumstances (Weiss, 2014), but may be related to aging well (e.g. gerotranscendence, Tornstam, 1996). How positive personal factors such as gratitude, wisdom and self-compassion might support the continuation of a positive sense of self in dementia are also important questions for future research to address.

## **5. Limitations**

Some comments must be made with regard to the limitations of this review, which relate both to the quality of the retrieved studies and the methodology employed by this review itself. Controversy exists in relation to whether and how qualitative studies of differing methodological and epistemological positions can be compared on methodological quality (Walsh & Downe, 2005) and we acknowledge this. However, according to the quality assessment we employed, only 5 of the 27 studies showed strong methodological quality, which raises important questions regarding scientific rigor generally in this field. Key problems with this literature base relate to variation in quality of data collection and sampling methods, lack of transparency in reporting issues such as researcher roles and also consistency of methodological critique. This has the potential to limit the validity of our own interpretations and may dilute the perceived value of the lived experience literature. The need to ensure high levels of rigor and transparency in future qualitative research into positive lived experiences in dementia is clearly important.

The generalisability of samples included in extant lived experience studies represents a further methodological limitation for this review. Participants involved in studies of lived experiences in dementia are invariably those who, despite their condition, are still able to communicate verbally (De Boer et al., 2007). As such, samples are often weighted toward people in the earlier stages of dementia, who are often community dwelling. Few studies have explored living with moderate to severe dementia and so we do not know if such positive experiences and states as we interpret and describe here can be generalized to those surviving longer with the condition in different contexts. In addition, the samples in



included studies are usually weighted toward white, educated middle-class women. It is therefore possible that the interpretations we have made with regard to the nature of positive lived experiences are unduly influenced by the relative privilege and dominant values and assumptions of that subgroup rather than representing people with dementia as a whole, thus inadvertently reflecting a process of marginalization in dementia that has been documented and discussed by others (see Hulko, 2009).

Further potential limitations exist regarding the methodology employed by this review. The synthesis of qualitative studies is challenging because of the divergent epistemological and methodological positions adopted and the resulting risk of losing the context and original meanings of participants' experiences when synthesizing across studies. Careful attention must be paid to examining convergences and divergences in interpretations of personal experiences between studies, which are potentially moderated by methodological quality and the influence of meta-theoretical positions (e.g. implicit loss-deficit paradigms). A related issue is that data extraction and re-interpretation were inevitably inferential processes subject to our own assumptions as researchers interested in positive experiences in dementia as well as the purposive nature of the review itself. For example, while some quotations selected for inclusion were explicitly positive others were more ambiguous and subjective: I hardly ever think about that, one wants to repress having a disease, even if one knows it is there (in Nygard & Borell, 1998; under the theme 'resistance and management of threat') and thus more open to a positive reinterpretation. Moreover, as a consequence of the way other researchers have managed positive reports, sometimes quotations were selected as positive that had not been attached to a particularly positive theme within the source paper. While it is our view that the extracted data and its interpretation do represent the experiences of participants in included studies this is open to debate and re-interpretation itself.

## **6. Conclusions**

The systematic and explicit exploration of positive strengths and virtues in the lives of people with dementia is necessary in order to understand lived experiences in their entirety and therefore inform person-centred perspectives. Our intention is not to make light of or to glamorize the experience of dementia and we must remain mindful of falling prey to the 'tyranny of the positives' (see Held, 2004) in relation to dementia. Nonetheless, this review and synthesis promotes a balanced perspective where positive experiences are not overlooked and can be understood using positive psychology perspectives and concepts. We conclude that people living with dementia can retain important strengths and have positive experiences in spite, and even because of, living with the condition. A positive person-centred approach to dementia care and research should transcend any ongoing debate about whether or not such experiences can be regarded as 'real' and instead should look toward how they can be facilitated and maximized in order to help the individual living with dementia achieve his or her optimal level of functioning.

### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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