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Positive Experiences In Older People With Early Stage Dementia

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by

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I would like to thank Chris and Esme for their supervision (and enduring hopefulness throughout this endeavour)! And on a personal note, I would like to thank Eddy for his support and endless patience.

I would like to dedicate this research to the hope; courage; humour; and strength of all the people that took part.

And to my Mum, for teaching me to see the strengths in people.

For the hope that she gave me.

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Overview

This thesis is divided into 3 parts:

Part 1 is a systematic literature review entitled 'Living Positively with Dementia'. The notion that people living with dementia can have positive experiences in spite of - or even *because* of - their illness remains widely disputed. In light of this controversy and the potential conceptual and clinical importance of documenting the subjective experience of dementia in all its variations, this review examines the current research evidence relating to positive lived experience in dementia. The review uncovered 63 studies containing evidence of positive experiences reported by people living with dementia. The methodological quality of the studies is evaluated along with consideration of how researchers have managed such reports. The findings of the review suggest that people with dementia are capable of experiencing positive emotions, and furthermore that dementia can uncover strengths in people, such as hope; faith; resilience; wisdom; altruism; humor; optimism; perseverance; and courage.

Part 2 is an empirical study which investigates one of the positive constructs highlighted by the review - hope. The paper examines the subjective experience of hope in older people with early-stage dementia and explores factors that facilitate or hinder hopefulness in this population. Ten participants were each interviewed and interpretative phenomenological analysis was used to identify themes within their accounts. The study considers how hopefulness in dementia compares with existing definitions of hope and the existing literature on age; dependency; and coping, in order to provide a thematic framework for understanding how hope may support individuals with dementia to maintain their quality of life, and to consider the scope for hope-fostering strategies.

Part 3 consists of the appendixes relating to the research, including a reflective statement on the process of carrying out the research. The statement includes reflection on all aspects of research from planning to carrying out the research project.

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Part 1: Systematic Literature Review

Living Positively with Dementia: A Systematic Review of the Literature

Living Positively with Dementia: A Systematic Review of the Literature

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ABSTRACT

Background: There is a widespread assumption that dementia is a state of terrible suffering. However, the reappraisal of dementia that has been undertaken in recent years, has allowed people with dementia to emerge as active agents and challenge many presumptions about the experience of living with dementia. Accounts of people living positively with dementia have emerged within the literature but they have caused some controversy. In light of this controversy and the potential conceptual, clinical and psychosocial importance of documenting the subjective experience of dementia in all its variations, this paper reviews and examines the current research evidence relating to positive lived experience in dementia.

Results: A total of 63 studies with various research aims were found to contain evidence of positive experience. No studies explicitly aimed to examine positive experience. Quality assessment revealed that views studies often fell significantly short of basic methodological standards.

Conclusions: The literature revealed that a diagnosis of dementia is not a wholly negative experience. People with dementia are capable of experiencing positive emotions and reported positive experiences as a direct result of their dementia. Dementia appeared to uncover strengths

in people, such as hope, faith, resilience, wisdom, altruism, humor, optimism, perseverance and courage. Whilst these positive constructs exist within the literature they appear to have been overlooked by researchers. Future research needs to examine positive experience and identify factors that promote well-being.

Key words: dementia, Alzheimer's disease, positive, patient perspective, views, lived experience, review

Living Positively with Dementia: A Systematic Review of the Literature

“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”

(Stuckey, Post, Ollerton, FallCreek and Whitehouse, 2002, p 206)

1. Introduction

Dementia has been described as the modern epidemic of later life and the most feared diagnosis of older adults (Vernooij-Dassen *et al.*, 2006). There is a widespread presumption that dementia is a state of terrible suffering and attitudes toward dementia amongst the general public and professional health care staff alike tend to be overwhelmingly negative (Keightley and Mitchell, 2004; Snyder, 1999; Clarke *et al.*, 1993). The standard medical paradigm framing dementia narrowly in terms of neurological decline and the research emphasis on the psychosocial, functional and behavioral consequences of the disease has undoubtedly contributed to the stigma and hopelessness embedded in public perceptions of dementia. However, the extent to which people actually experience dementia in this way has been relatively unclear to date. For many years it was felt that the subjective accounts of people with dementia could not be relied upon fully (Lawton, 1997) and consequently little was actually known about the experience of living with dementia and the degree to which this experience matches its common public perception.

A reappraisal of the value of exploring the subjectivity of dementia has been undertaken in recent years (for example see Keady, Nolan & Gilliard, 1995; Kitwood, 1997; Sabat, 2001) and this has led to a growth in research exploring the meaning of the illness from the perspective of the people living with dementia. This research has found that people with dementia are able to express their views, needs and experiences (for example, Clare, *et al.*, 2005; Phinney, 2002). Incorporating the

subjective experience of dementia into the research in this field, is important both clinically and conceptually. Clinically, it is important in order to focus care towards enhancing quality of life for the individual with dementia, instead of towards treating the disease (Grypdonck, 1996). Conceptually, it means that a more complex and multi-dimensional approach to dementia can evolve which incorporates an understanding of the person, their social and psychological resources and the impact these factors can have on the presentation of the disease (Kitwood, 1990).

Crucially, this re-appraisal has enabled some positive views of dementia to emerge, with a focus upon the whole person, drawing upon strengths as well as taking into account declining abilities in some areas. It has allowed people with dementia to emerge as active agents who do not passively suffer the consequences of having dementia but interact with their illness. As a result, researchers have now started to examine whether living with dementia actually involves the depth of suffering that so many fear (de Boer *et al.*, 2007).

The 'positive psychology' movement, has served to remind us that psychology itself is not merely the study of disease, weakness and damage, but also the study of strength and virtue. This branch of psychology encourages the systematic examination of such positive experiences because it reminds us that a psychologist's work is not just fixing what is wrong but building on what is right (Seligman, 2005). However, the notion that people living with dementia can have positive experiences in spite of - or even *because* of - their illness remains widely disputed and controversial. Some researchers have questioned whether positive experiences in dementia are even possible. Positive reports have been called a façade; denial; a defense mechanism; or even the result of a lack of awareness (Steeman, 2007). Schreiner *et al.* (2005) stated that while people

with dementia still possess the ability to passively experience happiness, they lack the cognitive skills necessary to actively pursue happiness.

In light of this controversy and the potential conceptual, clinical and psychosocial importance of documenting the subjective experience of dementia in all its variations, this paper reviews and examines the current research evidence relating to positive lived experience in dementia.

Aims

1. To conduct a systematic review of reports of positive experience in people who are living with dementia.
2. To evaluate the methodological quality of the reported studies.
3. To explore how researchers have conceptualized reports of positive experience in dementia where they exist in the literature.

2. Methods

Search Criteria

To identify published papers, a systematic literature search was conducted using three computerized databases; MEDLINE, CINAHL and PsychINFO. The search criteria were as follows:

The search used the subheadings (DEMENTIA) AND (ALZHEIMERS)
WITH

1. (EXPERIENCE), (PERSPECTIVE), (quality AND life), (WELLBEING), (ADJUSTMENT), (COPING), (MEANING) (LIVED EXPERIENCE). These terms were selected to access the lived experience literature in dementia that accounts for most of the views studies.
2. Additional searches were completed using the terms; happiness, wisdom, satisfaction, hope, optimism, resilience and faith. These terms are positive psychology constructs (see Seligman, 2005).

To ensure an extensive search, manual searches were conducted of the reference lists of all included articles. A focused hand search was also performed in the Journal of Dementia (Keady *et al.*, 2002).

Inclusion criteria

This review included articles meeting the following criteria:

- Articles published in referenced journals between January 1990 and January 2008 (inclusive). 1990 was chosen as in the late 1980s a call was made to include the perspective of people with dementia in research and care (e.g. Lyman, 1989).
- Studies where participants were people diagnosed with Alzheimer's disease, vascular dementia or other forms of dementia, according to ICD 10 (WHO, 1992), DSM IV (DSM-IV-R, 1987) or comparable criteria. It was decided to consider these diagnostic categories together, due to limitations in the available data, it was not expected to be possible to consider the specific diagnostic categories separately.

- Views studies; that is, studies that place people's own voices at the centre of analyses (Harden *et al.*, 2003). Views studies privilege people's attitudes, opinions, beliefs, feelings, understandings or experiences. They are non-intervention studies that may be quantitative, qualitative or mixed in design (for example; self-completion questionnaires, interview based studies both individual and group, focus groups). Essentially, these are studies in which the primary vehicle of data collection is subjective accounts.
- Articles containing evidence of positive lived experience in the results section. This evidence could take the form of either a theme title, a direct quotation from a participant or an item scored on a quantitative measure that was considered to demonstrate positive experience. For the purpose of this review a 'positive' experience was defined as one corresponding with any concept outlined in Seligman's (2005) definition of positive psychology, such as well-being, satisfaction, flow, joy, happiness, optimism, faith, hope, love, vocation, interpersonal skill, altruism, nurturance, perseverance, courage and wisdom. These terms could either have been used directly in the paper or be a description considered to correspond with one of these concepts.

Exclusion criteria

- Any study that did not include accounts of direct lived experience anywhere in it or any study that has examined lived experience but does not do this explicitly through direct subjective reports.
- Systematic literature review papers
- Studies published in a language other than English
- Studies which did not contain any positive reporting of lived experience in dementia

Screening

Sifting was carried out in three stages with papers excluded at each stage if they did not satisfy the inclusion and exclusion criteria. Firstly, retrieved papers were reviewed by title, to select only views studies. Then abstracts were screened to ensure that the studies contained subjective accounts and that participants were people with a diagnosis of dementia. Finally, full text papers were screened; a detailed examination of the results section was conducted to look for evidence of positive lived experience, this was either in the direct use of a positive psychology term (happiness, wisdom, satisfaction, hope, optimism, resilience, faith) by the researcher or participant, or in quotations judged to be describing positive experience.

3. Results

3.1 Identification and classification of relevant studies

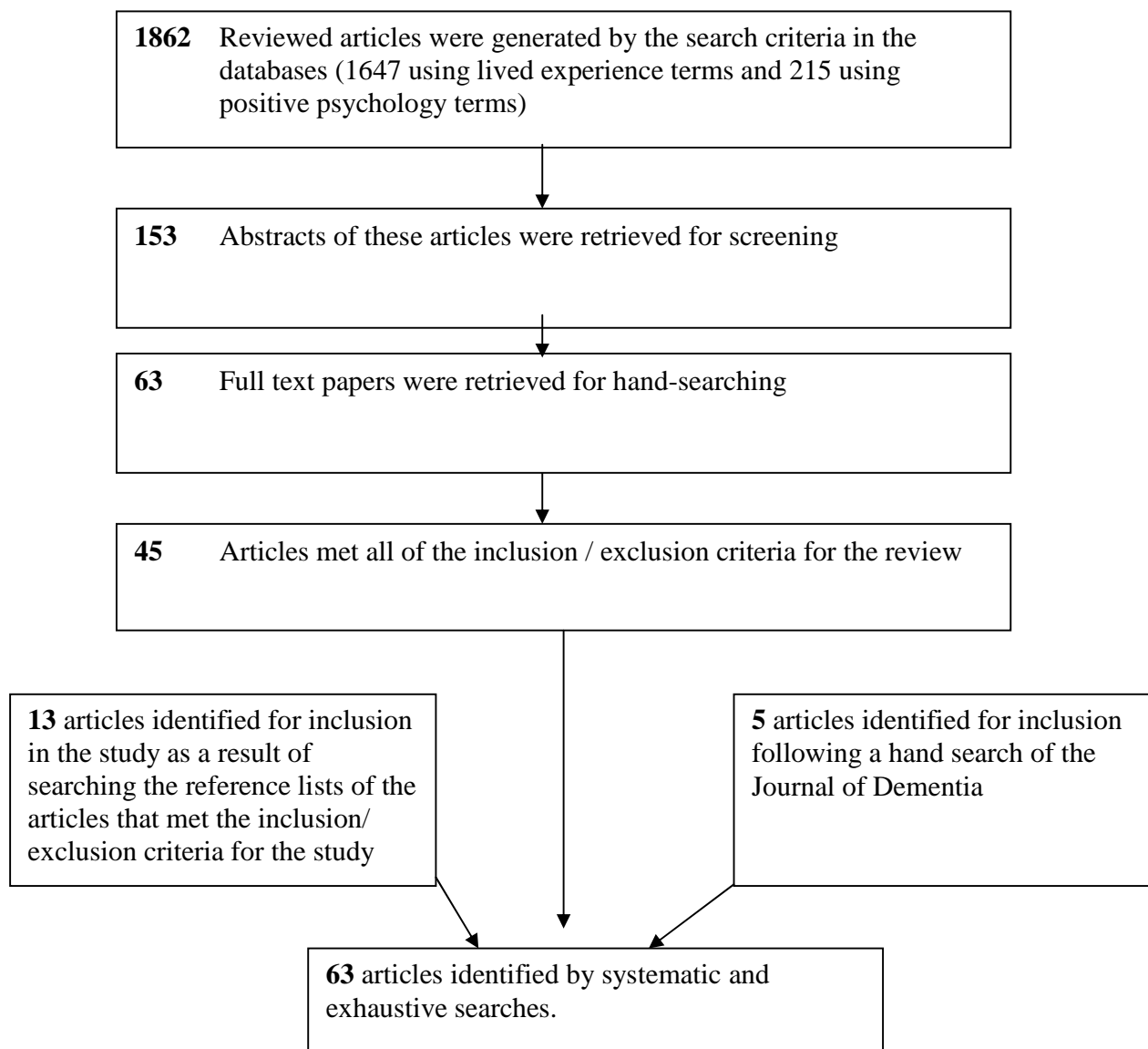


Figure 1: Review Process

The preliminary database searches yielded a tremendous number of results (1862), however many of these studies did not meet the inclusion criteria. Many were not views studies (many being intervention studies, editorials on dementia or reports of pharmacological trials), and many were excluded because participants were not people with dementia (many were studies of carers).

However, 153 of these results were relevant on the basis of their title and so the abstracts of these studies were retrieved. Of these 153 abstracts, 94 were excluded because they were not views studies (many being intervention studies, or only were only presenting peoples views as variables to be tested). A further 2 were excluded as they were systematic literature reviews. Following the abstract screening, 63 full text papers were retrieved for hand-searching because they fell within the lived experience literature. Of the 63 papers examined, 18 were excluded because they did not contain any positive reports.

3.2 Characteristics of Included Studies

In total, 63 articles meeting the inclusion criteria were included. Table 1 summarizes the characteristics of the included studies. The majority of participants sampled by the studies lived in the community (33 studies recruited from a community sample), 2 studies recruited from inpatient settings, 1 from residential homes, 12 studies examined participants living in a mixture of settings, and 15 studies did not specify where their participants resided. Geographically, samples were drawn from numerous countries including Belgium, France, Canada, China, England, Finland, Ireland, Japan, Lithuania, Luxemburg, Netherlands, Norway, Sweden, Switzerland, USA and Wales. All participants had a diagnosis of dementia, the most common subtype being AD (with 24 studies exclusively examining patients with AD) other subtypes examined in the studies were vascular dementia, frontal temporal dementia, mixed dementia, dementia with Lewy bodies, dementia with sub-cortical atrophy, Parkinson's disease, Picks disease, Huntington's diseases and dementia type not specified/ undetermined. It should be noted that 25 studies only stated that participants had dementia and did not specify a subtype. The sample sizes of the included studies ranged from 1-193 (with a mean of 23.6 participants), totalling 1489 people with dementia. Not all studies detailed the gender of their samples (12 did

not) but of those that did, overall, 473 men and 656 women were questioned. In 7 of the studies the experiences of family caregivers were also surveyed.

The studies included employed a variety of designs; descriptive (5), explorative (11), phenomenological (12), grounded theory (11), personal accounts (3), self-completion questionnaires (1), community dialogue (1), case study (1) and mixed designs (18). While all studies generally explored the experience of living with dementia, some focused on specific aspects, such as receiving a diagnosis (7 studies), coping and adaptation (8 studies), identity (1 studies), occupational self (4 studies), awareness (1 study), social interaction (3 studies), experience of services or care (5 studies), how people make sense of their illness (2 studies), values (2 studies), self-reported quality of life (10 studies), the experience of religion and spirituality (3 studies) and recall of emotional memories (1 study). Most studies were cross-sectional with the exception of 4 longitudinal studies (Clare *et al.*, 2005; Macquarrie, 2005; Nygard and Borell, 1998; Vernooij-Dassen *et al.*, 2006).

3.3 Quality Assessment

Studies meeting the inclusion criteria were assessed for their methodological quality. Study quality was appraised across study types using a revised version of the checklist developed by Harden *et al.* (2003) (see appendix A) according to seven criteria. Methodological quality was not used as an exclusion criterion, but is reported alongside study descriptions presented as an overall quality rating score out of 7 (see table 2), full details of which quality criteria were met can be seen in appendix B.

Only four studies met all seven quality criteria (Clare, Goater and Woods, 2006; Clare and Shakespeare, 2004; Harman and Clare, 2006; Katsuno, 2005). Just over half of the studies demonstrated an explicit theoretical framework and literature review (58.7 per cent), provided a clear description of methodology (55.5 per cent) and reported adequate details of attempts to establish the reliability and validity of data analysis (50.7 per cent). Most of the studies were considered to have stated their aims and objectives clearly (92 per cent) and have included sufficient original data (85.7 per cent). Only 30 per cent of the studies offered a clear description of context to the study, by providing a justification for the focus of the study by describing a distinct problem and clinical rationale that led to the study and justification for the methods chosen. Only 34.9 per cent provide adequate details of the sample. Table 1 shows the basic data from the methodological review of the included studies.

Quality Criteria	n	%
Explicit theoretical framework and literature review	37	58.7
Aims and objective clearly stated	58	92
A clear description of context	19	30
A clear description of sample	22	34.9
A clear description of methodology	35	55.5
Evidence of attempts to establish reliability and validity of data analysis	32	50.7
Inclusion of sufficient original data	54	85.7

TABLE 1: Number and proportion of studies displaying different methodological quality criteria (n=63)

A random sample of 20 studies was selected to be quality checked again by two independent raters (HW and MT) to assess the reliability of the quality checklist. The raters disagreed on the ratings of 4 studies (Langdon, Eagle & Warner, 2007; Menne, Kinney and Morhardt, 2002; Graneheim & Jansson, 2006; Nygard & Ohman, 2002) the final ratings were decided on after

mediation by a further researcher (CC). The inter-reporting reproducibility of the checklist was determined by calculation of a kappa statistic. These calculations were performed using the Statistical Package for the Social Sciences version 14.0 (SPSS, Inc. 2005). Reporting agreement between raters using a kappa statistic showed good agreement for criteria (A) the account of theoretical framework and inclusion of a literature review (kappa 0.894, SEM 0.103, $p < 0.000$); (B) clearly stated aims (kappa 1.000, SEM 0.000, $p < 0.000$); (C) description of context (kappa 0.794, SEM 0.135, $P < 0.000$); and (E) a clear description of methodology (kappa 0.762, SEM 0.159, $p < 0.001$). A moderate agreement for reporting was found between raters for criteria (F) evidence of attempts made to establish the reliability and validity of analysis (kappa 0.615, SEM 0.159, $p < 0.003$) and criteria (G) the inclusion of sufficient original data (kappa 0.692, SEM 0.196, $p < 0.001$). The weakest agreement between raters was for criteria (D) description of the sample (kappa 0.596, SEM 0.181, $p < 0.008$). Overall it appears the revised version of the quality checklist has good inter-rater reliability.

3.4 Positive Report

All included papers were examined carefully and found to contain examples of positive experience (see table 2). Our intention is not to give a full description of all the details covered in these papers, but to provide a general thematic overview of the current research evidence pertaining to positive lived experience in dementia. Therefore, all relevant information was analyzed and categorized into several themes as detailed below. This categorization arose naturally from reading and was used to provide a structure to the results. However, the themes are not mutually exclusive and, the majority of studies cover multiple themes.

Diagnosis

People with dementia express positive experiences related to receiving a diagnosis of dementia. Studies demonstrate that alongside the negative elements of receiving a diagnosis, some people experience diagnosis as positive and personally empowering (Beard, 2004). Some people find that receiving a diagnosis allows them to maximize their coping strategies (Aminzadeh *et al.*, 2007) and, develop positive attitudes and adaptations as part of coming to terms with the diagnosis (Pratt and Wilkinson, 2003; Robinson *et al.*, 2005). Some find that the diagnosis encourages them to make significant positive decisions about their future (Derksen *et al.*, 2006; Vernioij-Dassen *et al.*, 2006).

Quality of Life

People with dementia indicate that their quality of life (QoL) is multi-dimensional and items such as; a sense of well-being (Brod *et al.*, 1999); an appreciation of beauty and nature (Brod *et al.*, 1999); an evaluation of happiness (Byrne-Davis *et al.*, 2006; Droes *et al.*, 2006, Jonas-Simpson and Mitchell, 2005); cheerfulness (Cahill *et al.*, 2004; Jonas-Simpson and Mitchell, 2005), hope (Cahill *et al.*, 2004; Dabbs, 1999), contentment (Cahill *et al.*, 2004; Jonas-Simpson and Mitchell, 2005); laughter and humour (Cahill *et al.*, 2004; Dabbs, 1999; Droes *et al.*, 2006) and feelings of relaxation (Jonas-Simpson and Mitchell, 2005) are important for their quality of life. Several studies show that people with dementia report a good QoL overall, despite the limitations imposed by their cognitive impairments. Cahill *et al.* (2004) found that all their participants experienced positive affect and that three quarters of their participants reported that they enjoy a very good QoL. James *et al.*, (2005) found that the majority of their patients rated their QoL overall as 'good' or 'very good'. Katsuno (2005) found that 93% of participants stated that their QoL is either 'good' 'fairly good' or 'negative-positive'.

Experience and meaning of living with dementia

Several studies have attempted to learn more about the meaning and experience of living with dementia, and these studies also reveal evidence of positive experience. Some people describe living with dementia without experiencing many changes, expressing that they still enjoyed active and meaningful lives (Phinney, 1998; Phinney et al., 2002). Many people normalize their situation as natural and common (Langon *et al.*, 2007). Some people experience feelings of satisfaction (Morioka *et al.*, 2005), value (Nygard and Borell, 1998), pride, mastery and agency (Macquarrie, 2005). People describe positive experiences despite their dementia, such as feeling needed and appreciated (Graneheim and Jansson, 2006). Others describe positive experiences as a direct result of having dementia (Harris, 2004; Roger, 2006). People find ways to cope with memory problems by getting on with things (Aggarwal *et al.*, 2003), fighting to maintain their independence (Harris, 2006), and by emphasizing their remaining competencies (Steeman *et al.*, 2007).

Coping

Ostwald *et al.*, (2002) comments on how ‘enlightening and somewhat surprising’ it is that research evidence suggests that people with dementia have a wide variety of strategies which they use in dealing with their dementia. Research demonstrates that people are not passive but actively try to cope with their illness using cognitive, social and behavioural strategies. In spite of their impairments people with dementia describe ‘holding on’ and maintaining a sense of normality (Clare, 2002; Clare *et al.*, 2006; Harman and Clare, 2006). For some people little of their daily lives and activities are affected by their illness and they continue to make the best of things and get on with their life (Menne *et al.*, 2002; Mok *et al.*, 2007; Ohman and Nygarad, 2005; Pearce *et al.*, 2002).

Others cope positively by *accepting* the reality of their memory problems and live each day as it comes (Clare, 2002; Clare *et al.*, 2006; Gillies, 2000; Holst and Hallberg, 2003; Keady, Nolan & Gilliard, 1995; Mok *et al.*, 2007). This attitude of striving to accept the present situation (Nygard and Ohman; 2002) appears to be a cognitive strategy (Ostwald *et al.*, 2002) that involves attempting to balance the frustrations and losses (Pearce *et al.*, 2002) and feelings of hope and despair (Clare, 2002). By realizing what's important, making the best of things and letting go of worries (Nygard and Ohman, 2002), over time some people learn to adjust to their dementia and adapt positively to the changes they are experiencing (Clare *et al.*, 2005). Many people describe how learning to accept the disease as an integral, albeit unwelcome component of life allows them to get the best they can from their life (Truscott, 2003; Van Dijkhuizen *et al.*, 2006; Werezak and Stewart, 2002). Alternatively, other people, whilst acknowledging their dementia diagnosis describe their decision to confront their dementia head on and fight it (Clare, 2002). For others the way to cope is to reframe the disease as a challenge (Sterin, 2002) to resist the dementia (Clare and Shakespeare, 2004) and find ways to fight against it (Phinney *et al.*, 2007).

Some people describe learning from their dementia and find positive aspects to their illness experience (Clare *et al.*, 2006; Holst and Hallberg, 2003). The discovery of hidden talents they never had the opportunity to realize prior to their illness (Morhardt, 2004), working harder at their interests (Snyder, 2006), challenging themselves and advocating for themselves and others with dementia (Menne *et al.*, 2002). Those who adopt a positive outlook appear to do so because they have made sense of their illness and receive understanding and support from family and friends (Mok *et al.*, 2007).

Many people use practical behavioural strategies that help them to cope with their dementia (Harman and Clare, 2006). Some people cope by comparing themselves favorably with others

(Clare, 2002; Gillies, 2000; Harman and Clare, 2006; Van Dijkhuizen *et al.*, 2006). Positive emotion focused coping strategies are also helpful, people describe humour as an essential form of resilience (Keady, Nolan & Gilliard, 1995; Menne *et al.*, 2002; Snyder, 2001; Snyder, 2006; Van Dijkhuizen *et al.*, 2006; Werezak and Stewart, 2006). Faith and spiritual beliefs are described as a positive form of coping that allow some people to find support, strength, security and a sense of meaning and purpose (Katsuno, 2003; Snyder, 2003; Stuckey *et al.*, 2002). Many people state the crucial importance of social support in cushioning the effects of memory problems, despite their dementia many people still describe positive experiences of companionship, socialization and community (Snyder, 2006; Truscott, 2003; Van Dijkhuizen *et al.*, 2006).

Identity

Studies that examine the impact of dementia on sense of self and identity also contain some evidence of positive lived experience. People are ‘*living*’ with dementia, accepting their diagnosis and adjusting their lives and personal identities to include their illness (Harris and Sterin, 1999). Whilst many people describe a loss of personal competency, they do not experience a loss of personal identity. People use many strategies to maintain and reclaim their identity such as making references to their early self, maintaining a sense of purpose, making comparisons to others, through talking with others and through laughter (Gillies and Johnson, 2004; Lyman, 1998).

Evaluation of Services and of Receiving Care

The final area of research containing reports of positive experience are studies which have evaluated people’s experience of services or of receiving care. Some people report belonging to a group or attending a day service to be a positive experience, for some it provides social support

and bolsters feelings of acceptance (Mason *et al.*, 2005; Proctor, 2001). Additionally, some people report experiencing positive care-giving relationships, such as in Ward-Griffin et al. (2006) study on the experiences of receiving care from an adult daughters.

Author and Year	Design & aim of the Study	Quality Rating Awarded	Positive element extracted (Theme domain or subscale)	Example Quotation or statistic
Aggarwal, Vass, Minardi, Ward, Garfield and Cybyk (2003)	Mixed Design To explore how people with dementia and their relatives experience dementia and how they perceive care.	Met 2 / 7 criteria.	Coping: Getting on with things/ actively involved	'My memory is not what it was and I make a list. Oh I must do so and so – you know it helps'
Aminzadeh, Byszewski, Molnar and Eisner (2007)	Mixed Design To examine the emotional impact of disclosure of diagnosis on people with dementia and their caregivers	Met 6 / 7 criteria.	Optimism Maximizing	'I'm glad I went. It gave me a positive outlook on my health' 'It's up to me. There're ways one can help themselves. So, get on with it'
Beard (2004)	Mixed Design To examine the impact of being diagnosed with early AD on identity construction	Met 4 / 7 criteria.	Defining moments To tell or not to tell Preservation	'When I did get told about this I instantly felt that I'm gonna go day by day if I can and just make the best of it' 'I have it and I cant cure it for you or anybody else but, you know, just be nice to me...I don't mind telling anybody' 'I don't think we should let the AD eat us up. If you like to play checkers, play them!' Mean score 3.66 (/5)
Brod, Stewart, Sands, Walton (1999)	Mixed Design To conceptualize the domains of QoL appropriate for people with dementia. To develop an instrument based on that conceptualization.	Met 4 / 7 criteria.	Self esteem Positive affect / humor Feelings of belonging	Mean score 3.55 (/5) Mean score 3.66 (/5)
Byrne-Davis, Bennett and Wilcock (2006)	Grounded theory To aid conceptual clarification and facilitate construct validity testing of measures of QoL for people with dementia.	Met 5 / 7 criteria.	Sense of Aesthetics Feeling happy Feeling content Feeling useful Not being worried Feeling you've had a good life	Mean score 3.99 (/5) 'Me, I am just happy' 'I'm quite content as I am' 'If you could do a good turn for anybody, do it, that makes the quality of life don't it' 'I don't worry about nothing else' 'I've really enjoyed my life'

Cahill et al (2004)	Mixed Design To examine how people with dementia rate their QoL and to explore whether they can be considered good informants of their QoL.	Met 3 / 7 criteria.	Ways to spend time	'I suppose the most important is that you enjoy life'
			Positive affects	'I'm happy with what I've got. I like where I live, I generally get up in good humor. I worked all my life and am happy now just to relax and appreciate what I have and relax'
Clare (2002)	Phenomenological Study To explore the process of adjusting to the changes experienced in early-stage AD.	Met 6 / 7 criteria.	Self-esteem	'I'm confident when I'm with people, I've changed'
			Good self reported QOL	'My wife, my children and grandchildren are so dear'.
			Holding on	'It's also me facing up to things and making an effort'
Clare, Goater and Woods (2006)	Qualitative Exploratory Study To explore how people with dementia conceptualize their condition and its implications using the illness representations model.	Met 7 / 7 criteria.	Compensating	'Maybe it's rubbish and it wont work, but I'd never forgive myself for not trying'
			Developing a fighting spirit	'Then you decide, well ok, we'll fight it as long as we can.'
			Take things as they come	'I'll just cope. I don't worry about that'.
			Can't complain	'By and large, I don't find myself in any great difficulty'
Clare, Roth and Pratt (2005)	Phenomenological study One year follow up to explore participant's experiences over time and consider the implications for coping and awareness in early-stage AD.	Met 5 / 7 criteria.	Learned from it / positive aspects	'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'
			Fine in myself	'I feel well in myself'
			Making a contribution	'There's this kind of research...I managed to make a contribution...it's something positive'
			Still doing things	'Still enjoy walking and reading in particular... and I still enjoy listening to music'
Clare and Shakespeare (2004)	Qualitative Explorative Study	Met 7 / 7 criteria.	Cant complain	'I think I've had a good life...I've got a good family. I've got nothing to grumble about'
			Coping as best you can Getting a bit forgetful	'I cope you know' 'I find it (present situation) very happy'

	To investigate conversational interactions between people with-early stage dementia and their partners.		Helping each other out	'I think its right to be hopeful, but you cant go kidding yourself'
Dabbs (1999)	Qualitative Explorative Study	Met 1 / 7 criteria.	A memory problem Sense of well-being	'That's the main thing, agreeing that you have got a problem...you try and cope with it...doing my best to compensate for it' ' I should feel old, but I don't. Not old at all really'
Derksen, Vernooij-Dassen, Gillissen, Rikkert and Scheltens (2006)	To explore what people with dementia value most in life. Grounded theory To give an in-depth description of the impact of receiving a diagnosis of dementia on patients and proxies.	Met 6 / 7 criteria.	Positive experiences	'We want to marry because then you confirm whatever happens, I wont let you go. We want to settle things'
Droes, Boelens-Van der Knoop, Bos, Meihuzen, Ettema, Gerritsen, Hooegeveen, De Lange, Scholzel-Dorenbos (2006)	Grounded Theory To examine which domains of QoL are important to people with dementia.	Met 5 / 7 criteria.	Spirituality	'I am still alive and that is something to be grateful for'
Friedell (2002)	Personal account	Met 4 / 7 criteria.	QOL is an individual matter	'I do believe, though, in a God that, as long as I am me, I can turn to in need and who can help me face any truth and live in hope, not fear'
Fukushima, Nagahata, Ishibashi, Takahashi and Morlyama (2005)	A personal memoir of declining QoL in AD. Mixed Design To explore the existential nature of dementia.	Met 2 / 7 criteria.	Values personal relationships Cheerful Sings and dances	7/21 participants reported 6/21 participants reported 4/21 participants reported
Gillies (2000)	Qualitative Exploratory Study To explore accounts of living through dementia of people advanced into their dementia experience.	Met 3 / 7 criteria.	Comparing self with former abilities and with others 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'
Gillies and Johnson (2004)	Qualitative Exploratory Study	Met 2 / 7 criteria.	Preserving identity	'I like helping everybody. More or less, I like helping everybody'

Graneheim and Jansson (2006)	To explore similarities of identity loss between people with cancer and dementia. Phenomenological study	Met 4 / 7 criteria.	Being Included- Needed and appreciated	'Sometimes they ask for my knowledge and I enjoy giving information'
Harman and Clare (2006)	Explore the meaning of living with dementia and disturbing behavior . Phenomenological study	Met 7 / 7 criteria.	Accepted Finding ways to cope	'Its easier now....you may be yourself. Just an ordinary man' 'you come up with all sorts of wrinkles to make sure things get done efficiently and on time'
Harris (2004)	To explore the illness representations of people with early-stage dementia following diagnosis. Grounded Theory Study	Met 6 / 7 criteria.	I want to be me Changing roles / relationships	'I'll stand me ground and fight it at the moment, in my own way on my own' 'I think it (AD) has brought us closer together. Maybe closer than ever before'
Harris (2006)	To consider if being diagnosed with a dementing illness at a younger age a unique experience. Qualitative Study	Met 2 / 7 criteria.	Making it on my own	'I don't want to give up the fight, but I know there will be a time when I might have to'
	To explore what is it like to live alone with memory loss.		With a little help from my friends	'you know what you cant change, it's smart to accept'
Harris and Sterin (1999)	Grounded Theory	Met 4 / 7 criteria.	Meaningful activities Changing sense of self	'That's one of the fundamentals in terms of a living a good life, its accepting that you cannot control what happens to you' 'I have things that I still want to do, and say and BE'
	To explore how people with dementia define sense of self or personal identity.		I'll live until I die I accept what I have	'you need to live today like it's your only day. This was the hand you were dealt with. My brain is dying. I know, but you learn tricks to cope. Don't be frightened to live your life, look it in the face for what it is'
Holst and Hallberg (2003)	Qualitative Exploratory Study	Met 4 / 7 criteria.	Ways of coping	'I'm facing the facts' 'I accept it and let them carry on, otherwise it would be hard to cope'

James, Xie and Karlawish (2005)	To explore the meaning of everyday life for people with dementia. Self Report Questionnaire	Met 3 / 7 criteria.	QoL	The majority of patients, 71% (n = 129) rated their QoL as good or very good.
Jonas-Simpson and Mitchell (2005)	To examine how patients with AD rate their QoL by use of a single global rating. Qualitative descriptive study	Met 4 / 7 criteria.	Feeling content	'Oh my life is about as good as I ever enjoyed it'
Katsuno (2003)	To give voice to the expressions of QoL for people with dementia in long-term care. Mixed Designs	Met 6 / 7 criteria.	Importance of relationships Choosing an attitude for living on Feeling worthy Humor	'these people who I consider important...they have inspired me with confidence' 'Look on the positive side of life' 'Believe in yourself' 'I know I have AD, but what can I do about it? I do silly things now but we just try and laugh about it'
Katsuno (2005)	To describe the spiritual experiences of people with dementia and to explore the relationship between spirituality and QoL. Mixed Designs	Met 7 / 7 criteria.	Strength of belief Life value Help and Guidance Feeling of strength	'I never forgot about the Lord...he's all of my help' 'you gotta have something to believe in and a faith' 'He [God] is the only help in our life'
Keady, Nolan & Gilliard (1995)	Grounded theory To develop a tool to assess coping in the early-stages of dementia.	Met 3 / 7 criteria.	Self reported QOL- 93% of participant stated that their quality of life was either 'good' 'fairly good' or 'negative-positive'	'I feel very strong to have him [God]' 'My life is all right' (good) 'It's good, you know...I'm satisfied. I know it's a lot of things I don't have, but I'm happy with what I have' (fairly good)
Langdon, Eagle and Warner (2007)	Phenomenological study	Met 5 / 7 criteria.	Normal vs. abnormal memory loss-putting it into context	'I can't say I'm dissatisfied because I've got beautiful children' (negative-positive) 'Like leaves fall to the ground from a tree, old people lose their memories'

Lyman (1998)	To explore participant's perception of their condition, their understanding of others reactions to them. Phenomenological Study	Met 3 / 7 criteria.	Creating meaning and identity	'I come here grumpy, but then I end up laughing, I leave here laughing'
Macquarrie (2005)	To explore how people negotiate their relationships and individual identities to incorporate changes associated with dementia. Qualitative Exploratory Longitudinal study	Met 2 / 7 criteria.	All that I am: pride and enjoyment	'Whatever I want, I intend to do'
Mason, Clare and Pitstrang (2005)	Explore how people in the early-stages of AD experience their illness Mixed Design	Met 5 / 7 criteria.	All that I was: pride and enjoyment A useful group	'13 years in the armed forces, I know what it is to clean a barracks!' 'It takes you out of yourself'
Medina, Banks and Morhardt (2006)	To investigate the support processes that occur in dementia groups and how members perceive groups. Descriptive Study	Met 3 / 7 criteria.	Fighting spirit	'You have to keep positive or you're going to be crawling under the covers'
Menne, Kinney and Morhardt (2002)	To create a booklet of supportive messages from people living with AD, to assist the newly diagnosed. Qualitative Exploratory Study	Met 4 / 7 criteria.	Ways to cope	'I've absorbed my diagnosis into part of who I am'
			What to expect	'You realize you can live for quite a while and that you can have a decent life' 'Its very important for an AD patient to do what they can do'
Mok, Lai, Wong and Wan (2007)	To explore the day-to-day experiences of people living with dementia. Phenomenological study	Met 5 / 7 criteria.	Helping	'I certainly would like to help people who can be helped'
			Keeping an active mind	'I spend most of my time reading newspapers'
	To describe the lived experience of Chinese people with early-stage dementia and their ways of		Staying engaged	'I try to keep my usual routine' 'I found that it is no use worrying... I only wish I can continue to live each day as it comes'

	coping.		Live each day as it comes	'Be optimistic; I will comfort myself; I have to face the facts. I am not doing anything about them, but I am facing them'
Morhardt (2004)	Mixed Design To explore what helps people to maintain an optimum QoL while facing the challenges that dementia brings.	Met 2 / 7 criteria.	Letting go Satisfaction Independent life Social role Good personal relationships Acceptance of life	18 participants 6 participants 7 participants 11 participants 2 participants
Morioka, Tanaka, Matsubayashi and Kita (2005)	Mixed Design To explore acceptance of memory impairments in mild to moderate dementia and satisfaction with life.	Met 2 / 7 criteria..	Maintain as much of it for as long as possible Remain active and involved Remain positive	'But there are things you can do' 'I stay in touch with girlfriends and I see them a lot. I exercise, I started a new hobby' 'I stay up, stay high, I take one day at a time, because there are some bad days out there. Not everyday is going to be the same. Just because today is tough doesn't mean that tomorrow will be, too'
Nygard and Borell (1998)	Phenomenological Study To describe the experiences of 2 people with dementia over 3 years, as expressed in their everyday lives.	Met 3 / 7 criteria.	Don't be afraid to try something new Resistance and management of threat The meaning of experiencing and resisting the threat	'Often people approach me when I'm sketching and ask how I can do that. I've come close to saying well first you have to have AD' 'I hardly ever think about that, one wants to repress having a disease, even if one knows it is there' 'I do what I want to do and I don't feel restricted by the disease or anything else'
Nygarad and Ohman (2002)	Mixed Design To uncover how people with dementia respond to problems and challenges they experience in everyday occupations.	Met 5 / 7 criteria.	Acceptant attitude	No quotation to support
Ohman and Nygard (2005)	Mixed Design To understand the meanings and motives for engagement in self-chosen occupations	Met 4 / 7 criteria.	Maintaining ordinary patterns of life Being a person in a coherent context	'Doing the things that we do' 'Being someone'

	for people with AD.		Using occupations to stay active	'That you have a body that moves! That is really wonderful'.
Ostwald, Duggelby and Hepburn (2002)	Qualitative Descriptive Study	Met 4 / 7 criteria.	Cognitive management strategies	'What's going to happen is going to happen'
	To express the experiences of people with dementia; their losses, feelings; and attempts to cope.		Optimistic / satisfied	'Everyday I get up looking, hoping that everyday will be better than the last one'
Parse (1999)	Qualitative Descriptive Study	Met 3 / 7 criteria.	Love / appreciation Cotranscendence	'we have a good relationship with our family. That makes us all feel good' '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''
Pearce, Clare and Pitstrang (2002)	Phenomenological study	Met 5 / 7 criteria.	Limited impact	'I like to think I can shift things. Things that I want to remember I don't seem to have much trouble'
	To examine the appraisal and coping of men with AD and their wives.		Make the most of things	
Phinney (1998)	Mixed Study	Met 6 / 7 criteria.	Trying to be normal	'Make the best' 'When I got AD, it was very difficult at first, but now I can sit back and I do a lot of reading, so that things don't come out all garbled'
	To try and understand the experience of living with AD.			
Phinney, Chaudhury and O'Conner (2007)	Phenomenological Study	Met 4 / 7 criteria.	Types of activity	'I want to do everything I can for as long as I can'
	To explore what types of activities people with dementia identify as important in their everyday lives and what involvement in these activities means to them.		Enjoyment and pleasure	'I hope that we are able to do things and not just feel sorry for ourselves. I'd like to live to be 100'
			Autonomy and identity	'I have a little electric organ that I can use if I want to create music...that is integrated in me. I don't think AD is going to hurt that'
Phinney, Sands and Wallhagen (2002)	Mixed design	Met 6 / 7 criteria.	Its just old age- a narrative of unawareness	'You're not sharp like you were one time in your lifetime. So you have to learn to live with this'
	To explore how people with dementia with various degrees of awareness perceive and interpret the meaning and significance of their symptoms.		It just doesn't stick in the brain a narrative of mixed awareness	'I just live my life like I have always lived my life. I do the things I want to do'.

Pratt and Wilkinson (2003)	Qualitative Descriptive Study To elicit the perspectives of people with dementia on the process of disclosure of diagnosis	Met 4 / 7 criteria.	Maximizing strategies	'Oh we're full of all these clever dodges we Alzheimer's. You try and beat it, find ways around it. The one thing I won't be is pessimistic about it'
Proctor (2001)	Qualitative Explorative Study To listen to women's experience of services	Met 6 / 7 criteria.	Case example	'I can't read now, I can't play the piano, I can't cook, so I come here (day service). I've had a rough deal but I've done my best'.
Reid, Ryan and Enderby (2001)	Grounded Theory To investigate unmet need amongst caregivers and people with dementia	Met 4 / 7 criteria.	Satisfaction	'I've got plenty of friends now here (day centre). So I look forward to coming. I think its great having these places'
Robinson, Clare and Evans (2005)	Phenomenological study To offer a thematic framework for understanding how couples in the early-stages experience the process of receiving a diagnosis.	Met 6 / 7 criteria.	I quite accepted it	'I have what plenty of other people have'
Roger (2006)	Grounded Theory To examine social changes as experienced by participants with AD and HD.	Met 4 / 7 criteria.	Take it as it comes	'You adjust to it, I mean the abnormal has become normal (laughing) as you might say'
Sabat (1998)	Case Study To challenge the assumptions and interpretations, conscious or unconscious, that people make about the experiences and behavior of people with AD.	Met 3 / 7 criteria.	The new social addition	'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'
Snyder (2001)	Mixed Design To understand the feelings	Met 3 / 7 criteria.	Interactions with friends Humor	'I've accepted it, you know just do the best you can and that's all you can do' 'Well, I got a lot of dignity' 'Believe me, if I can help and my [fellow] man, I would do it'
				'Now I have Alzheimer's I can hide my own Easter eggs'

Snyder (2003)	<p>and subjective accounts of persons with AD. Mixed Design</p> <p>To examine the roles of religion and spirituality in the lives of people with dementia</p>	Met 2 / 7 criteria.	<p>Hope</p> <p>Finding meaning</p> <p>Gives hope</p> <p>The afterlife</p>	<p>‘Instead of believing ‘I think therefore I am’, I say ‘I hope therefore I am’ ‘Having AD made me face my ultimate realities...AD transferred me from what I call a trivial plane to the spiritual or personal plane’</p> <p>‘You’ve got to find something to hold onto. And my faith in God is what I’m holding onto’</p> <p>‘Since I am a Christian, I can stand it by looking beyond it’</p>
Snyder (2006)	<p>Mixed Design</p> <p>To examine what types of losses people with AD describe and the ways they cope with these losses.</p>	Met 2 / 7 criteria.	<p>Finding companionship</p> <p>Remaining active</p> <p>Advocacy</p> <p>Altruism</p>	<p>‘Why should I worry about everything that could happen? I deal with each problem as it comes up’ ‘Being in the group makes me feel like I am somebody. This experience makes me feel more alive and human’</p> <p>‘Diagnosis of AD in its early stages can be a life enhancer’</p> <p>‘While I am still able, I want to do whatever I can to speak about AD’</p> <p>‘The sharing which existed in our group gave me hope, confidence and faith to feel that although I may have a disease growing in my brain. I’m still a worthwhile and valued person’</p>
Steeman, Godderis, Grydonck, De Bal and Dierckx De Casterle (2007)	<p>Grounded theory</p> <p>To explore what it means to live with early-stage dementia and to develop a model that promotes proactive care.</p>	Met 6 / 7 criteria.	<p>Humor</p> <p>Emphasizing remaining competencies</p> <p>Being valued</p>	<p>‘This is what you’ve got right now and you’ve got to make the most of it’ ‘(proud) I am the granny’</p> <p>‘I’m pleased that I still am here’</p>
Sterin (2002)	<p>Personal Account</p> <p>A personal essay that explores the impact of being diagnosed with dementia on</p>	Met 2 / 7 criteria.	Essay on a word	‘You can reframe this disease. See it as a challenge project instead of a disease’

	social interactions and self concept.				
Stuckey, Post, Ollerton, FallCreek and Whitehouse (2002)	Community Dialogue To discuss what roles religion and spirituality play in helping families cope with a diagnosis of AD	Met 4 / 7 criteria.	Acceptance and Peace		'Maybe this was to slow me down to enjoy life and to enjoy my family and to enjoy what's out there...I can say that I'm a better person for it'
Truscott (2003)	Personal Account An account of lived experience of life in the slow lane with dementia.	Met 3 / 7 criteria.	Positive mental attitude		' And so I try and have a positive mental attitude every day that I can, and to push away the doubts, fears and tears'
Van Dijkhuizen, Clare and Pearce (2006)	Phenomenological study To examine appraisal and coping of women with early-stage AD.	Met 6 / 7 criteria.	Supportive family relationships Acceptance Normalizing		'So I suppose that's why I don't worry' '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'
Vernooij-Dassen, Derksen, Scheltens and Moniz-Cook (2006)	Grounded Theory Study To describe and understand the impact of receiving a diagnosis for individuals and their family over time.	Met 5 / 7 criteria.	Problem solving Changes in awareness Changes in partnership		'Quizzes and that, yes. I do them 'cause I can see if I can remember to answer them' 'I am more active, I do the things I can do' 'We married, after living together for many years'
Ward-Griffin, Bol and Oudshoorn (2006)	Qualitative Exploratory Study To explore how women with AD describe their experiences of receiving care from their adult daughters.	Met 5 / 7 criteria.	Doing Care Receiving Care		'I try not to give up the things that I'm interested in' 'I'm very lucky, and many people have told me that'
Werezak and Stewart (2002)	Grounded Theory To explore and conceptualize the process of learning to live with memory loss in early-stage dementia.	Met 5 / 7 criteria.	Seeing self as the same person Acceptance		'you've lost your memory but you haven't lost your mind. And you're still the same person' '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'

Table 2: Studies containing positive reports of lived experience in dementia; key findings, methodological characteristics and quality.

[Note: VD: vascular dementia; FT: frontal-temporal dementia; AD: Alzheimer's Disease, MID: Multi-infarct dementia; QoL: quality of life].

3.5 Researchers' Management and Conceptualization of Positive Reports

It is noteworthy that none of the studies retrieved directly set out to examine positive lived experience. Whilst all these papers contained evidence of positive reports, they all did so alongside reports of negative aspects of the illness. Many researchers seem to be 'surprised' by positive reports (Ohman and Nygard, 2005; Ostwald *et al.*, 2002). Some researchers have emphasized these positive reports because they contradict what may have been expected (Cahill, *et al.* 2004). Some papers clearly recognize and acknowledge the positive reports, (e.g. 'Fighting Spirit'. Medina *et al.* 2006). However, the majority of studies do not give these positive reports as much exposure as the negative experiences. Of the 63 studies included for containing evidence of positive lived experience, only 32 mentioned the positive elements in their abstract. Some researchers regard these positive reports as merely 'occasional episodes of togetherness' (for example Graneheim and Jansson, 2006) in the midst of suffering, and rarely mention or highlight them. Examples were also found of what appeared to be positive quotations not linked to a definite positive theme, for example in the paper by Beard (2004) the seemingly positive quotation, 'I have it and I can't cure it for you or anybody else but, you know, just be nice to me...I don't mind telling anybody' is recorded under the neutral theme of 'To Tell or Not To Tell' along with negative aspects of disclosure.

Other researchers are skeptical of positive reports. Positive quotations are seen as lacking awareness (Byrne-Davis *et al.*, 2006) or even as evidence of denial (Aggarwal *et al.*, 2003; Proctor, 2001). For example in Phinney *et al.*, (2002) the quotation, 'you're not sharp like you were one time in your lifetime. So you have to learn to live with this, what's left...I get older

everyday of my life so I have to cope with what my body does to go along with me' is placed under the themes 'A narrative of unawareness'. Some researchers such as Steeman *et al.* (2007) conclude that positive reports are a façade; a lack of awareness or the result of an unwillingness to discuss memory impairment and state that researchers should be careful to look beyond this.

4. Discussion

This article is the first to give a systematic overview of the views of people with dementia on positive lived experience. The literature studied tells us that the diagnosis and experience of dementia is not the wholly negative experience that may be expected.

The research demonstrates that people with dementia are still able to enjoy their lives (Cahill *et al.*, 2004; James *et al.*, 2005; Katsuno, 2005) and are capable of experiencing and expressing positive emotions (Cahill *et al.*, 2004; Dabbs, 1999; Droes, 2006). Moreover, people value a positive sense of well-being and strive to live active and meaningful lives despite their dementia (Menne *et al.*, 2002; Mok *et al.*, 2007; Ohman and Nygarad, 2005; Pearce *et al.*, 2002).

Whilst positive experiences clearly exist within the literature they appear to have been overlooked by researchers, given scant attention or dismissed out of hand. It appears that researchers have struggled to look positively at the lives of people with dementia, perhaps because of the dominance of the biomedical model of dementia, which frames dementia narrowly in terms of decline and loss. Whilst some researchers have expressed an interest in the conditions of living that allow for meaning and fulfillment, this review did not find any papers that set out to explore positive growth or that examined specifically and directly the strengths and resources of

people with dementia. Instead, dementia research appears to be based heavily on the language of illness and focused on deficits, weaknesses and losses.

It is interesting that whilst positive experiences in dementia are regarded as positive illusions that are not real or reflective of genuine change (Steeman, 2007), in other chronic illnesses such as cancer (Cordova *et al.*, 2001) and AIDS (Milam, 2004) these strengths are explicitly researched and seen as vital for survival. For example, the right to hope in the context of a cancer diagnosis has been the subject of much debate (Groopman, 2004), those who choose to ‘fight’ their cancer against the odds are often widely revered. Aminzadeh (2007) reminds us that dementia is a category of illnesses characterized by great variations in clinical manifestations and course, and it is this very uncertainty that creates the opportunity for hope; ‘this is the paradox of true hope: because nothing is absolutely determined there is not only reason for fear, but also reason for hope’ (Groopman, 2004). The evidence gathered in this review would suggest that it is time to undertake an examination of hope in dementia research.

Positive psychology warns that by allowing research to continue to be based in illness ideology we neglect the idea of a fulfilled individual, with choices, preferences, strengths and the possibility of becoming masterful and efficacious (Seligman, 2005). Highlighting positive elements of this illness is important to begin to challenge the stigma surrounding dementia. Crucially, understanding subjective experience in its entirety is essential to enable rehabilitation in dementia to move towards the promotion of conditions for optimal living rather than simply focusing of compensating for deficits. Research exploring what can be gained by living with dementia will allow therapy to look towards the possibility of building strength. The positive human strengths identified in this review are many and include; **hope** (Clare, 2002; Friedell,

2002; Fukushima *et al.*, 2004; Snyder, 2001; Snyder, 2003), **faith** (Katsuno, 2003; Snyder, 2003; Stuckey *et al.*, 2002), **resilience** (Beard, 2004; Harman and Clare, 2006; Macquarrie, 2005; Nygard and Borell, 1998; Robinson *et al.*, 2005; Van Dijkhuizen *et al.*, 2006), **wisdom** (Clare *et al.*, 2006; Harris and Sterin, 1999; Mok *et al.*, 2007; Parse, 1996), **altruism** (Menne *et al.*, 2002; Snyder, 2006), **humor** (Keady, Nolan & Gilliard, 1995; Menne *et al.*, 2002; Snyder, 2001; Snyder, 2006; Van Dijkhuizen *et al.*, 2006; Werezak and Stewart, 2006), **optimism** (Aminzadeh *et al.*, 2007; Mok *et al.*, 2007; Ostwald *et al.*, 2002), **perseverance** (Beard, 2004; Clare, 2002; Clare and Shakespeare, 2004; Clare *et al.*, 2005; Clare *et al.*, 2006; Harris, 2006) and **courage** (Clare, 2002; Friedell, 2002; Gillies, 2000; Harman and Clare, 2006; Harris and Sterin, 1999; Keady, Nolan & Gilliard, 1995).

Positive psychology needs to be extended into dementia research and future research should explore what makes life worth living for people with dementia. Specific questions that might be explored in this vein include: What are the goals of people with dementia? What conditions help to promote happiness in people with dementia? Where do people living with dementia draw their strength, perseverance and fighting spirit from? What is the meaning of hope for people living with dementia? If we can learn the answers to these questions, then we can start to help people identify and nurture these positive qualities and in doing so we can begin to assist people in living positively with dementia. By opening the door for research examining positive experience we can enter a new perspective of ‘daring to try to recover skills, develop new talents and create a new future invested with meaning and hope’ (Boden, 2002, p153).

Limitations

Some comments must be made with regard to the limitations of this review. The limitations relate to both the nature of the 'views studies' literature (namely the quality of the retrieved studies and the limited sample often accessed by such studies) and the methodology employed by this review (namely the effectiveness and reliability of synthesizing views studies and the reliability of the methods for extracting positive report).

To look at the limitations relating to the literature base first, the review's quality assessment revealed that views studies often fell significantly short of basic methodological standards (table 1). Only four of the studies met all seven criteria. Attention to these methodological shortcomings is essential as studies that lack reliability, validity and generalizeability may misrepresent, or simply fail to pick up on the views of people with dementia. This is a key challenge for future studies as poor quality studies are likely to dilute the perceived power of the lived experience literature. However, it should be mentioned that reliable methods for reviewing studies of people's views are not well established and the quality assessment tools need to be developed further. In particular this tool is of limited use in personal accounts where many quality criteria are not applicable.

In addition to the issue of quality, comments must be made about the limitations of the views studies sampled concerning the generalizeability of their samples. The nature of the lived experience literature is that participants are typically people who, despite their condition, are still able to communicate their feelings (De Boer *et al.*, 2007). Therefore the sample is largely weighted to people in the early-stages of dementia and who are often community dwelling, although there were exceptions (e.g. Graneheim and Jansson, 2006; Jonas-Simpson and Mitchell,

2005; Nygard and Borell, 1998). Few studies have gone beyond the early-stages to explore living with moderate to severe dementia and so we do not know if such experiences can be generalized. The presumption is that people are no longer able to communicate experiences in these later stages, however this was once thought of early-stage dementia and requires greater research attention and creativity.

A further limitation lies in the fact that the literature search was not limited to a specified type of dementia as studies tend to collate a variety of subtypes of dementia together within one paper or do not differentiate at all between the subtypes included. Therefore, this article gives an overview of the positive experience in dementia in general. Differences in personal experiences based on types of dementia can therefore not be made despite important prognostic, treatment and neurobehavioral issues that are likely to impact on lived experience.

Limitations also exist regarding the methodology employed by this review. The synthesis of 'views studies' is not without its difficulties. From a practical position, views studies are notoriously difficult to access in electronic databases (Harden *et al.*, 2003) and therefore the search terms were extremely broad and consequently required the researchers to sift through a large numbers of citations. Indeed, the studies finally included in this review represented only a small fraction of all those retrieved by the search engines (approximately 4%). However, finding 63 studies containing of positive lived experience in dementia when none of these had explicitly set out to research it is certainly notable. Furthermore, the included views studies varied considerably in terms of the depth of descriptions and analysis, and they existed within a wide range of the lived experience literature (diagnosis, service evaluation, coping etc). Whilst much has been written about the validity of integrating different types of study and data within the

same review (for example see Harden and Thomas, 2005) the prior purpose of all these studies was to privilege peoples views and present them as data that are valuable and interesting in themselves. The value in bring these studies together is that effectively they allowed a total of 2649 people to contribute their views and experiences to this review.

Finally, it should be noted that data extraction of positive experience central to this review, whilst conducted in a systematic manner, was subject to a great deal of discretion on the researcher's part. For example, whilst some quotations selected for inclusion were explicitly positive: *'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...you learn a lot from the process'* (in Clare, Goater & Woods, 2006, p 765; quoted under the theme 'learned from it positive aspects'). Other quotations included in the review were more subjective: *'I hardly ever think about that, one wants to repress having a disease, even if one knows it is there'* (in Nygard and Borell, 1998, p 126; under the theme 'resistance and management of threat') and thus more open to interpretation. 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 in the paper. Similarly themes that appeared neutral in title were, on occasion, extracted as positive because the quotations they included were considered to be positive. Whilst it was our view that the extracted data actually represented positive experience, this is of course open to debate.

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Conflicts of interest

None.

Description of author's roles

E. L. Radbourne designed the study, collected the data, carried out the analysis and wrote the paper. C. Clarke and E. Moniz-Cook assisted with and supervised the quality analysis of the papers and with writing the paper. M. Tredinick and H. Wilkinson assisted with the reliability checks on the quality checklist.

Part 2: Empirical Paper

Remaining Hopeful in Early-Stage Dementia: A Qualitative Study

Remaining hopeful in early-stage Dementia: A qualitative study

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Remaining hopeful in early-stage Dementia: A qualitative study

Abstract

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Title of manuscript: Remaining hopeful in early-stage Dementia: A qualitative study

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Objectives: Improving the quality of life for people living with dementia has been highlighted as important in recent dementia policy. It is important to understand what factors might help a person to maintain a good quality of life, therefore the purpose of this study was to investigate the subjective experience of hope in older people with dementia and explore what might facilitate or hinder hopefulness in this context.

Method: Ten volunteer participants over the age of 65 with early-stage dementia were recruited from a Memory Clinic. Semi-structured interviews were used to explore participants' hopes, particularly in terms of their personal meaning, their sources and the potential barriers and facilitators of hope in this clinical group. Interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Eight themes were extracted, subsumed under two higher-order themes ‘live in hope or die in despair’ and ‘keep living and keep living well’. Participants described how their internalised hope-fostering beliefs were challenged by the reality of hope-hindering experiences associated with old age and dementia. However, they also described how through a ‘homeostatic’ or balancing process of re-appraisal, a position of contentment or resolution could be achieved. This sense of stability allowed participants to develop positive attitudes towards health and social circumstances in ageing.

Conclusion: The findings suggest that hope is vital and present in the lives of people with early-stage dementia. A tentative model is suggested for understanding how hope may support individuals with dementia to maintain their quality of life and to consider the scope for hope-fostering strategies.

Key Words: hope, dementia, quality of life

Remaining hopeful in early-stage Dementia: A qualitative study

Introduction

Improving the quality of life for people living with dementia has been highlighted as important in recent dementia policy, see for example the National Dementia Strategy in the UK (Department of Health, 2008) and the French Dementia Plan (Portail du Gouvernement Français, 2008). Increasingly, such policies are enabling practitioners to use concepts of rehabilitation and recovery to develop psychosocial interventions (Moniz-Cook, 2008) that enable people with dementia to maintain a full and meaningful life. Rehabilitation refers to support that enables the person to achieve an *optimal* level of physical, psychological and social functioning (World Health Organisation, 1998), despite the limitations imposed by dementia. Recovery refers to ‘a way of living a satisfying, hopeful and contributing life even with limitations caused by illness’ (Anthony, 1993, p12) and has recently been applied to the support of people with dementia (Woods, 2007). Therefore it is important to understand what might help a person to maintain a good quality of life, irrespective of the very real challenges associated with dementia.

There is a limited but growing body of literature on the positive experiences of people living with dementia (see for example Bryden, 2005; Cahill et al., 2004; Katsuno, 2005). A recent systematic review of living positively with dementia (Radbourne, Clarke and Moniz-Cook, 2008) found a range of human strengths, capacities and resources to be present in the subjective accounts of people with dementia. One of these is the construct of hope (Clare, 2002; Friedell, 2002; Fukushima et al., 2004; L. Snyder, 2001; 2003).

Although the study of hope is not new (Lynch, 1965), there are a number of hurdles to overcome before hope as a construct can be translated into the clinical setting. These include definitional diversity; with no consensus on the definition of hope (Bergin and Walsh 2005) and different representations across the life course include that of old age (Cutcliffe & Grant, 2001). For example we examined the social science literature on hope, including ‘hope in older people’ and ‘hope in chronic illness’, from 1969 onwards, using PsychINFO and CINAHL databases and found eighteen definitions (See Appendix C) and thirteen different standardised measures. Although hope is clearly a multidimensional construct, examination of the overlaps in definitions, allow an extraction of seven key elements that can be associated with hope (Table 3).

Critical elements of hope	Present in definitions by
A positive future orientation – refers to hope as looking forward to a future that is good	Fryback, 1991; Mercier, Fawcett & Clark, 1984; Miller 1986; Obayuwana & Carter, 1982; Owen, 1989; Stanley 1978; Stephenson, 1991; Stoner, 1982
A sense of desire - refers to hope as a strong emotional ‘longing ‘ for something that is valued or important	Averill, Catlin & Chon, 1990; R. Erickson, Post & Paige, 1975; Gottschalk, 1974; Herth, 1988; Mercier, Fawcett & Clark, 1984; Miller, 1986; Obayuwana & Carter, 1982; Staats, 1989; Stanley, 1978; Stotland, 1969
Hope ‘for’ - refers to hoping for a specific, defined and measurable outcome or goal	Averill, Catlin & Chon, 1990; Dufault & Martocchio, 1985; Owen, 1989; R. Erickson, Post & Paige, 1975; Gottschalk, 1974; Herth, 1988; Morse & Doberneck, 1995; C. Snyder et al. , 1991; Stanley, 1978; Stotland, 1969
A generalised hope that - refers to a sense that life will be worth living in the future	Farran, 1995; Gottschalk, 1974; Miller, 1986; Obayuwana & Carter, 1982; Stanley, 1978
A context of uncertainty - refers to the notion that hope is activated in stressful life-situations.	Fryback, 1991; Herth, 1988; Miller, 1986; Morse & Doberneck, 1995; Nowotny, 1989; Stanley, 1978
A sense of force or energy - refers to hope as a ‘energising motivator’	Averill, Catlin & Chon, 1990; Herth, 1988; Morse & Doberneck, 1995; Owen, 1989; C. Snyder et al., 1991
Support from others - refers to hope as a interpersonal relational process that occurs between people	Dufault & Martocchio, 1985; Miller, 1986; Morse & Doberneck, 1995; Obayuwana & Carter, 1982; Stanley, 1978

Table 3: Elements associated with the construct of hope

Hope is associated with positive adjustment and coping in chronic illnesses such as: severe arthritis (Laird, 1991); major burns injuries (Barnum et al., 1998); spinal cord injuries (Elliott et al., 1991); fibromyalgia (Affleck & Tennen, 1996); blindness (Jackson et al., 1998); sickle cell disease (Kliwer and Lewis, 1995); cancer (Magaletta & Oliver, 1999); schizophrenia (Lovejoy, 1984) and AIDS (Moon & C. Snyder, 2000). Hopefulness in chronic illness is thought to improve quality of life through improved tolerance to pain (C. Snyder, 2002), better use of illness-related information and adherence to medical regimes (Moon et al., 2001) and improved coping and problem solving (C. Snyder et al., 2000). In addition, people with greater levels of hope are more able to find benefits and meaning within their illness experience (Linley & Joseph 2004) and a contextual exploration of hope may aid the effectiveness of psychological therapy in older adults (Bergin & Walsh 2005).

Hope has also been studied in older people (see, Farran, Sallowy & Clarke, 1990; Herth, 1993) where a complex relationship between hope and physical and psychosocial variables is described. These have included associations between hopefulness and physical illness (Farran, 1985); reduced energy levels (Herth, 1993); and impaired cognition (Herth, 1993). Thus age-associated cohort differences in definitions of hope have emerged, as studies have found that goal achievement, success and future orientation are relevant in hope constructs applied to younger but not older adults (Farran, Sallowy & Clarke, 1990).

The concept of hope and well being in older people with dementia is not entirely new (see Woods 2007). Cohen (1991) argued that hope can still exist for people with cognitive impairment and that, even until later stages of illness, people with dementia display qualities of faith and hope as well as the desire to 'live and love'. However there is a paucity of research on the application of

hope theory in dementia care, possibly because of the widespread belief that age and dependency combined with impaired cognition are hope-hindering experiences (Cutcliffe & Grant, 2001; Herth, 1993).

The purpose of this study was to investigate the subjective experience of hope in older people with dementia and explore what might facilitate or hinder hopefulness in this context. In addition, we aimed to examine how hopefulness in dementia compares with conceptualisations present in the literature outlined in Table 3 as well as the literature related to age, dependency and coping. In doing so we sought to provide a thematic framework for understanding how hope may support individuals with dementia to maintain their quality of life, and to consider the scope for hope-fostering strategies.

Since little is known about hope in older people with dementia, it appears appropriate to adopt an exploratory approach to understanding how individuals construe the concept of hope in the light of their knowledge of having dementia. The distinctive nature of dementia and its cohort-related interaction with constructs of dependency in old age (Moniz-Cook 2008) as well as the previously outlined definitional issues and wide-ranging approaches to the measurement of hope, suggests that a qualitative method of enquiry, rather than use of quantitative questionnaire methods, is needed. In addition, qualitative research is well suited to understanding phenomenology, the subjective meanings that people place on events in their lives and how these are connected to the social world around them (Miles & Huberman 1994).

Method

Design

Semi-structured interviews were used to enhance the range and quality of responses of the subjective accounts of people living with dementia. Demographic and descriptive questionnaire data were taken to contextualise the qualitative data.

Participants

Participants were recruited from a memory clinic in the north of England between July 2007 and January 2008, where all had been informed of their dementia diagnosis (see Table 4). The memory clinic caseloads were examined to identify people who met the following inclusion criteria:

1. Diagnosis of dementia according to DSM-IV criteria with a CAMCOG (Roth et al., 1986) (section B of the Cambridge Examination for Mental Disorders of the Elderly) score of ≤ 80 ;
2. Within the mild range of severity on the Mini Mental State Exam (Folstein, Folstein & McHugh, 1975) with a score of score of ≥ 18 out of a total of 30;
3. At least two months post-diagnosis, since this study aimed to explore the experience of hope in living with dementia, rather than the effects of a dementia-diagnosis itself;
4. People over the age of sixty-five, since we were interested in hope in dementia as well as its interaction with cohort-related constructs of age and dependency and differences in hope in people of different ages have long been recognised (Wright & Shontz, 1968) including in later life (Cheavens & Gum, 2000);
5. Sufficient fluency in English to take part in an interview and;

6. Able to give informed consent.

Participants included on the basis of the criteria above were screened with the Guidelines for Rating Awareness in Dementia (GRAD, Verhey et al., 1995, see appendix E), since awareness of their memory difficulties was a pre-requisite to this study. This measure requires ratings on a four-point scale using a structured set of open-ended questions compared with clinician-rated history taken from case notes at the Memory clinic. Higher scores indicate a high level of awareness-deficit that is congruent with recorded history.

Participants were not included if they had dementia caused by a reversible condition; a history of alcohol dependency; or significant depressed mood as identified by memory clinic clinicians who used a score of ≥ 5 on the Cornell Scale for Depression in Dementia CSDD (Alexopoulos et al., 1988) to augment mental state evaluation

People identified as suitable for inclusion in the study were provided with verbal and written information about the study. In total, 11 people were approached by memory clinic staff and one declined to participate. The total sample of 10 participants comprised 3 men and 7 women, aged 72-87 years (mean age 81.1 years) with MMSE scores ranging from 19-28 (mean MMSE score 23.2). Participants were from the range of socio-economic and past occupational backgrounds and all were white European in origin, reflecting the population served by the clinic. Participants varied in their level of current service involvement. Some attended a weekly 'ladies group' (n = 5); others had completed a course of reminiscence therapy (n = 2); weekly in-home psychosocial support (n = 1); and some simply had an annual clinic review (n = 2). Table 4 provides descriptive details of participants.

Participant	Age	Gender	Marital Status	Diagnosis	Date diagnosis received	MMSE	CAMCOG	HADS	SF-12	GRAD score
Participant 1	86	F	widowed	Vascular dementia	09/2006	21/30	74/105	A: 5 D: 7	PCS: 40.98 MCS: 29.03	4/4
Participant 2	83	F	widowed	Alzheimer's Disease	05/2005	20/30	73/105	A: 0 D: 3	PCS: 46.76 MCS: 63.09	3/4
Participant 3	72	F	widowed	Vascular dementia	04/2007	22/30	59/105	A: 2 D: 9	PCS: 56.61 MCS: 53.69	3/4
Participant 4	80	F	widowed	Alzheimer's Disease	11/2002	19/30	67/105	A: 3 D: 5	PCS: 50.41 MCS: 56.87	3/4
Participant 5	80	M	divorced	Vascular dementia	08/2007	28/30	80/105	A: 11 D: 8	PCS: 16.23 MCS: 50.19	4/4
Participant 6	87	F	widowed	Alzheimer's Disease	02/2005	25/30	68/105	A: 6 D: 3	PCS: 44.22 MCS: 60.17	4/4
Participant 7	80	F	single	Vascular dementia	06/2006	25/30	80/105	A: 11 D: 6	PCS: 47.37 MCS: 52.14	4/4
Participant 8	74	M	married	Vascular dementia	08/2007	22/30	79/105	A: 5 D: 1	PCS: 34.37 MCS: 55.98	4/4
Participant 9	87	F	widowed	Alzheimer's Disease	11/2005	23/30	74/105	A: 5 D: 5	PCS: 61.84 MCS: 52.21	4/4
Participant 10	82	M	married	Alzheimer's Disease	04/2006	27/30	70/105	A: 1 D: 4	PCS: 51.39 MCS: 56.04	3/4

Table 4: Table to show details of participants

[Note: A: anxiety; D: depression; PCS: physical health score; MCS: mental health score]

Data Collection

Participants who agreed to meet the researcher were contacted to arrange a convenient date, time and location. Five interviews were conducted in participants' homes and five at the memory clinic. Consent for the interview and tape recording was sought at the start of each interview, followed by completion of the GRAD (Verhey et al., 1995) required for inclusion to the study. Clinician-rated awareness of memory problems was accessed from the case notes since this was routinely recorded in this clinic. No discrepancies between clinician and participant ratings occurred, so all were included in the study.

The semi-structured interview schedule (see appendix D) was adapted from Herth (1993) where both reflection and the following open-ended questions were used:

'Tell me about your hope';

'If you could identify a source of hope for yourself what would it be?';

'What things/situations cause you to lose hope?';

'What kinds of things help you to regain your hope?';

'What helps you to maintain your hope or makes you feel hopeful?';

'What does hope mean to you?'; and

'How would you define hope?'

Interviews lasted between 30 and 60 minutes and were audio recorded.

Following the interview participants completed the following descriptive measures (see appendix E):

- The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) to screen for affect. This self report measure has been used with people in the early stages of dementia (Harrison, 2005; Wands et al., 1990). The HADS is a 14 item measure with a range of 0 - 21 for each of its two sub-scales i.e. anxiety and depression. A score of ≥ 11 indicates clinically significant mood problems.
- The SF-12 (Ware, Kosinski & Keller, 1996) version of the Medical Outcomes Summary Short Form Health Survey was used to assess quality of life and well being. The SF-12 is a multipurpose short form generic measure of health status. It generates two quality of life sub-scale scores, providing a mental health (MCS) and physical health (PCS) summary. Both sub-scales have a mean of 50 and a standard deviation of 10 relating to the general US population, with lower scores indicating poorer well-being.

All participants were given a stamped addressed envelope to contact the researcher should they have other insights on their hope following the interview and were offered a copy of their transcripts.

Data Analysis

Data from the interviews were transcribed and analysed using interpretive phenomenological analysis (IPA; Smith, Osborn & Jarman, 1999). This methodology has been successfully used in other qualitative studies of how people cope with dementia (see for example Clare, 2002). IPA is a method of adopting, as far as is possible, an 'insider's perspective' on the participant's world (Conrad, 1987), where the researcher attempts to understand subjective experience by assuming a link between what people report and their underlying cognitions. It is therefore particularly suitable for this study on the subjective experience of hope in dementia. It also acknowledges the

dynamic interaction between participant experience and the researchers' interpretation of this (Smith et al., 1999).

The analysis involved an iterative process of reading and re-reading each transcript to achieve familiarity, followed by noting key points on transcripts, remaining as close to the words of the interviewee and compiling a summary of the key words. Emerging themes identified in each transcript were then examined and re-examined and grouped under thematic headings until all accounts were covered. These accounts were also examined and re-examined by an IPA group of six researchers, who further reviewed and refined the thematic headings. This cyclical process continued until a final list of themes emerged that reflected all the participants' transcripts. Each transcript was then coded, so all instances of each theme were identified. One independent researcher familiar with IPA methodology audited anonymised sections of transcripts including checks that these were represented in the verbatim transcripts, to prevent the researcher's own biases influencing the selection of themes. Similarities and differences were resolved through independent checking by a further independent researcher and group discussion was used to reach a consensus of opinion. Then, in order to ensure internal coherence (Yardley, 2000) and participant validation (Smith, 1996) an independent focus group was convened consisting of four consenting people with dementia who attended a day centre. They were consulted about the analysis and asked whether the descriptive account of hope made sense and resonated with them (Yardley, 2000). On the basis of this the list of themes were refined further and agreed by the IPA research group. All the themes appeared in at least one third of the participants' accounts and most in two thirds or more. A final stage of the interpretative process of analysis was conducted to understand how themes related to, or challenged the current conceptualisations of hope, in light of cohort-related psychological theories of age, coping and dementia.

Results

All participants attested to hope as being a vital component of survival, indicating that it was natural for a human being to possess hope - 'You've got to have hope, its part of life'. Eight themes emerged from the qualitative data, with two higher order themes, '**live in hope or die in despair**' and '**keep living and keep living well**' (see Table 5).

The first theme reflected the tension between internalised hope-fostering beliefs and hope-hindering life experiences that, through a 'homeostatic' or balancing process of re-appraisal, facilitated a position of expressed contentment or resolution. Internalised hope-fostering beliefs were often apparently learned through childhood experiences - '*My father, he hoped for everything*' - and motivated coping and resilience - '*I always carry on*'. The reality of hope-hindering life experiences associated with age and dependency, existed in both personal - '*I'm completely dependent on her*' -and societal - '*People used to come to me for advice and now they don't bother*' - contexts. Participants balanced the tension through a process of re-appraisal and acceptance and thus achieved a sense of resolution '*You always hope for something better, but I don't see how it can get better ... I'm quite content as I am now*'.

The second higher order theme describes the positive attitudes towards health and social circumstances in ageing that arose from the sense of stability noted previously. These included attitudes about physical health - '*my hope is that I keep well and that my health doesn't let me down*' -, relationships - '*you've got to have somebody to talk to haven't you*' - and coping behaviours - '*you just take one day at a time*'.

Super-ordinate Themes	Sub- Themes	Illustrative Quotation
'live in hope or die in despair'	legacy of hope	'my father, he hoped for everything'
	self activating hope	'I always carry on'
	personal realism	'I'm completely dependent on her'
	contextual realism	'people used to come to me for advice and now they don't bother'
'keep living and keep living well'	re-appraisal and resolution	'you always hope for something better, but I don't see how it can get better, but I'm quite content as I am now'
	keeping healthy	'my hope is that I keep well and that my health doesn't let me down'
	keeping relationships	'you've got to have somebody to talk to haven't you'
	coping behaviours	'you just take one day at a time'

Table 5: Themes of hope in early stage dementia

This process of re-appraisal to achieve stability and acceptance in order to engender positive attitudes in dementia is outlined in Figure 2 (see page 90), along with suggestions for hope-fostering psychosocial intervention in early stage dementia. Next we will describe the data to support the themes outlined below.

'Live in hope or die in despair'

This higher-order theme encompassed five sub-themes relating to the process of maintaining hopefulness in old age. The first two sub-themes reflect a historical or learned aspect of hope as a context for motivation, which we describe as a 'legacy', since this was usually grounded in family experiences and self-activating hope, respectively.

1. The legacy of hope

Participants described hope as a process that was embedded in human developmental histories where hopeful thinking styles and views of the world commenced over the course of their childhood. The sources of learning histories were usually parents – and often fathers - who acted as role models for hope:

‘Where do I get my hope from? Well I don’t really know. I think it’s me father. My father, he hoped for everything.....he always knew what he wanted and what he wanted to do. And I think that’s a little bit of me’
(PARTICIPANT 6)

The lessons of hope seemed to have been nurtured by parents in a number of ways. They were either given directly as statements for living or observed indirectly through a parent’s accomplishments or dedication to a belief such as religion:

‘My Dad, he was a union man, he used to be for better for people, better wages and that for people’ (PARTICIPANT 7)

‘I used to go to band of hope when I was little, mother was a Methodist’ (PARTICIPANT 9)

What seemed to be gained was an internalised belief that there was ‘something better’; that is a sense of determination or strength in times of trial or suffering and a view that events would turn out for the best:

‘You always hope for something better don’t you really’ (PARTICIPANT 9)

Overall, participants described how early relationships with parents, a sense of connectedness to a family, and feelings of intimacy and attachment are intrinsically linked with their current experience of hope. The contrast was seen in the descriptions of one participant who did not have a close relationship with his father:

‘I guess I was always slightly lacking in self-confidence really, a bit introverted. My father on the other hand had been just the opposite. A great extrovert. And whether that sort of pushed me into silence I don’t know’
(PARTICIPANT 8)

Alongside the role of families, some participants cited the role of their society in their development of hope:

‘I think it’s this country. I wouldn’t like to live anywhere else. So I suppose I find my hope in my country and my family’ (PARTICIPANT 4)

The intrinsic nature of these hopeful beliefs was something seemingly so natural to them that participants did not anticipate change during age-associated decline in abilities:

‘Well I think its natural for a being to have hope....., I suppose there is something in the brain that has been preserved and hasn’t been destroyed.....’ (PARTICIPANT 8)

Whilst internalised hopeful beliefs were present in all accounts, there were few reports of future-orientated hope and where this existed it was associated mostly with their aspirations for the future welfare of family and ‘passing on the legacy of hope’ to them. For some the future of

society and the world was seen as important, although this was usually the case for participants without family:

'I mean hopes now are for my son and his wife and their two boys' (PARTICIPANT 10)

'Never a war again I hope! For anybodies sake. Peace in our time' (PARTICIPANT 7)

Thus the process of hope drawn out from participants descriptions suggested that hope was a development process arising from childhood that survived health and social circumstances, to be passed on within families and societies.

2. Self-activating hope

The internalised hope that participants described was not simply something that enabled participants to face the future, but served as a way of helping them to continue to live in the present. Their hopeful beliefs appeared to provide participants with an attitude, or an approach to life, that engendered them with a sense of energy and that mobilised them in the present:

'If we've got to do it, we've got to do it. I never let anything stand in my way...I always try to sort something out'
(PARTICIPANT 10)

'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!'
(PARTICIPANT 9)

In this way, hope was not described as a passive experience, but an active process. There were many accounts of how participants actively engaged with actions to 'keep going':

'I will keep going for as long as I possibility can' (PARTICIPANT 6)

A hopeful attitude appeared to frame the difficulties associated with ageing and dementia as challenges, and in doing so allowed participants to consider the future by looking at ways to take steps in the present to move beyond their current situation towards something better:

'I can't really see this condition (Alzheimer's disease) getting any better. But I have started, it's a little step, but I have started going to the gym' (PARTICIPANT 8)

One commonly reported way that hopefulness appeared to generate action, was through a process of reminiscence, drawing on autobiographical memories of survival and success. These memories seemed to allow people to recapture previous strengths, to create an attitude of 'if I made it through that I can make it through anything'. This process fuelled participants' motivation further, to maintain hopefulness in the face of present or future adversity:

'It [war] was an awful time but you see there was nothing you could do about it and you had to grin and bear it' (PARTICIPANT 4)

The next two sub-themes suggest that hopes are framed within a realistic appraisal of hope-hindering life experiences encountered due to the effects of ageing and memory loss on personal resources.

3. Personal realism

All participants in this study possessed a good understanding of their current difficulties and limitations at the time of interview according to GRAD scores (see table 4). In this way, hope was more than wishful thinking or naive optimism. Descriptions of limitations with regard to aging, dependency, and the inevitability of death were apparent in all the transcripts:

'She has to help me, I don't do anything for her. I can't even keep the garden' (PARTICIPANT 8)

Participants freely described limitations with regard to their dementia; they spoke knowingly about their decline and their current abilities:

'With more things as I say, I'm wrong, I call myself a silly old bee' (PARTICIPANT 6)

'I've only witnessed a sliding down, it's only a slow rate of progression but I feel sometimes that I'm worse than I was a year ago' (PARTICIPANT 8)

Whilst many participants shared their feelings of sorrow concerning the things they had lost (particularly loss of confidence, independence and memory), only two participants described having any hopes to try to regaining some areas of these losses:

'I would like to, just try to get the nerve back to say to go out and get on the bus and go into town again'
(PARTICIPANT 1)

Interestingly, all participants seemed to have accepted their condition was without the prospect of becoming better:

'I realise now that I am in my eightieth year and I aren't going to get any better, I don't expect to get better'
(PARTICIPANT 5)

Only one participant expressed a hope for a cure for dementia; however she stated this was a 'false hope' as she did not realistically think that it would come true, but she did say that she did not want to give up hope for it:

'They haven't come up with a cure for memory yet and I don't think that they will'
(PARTICIPANT 1)

4. Contextual realism

As well as describing the reality of their declining personal abilities, participants also shared a thoughtful appraisal of hope hindering limitations they encountered socially, describing the way they were treated by others and their position within society. Participants shared feelings of loss of role and respect, and loneliness and isolation were also commonly described. At worst, participants reported feeling left behind, having to take a back seat, being left out or even ignored:

'I tend to get left out a bit, not because anybody intended to do that they just don't hear. If I make a comment, it's not heard. They just don't hear' (PARTICIPANT 8)

'We're not silly buggers, we just lose our memory' (PARTICIPANT 6)

A realistic view of the prospects of the nation and society also seemed to be pertinent in shaping participants' hopes, several demonstrated a great awareness of current affairs and world events and shared their understanding and concerns about the state of the world 'nowadays':

'I am thankful that I am coming to the end of my life now, because of the way the worlds going' (PARTICIPANT 5)

5. Re-appraisal and resolution

Although all participants described that their inherent hopefulness and striving for something better remained, they described that their present day hopes as older people living with dementia were 'realistic hopes' balanced with the reality of considerations such as personal limitations, societal restrictions, and the fact that people were not going to get better:

'I would still say I hope for this and I hope for that. But do I really mean it? Well yes I do, I do hope to get better, but I do not expect to get better' (PARTICIPANT 8)

Participants described having to let go of old hopes that were no longer realistically feasible:

'I'm not one of these that hope for the moon and the stars' (PARTICIPANT 2)

'I don't set any impossible targets or anything like that' (PARTICIPANT 1)

Consequently, accounts of hope as an expectation of achieving a desired goal did not emerge, many participants spoke about 'hoping for less':

'What is there to hope for when you get to my age, I'm 73, I'm not sure' (PARTICIPANT 8)

'I mean a lot of older folk don't want the same' (PARTICIPANT 7)

However, it appeared that by letting go of old hopes and adjusting their expectations, participants were able to embrace new hopes and find new ways of being in the world. Consequently, participants described a degree of acceptance, of having made peace with their situation:

'You always hope for something better, but I don't see how it can get better, I'm quite content as I am now'
(PARTICIPANT 3)

'On the whole I haven't done so bad for myself' (PARTICIPANT 9)

Participants reflected on their lives as meaningful and rich and reported feeling content and satisfied, five participants explicitly stated without promoting that they felt happy:

'I mean there's nothing I don't think, that I would have like to have done, that I haven't done' (PARTICIPANT 4)

People reported being thankful for the life they had lived and expressed their feelings that they had been lucky in life:

'And you have got a lot to be thankful for haven't you' (PARTICIPANT 3)

'I think I've seen life you know' (PARTICIPANT 5)

'In my life I have been pretty lucky and had pretty good friends I don't seem to have a grumble with anybody'
(PARTICIPANT 10)

In fact, many felt that they could not complain about their current situations either. Particularly as they felt that there were others who were worse off, it seemed that comparing their own situation with that of peers allowed them to gain hope:

'I've got nothing to complain about really, I'm happy with my life' (PARTICIPANT 3)

'You make the most of what you've got' (PARTICIPANT 7)

'I always say there's folks far worse off than me. When I see people in a wheelchair or in a bed I think oh thank God I'm alright' (PARTICIPANT 6)

'We don't know what some people live in do we' (PARTICIPANT 7)

'Keep living and keep living well'

This high-order theme reflects the present day 'realistic hopes' of people with dementia and how rather than hoping for or anticipating specific goals and outcomes, participants' current and generalised hope was that they would maintain their current quality of life. Hope was described as an ingredient necessary for enhancing the quality of life each day through engendering positive attitudes associated coping with the aging process. Hope was manifest in the holistic well-being of participants in three areas key areas; keeping healthy, keeping relationships with others and the world and coping behaviours.

6. Keeping healthy

Key to maintaining quality of life for all participants was a hope to keep healthy. This related to both their physical health and a hope that their memory would keep with them for as long as possible. Participants described good health as vital to all their other hopes:

‘As long as I can get about, and I’ve got my health that’s everything’ (PARTICIPANT 3)

‘I mean without good health there is nothing’ (PARTICIPANT 4)

Keeping healthy was regarded as vital to remaining independent and being able to continue to carry out activities of daily living. Independence elicited a strong sense of hope in participants and remaining independent in functional activity was a hope expressed by all participants:

‘That I can do my own housework. Pay my own bills. That’s just what I hope for until I die’ (PARTICIPANT 6)

7. Keeping relationships

All participants expressed a hope to keep connected with other people, particularly family. The importance of family, particularly regular contact with children in maintaining hope was striking:

‘Without her[my daughter], I don’t think I’d be here now’ (PARTICIPANT 5)

Social contact was frequently cited as important for maintaining hope. In fact, two participants asked the interviewer if more groups and chances to meet people could be arranged:

‘I just wondered if another afternoon out might make me brighter?’ (PARTICIPANT 7)

The memory clinic was often cited as one way of keeping in touch with people and as something that helped people to continue feeling hopeful:

'Its nice to meet people and know there in the same boat as you...I like coming here, I enjoy the company, the nice people and the mix, it's a break' (PARTICIPANT 6)

'I like meeting people, for example I like coming here [clinic]' (PARTICIPANT 1)

8. Coping behaviours

Participants described strategies they used to help them cope with their current situation and maintain their hope. One such coping behaviour described by many participants was the importance of taking one day at a time:

'You just take each day as it comes' (PARTICIPANT 3)

'You live for the day' (PARTICIPANT 9)

In taking one day at a time hopes were framed in terms of continuation of current level of functioning and the maintenance of daily routines:

'Well to me hope is the majority of things, cleaning the house, shopping, that you look after yourselves your garden, owt like that, yes we do that, that's how it applies to me. Looking after me house and doing things for it that's all' (PARTICIPANT 10)

All participants also spoke about the importance of 'keeping busy' and how this helped to maintain their hope. Participants spoke about using activity when they felt low in hope:

'Well I think I've got to do something otherwise I should go, just sit here and feel sorry for myself'

(PARTICIPANT 7)

'You know if I'm feeling low, I think is there anything I could be doing?' (PARTICIPANT 2)

The most valued form of 'keeping busy' was to get out of the house and take part in pleasurable activity:

'I think getting about a bit, I think that is half the battle' (PARTICIPANT 3)

'I'm going out more nowadays. Going out more is the best thing to do' (PARTICIPANT 7)

Discussion

The results of this study provide insight into the experience of hope in people living with early-stage dementia. Participants' definitions of hope were consistent with literature that has emphasised hope as a sense of force or energy (Averill, Catlin & Chon, 1990; Herth, 1988; Morse & Doberneck, 1995; Owen, 1989; C. Snyder et al., 1991), as involving support from others (Dufault & Martocchio 1985; Miller, 1986; Morse & Doberneck, 1995; Obayuwana & Carter, 1982; Stanley, 1978) and as involving a context of uncertainty (Fryback, 1991; Herth, 1988; Miller, 1986; Morse & Doberneck, 1995; Nowotny, 1989; Stanley, 1978). This study suggests that there is a multi-functionality of hope in old age that can be understood within two theoretical

frameworks. First is that of hope which is established in early childhood relationships, where it acts as a stable trait that is consistent across situations and times, but where specific situations can influence the actual levels of hopefulness that are experienced (C. Snyder et al., 1991). Second, is the developmental model expressed by E. Erickson's (1977) 'Eight Ages of Man' that links hope with the resolution of the nuclear conflict between basic trust and basic mistrust.

There were some noticeable cohort-related differences in participants' descriptions of hope from that of other definitions of the meaning of hope, the first being the lack of future orientated goals relating to the self. A difficulty projecting hopes into the future has been observed in older adults without dementia (Herth, 1993; Farran, Salloway & Clark, 1990). Researchers have suggested that older adults may have their own unique interpretation of future and in this study the future seemed to lie in the hope of passing on a legacy of hope to their own children or to the world in some way. The presence of 'world related goals' in older people has been found in other studies. Nurmi (1992) felt that such goals reflect attempts to generate meaning and integrity. The notion of a 'legacy of hope', of wanting to leave something behind for others is often considered a natural part of old age, and this 'generosity of spirit', the capacity to pass on wisdom to others, has been associated with the development of ego integrity in later life (E. Erickson, 1977).

Another notable feature of participants' accounts was an apparent absence of hopes relating to the achievement of specific 'hoped for' goals or outcomes (Dufault & Martocchio, 1985; Morse & Doberneck, 1995; Owen, 1989; Stotland, 1969). Dufault & Martocchio (1985) stated that particularised hopes are characterised by the expectation that what exists at present can be improved on. The fact that participants in this study did not expect things to improve may explain the lack of such hopes. Studies of hope in older adults without dementia have found also that older people did not describe hopes in terms of achievement or goal attainment (Farran, Salloway

& Clark, 1990; Herth, 1993). Instead of holding particular hopes, participants demonstrated a more generalised sense of hope that is also evident in some definitions of hope (Farran, 1985; Gottschalk, 1974; Miller, 1986; Obayuwana & Carter, 1982; Stanley, 1978). A generalised sense of hope has been seen in accounts of hope in older people (Dufault & Martocchio, 1985) and in those living with chronic and life threatening illness (Miller, 1986). Generalised hopes are thought to exist when a person is deprived of particularised hopes to preserve meaning in life and so protects a person from despair (Dufault & Martocchio, 1985). Generalised hope has been described as imparting a motivation to continue with life and this was evident in the nature of the maintenance focus of participants' goals.

The notion of desire and longing evident in other definitions of hope (Averill, Catlin & Chon, 1990; R. Erickson, Post & Paige, 1975; Gottschalk, 1974; Herth, 1988; Mercier, Fawcett & Clark, 1984; Miller, 1986; Obayuwana & Carter, 1982; Staats, 1989; Stanley, 1978; Stotland, 1969) was not apparent in this study. Hopes were not 'yearned for' and desired in the way that they may have been when participants were younger. Instead, participants' expectations about achieving their hopes were firmly grounded in reality. Participants were realistic about the value of hope; *'Well you hope for things don't you, but I don't think it's all that important if you don't get them, you live'*. But they also seemed able to acknowledge their own limitations. For example, whilst they hoped to stay healthy for as long as possible, they understood that their health was declining. It may be that the lack of desire and longing associated with hopes preserves people from despair when goals are inevitably lost. The notion that hope is grounded in reality and open to painful feelings as seen in this study, has been acknowledged by researchers before (Farran, Hearth & Popovich, 1995; Moltman, 1975) and has been described as key to distinguishing hope from other short-term defence mechanisms such as wishing or denial.

However, the finding that people can be positive and hopeful about their future in the face of a seemingly hopeless situation (such as dementia) remains one of the most controversial findings in hope research. It is possible that people may dispute the notion that hope present in such circumstances can ever be truly realistic, suggesting that people are denying information or not accepting reality, wanting to appear a good patients or even acting in accordance with others expectations and social rules (Kellehear & Fook, 1989). Nevertheless, numerous studies document evidence for the existence of hope in people who have incurable illness (Herth, 1990; Hinds & Martin, 1988; Nowotny, 1989). In fact, Hearth (1990) found that the degree of hope reported by patients with cancer increased as signs of disease progression became evident. It is possible that the notion of whether hope in such circumstances is 'false' or 'realistic' may be unhelpful, for who can say that hope is only appropriate if it is grounded in reality and in any case, whose reality are we referring to when we make this assumption, health professionals or individuals? The positive outcomes identified in this research as a result of hope, such as emotional wellbeing, happiness and determination could render such arguments irrelevant.

This study confirms findings that people continually redefine and readjust their hopes (Ersek, 1992; Hearth, 1989) as conditions in their lives (their reality) changes. It appeared that the process of balancing feelings of inherent hope with reality was central to maintaining hope when dealing with challenges associated with old age and dementia. Socio-economic selectivity theory (see Lockenhoff & Carstensen, 2004) has also recognised the refocusing of goals in light of limitations in old age. It purports that perceived limitations on time initiate the reorganization of goal hierarchies, such that goals related to deriving emotional meaning from life are prioritized over goals that aim at expanding horizons, so that current well being is prioritized over the acquisition of new information. These goal shifts are thought to have adaptive benefits, resulting

in greater emotional well being and satisfaction with social support networks. The notion that goal shifts in later life result in increased well-being is not surprising given that essentially such adjustments reflects a coming to terms with life and the difficulties of old age, a process E. Erickson (1977) regarded as central to the development of ego integrity. Indeed, those participants who endeavoured to balance their feelings of hope with reality frequently described a sense of 'a life well lived' and positive attitudes towards old age.

The majority of participants appraised their lives as satisfactory, particularly in comparison to peers with physical disabilities who many regarded as being much worse off. This finding is in direct contrast to Cutcliffe & Grant (2001) who argue that it is not conceivable that clients with cognitive impairment are capable of comparing own situation with that of their peers and gaining hope from this. In addition, to promoting feelings of integrity in later life, this process of balancing and readjustment has also been frequently cited as a positive strategy in the literature on coping in dementia (see, Clare, 2002; Clare et al., 2006).

Changes in personal competence and environmental demands appeared to threaten to deflate participant's sense of hope in later life. Interestingly, many of these perceived 'hope-hindering' obstacles appeared to arise from the normative developmental course to dependency in later life rather than as a consequence of dementia. Ageing inevitably brings with it increased infirmity, impairments and losses that lead to reliance on others, all of which have been recognised to deflate hope in old age (Farran, 1985; Farran, Salloway & Clarke, 1990; Herth, 1993). However, the impact of psychosocial losses on hope, whilst not unique to dementia (Farran, Salloway & Clark, 1990) appeared to be of particular significance to this sample. Gerontological research on dependency has recognised that dependency in ageing is not simply the product of biological decline but of social breakdown (Baltes, 1996), and that the risk of losing personal autonomy can

arise from external causes such as the stereotypes of others. The impact of the attitudes of others on the hopes of older people has also been noted (Herth, 1993). Additionally, the social acceptability of a diagnosis is thought to be related to individuals; levels of hope. Herth (1990), for example, found that individuals with AIDS were found to have significantly lower levels of hope than those with any other chronic or life threatening illnesses. With dementia remaining a much stigmatised illness (Clarke et al., 1993; Keightley & Mitchell, 2004; L. Snyder, 1999), it appeared that in being old and living with dementia participants were in fact facing a double stigma that threatened their feelings of hopefulness. Although no participant explicitly spoke about stigma, they appeared to allude to the same through an initial reluctance to discuss hopes for fear of appearing 'foolish' and, as stated above, through their descriptions of loss of role and diminishing respect from others.

In light of threats to hope facing older people with dementia it is necessary to consider ways to support and foster hope in people living with dementia. Hope fostering strategies have been described as those that function to instil, support or restore hope by facilitating the hoping process in some way (Herth, 1990). Figure 2 outlines a proposed model of psychosocial interventions that has been derived from this qualitative study of hope in early-stage dementia. This conceptualisation may allow future research on the predictors and correlates of hope and the development of dementia-specific hope measurement. The tentative interventions outlined have been synthesised from the accounts of participants in a 'psychosocial-rich' memory clinic. Therefore practitioners may use some of the common interventions to support people with early-stage dementia (Moniz-Cook & Manthorpe, in press) and their families to improve hope and thus prevent mental health problems and associated disability in the future. Future study will need to

evaluate these interventions in terms of clinical outcomes such as quality of life and well being in dementia care.

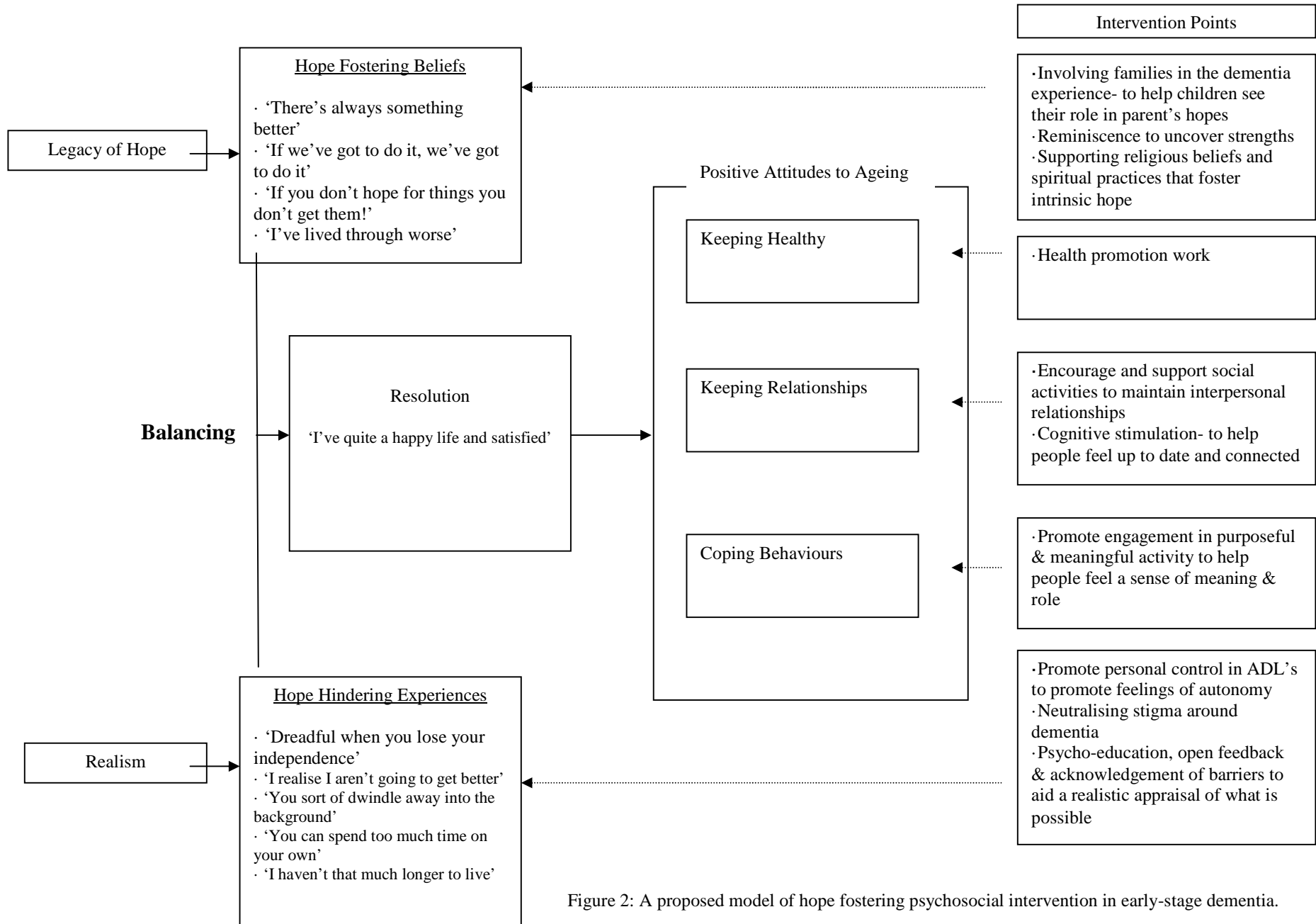


Figure 2: A proposed model of hope fostering psychosocial intervention in early-stage dementia.

The account of hope in early stage dementia outlined here must be viewed in light of a number of methodological limitations, most notably the homogenous sample of participants recruited. Hope in dementia is potentially an idiosyncratic experience and so it would be useful to explore the extent to which this account is applicable to other groups of people with dementia. For example, the participants in this study all had access to a specialist memory clinic offering assessment and psychosocial support. This may render these participants atypical of many people with dementia. It may be that such a group is more hopeful. Furthermore, the application of this account to other sub-groups such as those of differing social class and ethnicity would also be useful to explore, as there is a limited amount of research indicating that hope is influenced by cultural interpretation (Averill, Catlin & Chon et al., 1990). The mean age of the sample was quite old for people in the early-stages of dementia, it may be that advanced age made it easier for participants to refine their goals and accept their limitations. For people with young onset dementia or those receiving a diagnosis in their sixties soon after retirement it may be harder to redefine hopes. Such sample considerations could form the focus of future studies. In addition, it should also be considered that the participants volunteered to take part in a study exploring hope and so by both their character of wanting to take part in such a study and of being a volunteer they may be people who are pre-morbidly higher in hope and could lead to a bias in the results.

Future research is needed to gain a greater understanding of hope from the perspective of older people with dementia and to develop further the model presented here. A clear understanding of the building blocks of hope in this cohort is necessary for the development of tools to measure hope in dementia and to support the formulation of personal strengths in clinical settings. Future research should also incorporate longitudinal designs to explore how experiences of hope vary as losses accumulate and dementia progresses. It has been suggested that with the losses in

autonomy and increasing disintegration that confront people generally in later life, hope may easily give way to despair (E. Erickson, 1977). It would seem reasonable to assume that such losses and disintegration might be more evident for people living with dementia. However, preliminary studies of individuals with cancer have found no significant differences in levels of hope among individuals at various phases of their illness (Stoner & Keampfer, 1985). Future research on hope in dementia should also consider the impact of declining awareness on hope and whether hopes become less grounded in reality. In addition, the examination of the attitudes of other people (such as family members; health care professionals; lay people; and the local clergy) towards hope in dementia would be beneficial to exploring how the attitudes of others affect the hopes of people living with dementia.

In this paper we have explored the meaning and the experience of hope in older people living with early-stage dementia and outlined strategies that can be used by professionals working with them to increase hope. The consistent conclusion that is drawn from this research is that hope is vital and present in the lives of people with early-stage dementia and that such people have the capacity to make rich contributions to research exploring specific positive aspects of their lived experiences. As dementia care turns towards the enhancement of quality of life, research needs to continue an examination of variables that contribute to well being in dementia. The examination of other positive psychology constructs evident in this study such as humour, joy, courage, love might provide a starting point for future research.

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Part 3: Appendixes

Appendix A: Quality Checklist Criteria Applied to Studies

The checklist below is a revised version of the checklist developed by Harden et al (2003). Each study was thus assessed according to the following seven quality criteria:

(A) *Explicit account of theoretical framework and inclusion of a literature review.*

- Are key concepts relevant to the study explained / defined in the literature review?
- Does the literature review provide a logical link with the research purpose?
- Is the literature review related to the research problem?

(B) *Clearly stated aims and objectives:*

- Is there a clear set of research aims and/or questions?
- Are the research aims or questions are linked to the problem and/or to the review of the literature?
- Are the research questions are amenable to the studies chosen design?

(C) *A clear description of context:*

- Did the report provide an explanation of, and justification for, the focus of the study i.e. describe a distinct problem that led to the study?
- Did the report provide a clinical rational, i.e. a real world issue that justified the study?
- Did the report justify the methods chosen?

(D) *A clear description of sample:*

- Did the report provide adequate details of the sample used in the study, critical to the understanding of findings are described? (sample number, age, sex, dwelling, diagnosis).
- Did the report provide a clear description of sample recruitment procedures?
- Are sites of recruitment described ?
- Do the sites of recruitment fit the purpose and sampling strategy?

(E) *A clear description of methodology, including data collection and data analysis methods:*

- Did the report provide an adequate description of the measures used in the collection of data? (e.g. description of questionnaire or interview schedule or a description of interview topics)

- Did the report provide an adequate description of data collection procedures / methods ? (was it clear who the research was, where research took place, number times participant too part)
- Did the report provide an adequate description of the methods used in data analysis?

(F) Evidence of attempts made to establish the reliability and validity of data analysis:

- Does the research describe attempts had been made to assess the validity and reliability of the data analysis?

(G) The inclusion of sufficient original data to mediate between data and interpretation:

- Does the report present sufficient data in the form of, data tables, direct quotations from interviews or focus groups to enable the reader to see that the results and conclusions were grounded in the data?
- Could a clear path be identified between the data and the interpretation and conclusions?

Appendix B: Quality scores awarded to each study included in the review

Paper Author and Year	Criteria 'A' (tick if met criteria)	Criteria 'B'	Criteria 'C'	Criteria 'D'	Criteria 'E'	Criteria 'F'	Criteria 'G'	Total Rating Awarded
Aggarwal et al (2003)	√	√						2 out of the 7 criteria.
Aminzadeh et al (2007)		√	√	√	√	√	√	6 out of the 7 criteria.
Beard (2004)	√	√				√	√	4 out of the 7 criteria.
Brod et al (1999)	√	√			√	√		4 out of the 7 criteria.
Byrne-Davis et al (2006)	√	√	√		√		√	5 out of the 7 criteria.
Cahill et al (2004)		√		√	√			3 out of the 7 criteria.
Clare (2002)	√	√	√		√	√	√	6 out of the 7 criteria.
Clare et al (2006)	√	√	√	√	√	√	√	7 out of the 7 criteria.
Clare et al (2005)	√	√			√	√	√	5 out of the 7 criteria.
Clare & Shakespeare (2004)	√	√	√	√	√	√	√	7 out of the 7 criteria.
Dabbs (1999)							√	1 out of the 7 criteria.
Derksen et al (2006)	√	√	√		√	√	√	6 out of the 7 criteria.
Droes, et al (2006)	√	√			√	√	√	5 out of the 7 criteria.
Friedell (2002)	√	√		√			√	4 out of the 7 criteria.
Fukushima et al (2005)		√				√		2 out of the 7 criteria.
Gillies (2000)	√	√					√	3 out of the 7 criteria.
Gillies & Johnson (2004)		√					√	2 out of the 7 criteria.
Graneheim & Jansson (2005)		√		√	√		√	4 out of the 7 criteria.
Harman & Clare (2006)	√	√	√	√	√	√	√	7 out of the 7 criteria.
Harris (2004)	√	√	√	√	√		√	6 out of the 7 criteria.
Harris (2006)					√		√	2 out of the 7 criteria.
Harris & Sterin (1999)	√	√			√		√	4 out of the 7 criteria.
Holst & Hallberg (2003)		√	√			√	√	4 out of the 7 criteria.
James et al (2005)		√	√				√	3 out of the 7 criteria.
Jonas-Simpson (2005)	√	√			√		√	4 out of the 7 criteria.
Katsuno (2003)	√	√		√	√	√	√	6 out of the 7 criteria.
Katsuno (2005)	√	√	√	√	√	√	√	7 out of the 7 criteria.
Keady, Nolan & Gilliard (1995)		√					√	3 out of the 7 criteria.
Langdon et al (2007)	√	√		√	√		√	5 out of the 7 criteria.
Lyman (1998)	√	√					√	3 out of the 7 criteria.
Macquarrie (2005)					√		√	2 out of the 7 criteria.
Mason et al (2005)		√	√		√	√	√	5 out of the 7 criteria.
Medina et al (2006)		√			√		√	3 out of the 7 criteria.
Menne et al (2002)	√	√		√		√		4 out of the 7 criteria.
Mok et al (2007)	√	√			√	√	√	5 out of the 7 criteria.
Morhardt (2004)		√					√	2 out of the 7 criteria.
Morioka et al (2005)		√					√	2 out of the 7 criteria.
Nygaard & Borell (1998)		√				√	√	3 out of the 7 criteria.
Nygaard & Ohman (2002)	√	√	√	√	√			5 out of the 7 criteria.

Ohman & Nygard (2005)	√	√			√	√		4 out of the 7 criteria.
Ostwald et al (2002)	√				√	√	√	4 out of the 7 criteria.
Parse (1999)	√	√					√	3 out of the 7 criteria.
Pearce et al (2002)	√	√		√	√	√		5 out of the 7 criteria.
Phinney (1998)		√	√	√	√	√	√	6 out of the 7 criteria.
Phinney et al (2007)	√	√				√	√	4 out of the 7 criteria.
Pratt & Wilkinson (2003)	√	√			√		√	4 out of the 7 criteria.
Proctor (2001)	√	√	√		√	√	√	6 out of the 7 criteria.
Reid et al (2001)	√	√	√				√	4 out of the 7 criteria.
Robinson et al (2005)	√	√		√	√	√	√	6 out of the 7 criteria.
Roger (2006)		√		√		√	√	4 out of the 7 criteria.
Sabat (1998)	√	√					√	3 out of the 7 criteria.
Sands (2002)	√	√		√	√	√	√	6 out of the 7 criteria.
Snyder (2001)	√	√					√	3 out of the 7 criteria.
Snyder (2003)		√					√	2 out of the 7 criteria.
Snyder (2006)		√					√	2 out of the 7 criteria.
Steehan et al (2007)		√	√	√	√	√	√	6 out of the 7 criteria.
Sterin (2002)		√					√	2 out of the 7 criteria.
Stuckey et al (2002)	√	√	√				√	4 out of the 7 criteria.
Truscott (2003)		√		√			√	3 out of the 7 criteria.
Van Dijkhuizen et al (2006)	√	√		√	√	√	√	6 out of the 7 criteria.
Vernooij-Dassen et al (2006)		√	√	√	√	√	√	5 out of the 7 criteria.
Ward-Griffin et al (2006)		√	√	√		√	√	5 out of the 7 criteria.
Werezak & Stewart (2002)	√	√			√	√	√	5 out of the 7 criteria.

Appendix C: Existing Definitions of Hope

Researcher (s)	Date	Definition
Stotland	1969	The core of hope is 'an expectation greater than zero of achieving a goal'. Some minimal level of goal importance necessary for hope to be operative. Hope is energised by the belief in the ability to accomplish something. Hopefulness refers to high expectancies and hopelessness low expectancies of success. Hopefulness is a factor in maladaptive behaviour and positive affect.
Gottschalk	1974	A measure of optimism that a favourable outcome is likely to occur, not only in one's personal earthly activities but also in cosmic phenomena and even in spiritual or imaginary events.. An intense assurance that a favourable outcome is likely to occur in all activities including spiritual or imaginary events.
Stanley	1978	A confident expectation that a future good, although accompanied by fear and doubt, is realistically possible through active endeavour, supportive interpersonal relationships and a religious faith. There are seven common elements of hope- expectation of a significant future outcome, feeling of confidence in that outcome, transcendence, interpersonal relatedness, a comfortable feeling, an uncomfortable feeling and action to affect outcomes.
Stoner	1982	Hope is viewed as an interactive process that is future orientated
Mercier, Fawcett & Clark	1984	Anticipation of positive future expectancies
Grimm	1984	Hope is conceptualised as a psychological characteristic with state and trait dimensions
Dufault & Martocchio	1985	Hope is a multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a desired future good which, to the hoping person, is realistically possible and personally significant. Hope has implications for actions and for interpersonal relatedness. Hope is conceptualised as being composed of two spheres; particularized and generalised hope. Particularised hope is concerned with an anticipation of achieving a specific desired goal. Generalised hope is a feeling of well-being and a sense that life is worthwhile. Each of these spheres is conceptualised as being composed of six common dimensions; affective, cognitions, afflictive, behavioural, temporal and contextual.
Miller	1986	Hope is a state of being, characterized by an anticipation of a continued good state, an improved state or a release from a perceived entrapment. The anticipation may or may not be founded on concrete, real world evidence. Hope is an anticipation of a future that is good and based upon: mutuality (relationships with others), a sense of personal competence, coping ability and psychological well being, purpose and meaning in life, as well as a sense of "the possible". Everything human being do in life is based upon some level of hope.
Herth	1988	A multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving good, which to the hoping person, is realistically possible and personally significant
Nowotny	1989	A six dimensional dynamic attribute of the individual that is activated when the individual is confronted with a stressful stimulus. Dimensions include; confidence in outcome, possibility of a future, relates to others, spiritual beliefs, comes from within and active involvement.
Staats	1989	Hope defined as the interaction between particular wishes and expectations of their occurrence and is theoretically based on Beck's self-world-other depressive triad.
Owen	1989	There are six attributes of hope: goal setting, positive personal attributes (optimism, courage, positive attitude), future redefinition, meaning of life, peace and energy

Averill, Catlin & Chon	1990	Hope is an emotion that has cognitive rules governing it, it is appropriate when a goal is important, under some control, at the midrange in terms of probability of attainment and socially acceptable. Hope- a vital principle, a source of light and warmth, an elevated space, a form of support, a physical object or thing, deception, a pressure.
Snyder et al.	1991	A cognitive set that is based on a reciprocally derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals). Hope is primarily a way of thinking with feelings playing an important albeit contributory role
Stephenson	1991	A process of anticipation that involves the interaction of thinking, acting, feeling and is directed towards a future fulfilment that is personally meaningful
Fryback	1993	Hope is a future orientated attitude that helps person to maintain their struggle whilst they continue to enjoy life
Farran, Hearth & Popivick	1995	Hope constitutes an essential experience of the human condition. It functions as a way of feeling, thinking, a way of behaving and way of relating to oneself and ones world. Hope has the ability to be fluid in its expectations and in the event that the desired object or outcome does not occur hope can still be present.
Morse & Doberneck	1995	A realistic initial assessment of the prediction of threat, the envisioning of alternatives and setting of goals. A bracing for a negative outcome and a realistic assessment of personal resources, the solicitation of mutually supportive relationships, the constant evaluation for signs that reinforce the selected goals and the determination to endure.

Appendix D: Interview Structure

Proposed interview structure adapted from Herth (1993)

Thinking about all those things you have just told me, I would like you to tell me about your experiences of hope in living with dementia...

1. Tell me about your hope.

Prompts

- What does hope mean to you?
- What kinds of things do you hope for?
- Do you have hope?

2. If you could identify a source of hope for yourself what would it be?

Prompts

- Where do you think you get your hope from?
- Is there a place you draw hope from?

3. Are there things/situations cause you to loose hope?

Prompt

- Can you think of a time when your hope felt low?

4. When you hope has been low, what kinds of things do you do to help yourself regain your hope?

Prompt

- Are there things that help you to feel hopeful?

5. What helps you to maintain your hope or makes you feel hopeful?

Prompts

- how do you stay hopeful?
- What helps you keep hope / hopeful?

6. How would you define hope?

Prompts

- how would you explain hope to someone else what would you say?
- If we were trying to write a definition for a dictionary what would you put?
- What would you want to tell people that hope means?

7. Is there anything else, that I haven't asked you that you think I should know? Or anything else that you think its important I should know about hope?

Appendix E: Descriptive Measures Employed

Hospital Anxiety and Depression Scale (HADS)

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

A	I feel tense or 'wound up':	
	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0

D	I still enjoy the things I used to enjoy:	
	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3

A	I get a sort of frightened feeling as if something awful is about to happen:	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0

D	I can laugh and see the funny side of things:	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3

A	Worrying thoughts go through my mind:	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0

D	I feel cheerful:	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0

A	I can sit at ease and feel relaxed:	
	Definitely	0
	Usually	1
	Not Often	2
	Not at all	3

D	I feel as if I am slowed down:	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

A	I get a sort of frightened feeling like 'butterflies' in the stomach:	
	Not at all	0
	Occasionally	1
	Quite Often	2
	Very Often	3

D	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0

A	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0

D	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3

A	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0

D	I can enjoy a good book or radio or TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

SF-12

Question 1	In general, would you say your health is excellent, very good, good, fair, or poor?	Excellent ... Very Good ... Good ... Fair ... Poor ...
Question 2	The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? First, moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all.	Limited a lot ... Limited a little ... Not limited at all ...
Question 3	Climbing several flights of stairs. Does your health now limit you a lot, limit you a little, or not limit you at all?	Limited a lot ... Limited a little ... Not limited at all ...
Question 4	During the past four weeks, have you accomplished less than you would like as a result of your physical health?	No ... Yes ...
Question 5	During the past four weeks, were you limited in the kind of work or other regular activities you do as a result of your physical health?	No ... Yes ...
Question 6	During the past four weeks, have you accomplished less than you would like to as a result of any emotional problems, such as feeling depressed or anxious?	No ... Yes ...
Question 7	During the past four weeks, did you not do work or other regular activities as carefully as usual as a result of any emotional	

problems such as feeling depressed or anxious?

No ...

Yes ...

Question 8	During the past four weeks, how much did pain interfere with your normal work, including both work outside the home and housework? Did it interfere not at all, slightly, moderately, quite a bit, or extremely?	<p>Not at all ...</p> <p>Slightly ...</p> <p>Moderately ...</p> <p>Quite a bit ...</p> <p>Extremely ...</p>
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Question 9	<p>These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.</p> <p>How much time during the past 4 weeks have you felt calm and peaceful? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?</p>	<p>All of the time ...</p> <p>Most of the time ...</p> <p>A good bit of the time ...</p> <p>...</p> <p>Some of the time ...</p> <p>A little of the time ...</p> <p>None of the time ...</p>
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Question 10	How much of the time during the past 4 weeks did you have a lot of energy? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?	<p>All of the time ...</p> <p>Most of the time ...</p> <p>A good bit of the time ...</p> <p>...</p> <p>Some of the time ...</p> <p>A little of the time ...</p> <p>None of the time ...</p>
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Question 11	How much time during the past 4 weeks have you felt down? All of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?	<p>All of the time ...</p> <p>Most of the time ...</p> <p>A good bit of the time ...</p> <p>...</p> <p>Some of the time ...</p> <p>A little of the time ...</p> <p>None of the time ...</p>
-------------	---	---

Question 12	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends, relatives etc? All of the time, most of the time, some of the time, a little of the time, or none of the time?	<p>All of the time ...</p> <p>Most of the time ...</p> <p>Some of the time ...</p> <p>A little of the time ...</p> <p>None of the time ...</p>
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Guidelines for the Rating of Awareness in Dementia (GRAD)
FRJ Verhey

General Instructions:

1. After the clinician has introduced himself, he concentrates on the patient and any caregivers present are requested to refrain from comment. The following questions are asked:

Please tell me about the problems you are here for. Why did Dr _____ send you to this clinic?

When the patient has other complaints that are not directly related to dementia:
Do you have any other complaints?

When the patient has no spontaneous complaints about his cognitive functions:
How is your memory functioning? Do you think you have a poor memory?

When the patient denies deficits of memory or other cognitive functions:
So there are no memory problems at all. Is everything going all right for you?

2. After these opening questions, the complaints are discussed more extensively in an open interview, in which the clinician tries to get an impression of the degree and nature of the cognitive symptoms and the patient is asked to provide examples.

Scoring

Scoring of awareness is made directly after the interview. Allowances should be made in scoring the cognitive impairments such as paraphasias or concretisms (e.g. "there is a whole in my brain").

4 Adequate

Patient has adequate knowledge of his cognitive deficits. Spontaneous complaints about the memory or other cognitive disturbances. Gives examples. History of patient is congruent with recorded history.

3 Mildly disturbed

Patient has some knowledge of his cognitive deficits, but with some gaps. Spontaneous complaints about memory. History of the patient shows some discrepancies with recorded. History

2 Moderately Disturbed

Patient has only vague and passive knowledge of cognitive deficits. No spontaneous complaints, admits to memory deficits only when questioned about them. Obvious discrepancies with the recorded history.

1 Severely Disturbed

Denies any deficits. No complaints about memory whatsoever, even after explicit questioning.

Appendix F: Guidelines for submission to International Psychogeriatrics applied to the Systematic Literature Review

International Psychogeriatrics

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought. Contributions include original research articles, reviews of the literature, “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 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 six times per annum. The journal’s Science Citation Index Impact Factor (2007) is 2.207. 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. *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. The Editor-in-Chief has formed a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission.

Submission of manuscripts

Each paper should be submitted by email as an attachment, to ipaj-ed@unimelb.edu.au with a cover letter that should have the abstract attached for circulation to potential reviewers as detailed below. Authors with no access to email may submit papers on disc by post to the Kew, Victoria, Australia address below, but submission by email is strongly preferred. The text file should be 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 ii. If the research was paid for by a funding organization, the cover letter must contain the following three statements. If the research was not paid for by a funding organization only the third statement is required: 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. That the authors have had full control of all the primary data. 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, the paper will be assessed by a third reviewer. The Editor-in-Chief's decision to accept or reject 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 two 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 David Ames, Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +66 3 9816 0477, Fax: +61 9816 0432 or + 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. 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 should be brief, structured and should incorporate the sub-headings: background, method(s), results and conclusion(s). Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words which are not included in the title of the article, 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.

Method(s): 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.

Further advice about statistics and *International Psychogeriatrics* can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. *International Psychogeriatrics*, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in *International Psychogeriatrics* for the year 2003. *International Psychogeriatrics* 16, 389-396. Both of these are available at the *International Psychogeriatrics* website by following the link to [Statistical Advice for intending contributors](#).

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 , η^2 , 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 , χ^2).

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. Even where there is no conflict of interest perceived to be present, this heading should be included. For full details see below.

Description of authors' roles: **This section must be completed.** 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: **No more than 30** articles that have been published or are in press should be cited. If authors believe that more than 30 references are essential this must be justified in the cover letter.

Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. *International Psychogeriatrics* uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “*et al.*” should be employed, i.e., (Smith *et al.*, 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith *et al.*, 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (DOI) is known, it should be added to the reference.

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. Figures that require color to communicate the data will be published only on payment of the additional cost by the authors.

Figure and 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.

Supplementary material: More detail about the submission of supplementary material is available below – see “Supplementary Material for online only publication” and “Instructions for contributors – Supplementary Material” in subsequent pages of this document.

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 1 or 2 literature reviews in each issue. Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

Appendix G: Guidelines for submission to *Aging and Mental Health* applied to the Empirical Paper

Journal Details: *Aging & Mental Health*

Instructions for Authors

Aging & Mental Health welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. We encourage the submission of timely review articles that summarize emerging trends in an area of mental health and aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher.

Manuscripts

All submissions should be made online at [Aging & Mental Health's Manuscript Central site](#). New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

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 from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

Books for review should be sent to **Professor Murna Downs**, Bradford Dementia Group, School of Health Studies, University of Bradford, Bradford BD5 0BB, UK.

All submissions should be in the style of the **Publication Manual** of the American Psychological Association (4th edition, 1994). Papers should be double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain **an abstract of not more than 250 words**. The third page should repeat the title as a heading to the main body of the text.

Structured abstracts: The main text should be preceded by a short structured abstract, accompanied by a list of keywords. The abstract should be arranged as follows: Name of author(s); title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion. **Key words:** A list of 3-5 keywords should be provided. Words already used in the title should be avoided if possible. 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. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

Style guidelines

Description of the Journal's [article style](#) Description of the Journal's [reference style](#), [Quick guide](#)

A [Word template](#) is available for this journal (please save the Word template to your hard drive and open it for use by clicking on the icon in Windows Explorer). If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk

Units of measurement

All measurements must be cited in SI units.

Illustrations

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate page, should include keys to symbols, and should make interpretation possible without reference to the text. Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 x 210 mm) in mind and should be capable of reduction.

Tables

Tables should be submitted on separate pages, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

Proofs

Proofs will be sent to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned within 72 hours of receipt.

Free article access Corresponding authors will receive free online access to their article through our website (www.informaworld.com) and a complimentary copy of the issue containing their article. Reprints of articles published in this journal can be purchased through Rightslink® when proofs are received. If you have any queries, please contact our reprints department at reprints@tandf.co.uk

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Ageing & Mental Health has a new editorial e-mail address: amh@ucl.ac.uk. General enquires can be sent to m.orrell@ucl.ac.uk.

Appendix H: Patient Information Sheet

Information about the research

You are being invited to take part in a research study, which is trying learn something about the experience of hope for people who are experiencing memory problems.

Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this information.

What is the purpose of the study?

This study is looking to understand more about experience of hope for people who are experiencing memory difficulties. We all know that our hopes change as we go through life and that the things we hope for can differ from person to person. This study wants to investigate; what hope means to people with memory difficulties, what kind of things people hope for, what helps to foster hope and what factors hinder hope.

Why have I been chosen?

This information is being given to all new clients who come to the memory clinic. It is also being given to a number of people who are current clients at the clinic, who staff members felt might be interested in taking part.

Do I have to take part?

No, the study is voluntary. If you decide to take part you will be asked to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What would I have to do?

If you agree to take part, then you will be contacted to arrange a convenient time and place to meet. The interviews will be conducted by a trainee clinical psychologist and the conversation will be audio taped. There are no right or wrong answers to any of the questions, we want you opinions. After the interview you will also be asked to complete a number of short questionnaires, which look at how you have been feeling over the last couple of weeks. You may also be asked a few short questions to see how your memory is currently functioning, if it was a while since your memory was last tested.

What are the possible disadvantages of taking part?

The questions require you to think about the experience of hope in living with memory difficulties. If you feel that this will be too distressing you do not have to take part. If at any point during the study you feel uncomfortable in any way or that it is too much trouble, you can

withdraw from the study. If following the study you feel concerned about any of the issues raised you will be able to contact the researcher to discuss what further action you wish to take.

What are the possible benefits of taking part?

We cannot promise the study will help you, although previous research has found that people can find talking about their hopes to be beneficial. It is hoped that the information we get from this study will help improve the understanding and treatment of memory difficulties.

Will my taking part in this research be confidential?

Yes. All personal information collected about you during the course of this study will be kept strictly confidential. Any details that could be used to identify you will not be used in the research. Each person will be recorded and identified by a number. All audiotapes made during the interview will be destroyed after use.

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time, without giving a reason. This will not affect the care you receive at the clinic.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (01482 328807). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the memory clinic.

What will happen with the findings from the research?

Upon completion of the study, you will not be contacted again, unless you wish to receive the results. The results will be written up and submitted for publication in an academic journal. No details will be included in the write up that could be used to identify individual participants.

Who is organising and funding the research?

The study is being conducted by the researcher as part of the academic requirement for the qualification of a doctorate in clinical psychology. The research is supported by the Memory Clinic Team and is funded by Humber Mental Health.

Who has reviewed the research?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favorable opinion by Hull and East Riding Research Ethics Committee.

Contact for further information

Emma Radbourne

Tel: 01482 328807

Add: Department of Clinical Psychology
Hertford Building
The University of Hull
Cottingham Road

Hull
HU6 7RX

If you have any queries please do not hesitate to contact me. Whether or not you decide to take part in this research project, I would like to thank you for taking time to read the information.

Yours Sincerely,

Emma Radbourne

Appendix I: Consent Form

Center Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Understanding the Experience of Hope in Older People with Memory Problems

Name of Researcher: Emma Radbourne

1. I confirm that I have read and understand the information sheet dated 24th February 2007, (version 2) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that a responsible individual will conduct interviews with myself and that these will be audio-recorded.
4. I give permission for the researcher to have access to my clinical notes for the collection of data.
5. I agree to take part in the above study.

Name of Participant

Signature

Date

Name of Person
taking consent
(if different from
the researcher)

Signature

Date

Researcher

Signature

Date

Appendix J: Ethical Approval



Hull and East Riding Local Research Ethics Committee

Room SC39
Coniston House (Trust Headquarters)
Willerby Hill Business Park
Willerby
HULL
HU10 6ED

Telephone: 01482 389246
Facsimile: 01482 303908

20 March 2007

Miss Emma Louise Radbourne
Trainee Clinical Psychologist
The University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Miss Radbourne

Full title of study: Understanding the Experience of Hope In Older People
with Early-Stage Dementia
REC reference number: 07/Q1104/27

The Research Ethics Committee reviewed the above application at the meeting held on 19 March 2007. Thank you for attending the meeting along with your academic supervisor Professor Cook in support of the review of this application

Ethical opinion

- Members required clarification regarding the timing of the initial approach to the potential participant. You confirmed that the patients will be attendees of the memory clinic and will have already received their diagnosis of dementia. The committee were satisfied with this response
- The committee wish to point out that if the interviews are to take place in the patients home then appropriate safety measures must be in place
- It is noted that the initial consent form is to allow you to access the patients medical records in order to ensure that the necessary inclusion / exclusion criteria are met
- Members agreed that there would be no requirement to inform the participants GP of their participation in this study
- It was suggested that you take advice from your supervisor regarding the possibility of some patients losing capacity to participate during study, consideration should be given to how this would be addressed. For information purposes the committee wishes to receive feedback on this matter
- It is noted that the information sheet gives a contact mobile telephone number. Members wish to point out that it is not advisable to use a personal phone number and recommend the use of a departmental mobile or land line contact number

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The committee agreed that this study should be exempt from Site Specific Assessment (SSA)

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	Parts A&B only as SSA Exempt	02 March 2007
Investigator CV	Miss E L Radbourne	02 March 2007
Protocol	v3	02 March 2007
Covering Letter		02 March 2007
Interview Schedules/Topic Guides	v1	02 March 2007
Questionnaire: HAD Scale		
Questionnaire: SF 12		
Questionnaire: Mini Mental State Examination		
Participant Information Sheet	v1	02 March 2007
Participant Consent Form: Consent form 2	v1	02 March 2007
Participant Consent Form: Consent Form 1	v1	02 March 2007
CV Supervisor	Dr C J Clarke	
GRAD - Guidelines for Rating awareness in Dementia		

R&D approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1104/27**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely


 **Mr Graeme Duthie**
Chair


Email: louise.hunn@humber.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

Standard approval conditions

Copy to: Humber Mental Health NHS Teaching Trust

Appendix K: R & D Approval

Humber Mental Health 

Teaching NHS Trust

Research & Development Department
Trust Headquarters
Willerby Hill
Beverley Road
WILLERBY
HU10 6ED

Our Ref: SW-10/04/07-Emma Radbourne.doc

10 April 2007

Emma Radbourne
Trainee Clinical Psychologist
The University Of Hull
The Department of Clinical Psychology
The Hertford Building
Cottingham Road, Hull, HU6 7RX

Dear Emma

Re: Understanding the Experience of Hope In Older People with Early-Stage Dementia

I am please to notify you formally that this study has been approved by the Trust and may now proceed.

Humber Mental Health Teaching NHS Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported

The Trust is required to return information on the progress of studies to the National Research Register, and to report research findings. We will, therefore, ask you every 6 months for such updates. This includes full reference of any publications arising from the project.

I would like to wish you every success with this project

Yours sincerely



Mr Duncan Courtney
Senior Projects Officer
Humber Mental Health Teaching NHS Trust

Appendix L: Reflective Statement

Reflective Statement

- *Introduction*

This statement reflects on the process of carrying out this research and encompasses all aspects of the research process including how the project was developed; the process of conducting the literature review; how choices were made about the design of the empirical study; the participants; the interview; the analysis; a reflection on the results; and future research, so to consider what I have learnt about my approach to research and particularly what I have learnt that will help me in future research endeavours.

- *How the Project was Developed*

This project was borne of a desire to document the experience of living with dementia in its entirety. Much of the literature available frames dementia very narrowly, focusing heavily on decline and loss, something that is at odds with my own clinical experience. My own theoretical interest is in the positive psychology movement and this is the second stream of literature that informed this research. Positive psychology aims to restore the balance in psychological research, shifting the focus away from deficits. This led me to consider extending the systematic examination of strengths into dementia research. The literature review provided a solid starting point for the research by allowing me to review the current evidence relating to positive constructs in dementia research, whilst the empirical paper provided me with a chance to study one these positive psychology constructs in depth. I selected the construct of hope as it seemed the most salient against the current body of apparently hopeless dementia research, where the only references to hope are often in relation to medication. As the project arose from my own clinical interest, I have had to be extremely aware of, and continually reflect on, my beliefs (in effect, that people with dementia can provide reliable and valid accounts on personal experiences; are capable of experiencing positive emotions in spite of or even *because* of their dementia; and that people living with dementia are not without hope). Whilst of course I accept that it is not possible to completely set aside my own perspective, throughout this research I have attempted to bracket my own values, perspectives and knowledge of existing theory, through self reflection

and owing my own perspective. I have attempted to consider how my own background, concerns and interests might affect the project at its various stages and put in place a number of safeguards to ensure rigour in this project.

- *The Literature Review*

The idea of conducting a systematic review initially felt quite daunting. However, I found that the explicit methods of such reviews (particularly the comprehensive methods of searching) made the process more organized and structured. Reviewing ‘positive experience’ presented some challenges. Firstly, forming an operational definition of the type of studies I wanted to include (essentially subjective accounts) took some thought, as these existed with a variety of different research areas. I looked at how other reviews had accessed people’s experiences, as they came across a recent series of systematic reviews that included ‘views studies’ alongside trials in public health research (see Harden et al., 2003). This definition fitted with my research and so I was able to use their methods as a guide for my review. However, even with this definition, I found such studies difficult to access. As one cannot search specifically for ‘views studies’ on electronic databases, I had to sift through large numbers of citations, which was a time-consuming process. Another difficulty I encountered was that whilst systematic review methodology is well developed for trials, the views studies I accessed were qualitative or mixed in design and thus it was not as easy to extract and synthesize data in a standardized manner. Unlike the extraction of data such as study design and characteristics, the evidence that I extracted on positive experiences was more subjective, particularly as they had not always been highlighted as positive by the researcher writing the paper. Whilst supervision was used to check the validity of the extracted data as a positive account, it may be that some people may not agree that what has been found was positive and I found this quite disconcerting. There is a growing debate about the application of systematic approaches to reviewing non-experimental research, particularly around the synthesis of qualitative research, and of the validity of the synthesis of studies of different designs (Dixon-Woods et al., 2006). After conducting such a review I feel that the richness of data extracted justifies further exploration of such review methods.

- *The Design of the Empirical Study*

The extraction of hope as a positive experience from the literature review formed the basis of the empirical study. The lack of existing research on hope in dementia and the studies aim to discover subjective meanings of hope, necessitated the qualitative research design. Originally I had an ambitious design to try and develop and pilot a measure of hope following the interviews. However I realised after presentation of this design to peers that this was a separate study that would only follow after the building block of hope in dementia were well understood. Whilst I found this realisation initially disappointing, I understand on reflection that the design would just not have been possible in the time period and that perhaps a point for me to consider in future research is not to be over ambitious.

- *The Participants*

The participants in this study were not typical of all people living with dementia, particularly as all participants were involved (at varying levels) in a 'psychosocial-rich' memory clinic. However, IPA makes no pretence of attempting to obtain a random or representative sample. Instead, it is interested in understanding a phenomenon from the perspective of this particular group (Smith & Osborn, 2004). In light of the distinctiveness of this sample, which might be criticized as a limitation of the study, I felt it was important to provide ample details about the sample. Based on guidelines for qualitative research, I attempted to 'situate the sample' for readers (Elliot, Fischer & Rennie, 1999) through the presentation of a number of descriptive measures of participants and their life circumstances that may be relevant to their experience of hope.

I recruited 10 participants in total for the study, however I found it difficult to identify when I had reached 'data saturation'; after 8 interviews, I was noticing significant similarities and differences between participants accounts and as such I was unsure whether to stop. Perhaps as a result of my lack of confidence in my own experiences of qualitative methods, I went on to collect two more samples. I then stopped at 10 because I felt that I was in danger of being overloaded by the amount of data. Data saturation is clearly a subjective matter - some studies have been done on one case and some on as many as 15 - and although there is no right answer to what is an appropriate sample size, I imagine that knowing when this point is reached is a skill that will develop as one gets more confident in IPA approach.

It was interesting to see how participants spoke about hope during the study, as the majority of the interviews appeared to follow a similar basic pattern. Although participants had consented to take part in a study on hope, they all initially played down their hope telling me that they didn't hope for much and that they weren't foolish in their hopes. Some even made jokes about hope - 'I don't hope to meet a millionaire.' But when I reflected this back to participants, saying for example 'so you don't have much hope', they instantly rejected this idea and were very clear that they had hope and then went on to tell me about their present hopes. This was an interesting process as it seemed that participants did not want me to think they were foolish for having hope. I would be interested to explore further if such patterns exist in other hope studies, or whether it reflects something about how comfortable this cohort feel in talking about hope. I have reflected on the idea that the participants' denial of any feelings of hopelessness may be result of their desire to be seen as 'good patient' at the memory clinic which they linked me, as a researcher, with. I have also questioned whether my age as an interviewer could have affected participants' responses – were they trying protect me from the despair to come that we must all face? Would they be more willing to talk about the losses associated with someone of similar age?

- *The Interview*

Administering the GRAD (Verhey, 1999) before the interview was incredibly useful and something that I would recommend to other researchers. It set the scene by helping to shape the subsequent interview. My interview style developed over the course of the project and I redrafted my schedule as I discovered ways to make participants feel more relaxed and confident. For example, starting with questions that participants could answer about their own experiences; being explicit that although I had some questions, these were only a guide and I wanted them to talk freely, and through stating that there was no right or wrong answers. On my way out of the first interview, the participant stated 'I'm surprised you didn't ask about my wife, because she helps me to feel hopeful'. This taught me to add a closing question - 'Is there anything else that I haven't asked you that you think I should know, or anything else that you think it is important for me to know about hope?' - which proved very fruitful.

During the interview process I found that I had to be aware of my own assumptions influencing the progression of the interview. Good practice in IPA interviewing is to allow people to tell their

stories (Smith, 1995) with minimal intervention from the researcher only when necessary to steer interview back on topic. There were times early on in the research when I interjected as I assumed participants had gone off topic, which on reflection was as a result of my beliefs about verbosity and story-telling in old age –the most pertinent example being the first time a participant started talking about the war. However, when the war was mentioned in subsequent interviews, I started to realise that it might be something relevant to hope. I reminded myself that adopting a phenomenological perspective meant assuming that ‘what the respondent is saying has some ongoing significance for him/her in some, though not a transparent, relationship between what the person says and beliefs or psychological constructs that can be said to hold’ (Smith, Flowers & Osborn, 1997). I realised that it was crucial in subsequent interviews to reflect ‘in action’ during the interview on my reactions to what was being said.

Something that I had not expected during interviews was participants using more than words to communicate. During one interview a participant got up and got her calendar and began reading to me what she had done over previous months. I was initially unsure of why she was doing this as it did not appear to answer my question about hope. It was only when I asked the participant if this was something that she did often, that she explained that as could remember all that she had done, she looked at calendar and doing this helped her to feel hopeful. I wondered if in future research we should be considering how we can adapt interview style to get most information from people with dementia perhaps through more creative methods such as the use of video diaries.

- *The Analysis*

The analysis of the transcripts using the IPA approach (Smith & Osborn, 2004) presented some challenges. The first came in the initial phase of the analysis, where the researcher was required to annotate anything ‘interesting or significant’ in the transcripts. IPA recognises that this is a personal process and that the analysis is both dependent on, and complicated by, researchers own conceptions. I think one of the strengths of my research was the number of credibility checks that I had in place to ensure the reliability of analysis and to avoid confirmation bias. I kept meticulous records of the analysis process and a reflective journal over the course of the project. I have a number of safeguards in place to ensure that I stayed grounded in the text - the IPA group

and research supervision were both essential. The use of the focus group was also key to ensuring the comprehensibility of the account and that it resonated with listeners.

The second challenge that I faced was knowing when my analysis was complete and that I had reached my final list of themes. Constructing a final list of themes is challenging - it is hard to prioritise data when the accounts obtained are so rich. At one point I had decided on 8 themes and 4 higher order themes. It was when I had written both my results and discussion section that I realised that what I had essentially was simply a 'first-order' analysis. I had collected and described what people had said but I had not developed this further; essentially I had not moved on to the 'interpretative bit' of the analysis. At this point I went back to my theoretical constructs about hope, ageing and dependency and started to consider what these accounts meant about participants made sense of their experiences to contextualise and interpret my results. Larkin, Watts & Clifton have encouraged IPA researchers to embrace the interpretive opportunities offered by this approach rather than be 'too easily satisfied' with descriptive analysis. However I do not think stopping at descriptive accounts is about being 'easily satisfied' but the result of being over-cautious about using ones own theoretical knowledge after being so conscious about limiting its influence in the initial stage of the analysis.

- *Reflection on the Results*

My findings suggested that all participants had hope despite all the challenges they faced as a result of being old and living with dementia. I shared my findings at the 18th annual Alzheimer's Europe conference where they received a good reception, however, given the controversy surrounding positive experience in dementia understandably some people remained sceptical about whether hope in dementia was a 'true hope' or represented a defence mechanism or a denial. Given that my participants had shown such deep awareness of their limitations, I found such comments challenging. Whilst, clearly this is a small qualitative study and the intention is not for these results to be generalised to all people living with dementia, ultimately the value of any scientific research is in its ability to provide meaningful and useful information and to generate interest. Accordingly I hope that this research generates debate on both sides so that future research will continue to look positively at the lives of people with dementia.

- *Future Research*

There remains a paucity of research examining factors related to quality of life in dementia and a debate about whether people with dementia can be considered reliable informants on such a matter. This study adds to the growing research evidence that people with dementia can provide information about their quality of life and experiences, these participants had not lost their ability for self-reflection and in fact wanted to tell their story in their own words. The findings suggest that future research should include the perspectives and subjective accounts of people living with dementia. Participants enjoyed taking part in this research, but significantly they also said that such endeavours helped them to feel hopeful. Therefore I think that future research should encourage participants to be included more closely in research projects. I think that research should consider the possibility of a co-operative research endeavour where people with dementia are co-researchers who have a more equal stake at every stage of the research – from inception to dissemination.

For researchers embarking on similar projects I would suggest that good planning is crucial. I would encourage researchers to plan regular research supervision as I found this research to be personally demanding in a number of ways, mainly because talking with patients about chronic health conditions is distressing and in a different way to that which we encounter in clinical practice as we are not there to offer any assistance. I would encourage people to plan in advance how they will ensure rigour in their research. Obviously this is key to all IPA research, but particularly important in novel studies such as this where one is not sure what to expect. The systematic literature review helped to ground the project in an evidence base, a reflective diary, regular research supervision and IPA groups all proved to be useful validity checks. Finally, I would advise future researchers to consider ways that their methodology can allow people with dementia to feel confident and comfortable in taking part. I would like to see the exploration of more novel methods into dementia research and the development of more focus groups.

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