

THE UNIVERSITY OF HULL

Hope and Stigma in Early Stage Dementia

being a Thesis submitted for the Degree of Doctor of Clinical Psychology

in the University of Hull

by

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Overview

This portfolio thesis consists of three parts:

Part one is a systematic review of the literature relating to perceived stigma and support amongst family caregivers of people with dementia. Numerous studies have suggested stigma is associated with negative outcomes in various mental and physical health difficulties. Older people with dementia and their family caregivers could be especially vulnerable to experiencing stigma and this could have a negative impact on their engagement with services. Out of an initial literature search resulting in 101 articles, 15 articles met the inclusion criteria for the present review and their methodological quality was assessed. The 15 articles were critically analysed and four main themes from the articles were extracted. The themes were sociocultural aspects, services use and diagnosis, stigma and aging and managing stigma. A proposed model of perceived stigma that explained the potential origins of stigma, the difficulties it may bring and possible links to service engagement was developed from the results of this review. The clinical implications of this and possible further research areas was discussed.

Part two is an empirical paper consisting of two aims. The first aim investigated levels and types of hope experienced by older people with and without dementia. The second aim focused on potential relationships between stigma, hope and quality of life in older people with dementia. Many studies have indicated that hope is positively associated with quality of life in chronic health conditions and there are two contrasting theories of hope, multi-dimensional hope and goal directed hope. Preliminary studies suggested that older people with dementia may predominantly experience multi-dimensional hope

and that stigma may be a barrier towards hope. A group of 60 older people without dementia completed two different questionnaires on hope and a group of 40 older people with dementia completed two additional questionnaires on their experiences of stigma and their quality of life. The results supported the hypothesis that older people with dementia experienced higher levels of multi-dimensional hope but stigma was not a statistically significant barrier towards this. Implications for services, including the development of psychosocial interventions and possible further research were discussed.

Part three are the appendixes including a reflective statement on the designing, planning and implementation of the research.

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Part One: Systematic Literature Review

Perceived stigma and engagement with support amongst family caregivers
of people with dementia: A systematic review of the literature

This paper is written in the format ready for submission to *Aging & Mental
Health*.

Please see appendix A for author guidelines

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Perceived stigma and engagement with support amongst family caregivers of people with dementia: A systematic review of the literature

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Abbreviated title: A review of stigma amongst dementia caregivers

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Perceived stigma and engagement with support amongst family caregivers of people with dementia: A systematic review of the literature

Abstract

Title of manuscript: Perceived stigma and engagement with support amongst family caregivers of people with dementia: A systematic review of the literature

Name of Journal: Aging & Mental Health

Objectives: The aim of this study was to systematically review the literature on perceived stigma and engagement with support in family caregivers of people diagnosed with dementia.

Method: There was a search of PsycInfo, MEDLINE and CINAHL electronic databases and manual searches of the Journal of Dementia. Studies were included in the review if they were peer-reviewed, appeared after 1988 and focused on perceived stigma amongst family caregivers of people with dementia. 101 articles were retrieved and 15 met the inclusion criteria and the average quality rating was 7.6 out of 11.

Results: The results comprised of four themes: sociocultural aspects, service use and diagnosis, stigma and aging and managing stigma.

Conclusion: From those themes and existing literature on stigma, a provisional model of perceived stigma in family caregivers is proposed. This model describes the potential

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origins of perceived stigma in family caregivers in dementia, the psychological difficulties associated with it and how the management of stigma impacts on engagement with services.

Keywords: stigma; dementia; caregivers; engagement; review

Introduction

The concept of stigma in mental health originated from Goffman's seminal work, where stigma is defined as an 'attribute that is deeply discrediting' which diminishes the holder 'from a whole and usual person to a tainted, discounted one' (Goffman 1963, p. 3). Link & Phelan (2001) expanded this by suggesting that stigma consists of four interconnected factors, (1) labelling, (2) negative stereotyping (3) separation of 'them' from 'us' and (4) status loss for the stigmatised individual.

The experience of stigma has been linked with various physical and mental health difficulties (Weiss, Ramakrishna, & Sooma, 2006; Horsfall, Cleary, & Hunt, 2010). It has been associated with negative outcomes in people with mental health difficulties such as schizophrenia spectrum disorders (Yanos, Roe, Markus, & Lysaker, 2008), substance abuse (Rae Olmsted, et al., 2011), depression (Conner, et al., 2010), anxiety (Alonso, et al., 2008) and eating disorders (Almeida, Savoy, Stephen, & Boxer, 2011). The experience of stigma has also been associated with negative outcomes in physical health conditions including, cancer (Else-Quest, LoConte, Schiller, & Hyde, 2009), incontinence (Garcia, Crocker, & Wyman, 2005) and AIDS (Young & Bendavid, 2010) as well as chronic neurological conditions, including epilepsy (Kumari, Ram, Nizamie, & Goyal, 2009) and dementia (Burgener & Berger, 2008).

It has been suggested that individuals with dementia are particularly vulnerable to being stigmatised due to the impact of Western European cultural values of productivity, self control and mastery (Herskovits & Mitteness, 1994). The difficulties associated with dementia mean that individuals struggle to meet these values and are effectively devalued in social terms (Clarke, 2005), leading to the experience of stigma

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and discrimination (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Burgener & Berger (2008) suggested that the experience of perceived stigma in dementia consists of social rejection, financial insecurity, internalised shame and isolation and this impacts on an individual's self esteem, sense of control, levels of fear and mood.

Over 60% of people with dementia in the UK currently live at home (Personal Social Services Research Unit, 2007) and the progressive cognitive and functional impairments they encounter can place family and spousal caregivers under increasing strain. Caregiver well-being is important clinically as it could have an impact on the quality of life of the person with dementia and the quality of their relationship.

Reflecting this, the well-being of carers is a national priority as described by objective 7 in the National Dementia Strategy (Department of Health, 2008) and by the Carer's Strategy (The Department of Health, 1999).

The potential for family caregivers of people with dementia to experience stigma which influences their well being and engagement with support services has increasingly become the focus of research. Some studies have suggested that family caregivers experience stigma themselves and this has been termed, 'courtesy stigma' or 'stigma by association' (Werner & Heinik, 2008). This is a process by which perceived stigma affects the individual with dementia and spreads to others close to them, such as a key family caregiver. Angermeyer, Schultze, & Dietrich, (2003) proposed that there are four dimensions to stigma by association; (1) interpersonal interactions, which is negative stigmatising attitudes and behaviors from relating to others, (2) concealment of the difficulties experienced with their relative with dementia, (3) structural discrimination and (4) performing social roles. Studies have suggested that family

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caregivers who experience stigma also experience low-self esteem (Byrne, 2001), difficulties in coping (Ostman & Kjelin, 2002), fear and embarrassment (MacRae, 1999) and hopelessness (Phelan, Bromer, & Link, 1998).

In addition to stigma being important at a clinical level, it could be important at a service level, effectively representing a barrier for family caregivers in accessing and engaging with formal and informal support. Existing research has suggested that stigma acts as a barrier to accessing support in carers of people with depression (Choi & Kimbell, 2009), AIDS (Poindexter & Linsk, 1999), mental health difficulties (Tsang, Tam, Chan, & Chang, 2003) and cerebral palsy (Pimm, 1996). This could have important implications for the practice and development of psycho-social interventions and services may benefit from a focus on the perceived stigma associated with dementia.

There have been previous attempts to systematically review the literature of stigma associated with chronic health conditions and with mental health difficulties but not specifically in dementia. It would be important to have an overview of the experience and impact of perceived stigma amongst caregivers of people with dementia. Conceptually this would aid in understanding stigma by association and courtesy stigma and clinically in developing interventions that help caregivers and people with dementia manage their experience of stigma. Therefore, this review aimed to answer the following questions:

- (1) How is perceived stigma experienced and managed by family caregivers of people with dementia?

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- (2) What is the impact of perceived stigma on their engagement with formal and informal support?

Aims

- (1) To conduct a systematic review of the empirical literature relating to perceived stigma in family caregivers of people diagnosed with dementia.
- (2) To analyse the literature in terms of methodological quality
- (3) To investigate the impact of perceived stigma on the engagement of family caregivers with formal and informal support
- (4) To investigate the management of perceived stigma in family caregivers of people diagnosed with dementia.

Method

Search Sources and Terms

A systematic search was completed using the PsycInfo, MEDLINE and CINAHL electronic databases and manual searches of the Journal of Dementia (e.g. Keady, Harris, & Wilkinson, 1995) and the references lists of all the included studies.

The search used the following terms:

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(DEMENTIA) OR (ALZHEIMER*)

AND

(STIGMA)

Inclusion Criteria

Studies were included in the review if they:

- (1) Focused on perceived stigma amongst family caregivers of people with dementia in their aims, recruitment or analyses
- (2) Appeared in a peer-reviewed publication (excluding conference papers and dissertations)
- (3) Appeared after 1988, as a different conceptualisation of stigma was beginning to be developed based on modified labelling theory (Link, Cullen, Frank, & Wozniack, 1987). This postulated that stigma involves labelling the individual and this leads to a stereotype. Theories prior to this were often imprecise and frequently focused solely on the individual experiencing stigma and neglected systemic factors to some extent (Link & Phelan, 2001).

Exclusion Criteria

Studies were not included if they were:

- (1) Not written in English
- (2) Review articles
- (3) Focused solely on biological and neurological factors

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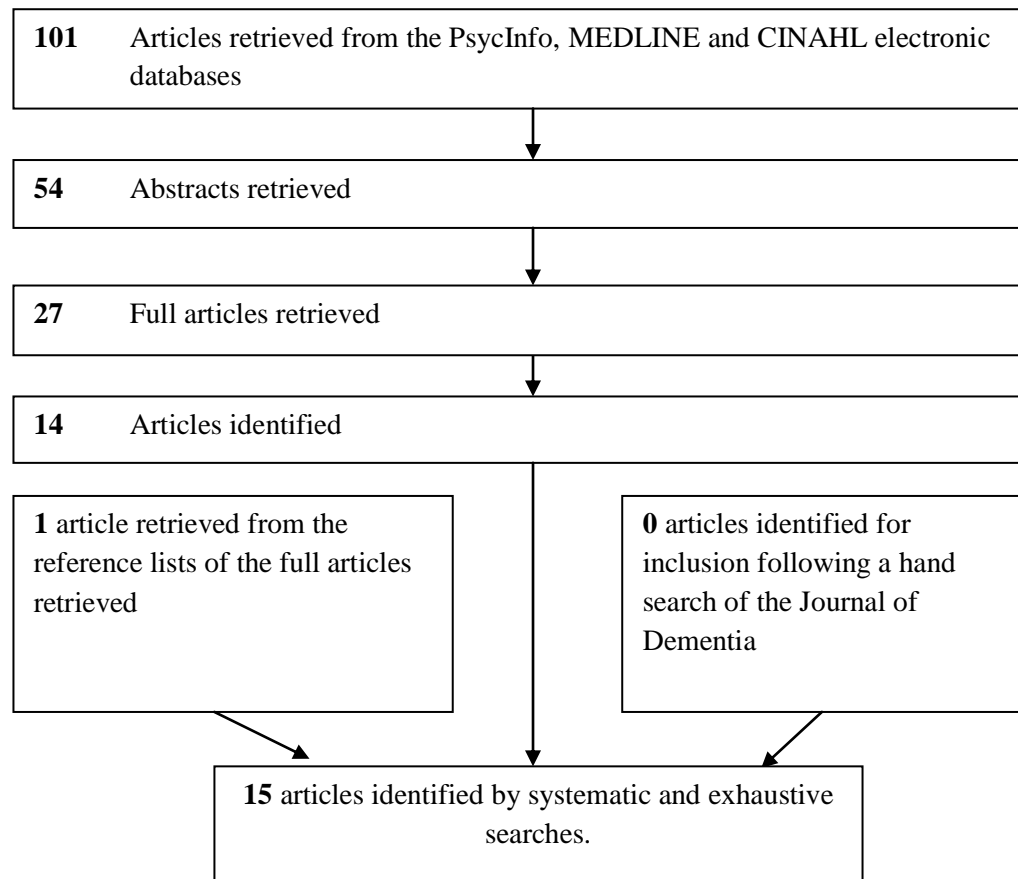
(4) Not focused on the experience of perceived stigma and its impact

Screening

All the literature from the database and manual searches were firstly screened by title and abstract to determine their eligibility for inclusion in the review. This was followed by the screening of the entire article and data extraction and at each stage the inclusion and exclusion criteria were applied.

Results

Figure 1. The Search Process



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The initial search of PsycInfo, MEDLINE and CINAHL electronic databases on 4th April 2011 resulted in 101 articles of which 47 were excluded on the basis of their titles, in accordance with the inclusion and exclusion criteria outlined above. The abstracts of the remaining 54 articles were retrieved in order to identify their suitability and a further 27 were excluded at this point. A further 13 were excluded following a review of the full papers based on the inclusion and exclusion criteria. A hand search of the reference lists of retrieved articles and of the Journal of Dementia yielded one further study. On the basis of these searches, 15 articles were eventually deemed relevant and included in the review (see Figure 1). The majority of the articles (27) excluded from the systematic search of 101 were review articles. Other excluded articles focused on those with stigmatizing attitudes such as lay person's attitudes towards people with dementia (11), articles focusing on health policy or ethical issues (13) and articles focusing on interventions (10).

Studies included in the review are included in table 1. Studies drew participants from a range of settings. Eight studies recruited from support groups for people with dementia and their caregivers, four from primary care services and three from different residential care settings including traditional and new model designs with a small to large number of beds. In addition, various community and religious centers, memory clinics and a private hospital were used as recruitment sites. Of those studies that described their sample in enough detail (8 studies) described all the participants as family caregivers with the majority of participants having either a parental or spousal relationship with the person with dementia. The degree of impairment in the family

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members with dementia was varied and not reported in the majority of studies. Five studies reported they had a diagnosis with dementia, one study reported they had a range of different types of dementia and the majority of studies did not report their diagnosis (9). Two studies reported that the family members with dementia had been diagnosed 2-6 years ago, one study reported that they needed 'substantial day to day care', another reported that their level of impairment varied and the majority did not report the stage of dementia or level of impairment (11). The majority of studies did not report whether the family member with dementia was living with their caregiver, living independently or in a residential home (9). Those studies that did report this, four reported a mix of those living with the caregiver and in a residential home, one reported they were community dwelling and one reported they were in a residential home. There was a wide range of different ethnicities of participants including, African-American, Chinese, Vietnamese, Japanese, Pakistani, Indian, Polish, Ukrainian, Hispanic and Latino. All of the studies included family caregivers and in the two studies that referred to paid carers and clinicians, only data from family caregivers was included in the results. 14 of the studies focused on family caregivers who were in late adulthood with one study focusing on a younger sample with a mean age of 19. As the studies were mainly qualitative (14) the sample sizes were small with the largest qualitative sample having 1183 participants (Rodriguez, Kosloski, Kercher, & Montgomery, 2009) and there were 1851 participants in total across the studies.

The designs of studies were overwhelmingly qualitative and cross sectional, with one quantitative correlational study. In terms of qualitative methodology, both grounded theory (Glaser & Strauss, 1967) and phenomenological approaches (Giorgi,

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2009) were used. The interviews conducted with participants ranged from in depth with little structure to semi-structured interviews. In addition, one study used focus groups (Robinson, et al., 2008) and another phone interviews (Werner & Heinik, 2008). The aims of the majority of studies were exploratory and not hypothesis driven. The studies focused on various topics associated with the experience of perceived stigma, including the management of stigma (Blum, 1991; Dobbs, et al., 2008), stigma by association (Werner & Heinik, 2008), barriers to the use of services (Robinson, et al., 2008; Morgan, 2002; Yamamoto & Wallhagen, 1998) and cross cultural factors (Liu, Hinton, Tran, Hinton, & Barker, 2008; Mackenzie, 2006; Hinton, Guo, Hillygus, & Levkoff, 2000).

Methodological Quality

Due to the methodological quality of the retrieved studies being an essential part of the results synthesis, quality checklists previously developed by Harden, (2003) (see also Mays & Pope, 2000; Thomas & Harden, 2008) were adapted and used by the author (DC). This was because the studies retrieved used both quantitative and qualitative designs and no specific quality checklist that had been developed was deemed suitable. The resultant checklist (see appendix B) consisted of 10 criteria for qualitative studies and 8 for quantitative, all focusing on aspects of reporting, sampling and data analysis. Of the articles retrieved only one (Werner, Goldstein, & Buchbinder, 2010) met all 10 of the quality criteria with Blum (1991) meeting the least at 2 out of 10. The average rating of the qualitative studies was 7.6. The criteria most commonly met was criteria one - an adequate and clearly described context (14 studies) and the least met was

criteria 6 - justification of sampling strategy (7 studies) (see appendix C).

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Reports of Perceived stigma

A thematic, meta-synthesis approach based on Ritchie and Spencer (1994) was used to interpret and synthesise the findings of the qualitative studies. This was an approach whereby a framework was developed to aid in defining, mapping, creating typologies, finding associations, seeking explanations and developing new ideas between the studies. This approach was used as it structured the results of the studies in a coherent, systematic and comprehensive manner. The 13 qualitative studies retrieved went through a familiarisation process whereby notes were made by the researcher (DC) regarding main and recurrent issues and themes. A thematic framework was developed from this familiarisation process with reference to the aims of the review. The resultant framework consisted of four main themes; sociocultural aspects, service use and diagnosis, stigma and aging and managing stigma. The sole quantitative study retrieved for the review was analysed separately.

Sociocultural aspects

Three of the studies recruited participants from different cultural groups and explored sociocultural aspects of perceived stigma (Liu, Hinton, Tran, Hinton, & Barker, 2008; Mackenzie, 2006; Hinton, Guo, Hillygus, & Levkoff, 2000). These studies highlighted potential differences across cultural groups in their understanding of dementia, views of 'normal' ageing and the impact of these on perceived stigma (Hinton, Guo, Hillygus, & Levkoff, 2000). Reports from Chinese family caregivers stated that they were not familiar with the diagnosis of Alzheimer's disease and viewed it as an "old age illness"

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(Hinton, Guo, Hillygus, & Levkoff, 2000). Among Chinese family caregivers, some reported that Alzheimer's disease is associated with stigmatised mental illness and results from a 'personal moral failure' (Hinton, Guo, Hillygus, & Levkoff, 2000). This 'personal moral failure' could be linked to a spiritual and religious explanation of mental illness as reported by some South Asian carers, which also carries stigma (Mackenzie, 2006). Some studies indicated that participants felt it was important to hide memory difficulties, to normalise the difficulties and to avoid taking part in research or pursue any sort of diagnosis as this would be stigmatising. (Hinton, Guo, Hillygus, & Levkoff, 2000). This was further supported by the findings of Liu, Hinton, Tran, Hinton, & Barker (2008) who reported that Chinese and Vietnamese family caregiver's experienced perceived stigma and this was associated with their broader views about the causes of dementia. This stigma was based on dementia being seen as a chronic and severe mental illness and that it also reflected negative stereotypes of ageing and the aged. It was further suggested that stigma served as a barrier to using formal services amongst Eastern European family caregivers reporting its impact on engaging with formal and informal support (Mackenzie, 2006). Due to their cultural past, keeping problems within the family and not engaging with 'outside help' was a necessity for survival and violating this social norm would led to feelings of stigma and shame amongst several of the groups studied (e.g. Mackenzie, 2006).

Service use and diagnosis

Several studies indicated that perceived stigma has a negative impact on family caregivers' engagement with services. In rural areas, the stigma associated with

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dementia was seen as a direct and indirect barrier towards the use of formal services (Morgan, 2002). Many family caregivers reported that the perceived stigma was due to dementia's association with mental illness. Stigma was also reported as being a barrier to accessing services because family members often tried to manage the dementia by denying there were any difficulties. Family caregivers' decisions on the use of formal services were also influenced by stigma. For example, Yamamoto & Wallhagen, (1998) studied Japanese family caregivers, and reported that the use of formal services was seen as stigmatising and this was attributed to Japanese culture placing an emphasis on keeping caregiving within the family system. Another study examined attitudes towards the diagnosis of dementia, utilising family caregiver's focus groups (Robinson, et al., 2008). Key themes included the perceived stigma associated with the diagnosis and the futility of a diagnosis and the term itself. Family caregivers reported their relative with dementia not wanting to report their difficulties and General Practitioners (GPs) not wanting to diagnose dementia because of the stigma surrounding the condition. It was suggested that this could also lead to delays in diagnosis, support and intervention (Robinson, et al., 2008).

Stigma and aging

A number of studies suggested that the perceived stigma associated with dementia is also part of a wide ranging stigma felt by those in later life termed ageism. Dobbs et al. (2008) explored stigma in residential care and assisted living communities using ethnographic interviews and observations. It was suggested in this sample that stigma associated with dementia was linked to ageism in long-term care from the responses of questions about daily living in residential care and assisted living. In a sample of

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Vietnamese and Chinese family caregivers perceived stigma in dementia also appeared to reflect negative stereotypes of aging or the aged (Liu, Hinton, Tran, Hinton, & Barker, 2008). Those with dementia were seen as 'old' and this was associated with being 'confused' and having 'aged poorly'. The authors suggested that such views could lead to social distancing and thus the social exclusion of those with dementia. This in turn could be internalised, resulting in those with dementia seeing themselves as having little value and being 'useless'.

Managing stigma

Two studies explored how family caregivers manage perceived stigma (Blum, 1991; Dobbs, et al., 2008). Blum (1991) explored the management of stigma among family caregivers, using in depth interviews. It was suggested that stigma was managed by colluding with the person with dementia being 'in hiding' and disregarding the memory difficulties. This often took the form of normalising the difficulties in terms of old age. It was also reported that stigma was managed by colluding with people outside of the family as the dementia gradually worsened. Dobbs (2008) explored stigma management in a different setting of residential care and assisted living communities. The results indicated that the most prominent barrier to managing stigma was that residential care and assisted living settings were perceived as stigmatising themselves. This was because they were seen as dehumanising environments with numerous rules and regulations impacting negatively on the well-being and sense of independence of people with dementia.

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Quantitative article

One of the articles retrieved had quantitative designs (Rodriguez, Kosloski, Kercher, & Montgomery, 2009) and was analysed separately. Rodriguez, Kosloski, Kercher, & Montgomery (2009) aimed to test whether social embarrassment is a unique component of caregiving distress and whether this varies based on ethnicity. The study had a large sample size of 1183 with 323 hispanic, 320 african american and 540 caucasain participants. Their results suggested that both discreditable and discredited embarrassment had a significant positive relationship with caregiver depression. Those different types of embarrassment were derived from Goffman's (1963) conceptualisation of stigma; discreditable embarrassment relates to perceived embarrassment in public situations with people the carer does not know, whereas discredited embarrassment was in situations with people that the caregiver is acquainted with.

Table 1 Details of the 15 articles reviewed

Author and Year	Aim	Design & Participants	Quality rating	Results/themes
Allen & Oyebode, 2009	To explore the well-being of young people who have a parent with early onset dementia	Qualitative Grounded theory N= 12 Parental relationship=12 Mean age=19	9/10	Five main themes - Damage of dementia - Reconfiguration of relationships - Strain (including stigma) - Caring - Coping
Blum, 1991	To explore the management of	Qualitative	2/10	Stigma managed through:

	stigma perceived by family caregivers of people with Alzheimer's disease	In depth interviews N=34		<ol style="list-style-type: none"> 1. Collusion with the person with Alzheimer's 2. Realignment and collusion with an expanding circle of others
Dobbs, et al., 2008	To explore the stigma and its management of older people living in residential care or assisted living (RC-AL) communities	Qualitative Ethnographic interviews and observations N=309 Residents=153	8/10	<p>Four main themes</p> <ul style="list-style-type: none"> - Ageism in long-term care - Stigma as related to disease and illness - Sociocultural aspects of stigma

		Staff=80			- Residential care or assisted living (RC-AL) as a stigmatising setting
		Family members=76			
Hinton, Guo, Hillygus, & Levkoff, 2000	To explore sociocultural barriers to recruitment for a study of dementia family caregiving with Chinese families.	Qualitative N=not reported Chinese participants	8/10	Four main themes	- difficulties were viewed as part of aging process not a disease - research participation was seen as leading to excessive worry - Alzheimer's disease carries stigma

				- Practitioners viewed research as having no benefit to participants.
Liu, Hinton, Tran, Hinton, & Barker, 2008	To explore the relationship between stigma and dementia with Vietnamese and Chinese family caregivers	Qualitative In depth interviews N=32	8/10	Main themes - Stigma of chronic and severe mental illness - Stigma reflecting negative stereotypes of aging or the aged.
MacRae, 1999	To explore perceived stigma of family caregivers of people with	Qualitative	4/10	The majority of family caregivers perceive stigma with some

	Alzheimer's disease	Semi-structured interviews		reporting not to have experienced stigma and not trying to avoid it. Those that try and manage the stigma use various strategies such as concealment, mediatisation, and condemning those with stigmatising attitudes.
		N=31		
		Spousal relationship=14		
		Parental relationship=7		
Mackenzie, 2006	To develop appropriate support group materials for South Asian and Eastern European family caregivers of people with dementia	Qualitative	9/10	Dementia in different cultural contexts can be operationalized by stigma processes Stigma impacts on the manner in which those family caregivers
		N=21		
		Pakistani caregivers=11		
		Indian caregivers=5		

		Polish caregivers=4		engage with formal and informal support.
		Ukrainian caregivers=1		
Morgan, 2002	To explore barriers to the use of dementia services in rural areas among different stakeholders	Qualitative and quantitative methods N=26	9/10	Eight barriers to the use of formal services including stigma of dementia lack of privacy and lack of awareness.
		Formal caregivers=13		
		Family caregivers=13		
Robinson, et al., 2008	To explore the attitudes of carers of people with dementia towards diagnosis	Qualitative Focus Groups N=101	9/10	The main themes of diagnosis - Stigma and futility - GP's are important but have

	General Practitioners=7			poor diagnostic and
	Community nurses=20			treatment choices
	Home carers=23			- Health professionals
	Residential staff=18			supported a longitudinal
	Aged Care Assessment			diagnostic process
	Team=16			- Family carers who sought a
	Family carers=17			quick diagnosis
Rodriguez, Kosloski, Kercher, & Montgomery, 2009	Hypothesis1. Social embarrassment adds a unique component of distress to	Quantitative Non-experimental	8/8	Social embarrassment has a positive relationship with caregiver depression and does not

	caregivers of Alzheimer's patients	Cross sectional N=1183		significantly vary across cultural groups
	Hypothesis 2. The negativity of embarrassment varies according to caregiver ethnicity	Hispanic=323 African American=320 Caucasian=540		
Shifflett & Blieszner, 1988	1. Does the stigma for Alzheimer's disease fall into the three types Goffman delineates? 2. How does the social support group react to the	Quantitative Longitudinal N=11 Spousal relationship=6	6/10	Stigma in Alzheimer's Disease could be categorised into - Conduct stigma - Tribal stigma

	stigma of Alzheimer's disease?	Parental relationships=5		
	3. What management strategies do social support group members use to cope with the stigma of Alzheimer's disease?			
Werner & Heinik, 2008	To explore four factors of stigma by association—interpersonal interaction, concealment, structural discrimination and	Mixed design Phone Interviews N=61	7/8	Low perceived stigma of family caregivers towards themselves High perceived stigma of family caregivers towards the person

	access to social roles.			with Alzheimer's disease they are caring for
				High perceived structural discrimination towards the family caregiver and the person with Alzheimer's disease
Werner, Goldstein, & Buchbinder, 2010	To explore perceived family stigma reported by children of persons with Alzheimer's disease.	Qualitative N=10 Parental relationship=10	10/10	Three main themes - Caregivers stigma Triggered by the individual with dementia's changes in

				cognition, behaviour and functional ability.
				- Lay public's stigma.
				Fear and disgust attributed to members of the community
				- Structural stigma
				The impact of stigma on wider society
Yamamoto & Wallhagen, 1998	The decision making of family care givers towards the use of formal services	Qualitative Grounded Theory	9/10	Stigma impacted on the use of formal services as caregiving was seen as being part of the family

		N=26		system. Stigma was a key part of the three main themes
		Parental relationship=26		<ul style="list-style-type: none"> - the availability of services; - their authority level within the family; - Whether or not they could justify their tolerance limit
Zhan, 2004	To explore Chinese American family caregivers' experiences of caring for someone with Alzheimer's Disease	Qualitative In-depth interviews N=4	9/10	<p>Main theme</p> <ul style="list-style-type: none"> - Structural and ethno-cultural barriers such as language, knowledge,

Parental=3

culturally insensitive

Other=1

services

Discussion

The results of the present review indicated four main themes of stigma amongst dementia caregivers, sociocultural aspects, service use and diagnosis, stigma and aging and managing stigma. In the sociocultural theme, views and attributions of dementia are influenced by different aspects of culture which then appear to contribute to perceived stigma in family caregivers. Different cultural groups seem to manage this stigma in different ways, including seeing it as part of normal aging, concealment, 'old timers disease' or 'craziness' and for some cultural groups there was not an equivalent word for 'dementia' in their language (Hinton, Guo, Hillygus, & Levkoff, 2000; Zhan, 2004). This suggests that dementia may not be recognised or experienced in the same way as in Western-European cultures.

A second theme from the results was the relationship between perceived stigma and service use. The way family caregivers manage perceived stigma appears to influence the ways in which they use services (Yamamoto & Wallhagen, 1998; Morgan, 2002; Robinson, et al., 2008). A common way of managing stigma was through concealment, as conceptualised by Angermeyer, Schultze, & Dietrich (2003), who defined this as the second dimension of stigma by association. As stigma was commonly managed by normalising the difficulties this contributed to family caregivers not seeking a diagnosis (Robinson, et al., 2008) and not engaging with support services.

Another theme suggested that perceived stigma may relate to a broader theme of ageism. Some results indicate that ageism in dementia can lead to people with dementia not being involved in care decisions (e.g. Dobbs, et al., 2008). This could be interpreted

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as part of a third dimension of stigma by association; structural discrimination (Angermeyer, Schultze, & Dietrich, 2003).

Overall the results suggest that family caregivers experience perceived stigma and the management of this can impact on their interaction with services. The results also partially support Angermeyer, Schultze, & Dietrich's (2003) definition of courtesy stigma with the concealment of difficulties in terms of managing stigma and structural discrimination in terms of ageism. Based on the results of this literature review and from existing literature, illustrated in figure two is a provisional model of perceived stigma in family caregivers of people with dementia. Part one of the present model follows the model developed by Burgener & Berger, (2008) of perceived stigma in people with dementia with an additional predisposing factor of western cultural values (Herskovits & Mitteness, 1994). Part two of the present model is an original development that focuses on perceived stigma in family caregivers of people with dementia.

Part one of the present model follows the Burgener & Berger, (2008) model with numerous predisposing factors aiding in developing perceived stigma in people with dementia. Dementia having a possible genetic component may be a predisposing factor to perceived stigma due to unsupported ideas that it could be passed from person to person (Holston, 2005) along with ageist stigmatising attitudes (Clarke, 2005) and mental impairment (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Additionally to Burgener & Berger (2008), the present model also proposes that not meeting western cultural values of productivity, self-control and mastery (Herskovits & Mitteness, 1994) may be a predisposing factor.

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Following the Burgener & Berger, (2008) model, the present model explains perceived stigma in people with dementia using the four mechanisms of social rejection, financial insecurity, internalised shame and isolation. The perceived stigma could then lead to psychological difficulties with self-esteem and low mood/affect.

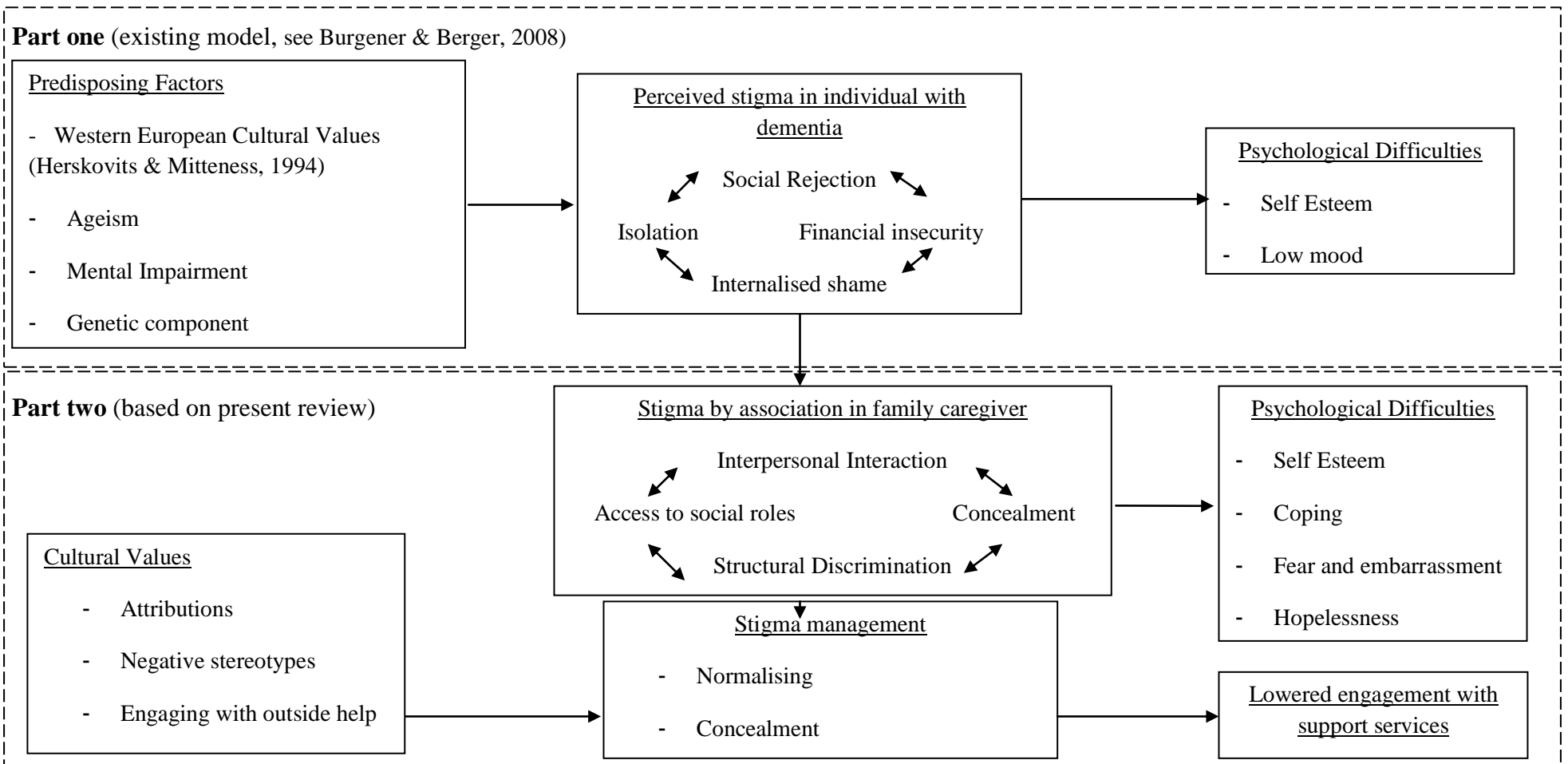
Part two of the model focuses on perceived stigma in family caregivers developed from the results of the present review and is an additional development from the Burgener & Berger (2008) model. Studies have suggested that family caregivers of people with dementia can also feel stigmatised as the perceived stigma from the person with dementia is also shared by them. This has been termed ‘courtesy stigma’ or ‘stigma by association’ (Werner & Heinik, 2008). In the present model, stigma by association in family caregivers is understood in the context of four factors: interpersonal interaction, concealment of the difficulties, structural discrimination and performing of social roles (Angermeyer, Schultze, & Dietrich’s, 2003). Research has suggested stigma by association could contribute to psychological difficulties including low self esteem (Byrne, 2001), difficulties in coping (Ostman & Kjelin, 2002), fear and embarrassment (MacRae, 1999) and hopelessness (Phelan, Bromer, & Link, 1998) in family caregivers.

Finally, the present model suggests that the management of stigma by association can lead to difficulties engaging with services. This is because trying to manage the stigma either by normalising memory difficulties or by concealment could lead to a diagnosis not being sought and engagement with services being hindered due to the shame and stigma that the family caregiver may feel. The management of stigma is also heavily influenced by the family caregiver’s cultural values regarding the attributions of mental illness as a ‘personal moral failure’ (Hinton, Guo, Hillygus, &

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Levkoff, 2000), negative stereotypes of ageing and the aged (Liu, Hinton, Tran, Hinton, & Barker, 2008) and keeping problems in the family (Mackenzie, 2006). It can also be hypothesised that lower engagement with support services could contribute to greater psychological difficulties.

Figure 2. Proposed model of stigma by association amongst family caregivers in dementia



The weak points of this model are that it does not account for how perceived stigma in both the person with dementia and their caregiver may change as the dementia progresses. This is important as the methods of managing stigma and the psychological difficulties could alter as the individual with dementia begins to lose insight and their functioning becomes further impaired. Additional weak points focus on the mechanisms involved between stigma and the development of psychological difficulties and between perceived stigma in the person with dementia and stigma by association. It is not clear what, if any additional mediating or moderating factors play a role in those relationships. As this is a provisional model based almost entirely on qualitative research, further empirical testing is needed to test those relationships proposed. The most essential of those relationships is between perceived stigma in the person with dementia compared to perceived stigma in the family caregiver (stigma by association). The proposed model could also benefit from further research into intervention studies aimed at reducing and managing stigma individually and systemically.

This review has some limitations, relating both to the searching and synthesising of the studies and methodological quality of the studies included. The term 'stigma' used as a search term for the initial database searches led to large numbers of studies being discarded as they focused on stigmatising attitudes of others and not perceived stigma. Using the search term 'perceived stigma' instead was considered but this could have yielded only a small number of articles and relevant studies could have been missed. A further limitation is the relatively small number of retrieved articles (15

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studies) and their heterogeneity in designs that were qualitative for the vast majority (14 studies).

Articles included in the review appeared in a peer-reviewed publications as this ensured included studies would have high scientific quality. Others have suggested that this may not be the case (Goldbeck-Wood, 1999; Ware, 2008) as there is some debate as to whether peer review is effective in ensuring the quality of articles published (Jefferson, Rudin, Bridney Folse, & Davidoff, 2007). Studies have shown that it can be unreliable (Rothwell & Martyn, 2000) and that errors in the articles submitted may not be recognised (Godlee, Gale, & Martyn, 1998).

A further limitation relates to the methodological quality of the included studies. A specific issue is with the sampling of participants, as 8 out of the 15 included articles did not justify their sampling strategy. This has an impact on generalising a study's results to the dementia family caregiver population. Another issue is that 14 out of the 15 articles retrieved were qualitative and concerned with hypothesis generating rather than hypothesis testing. This is a limitation because the findings of the included studies have not been empirically tested and may not be reliable as the results could differ when the hypotheses are tested on a larger sample of participants.

A strength of the present review is that it offers an integrated understanding of family caregivers' experiences of perceived stigma, taking into account cross-cultural factors. The review highlights the ways in which caregivers might experience stigma and that it is possible to conceptualise this as stigma by association, which can have a negative impact on aspects of their well-being, for example their self esteem. The results are also important as they aid our understanding of the development of perceived

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stigma in dementia as relating in part at least to ageism. The review highlights the impact of cultural values on the ways in which family caregivers manage stigma, by means of normalising the difficulties and colluding with the person with dementia.

Clinically, the findings of this review could help clinicians become more aware of how stigma may affect family caregivers as well as the person with dementia. The findings and provisional model of stigma by association in dementia could help in the development and practice of psychosocial interventions for family and spousal caregivers. At a service level the review highlights how perceived stigma can act as a powerful barrier in accessing and engaging with health and social care services. This implies that services and agencies involved in dementia care should direct efforts towards reducing stigma towards dementia in local communities. This could be done through media campaigns that help inform the public by giving accurate and balanced information on dementia and the issues associated with it. Other initiatives could include training and resources available for GP's, social services and other professional groups, and the setting up of networks and support groups for people with dementia and their carers.

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Part two: Empirical Paper

Hope, perceived stigma and quality of life in later life and in early stage
dementia

This paper is written in the format ready for submission to *Aging and
Mental Health*.

Please see appendix A for author guidelines

Word Count: 5331 (Excluding headings, tables, figures and references)

**Hope, perceived stigma and quality of life in later life and in early
stage dementia**

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Abbreviated title: Hope, stigma and quality of life in dementia

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Hope, perceived stigma and quality of life in later life and in early stage dementia

Abstract

Title of manuscript: Hope, perceived stigma and quality of life in later life and in early stage dementia

Name of Journal: Aging & Mental Health

Objectives: The first aim of this study was to explore hope in older people with early stage dementia by measuring their levels of goal directed hope and multi-dimensional hope and comparing this to older people without dementia. The second aim was to examine perceived stigma as a mediating factor between multi-dimensional hope and quality of life in older people with early stage dementia.

Method: The sample comprised of 60 older people without dementia (group one) and 40 older people with early stage dementia (group two). Both groups completed the Snyder Adult Hope Scale and the Herth Hope Index and group two additionally completed the Stigma Impact Scale and the Quality of Life in Alzheimer's disease scale.

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Results: Results showed people with dementia had significantly lower hope and that dementia could have a significantly greater impact on goal directed hope and that perceived stigma was not significantly a mediating factor.

Conclusion: Older people with early stage dementia experience multi-dimensional hope and other psychosocial issues associated with dementia could be a barrier towards hope. Implications for services and further research are discussed.

Keywords: hope; dementia; stigma; quality of life

Introduction

There are an estimated 24 million people globally living with dementia and this is set to rise to 80 million by 2040 (Alzheimer's Disease International, 2007). The expense of caring for those with dementia in the United Kingdom is 17 billion pounds per year (Department of Health, 2008) and in 30 years this is estimated to treble to over 50 billion (Comas-Herrera, Wittenberg, Pickard, & Knapp, 2007). As there is currently no cure for dementia, the focus of care remains on helping people with dementia maintain an optimum quality of life, as highlighted by the National Dementia Strategy in England (Department of Health, 2008).

The term quality of life is used in dementia care to operationalise personal well-being and because dementia can impact on many areas of functioning, the construct of quality of life is more suitable than specific constructs such as coping (Clare, 2002). There is no clear definition of quality of life in dementia (Lawton, 1991; Bond, 1999), although there is a consensus that it is multi-dimensional and subjective in nature, as it is based on an individual's lived experiences, beliefs and values (Selai & Trimble, 1999; Lawton, 1991; Bond, Gregson, & Atkinson, 1989). Quality of life is regularly used as an outcome measure for psychosocial interventions such as support groups (Coaten, 2002; Yale, 1995), reminiscence therapies (Kunz, 2002), life reviews (Kiernat, 1979), and behavioural approaches (Horgas, Wahl, & Baltes, 1996). Given its importance in dementia care, research is needed to understand what factors may improve and maintain an optimum quality of life in this client group.

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One factor emerging within the literature that may contribute to both quality of life and effective psychological interventions with older people with and without dementia is hope (Bergin & Walsh, 2005; Babits, 2001; Yalom, 1989). Hope emerged from the field of positive psychology and like quality of life, it is widely recognised to be a multi-faceted construct; there are currently 49 different empirical definitions with 32 different psychometric measures of hope (see Schrank, Stanghellini, & Slade, 2008).

There are two prominent and contrasting theories of hope, Snyder's Hope Theory assessed using the Snyder Adult Hope Scale (Snyder et al. 1991), and the Multi-dimensional account of Hope (Dufault & Martocchio, 1985), assessed using the Herth Hope Index (Herth, 1992) and both measures have strong psychometric properties (Schrank, Stanghellini, & Slade, 2008). Snyder's Hope Theory (Snyder et al. 1991) defines hope as a goal driven cognitive process that consists of two components; agency and pathways. Agency relates to goal-directed motivation and pathways represents the cognitive planning of ways to meet those goals. Dufault and Martocchio define hope as 'a multi-dimensional life force that is characterised by a confident yet uncertain expectation of achieving a future good' (Dufault & Martocchio, 1985, p. 380). Hope is conceptualised as having two spheres; generalised and particularised - with six common dimensions; cognitive and temporal, affective and behavioural, affiliative and contextual. Generalised hope is described as 'an intangible umbrella that protects hoping persons by casting a positive glow on life' (Dufault & Martocchio, 1985, p. 380) and particularised hope is concerned with a specific valued goal or outcome.

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Both multi-dimensional and goal directed hope have been investigated in other chronic health conditions. Goal directed hope has been associated with outcomes and adjustment in chronic conditions such as visual impairment (Jackson, Taylor, Palmatier, Elliot, & Elliot, 1998) breast cancer, (Irving, Snyder, & Crowson, 1998) and with severe physical disabilities, (Elliott, Witty, Herrick, & Hoffman, 1991). Multi-dimensional hope has been investigated with newly diagnosed cancer patients (Rustoen & Wiklund, 2000), advanced cancer patients (McClement & Chochinov, 2008) pain (Mei-Ling, 2003) and heart transplant patients (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003). In such studies, hope is consistently identified as an important resource in helping people maintain an optimum quality of life.

In addition to hope maintaining and improving quality of life in chronic health conditions, both generalised and goal directed hope have been investigated in old age. Research has indicated that older people have fewer explicit individual goals (Morse & Doberneck, 1995; Farran, Salloway, & Clark, 1990) with an increased on 'world related goals' (Nurmi, 1992) and goals that are emotionally and intrinsically meaningful (Carstensen, Isaacowitz, & Charles, 1999; Sheldon & Kasser, 2001). Those type of goals can be linked to Erikson's stages of psychosocial development with the social focus on human kind in later life (Erikson, 1982), personality development (Jung, 1960) and the socio-emotional selectivity theory (Lockenhoff & Carstensen, 2004). Wolverson, Clarke, & Moniz-Cook, (2010) suggested that as time is limited in later life and energy may be depleted, some goals may be no longer attainable. As such older people may experience hope in a range of different ways and hope is more likely to be

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multi-dimensional. Furthermore, as older people with early stage dementia may have difficulties with verbal memory, speech production, comprehension and sometimes executive functioning (Huff, Becker, Belle, & Nebes, 1987; Lezak, 1995) they may find planning to achieve goals difficult and so may experience hope as less goal directed compared to older people without dementia. Further to this, dementia is also likely to have a greater impact on the pathway component of goal directed hope, as this is concerned with planning to try and achieve goals.

Although both goal directed and multi-dimensional hope have been positively associated with quality of life in health conditions and with older people, there has been limited research exploring hope in dementia. One possible reason for this paucity in research may be that people with dementia are often assumed to lack awareness, or that hope could be viewed as the result of denial (Steeman, Godderis, Grypdonck, & De Bal, 2007). However, in the past 10 years this has begun to change, with the emergence of qualitative studies documenting hope in those with dementia and their caregivers (Wolverson, Clarke, & Moniz-Cook, 2010; Clare, 2002; Woods, 2007; Duggleby, Willimas, Wright, & Bollinger, 2009). Reviewing this literature using a concept analysis (Walker & Avant, 2005), Cotter (2009) suggested that hope in early stage dementia consists of, (1) hope in the experience of loss and ongoing adjustment; (2) future orientation of hope; (3) hope and social identity and social network; and (4) hope and adaptation to daily living. In addition to those key domains, Wolverson, et al., (2010) suggested that older people with dementia could experience hope differently compared to older people without dementia because of the varied psychosocial issues

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associated with dementia such as the care they receive (Hulme, Wright, Crocker, Oluboyede, & House, 2010), their physical health (Cook, Niven, & Downs, 1999) and their level of social interaction (Kolanowski & Litaker, 2006). These psychosocial issues could also represent a ‘barrier’ to quality of life in dementia and consequently may have a negative impact on hope. Perceived stigma is likely to be one such barrier (Warner, Milne, & Peet, 2010).

Stigma can be defined as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p.3). The concept of stigma has been developed from the work of Goffman (1963) and modified labelling theory (Link, Struening, Cullen, Shrout, & Donrhenwend, 1989). Research has suggested that people with dementia experience perceived stigma (Burgener & Berger, 2008) and Kitwood (1990) suggested that this is an element of a ‘malignant social psychology’ in dementia that can depersonalize people with dementia and that this is influenced by a negative social discourse that surrounds the condition. Media representations invariably focus on the debilitating aspects of dementia in terms of having a diagnosis and the effects of caring for someone with the condition (Harris & Keady, 2008). Dementia is often portrayed as akin to ‘social death’ (George, 2010) and can lead to a climate of fear around the diagnosis (Moniz-Cook, 2006). This negative social discourse regarding dementia is perhaps influenced by a dominant deterministic medical model which emphasises neurological aspects of the condition rather than a person’s actual lived experience (Keightley & Mitchell, 2004; Kirkman, 2006).

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Links between stigma, hope and quality of life have been explored in relation to other chronic health conditions such as epilepsy, where it has been suggested that internalised stigma can lead to feelings of hopelessness (Smith, Ferguson, Saunders, Wagner, Wannamaker & Selassie, 2009). Graves (2009) proposed that levels of stigma and hope are significant predictors of quality of life in African-American women diagnosed with HIV/AIDS. This relationship has also been researched in relation to mental health problems; for example, recovery in schizophrenia spectrum disorders is thought to be mediated by the impact of internalised stigma on hope and self-esteem (Yanos, Roe, Markus, & Lysaker, 2008). To date, however, the relationships between perceived stigma, hope and quality of life in dementia have not been examined.

On the basis of the literature described above, the first aim of this study was to further explore how older people living with dementia might experience hope by measuring it from two different conceptual backgrounds; Snyder's theory of hope (Snyder, et al., 1991) and Dufault & Martocchio's multi-dimensional theory of hope (Dufault & Martocchio, 1985) and comparing reported levels of hope to that reported by older people without dementia.

The hypotheses relating to this first aim (Part 1) of the study were:

- (1) There will be a significant correlation between measurements of goal directed and multi-dimensional hope in both older people and older people with dementia
- (2) Older people with dementia will report lower levels of hope compared to older people without dementia
- (3) There will be higher levels of multi-dimensional hope compared to goal directed hope in older people with dementia compared to the differences in the older people without dementia
- (4) Older people with dementia will have lower levels of the pathway component of goal directed hope compared to older people without dementia.

The second aim of the study was to examine the extent to which perceived stigma acts as a potential mediating factor between multi-dimensional hope and quality of life in people living with dementia.

The hypotheses for the second aim (Part 2) of the study were:

- (1) High levels of perceived stigma will be predictive of lower levels of quality of life in older people with dementia
- (2) High levels of multi-dimensional hope will be predictive of higher levels of quality of life in older people with dementia
- (3) Levels of perceived stigma will mediate the relationship between multi-dimensional hope and quality of life in dementia

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Method

Design

The study took a quantitative approach using a non-experimental cross sectional design with self report measures. For part one of the study the two dependent variables were goal directed hope (total goal directed hope) and multi-dimensional hope (total global hope). For part two, the independent variable was multi-dimensional hope, the mediator variable was perceived stigma (stigma impact scale) and the dependent variable was quality of life.

Participants

Group 1: Community dwelling older people without dementia

Sixty older people (*modal age range=71-75*) were recruited from various community and voluntary sector groups for older people. The inclusion criteria included people aged over 60 years with sufficient fluency in English to read questionnaires. Excluded were those with a self-reported diagnosis of dementia or self-reported severe mental health problems.

Group 2: Community dwelling older people with early stage dementia

Forty older people (*modal age range=76-80*) were recruited via NHS services and the Alzheimer's Society in the north of England. Participants were referred into the study and invited to take part if they met the following inclusion criteria:

- (1) A diagnosis of dementia according to the Diagnostic and Statistical Manual of Mental Disorders-fourth edition (DSM-fourth edition)

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- (2) A score of 18 or above on the Mini-Mental State Exam (Folstein & McHugh, 1975)
- (3) Had capacity to give consent to participate in the research study (as determined by referring clinicians)
- (4) Had been informed and were aware of their diagnosis when taking part in the study (determined when the participant completed the demographic form)
- (5) There was a minimum of two months since dementia diagnosis, as the potential effects of receiving a diagnosis of dementia were not being investigated
- (6) Sufficient fluency in English to read and respond to self-report questionnaires.

Excluded were those with self-reported severe mental health problems.

Procedure

Before the study commenced ethical approval was sought and granted from the NHS National Research Ethics Service and the NHS Research & Development department.

Group 1: Community dwelling older people without dementia.

Participants were approached to take part in the study informally in community and voluntary groups the study was explained both verbally and using a written information sheet and the exclusion and inclusion criteria were applied (this is also contained in the information sheet provided to participants). When people expressed an interest in taking part, their written consent was requested. Participants individually completed two scales, the Snyder Adult Hope Scale and the Herth Hope Index. The researcher was available to respond to any difficulties the participants had experienced in completing the scales. Following this, participants were thanked and given a de-brief slip.

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Group 2: Community dwelling older people with early stage dementia.

Participants were approached by their known clinicians (e.g. community mental health nurses), given an information sheet about the study and asked if they would consider taking part. Once their consent had been gained, participants completed the demographic form and all four scales, the Snyder Adult Hope Scale, the Herth Hope Index, the Stigma Impact Scale and the Quality of Life in Alzheimer's disease questionnaire in a semi-structured interview format with the researcher. Following this, participants were thanked and given a de-brief slip.

Measures

Snyder Adult Hope Scale (Snyder, et al., 1991).

The Snyder Hope Scale is a self-report measure of goal directed hope where respondents are asked to rate 12 different statements on a four point likert-type scale ranging from 1 (definitely false) to 4 (definitely true). There are four filler items, four items that measure a factor termed 'agency' (goal directed motivation and determination) and four items that measure a factor termed 'pathway's' (cognitive planning to meet goals). There are two subscale scores, the agency score and the pathway score, with their sum being the total hope score. The Snyder Hope Scale's internal consistency ranges from cronbach's alphas of 0.74 to 0.76 and it has shown good test-retest reliability over a 10 week period of 0.82 $p < 0.001$ with a sample of 133 (Yoshinobu, 1989) . It has been shown to have good divergent validity of -0.51 $p < 0.005$ with the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974) and convergent validity of 0.60 $p < 0.005$ with a measure of optimism, the Life Orientation

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Test (Scheier & Carver, 1985) and $0.58 p < 0.005$ with the Rosenberg Self-Esteem Scale (Gibb, 1990).

Herth Hope Index (Herth, 1992).

The Herth Hope Index is a self-report measure that asks participants to rate 12 different statements about generalised and particularised hope. Responses are measured on a four point likert-type scale, ranging from 1= strongly disagree to 4=strongly agree.

There are three subscales; temporality and future (particularised hope), positive readiness and expectancy (particularised hope) and interconnectedness (generalised hope), their sum giving a total global hope score (multi-dimensional hope). The Herth Hope Index has a very good two week test-retest reliability of $0.91 p < 0.001$ and divergent validity of $-0.73 p < 0.005$ with the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974). It had convergent validity of $0.81 p < 0.005$ with the Nowotny Hope Scale (Nowotny, 1989) and $0.84 p < 0.005$ with the Existential Well-Being Scale (Paloutzian & Ellison, 1982).

Stigma Impact Scale (SIS) (Fife & Wright, 2000).

The SIS is a self-report measure of perceived stigma with each participant asked to rate 24 statements on a five point likert-type scale ranging from 0 (not applicable) to 5 (strongly agree). It consists of four subscales, social rejection (nine items), financial insecurity (three items), internalized shame (five items), and social isolation (seven items) and gives a total score. This is the only available measure of perceived stigma that had been used to measure perceived stigma in older people with early stage dementia (Burgener & Berger, 2008). It has convergent validity of $0.64 p < 0.01$ with the

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Geriatric Depression Scale (Lyness, Noel, Cox, King, Conwell & Caine, 1997) measure of depression and divergent validity of -0.40 $p < 0.05$ with the Rosenberg's Self-Esteem Scale (RSS) (Rosenberg, 1979) and it has reliability of an alpha value of 0.89 (Burgener & Berger, 2008).

Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon, Gibbons, McCurry, & Teri, 1999)

The QoL-AD is a dementia specific measure of quality of life completed by participants in an interview format. Each participant rates 13 items on a four point likert -type scale ranging from poor to excellent. It is used widely internationally (Thorgrimsen, et al. 2003) and has fared well in quality ratings (Moniz-Cook, et al., 2008; Ettema, Droes, de Lange, Mellenberg, & Ribbe, 2005). It has convergent validity with measures of functional ability, mood and pleasant events (Logsdon, et al., 1999) and it has test-retest reliability is 0.76 over one week and internal consistency from 0.83-0.90 (Logsdon, et al., 1999).

Results

Part 1 - Exploring how older people living with and without dementia experience hope

Hypothesis one

The Herth Hope Index and Snyder Hope Scale were analysed using Pearson's r bivariate correlation coefficients to test whether there was a significant correlation between measurements of goal directed and multi-dimensional hope in both groups.

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There was a medium positive correlation between the measures of multi-dimensional and goal directed hope, $r = 0.47$, $n = 100$, $p < 0.01$. This indicated that high levels of multi-dimensional hope are associated with higher levels of goal directed hope and supports this hypothesis.

Hypothesis two

The mean and standard deviations for the Herth Hope Index Scale, the Snyder Hope Scale, the Stigma Impact Scale and the Quality of Life-AD scale for both groups of participants are shown in Table 1 and the data analysis was performed using SPSS version 16.0 (SPSS, 2008). The results suggest that older people have similar levels of hope compared to the general population, with a mean total global hope score (multi-dimensional hope) is 37.88, which compares to a mean of 36.7 in the general older people population (Wahl, et al., 2004) and the mean total goal directed hope score is 24.85 compared to an average hope score of approximately 24.00 for college and non-college student samples (Lopez, Ciarlelli, Coffman, Stone, & Wyatt, 2000) and 22.60 for those in psychological treatment (Snyder, et al., 1991).

Table 1 Descriptive statistics³

³ Community dwelling older people and older people with early stage dementia mean scores and standard deviation for the scales they completed

	Group			
	Community Dwelling		Early Stage Dementia	
	Mean	S.D	Mean	S.D
Herth Hope Index				
Temporality and Future	12.58	2.14	10.55	1.84
Positive readiness and expectancy	12.80	2.15	12.22	1.60
Interconnectedness	12.50	2.24	12.27	2.15
Total Global Hope (multi- dimensional hope)	37.88	5.46	35.50	3.05
Snyder Hope Scale				
Agency	12.50	1.83	12.05	1.34
Pathways	12.40	1.44	10.32	2.55
Total Goal Directed Hope	24.85	3.04	22.28	3.50

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Hypothesis three

An independent t-test showed a significant difference in the mean total goal directed hope scores for the community dwelling group ($M=24.85$, $SD=3.04$) and the dementia group, $M=22.28$, $SD=3.46$; $t(98) = 3.93$, $P=0.000$. The effect size between the scores was large at $D= 0.80$ (Cohen, 1988, pp. 284-7). An independent t-test showed a significant difference in the global hope (multi-dimensional hope) mean scores for the community dwelling group ($M=37.88$, $SD=5.46$) and the early stage dementia group, $M=35.50$, $SD=3.05$; $t(95.48) = 2.80$, $P=0.006$. The effect size between the means was moderate at $D=0.51$ (Cohen, 1988, P. 22). These results imply that older people without dementia are significantly more hopeful than those with dementia.

The 95% confidence interval for the effect size of total goal directed hope was (0.38, 1.21) and was (0.10, 0.92) for total global hope (multi-dimensional hope). The 95% confidence intervals for the effect sizes were calculated using the MBESS package within R Version 2.11.0 for Windows (Kelley & Lai, 2010; R Development Core Team, 2010). As the two confidence intervals overlap, the difference between the effect sizes is not statistically significant. Nevertheless, the higher observed effect size for total goal directed hope is consistent with the hypothesis that dementia has a greater impact on goal directed hope.

Hypothesis four

Further exploratory data analysis was conducted to identify whether dementia might have a greater negative impact on the agency or pathway subscale scores of the

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Snyder Hope Scale. An independent t-test showed that the difference between the community dwelling group ($M=12.50$, $SD=1.83$) and the early stage dementia group, ($M=12.05$, $SD=1.34$; $t(97)=1.42$, $P=0.159$) agency scores were not significant.

However, an independent t-test showed a significant difference in the mean pathway scores for the community dwelling group ($M=12.40$, $SD=1.44$) and the early stage dementia group, ($M=10.32$, $SD=2.55$; $t(55)=4.68$, $P<0.000$). The effect size between the means was moderate at $D=0.54$ (Cohen, 1988, P. 22). These results indicate that dementia has a greater negative impact on levels of the pathway component of goal directed hope, (i.e the cognitive planning needed to try and achieve their goals) and this is consistent with the hypothesis that older people with dementia will have lower levels of the pathway component of goal directed hope.

Part 2 - Examining perceived stigma as a potential mediating factor between multi-dimensional hope and quality of life in older people living with dementia.

Mean scores on the SIS and QoL-AD for the early stage dementia group were 43.12, ($SD=4.40$) and 37.55, ($SD=4.15$) respectively. The mediational analysis used was based Baron & Kenny's (1986) mediator model. This tested the hypothesis that perceived stigma mediates any association between the independent variable multi-dimensional hope and the dependent variable, quality of life.

Hypothesis one and two

Regression analyses showed that the effect of multi-dimensional hope on perceived stigma was negative and approaching statistical significance ($B=-0.19$, $SE=0.108$, $p<0.085$), between multi-dimensional hope and quality of life was positive and significant ($B=0.663$, $SE=0.193$, $p<0.001$) and between perceived stigma and quality of life was negative but not significant ($B=-0.214$, $SE=0.149$, $p<0.159$).

Hypothesis three

The results of regression analyses suggest that perceived stigma is not a mediating factor between multi-dimensional hope and quality of life. According to Baron & Kenny (1986), perceived stigma violates criteria one and three of the three criteria needed to be a mediating variable. Criteria 1-variations in multi-dimensional hope do not significantly predict variations in perceived stigma, criteria 2-varitions in multi-dimensional hope significantly predict variations in quality of life and criteria 3-when criteria 1 and 2 are controlled, previously significant relationships between perceived stigma and quality of life are no longer significant. This refutes the hypothesis that perceived stigma is a mediating factor between multi-dimensional hope and quality of life.

Discussion

The results of part 1 of this study appear to support the hypothesis that older people with dementia generally experience lower levels of hope compared to older people without dementia. This is consistent with the idea that psychosocial difficulties

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associated with dementia could act as a 'barrier' towards hope. Although the differences in hope scores between the two groups are significant, the actual differences between the two groups are small, indicating they may not be clinically meaningful. A possible explanation for this is the dementia group may not be entirely representative of this population as they were largely recruited from a memory clinic that was offering psychosocial interventions that were likely to foster hope.

The results of part 1 also suggest that older people with dementia have higher levels of multi-dimensional hope and have lower levels of the pathway component of goal directed hope. These results may be explained by the individual difficulties associated with dementia. People with early stage dementia can have difficulties with verbal memory, commonly followed by impairments in speech production and executive functioning (Huff, Becker, Belle, & Nebes, 1987; Lezak, 1995). Impairments in executive functioning could impact on pathways, the planning needed to meet personal goals (Snyder et al. 1991). Furthermore, studies have indicated that older people have different goals (Morse & Doberneck, 1995; Farran, Salloway, & Clark, 1990). Less emphasis may be placed on specific individualistic goals with more emphasis on emotionally meaningful (Carstensen, Isaacowitz, & Charles, 1999), intrinsically meaningful (Sheldon & Kasser, 2001) and world related (Nurmi, 1992) goals. Authors such as Erikson, (1982) and (Jung, 1960) have suggested this is part of personality and lifespan development.

The regression analysis for part two of the study indicates that perceived stigma is not a mediating factor. A possible explanation for this finding is the relationship

between multi-dimensional hope, perceived stigma and quality of life could be more
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complex than was hypothesised. It is possible that other psychosocial factors associated with dementia could be mediator variables instead of, or in addition to perceived stigma. Those could be their level of social interaction (Kolanowski & Litaker, 2006), the care and support they are receiving (Hulme, Wright, Crocker, Oluboyede, & House, 2010) and their physical health (Cook, Niven, & Downs, 1999). Another possible explanation is that as participants were recruited from a memory clinic they may experience less perceived stigma as reducing stigma is an aim of memory clinics. In addition, studies have indicated those experiencing perceived stigma are less likely to take part in research (Connell, Shaw, Holmes, & Foster, 2001; Woodall, Morgan, Sloan, & Howard, 2010) leading to a sampling bias.

Nevertheless, the results of part 2 are consistent with the hypothesis that levels of multi-dimensional hope predict levels of quality of life. This suggestion supports the conclusions from previous studies that found balancing intrinsic hope and realism could lead to positive attitudes to aging (Wolverson, et al., 2010). This means balancing hopeful beliefs, such as wishing for a better future with the present difficulties they are experiencing, such as the decline in cognitive functioning. Other studies and personal accounts suggested the value of humour and hope (Snyder, 2001) in enabling people with dementia to be less fearful about the future (Fridell, 2001), in accepting adjusting and coping with the condition (Clare, 2002) and their diagnosis (Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2004) and as part of personal spirituality in generating meaning in dementia (Snyder, 2003).

The present study had methodological limitations relating to both the first and second aims of the study. This study was the first to quantify levels and type of hope in

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older people with dementia and the Herth Hope Index and the Snyder Hope Scale had not been used with this population before. As such there were some difficulties administering the questionnaires. In the Herth Hope Index (Herth, 1992), item 4, “I can see a light in a tunnel” commonly needed further clarification as did item 6, “I can think of many ways to get the things in life that are most important to me” in the Snyder Hope Scale (Snyder, et al., 1991). It would have been pertinent to conduct a pilot study of the scales before commencing with the study as this could have led to a re-wording of some of the items.

Further limitations relate to the sample of participants used. The sample may be biased as the majority of participants were recruited from a memory clinic that offers psychosocial interventions. Therefore, the participants may have experienced less perceived stigma and more hope than those who may not access such services. As there were precise inclusion and exclusion criteria for the dementia group it was difficult to ascertain a larger and more representative sample of participants and a larger sample may have led to some findings reaching statistical significance.

It is also important to consider whether participants responded to the scale items in a socially desirable way. As some studies have suggested that older people may respond in a socially desirable manner due to elevated levels of conscientiousness and agreeableness (Stober, 2001; McCrae, Costa, de Lima, Simoes, Ostendorf, Abgleitmer, 1999). Furthermore, the responses to the items may not be accurate or valid. This is because there is still some debate as to whether people with dementia have the insight to give an accurate and valid portrayal of their lived experience (Bedard, 2003; Steeman,

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Godderis, Grypdonck, De Bal, 2007) although many studies suggest that they can (see; Radbourne, Clarke, Moniz-Cook, Wilkinson, & Tredinick, 2006).

There are numerous theories and measures of hope (see Schrank, Stanghellini, & Slade, 2008) but this is the first study of its kind to measure hope in older people with early stage dementia. It provides some support for that hope is experienced as a multi-dimensional construct and not as a single goal directed process. The findings of the present study also lend support to conclusions from other studies that older people with early stage dementia do experience some degree of hope (Wolverson, Clarke, & Moniz-Cook, 2010; Spector & Orrell, 2006; Clare, 2002; Fridell, 2001; Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2004; Snyder, 2001; Snyder, 2003) and that their level of hope appears comparable to people with chronic health conditions (Rustoen & Wiklund, 2000; McClement & Chochinov, 2008; Mei-Ling, 2003; Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003). Research such as this may help to challenge the negative social discourses that surround dementia as people with early stage dementia can be hopeful and maintain an optimum quality of life.

The findings of the present study suggest that a model of hope in early stage dementia could be developed as there is a growing body of research that has investigated hope in dementia. A model should be developed as it could be a useful framework to explain hope in dementia to the person with dementia and their family. Thus, it is useful knowing that hope is more likely to be multi-dimensional within this cohort. It could also inform residential care staff and wider society that those with dementia can experience hope. Furthermore, it may help focus future research and help target specific psychosocial interventions to foster hope. The model would need to

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explain the origins of hope in this population, potential barriers towards hope, the nature or type of hope, hope and adjustment and its relationship with quality of life.

There could be many possible factors included in the model starting with the awareness of dementia difficulties and the diagnosis and the activation of a hope process (see; Cotter, 2009), multi-dimensional hope (Herth, 1991; Wolverson, Clarke, & Moniz-Cook, 2010; Spector & Orrell, 2006; Clare, 2002; Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2004; Snyder, 2001; Snyder, 2003; see Cotter, 2009) and the adjustment to dementia (see; Cotter, 2009; Wolverson, Clarke, & Moniz-Cook, 2010). Concepts applied to other chronic health conditions could also be incorporated such as meaning and mastery (Taylor & Stanton, 2007) employing coping skills (Preston, Marshall, & Bucks, 2007), completion of psychological adaptive tasks (Holahan, Moos, & Schaefer, 1996) and illness representations (Clare, Goater, & Woods, 2006).

In addition to a model of hope, psychosocial interventions could also be developed to aid in facilitating hope. This is with the results suggesting older adults with early stage dementia experiencing high levels of hope have a better quality of life. Individual interventions to facilitate hope could include an 'about me' and 'hope' collections (Duggleby, et al., 2007), these are similar to reminiscence therapies (Kunz, 2002) with the focus on collecting items such as photos, letters and personal objects from the past that inspire hope. Support groups can also help inspire hope (Kasl-Godley & Gatz, 2000) and group interventions can focus on finding topics of hope, identifying barriers and reflecting on the meaning purpose of life (Herth, 2000). It is useful that the

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results suggested that hope in this cohort is less likely to be experienced in an individualist goal directed way (i.e. the pathway component of goal directed hope) as it therefore may be beneficial for interventions to focus on emotionally and intrinsically meaningful and world related goals. Furthermore, knowing that multi-dimensional hope is most likely to be experienced, this type of hope can be assessed when measuring the efficacy of interventions to foster hope. Due to possible interventions involving individual 1-1 work, and group work and dementia care focusing on physical in addition to mental well-being, services may continue to benefit from being structured as multi-multidisciplinary teams (MDT) such as memory clinics to enable holistic approaches to dementia care.

This study adds to a growing body of literature which indicates that people with dementia experience hope differently. The development of a scale to reliably and validly assess hope in dementia would aid future research and clinical practice and should be a focus of further research. It would also be worthwhile for further research to focus on alternative variables that could constitute barriers towards hope in dementia. This could enable psychosocial interventions to focus on specific issues associated with dementia that could promote hope. Hope has not been investigated in relation to different types of dementia and this could be beneficial as there may be some idiosyncratic differences in the difficulties associated with different forms of dementia. Additional research could also focus on young onset dementia; this would provide a valuable insight into the experience of hope in different cohorts and explain whether it is only those in later life who experience a less goal directed form of hope.

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The present study has added to the growing body of evidence that people with early stage dementia can be involved in research and that it can provide some validation to their experiences and may help reduce their experience of stigma. Although the results of this study suggest that people with dementia may have lower levels of hope than those without, they still have the capacity to experience hope. This finding can challenge many assumptions and negative stigmatising images about dementia. It is hoped that this study will encourage clinicians to identify positive strengths in people with dementia to enable them to maintain an optimum quality of life in spite of the difficulties that dementia can bring.

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Part three: Appendixes

Reflective statement

Introduction

This section contains my personal reflections on the research process from the initial discussion of ideas, to carrying out the research and the results that followed. Although the reflections are indelibly linked, they have been split into sections for clarity of thought and understanding.

Background

It was the concept of hope that initially captured my attention; it stood out for me because it focused on positive aspects of our psychological makeup, i.e. our strengths. In my opinion, psychiatric literature and to a lesser extent psychological literature seemed to neglect this. I think this is understandable as the focus of health care is trying to alleviate the difficulties we experience and this is commonly what clients want to focus on. However, many icons of the western world, should it be great thinkers, artists of humanitarians are revered because of the strengths. The idea of then applying our positive strengths and more specifically 'hope' to dementia, a condition many view as hopeless, did lead me to have some reservations. Could anyone with dementia experience hope? Personal experience had shaped my ideas that it could be a difficult, long and tiring condition for family members. On the other hand, hope has appeared in the most unlikely of situations, in the face of great suffering such as during the holocaust. This helped me decide that I was not going to dismiss hope in dementia and that it was worthy of further exploration.

Planning and design

At times, the planning and design stage was frustrating due to the practical constraints placed on the project such as time to complete it and access to participants. This was an inevitable part of the doctorate degree in clinical psychology as you had to balance the clinical, academic and research elements of the course. Reviewing the literature was an arduous process with the many different definitions and measures of hope. I was surprised at how much research into this area there had already been (but very little with dementia and hope). This reminded me of 'intelligence' a concept that has also bewildered researchers with its numerous measures and theories. It was satisfying when I finally made clear the key themes, theories and measures of hope and how it had been explored in dementia. The design of the study was firstly focussed on the development of hypotheses. I had to be mindful not to 'jump ahead' in making hypothesis that were speculative and not grounded in the research literature. This is why early ideas such as developing a hope scale in dementia were dropped. I found attempting to write the hypothesis challenging, as they had to be clear and understandable and very precise. This led to more hypotheses being generated than I had planned but they were all suitable.

Recruitment of participants

I found the recruitment of participants the most challenging phase and it was far more time consuming than I planned. I think many of the health clinicians I approached to help with the research, realised its importance but because of their own workload it was often at the bottom of their list of priorities. I found myself having to motivate and encourage some services to help and had to develop a fine balance between actively promote my research and not doing this too frequently as to disengage them. I feel as

though I struggled with this at first but made gains in self-confidence as the recruitment process continued. Although I had some experience working with older people, I had not worked in NHS services with older people before and so it took time to adjust to this environment. I think some of the problems with the recruitment could have been avoided if I had started it earlier and had met with potential recruitment sites at an earlier stage i.e. when completing my research proposals. This would have given me a better understanding of the number of participants I could recruit and helped me develop professional relationships with clinicians.

Conducting research with the participants

Meeting and talking to the participants about their quality life, the reactions of others and their hopes about having dementia was very rewarding and is the most memorable positive aspect of the project. I was surprised how many participants seemed content with their lives and the importance of spending time with those they were close to. I found it very easy to get distracted from the questionnaire items as some participants enjoyed reflecting on their memories of the past. In conducting the research, it made me consider my own and society's attitudes to aging. I had thoughts around whether entering later life is something to be feared and the concept of successful aging. I had to be organised when conducting the research with participants as I would be travelling around meeting participants at different locations throughout the day. I feel as though I successfully managed my time as meeting with participants could only happen on certain days due to other commitments from the course.

Systematic Literature review

There was much discussion between myself and my supervisors regarding the topic of the literature review. This was around whether the topic was viable in terms of the number of articles that might be available and whether it was linked to my empirical paper. I found that I had to be very meticulous in searching the literature and recording at what stage of the search process articles were excluded and included. As the vast majority of the articles were qualitative, careful consideration was given on how to analyse them. I found the accounts of how dementia is perceived by different cultural groups very interesting. This was because I had not realised how dementia is partly culturally specific to Western Europe and North America and how the difficulties with dementia are attributed and managed differently in other cultural groups. This is something that I will consider in my own clinical practice. I was pleased with the model that was developed from the literature review results as it provided a framework for further research and psychosocial interventions to develop from.

Reflection on the results

Although, there are many clinical and research implications of my results I am left uncertain whether further research will take place in this area and whether services will take action in light of the results. I would like things to be developed further and how the results are disseminated play a part in this. This is one of the reasons why I would like the study to be published as it increases the likelihood that the results will be acted upon. It will also be interesting to see how others react to results. Some may reject the results stating that the participants lacked awareness or that the sample was biased. Others may welcome the results as a validation of their experiences of working with this client group. The results that did surprise me were the small number of participants that

experienced perceived stigma. A possible reason for this is a biased sample (documented in the discussion). This is a paradox for research like this, as those who experienced stigma are less likely to take part in the research and maybe this is the case for people who experience hopelessness, social anxiety or depression.

My approach to research

I think I have a steady approach to research with frequent self-imposed deadlines. I think this has managed to contain my anxiety from the pressure of the project and the other commitments from the course. I have tended to get frustrated when parts of the research have taken longer to complete than planned, whether this has been waiting for the response of R&D departments, recruiting participants or writing up the research. I have tried to bear in mind that this is encountered by researchers including those with many more years experience.

Summary

To summarise, I think hope in dementia is a very worthy topic to research and my interest in exploring the strengths in people has kept me motivated in this project when things have got difficult. I feel I have learnt the importance of regular supervision and goals to aim for, otherwise the research could have gone off track quickly with the other competing commitments on the course. I have also learnt the importance of being very thorough and scientific throughout the process as this helps to ensure high quality work and results in less changes being made later in the process. For future researchers in this area, I would recommend careful planning of the project, although this may be time consuming, time can be saved later on. I would also recommend setting self-imposed deadlines through the project as it is easy to lose focus. I would also recommend

making contact with potential recruitment sites very early on as this could help in recruitment at a later date and will help you set a realistic sample size target.

Appendixes

Appendix A: Guidelines to submission to 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

Manuscripts may be in the form of: (i) regular articles not usually exceeding 5,000 words (under special circumstances, the Editors will consider articles up to 10,000 words); or (ii) short reports not exceeding 2,000 words. These word limits exclude references and tables.

All submissions should be made online at *Aging & Mental Health's* [ScholarOne Manuscripts 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".

All submissions should be in the style of the Publication Manual of the American Psychological Association (6th edition, 2009). 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: 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](#)

Any consistent spelling style is acceptable. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Word Templates

[Word templates](#) are available for this journal.

If you are not able to use the template via the links or if you have any other queries, please contact authortemplate@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, Taylor & Francis Online, 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

Copyright

It is a condition of publication that authors assign copyright or licence the publication rights in their articles, including abstracts, to Taylor & Francis. This enables us to ensure full copyright protection and to disseminate the article, and the journal, to the widest possible readership in print and electronic formats as appropriate. Authors retain many rights under the Taylor & Francis rights policies, which can be found at

<http://journalauthors.tandf.co.uk/preparation/copyright.asp>. Authors are themselves responsible for obtaining permission to reproduce copyright material from other sources.

Exceptions are made for certain Governments' employees whose policies require that copyright

cannot be transferred to other parties. We ask that a signed statement to this effect is submitted when returning proofs for accepted papers.

Aging & 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 B: Methodological quality checklist

Criteria	Reporting (Yes=1, No=0, Not reported=0)
1	<p>Was there an adequate and clearly described context?</p> <ul style="list-style-type: none"> • Justification for the study? • Clinical rationale?
2	<p>Was there adequate and clearly described aims and objectives?</p> <ul style="list-style-type: none"> • Linked to the literature?
3	<p>Was there a clearly described sample?</p> <ul style="list-style-type: none"> • Number of participants? • Sample age, sex, relationship etc? • Recruitment procedure? • Recruitment sites?
4	<p>Was the data collection clearly described?</p> <ul style="list-style-type: none"> • Measures/interview schedule used? • Where research took place? • Number of times participant took place/how long it lasted?
5	<p>Was the data analysis clearly described?</p> <p>Sampling</p>
6	<p>Was the sample/sampling justified?</p> <p>Data collection</p>
7	<p>Were the methods of data collection theoretically justified?</p> <ul style="list-style-type: none"> • Rationale behind the approach/design? <p>Data Analysis</p>
8	<p>Were the procedures for data analysis theoretically justified/appropriate?</p> <ul style="list-style-type: none"> • Linked to theory?

-
- Specific statistical tests used?

Reliability and Validity (Qualitative only)

- 9 Was the analysis repeated by more than one researcher to ensure reliability?
- 10 Was their inclusion of sufficient primary data to mediate between data and interpretation?
-

Appendix C: Methodological quality scores for each article

Author and Year	Criteria scores										Total Score
	1	2	3	4	5	6	7	8	9	10	
Allen & Oyebode, 2009	1	1	1	1	1	0	1	1	1	1	9
Blum, 1991	0	1	0	0	0	0	0	0	0	1	2
Dobbs, et al., 2008	1	1	1	1	1	1	0	0	1	1	8
Hinton, Guo, Hillygus, & Levkoff, 2000	1	1	0	1	1	1	1	1	0	1	8
Liu, Hinton, Tran, Hinton, & Barker, 2008	1	1	1	1	1	0	0	1	1	1	8
MacRae, 1999	1	1	1	1	0	0	0	0	0	0	4
Mackenzie, 2006	1	1	1	1	1	1	1	1	0	1	9
Morgan, 2002	1	1	1	1	1	1	1	1	0	1	9
Robinson, Emden, Elder, Lea, Vickers, & Turner, 2008	1	0	1	1	1	1	1	1	1	1	9
Rodriguez, Kosloski, Kercher, & Montgomery, 2009	1	1	1	1	1	1	1	1			8

Shifflett & Blieszner, 1988	1	1	1	1	1	0	0	0	0	1	6
Werner & Heinik, 2008	1	1	1	1	1	0	1	1	0	1	8
Werner, Goldstein, & Buchbinder, 2010	1	1	1	1	1	1	1	1	1	1	10
Yamamoto & Wallhagen, 1998	1	1	1	1	1	0	1	1	1	1	9
Zhan, 2004	1	1	1	1	1	0	1	1	1	1	9

Appendix D: NHS National research ethics approval



National Research Ethics Service

Trent Research Ethics Committee

Research Ethics Office
Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Telephone: 01332 868905
Facsimile: 01332 868930

13 August 2010

Mr David Chapman
Trainee Clinical Psychologist
Humber NHS Foundation Trust
Willerby Hill
Beverley Road, Willerby
HU10 6ED

Dear Mr Chapman

Study Title: Hope, Perceived Stigma and Quality of Life in Later Life
and in Early-stage Dementia
REC reference number: 10/H0405/50

Thank you for your letter of 05 August 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within the
National Patient Safety Agency and Research Ethics Committees in England*

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV		02 June 2010
Protocol	1	02 June 2010
CV - Christopher Clarke		
Demographic Form	1	01 June 2010
REC application		02 June 2010
Advertisement		
Participant Information Sheet: Non Dementia People	3	05 August 2010
Response to Request for Further Information		05 August 2010
Participant Information Sheet: Dementia	4	05 August 2010
Participant Consent Form	1	01 June 2010
Questionnaire: Herth Hope Index		
The Goals scale		
Demographic Form	2	01 June 2010
Stigma Impact scale		
Debrief slip	1	01 June 2010
Quality of life-AD Instructions for interviewers		
Peer review form		07 May 2010
Quality of life: AD		

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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0405/50

Please quote this number on all correspondence

Yours sincerely



Mr Peter Korczak
Chair

Email: carol.marten@derwentsharedservices.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mr Steven Walker
Humber NHS Foundation Trust
Research and Development Department
Trust Headquarters, Willerby Hill
Willerby East Yorkshire HU10 6ED



National Research Ethics Service

Trent Research Ethics Committee

Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839436
Fax: 0115 8839294

04 February 2011

Mr David Chapman
Trainee Clinical Psychologist
Humber NHS Foundation Trust
Willerby Hill
Beverley Road, Willerby
HU10 6ED

Dear Mr Chapman

Study title: Hope, Perceived Stigma and Quality of Life in Later Life
and in Early-stage Dementia
REC reference: 10/H0405/50
Amendment number: 1
Amendment date: 24 January 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 03 February 2011.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Questionnaire: The Mini Mental State Exam		
Notice of Substantial Amendment (non-CTIMPs)		
Covering Letter		20 January 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

10/H0405/50:

Please quote this number on all correspondence

Yours sincerely



Mrs Carol Marten
Committee Co-ordinator

E-mail: carol.marten@nottspct.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Mr Steven Walker
Humber NHS Foundation Trust
Research and Development Department
Trust Headquarters, Willerby Hill
Willerby East Yorkshire HU10 6ED

Appendix E: Research and development approval

Humber 
 NHS Foundation Trust
 Research & Development Department
 Trust Headquarters
 Willerby Hill
 Beverley Road
 WILLERBY
 HU10 6EC

06/09/2010

David Chapman
 Dept clinical psychology
 Hertford Building,
 University of Hull
 Cottingham Road, Hull
 HU6 7RX

Dear David Chapman

Re: R&D ID: 10/06/448 REC ID: 10/H1313/62
Hope, Perceived Stigma and Quality of Life in Later Life and in Early stage
Dementia

I am please to notify you formally that this study has been approved by the Humber NHS Foundation Trust.

Your research has been approved to be undertaken in the **Hull Memory Clinic**.

Humber NHS Foundation 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

You must ensure that the protocol is followed at all times. Should you need to amend the protocol, please follow the national research ethics service procedures. You should forward a copy of all amended versions of the protocol and/or documentation together with written confirmation that a favourable opinion has been given by the REC, to the R&D office at the trust.

You will be required to complete electronic progress reports and a final monitoring form on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum, however, if you fail to supply the information requested, the trust may withdraw approval.

I would like to wish you every success with this project

Yours sincerely



Duncan Courtney
 Clinical and Research Governance Manager

Appendix F: Information Sheet 1

Ref

Hope, Stigma and Quality of Life in Later Life

We would like to invite you to take part in our research study. Before you decide if you wish to take part we would like you to understand why the research is being carried out and what taking part will involve. Please read the following information carefully, this should take about 5 minutes.

Talk to others about the study if you wish

Ask us if anything is not clear or if you would like more information.

The purpose of the study

1. To explore differences in feelings of hope between different groups of older people
2. To find out if feelings of stigma is linked to hope and well-being in older people with dementia

Having a strong sense of hope could help maintain or improve the well-being of people who have problems like dementia in later life. It is important to research this so that health professionals can support people in the most effective way.

Why you have been invited to take part

We would like to compare older people who do not have dementia with those that do. You have been invited to take part because you are 60 years old or above; you have reported that you do not have a diagnosis of dementia or severe mental health problems; and that

you are fluent in English. We are inviting over 100 older people to take part in this study.

Do I have to take part?

It is up to you to decide if you wish to take part. If you agree to take part, we will ask you to sign a consent form. You are free to change your mind at any time without giving a reason.

What I will have to do?

You will complete 2 brief questionnaires about your sense of hope.

It will take around 15 minutes to complete the questionnaires. You can ask the researcher if you are unsure what a question means and he will help you complete them. There are no right or wrong answers to any of the questions; we want your personal opinions.

The possible disadvantages of taking part

The questions require you to think about the experience of hope in later life. If you feel that this may be upsetting then you do not have to take part. If at any point during the study you feel uncomfortable in any way you are free to withdraw at any time.

The possible benefits of taking part

We cannot promise the study will help you but the information we get from this study may help improve the general well-being of people in later life and contribute to better ways of supporting older people who have dementia

What will happen to any data I give?

The questionnaires will be returned to the researcher and will be securely stored at the University of Hull. The questionnaires will not have your name or any other contact details on them. The questionnaires will be securely disposed of after 5 years.

When the research study stops

The research stops when you have completed the questionnaires. This will be your last contact with the researcher, unless you have any further questions.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be kept strictly confidential. The data will be collected by the researcher. It will be securely stored by the researcher at The University of Hull. A number rather than your name will be used on the questionnaires so none of the information will be identifiable. The questionnaires will be kept for 5 years and then securely disposed.

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

You can stop taking part in the study at any time and we will destroy all your questionnaires.

What happens to the results of the research study?

The results of the study will be written in a report and will be submitted for publication in a scientific journal and in a thesis at the University of Hull. This is so that other professionals and students can read the report. You will not be personally identified in any report or publication. Unfortunately it is not possible to tell people their individual results. However, you can ask for a summary of the results of the study.

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. If you remain unhappy and wish to complain formally, you can do this by sending your complaint to:

The Complaints and PALS Manager
Humber Foundation NHS Trust
Trust Headquarters
Willerby Hill
Beverley Road
Willerby

HU10 6ED

The complaints department can be contacted on
(01482) 303930

You can send an email to complaints@humber.nhs.uk

Who is organising and funding the research?

Humber NHS Foundation Trust and the University of Hull are funding the research. It is part of the research requirement for a Doctorate in Clinical Psychology qualification.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Trent Research Ethics Committee and NHS R&D approval

Further information and contact details

If you would like any further information about the study or to ask any questions please feel free to contact:

David Chapman (Chief Investigator)

Trainee Clinical Psychologist

Department of Clinical Psychology and Psychological Therapies

Hertford Building

University of Hull

Cottingham Road

Hull

d.chapman@2005.hull.ac.uk

Appendix G: Information sheet 2

Ref

Hope, Stigma and Quality of Life in Later Life

We would like to invite you to take part in our research study. Before you decide if you wish to take part we would like you to understand why the research is being conducted and what taking part will involve. Please read the following information carefully, this should take about 5 minutes.

Talk to others about the study if you wish

Ask us if anything is not clear or if you would like more information.

This study has two aims:

3. To explore differences in feelings of hope between different groups of older people
4. To find out if feelings of stigma are linked to hope and general well-being in older people with dementia

Having a strong sense of hope could help maintain or improve the well-being of people who have problems like dementia in later life. It is important to research this so that health care professionals can support people in the most effective way.

Why have I been invited?

We would like to compare older people who do not have dementia with those that do. You are invited to take part because you are older than 60 and you have a diagnosis of dementia. We will be inviting around 100 older people to take part in this research.

Do I have to take part?

It is up to you to decide if you wish to take part. If you agree to take part, we ask you to sign a consent form. You are free to change your mind at any time without giving a reason. If you decide not to take part, your care and support from the NHS will not be affected in any way.

What I will have to do?

You will complete 4 brief questionnaires:

- One questionnaire asks about feelings of stigma you may or may not experience
- Two questionnaires ask about your sense of hope
- One questionnaire asks about how you rate your quality of life (i.e. your general well-being)

It will take around 30 minutes to do these questionnaires. You can ask the researcher if you are unsure what a question means and he will help you complete them. There are no right or wrong answers to any of the questions; we are interested in your personal opinions. You can complete the questionnaires with the researcher at where is most convenient and comfortable for you, this could be at your home or at the clinic.

The possible disadvantages of taking part

The questions require you to think about the experience of hope in later life. If you feel that this may be upsetting you do not have to take part. If at any point during the study you feel uncomfortable in any way you are free to withdraw at any time. In the unlikely event that this happens, and you feel you need further support, the researcher can arrange this through existing professionals involved in your care with your consent

The possible benefits of taking part

We cannot promise the study will help you directly but we hope that the information we get from this study may help improve the general well-being of people in later life and contribute to better ways of supporting older people who have dementia

What will happen to any data I give?

The questionnaires will be returned to the researcher and will be securely stored at the University of Hull. The questionnaires will not have your name or any other contact details on them. The data will only be used for this study and questionnaires will be securely disposed of after 5 years.

When the research study stops?

The research stops when you have completed the questionnaires. This will be your last contact with the researcher, unless you have any further questions.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be kept strictly confidential. The data will be collected by the researcher. It will be securely stored by the researcher at The University of Hull. A number rather than your name will be used on the questionnaires so none of the information will be identifiable. The questionnaires will be kept for 5 years and then securely disposed.

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

You can stop taking part in the study at any time and we will destroy all your questionnaires.

What happens to the results of the research study?

The results of the study will be written in a report and will be submitted for publication in a scientific journal and in a thesis at the University of Hull. This is so that other professionals and students can read the report. You will not be personally identified in any report or publication. Unfortunately it is not possible to tell people their individual results. However, you can ask for a summary of the results of the study.

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. If you remain unhappy and wish to complain formally, you can do this by sending your complaint to:

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Humber Foundation NHS Trust

Trust Headquarters
Willerby Hill

Beverley Road
Willerby

HU10 6ED

The complaints department can be contacted on
(01482) 303930

You can send an email to complaints@humber.nhs.uk

Who is organising and funding the research?

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Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Trent Research Ethics Committee and NHS R&D approval.

Further information and contact details

If you would like any further information about the study or to ask any questions please feel free to contact:

David Chapman (Chief Investigator)

Trainee Clinical Psychologist

Department of Clinical Psychology and Psychological
Therapies

Hertford Building

University of Hull

Cottingham Road

Hull

d.chapman@2005.hull.ac.uk

Thank you for reading this information sheet

|

Appendix H: Consent form

Ref

CONSENT FORM

Title of Project: Hope, Stigma and Quality of Life in Later Life

Name of Researcher: David Chapman

1. I confirm that I have read and understand the information sheet dated.....

(version.....) for the above study. I 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 and without my medical care or legal rights being affected.

3. I agree to take part in the above study.

Name of Person

Date

Signature

Appendix I: Demographic form 1

Ref

DEMOGRAPHIC FORM

Please, could you tell us some information about yourself.
This information will be anonymised and is treated
confidentially

What is your age? (please tick a box)

60-64	<input type="checkbox"/>	65-70	<input type="checkbox"/>	71-75	<input type="checkbox"/>
76-80	<input type="checkbox"/>	81-85	<input type="checkbox"/>	85+	<input type="checkbox"/>

Have you ever received a diagnosis of dementia?

Yes No

Are you currently receiving treatment for any mental health
problems (such as depression)?

Yes No

Appendix J: Demographic form 2

Ref

DEMOGRAPHIC FORM

Please could you tell us some information about yourself.
This information will be anonymised and is treated
confidentially

What is your age? (please tick a box):

60-64 65-70 71-75
76-80 81-85 85+

How long have services been supporting you with regards
to memory problems?

0-3 months 3-6 months 6-9 months
12 months+ Not sure

Are you currently receiving treatment for any other mental
health problems (such as depression)?

Yes No

Appendix K: Debrief slip

Ref

DEBRIEF SLIP

Thank you for taking part in this study on hope, stigma and quality of life in later life. If you would like any further information or should you decide that you would like to withdraw your data from the study, please contact the researcher whose details are given below.

Mr David Chapman (Chief Investigator)

Trainee Clinical Psychologist

Department of Clinical Psychology and Psychological Therapies

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University of Hull

Cottingham Road

Hull

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01482 464106

Thank you for your time

Appendix L: Snyder Hope Scale (removed for hard binding)The Goals Scale

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1 = Definitely False 2 = Mostly False 3 = Mostly True 4 = Definitely True

- ___ 1. I can think of many ways to get out of a jam.
- ___ 2. I energetically pursue my goals.
- ___ 3. I feel tired most of the time.
- ___ 4. There are lots of ways around any problem.
- ___ 5. I am easily downed in an argument.
- ___ 6. I can think of many ways to get the things in life that are most important to me.
- ___ 7. I worry about my health.
- ___ 8. Even when others get discouraged, I know I can find a way to solve the problem.
- ___ 9. My past experiences have prepared me well for my future.
- ___ 10. I've been pretty successful in life.
- ___ 11. I usually find myself worrying about something.
- ___ 12. I meet the goals that I set for myself.

Appendix M: Herth Hope Index (removed for hard binding)

Herth Hope Index

Listed below are a number of statements. Read each statement and place a (X) in the box that describes how much you agree with that statement *right now*.

	Strongly Disagree	Disagree	Agree	Strongly agree
1. I have a positive outlook toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have short, intermediate, and/ or long range goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel all alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I can see a light in a tunnel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I have faith that gives me comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel scared about my future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I can recall happy / joyful times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I have deep inner strength	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am able to give and receive caring / love	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have a sense of direction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I believe that each day has potential	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I feel my life has value and worth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix N: Stigma Impact Scale (removed for hard binding)

STIGMA IMPACT SCALE

Listed below are a number of statements. Read each statement carefully and circle the response that best describes your experiences during the past few weeks.

0	1	2	3	4
Not applicable	Strongly disagree	Disagree	Agree	Strongly agree

1	My employer/co-workers have discriminated against me	0	1	2	3	4
2	Some people act as though I am less competent than usual	0	1	2	3	4
3	I feel I have been treated with less respect than usual by others	0	1	2	3	4
4	I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I prepare	0	1	2	3	4
5	I feel others avoid me because of my illness	0	1	2	3	4
6	Some Family members have rejected me because of my illness	0	1	2	3	4
7	I feel some friends have rejected me because of my illness	0	1	2	3	4
8	I encounter embarrassing situations as a result of my illness	0	1	2	3	4
9	Due to my illness others seem to feel awkward and tense when they are around me	0	1	2	3	4
10	I have experienced financial hardship that has affected how I feel about myself	0	1	2	3	4
11	My job security has been affected by my illness	0	1	2	3	4
12	I have experienced financial hardship that has affected my relationship with others	0	1	2	3	4

13	I feel others think I am to blame for my illness	0 1 2 3 4
14	I do not feel I can be open with others about my illness	0 1 2 3 4
15	I fear someone telling others about my illness without permission	0 1 2 3 4
16	I feel I need to keep my illness a secret	0 1 2 3 4
17	I feel I am at least partially to blame for my illness	0 1 2 3 4
18	I feel set apart from others who are well	0 1 2 3 4
19	I have a greater need than usual for reassurance that others care about me	0 1 2 3 4
20	I feel lonely more often than usual	0 1 2 3 4
21	Due to my illness, I have a sense of being unequal in my relationships with others	0 1 2 3 4
22	I feel less competent than I did before my illness	0 1 2 3 4
23	Due to my illness, I sometimes feel useless	0 1 2 3 4
24	Changes in my appearance have affected my social relationships.	0 1 2 3 4

Appendix O: Quality of Life in Alzheimer's disease questionnaire (removed for hard binding)

Quality of Life: AD (Interview Version for the person with dementia)				
Interviewer administer according to standard instructions. Circle responses.				
1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments: _____

Appendix P: SPSS Output

Descriptives

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Group	60	1	1	1.00	.000
HHS1	60	6	16	12.58	2.142
HHS2	60	5	16	12.80	2.146
HHS3	60	6	16	12.50	2.236
HHTotal	60	21	48	37.88	5.459
SHS1	60	8	17	12.50	1.827
SHS2	60	8	16	12.40	1.440
SHTotal	60	14	31	24.85	3.036
Valid N (listwise)	60				

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Group	40	2	2	2.00	.000
HHS1	40	7	14	10.55	1.839
HHS2	40	9	15	12.22	1.593
HHS3	40	8	16	12.27	2.148
HHTotal	40	30	42	35.50	3.047
SHS1	40	9	15	12.05	1.339
SHS2	40	2	15	10.32	2.546
SHTotal	40	13	30	22.28	3.457
Valid N (listwise)	40				

T-Tests

Independent Samples Test										
		Levene's Test for Equality of Variances				t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
HHTotal	Equal variances assumed	9.417	.003	2.510	98	.014	2.383	.949	.499	4.267
	Equal variances not assumed			2.792	95.480	.006	2.383	.854	.689	4.078

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SHTotal	Equal variances assumed	.294	.589	3.930	98	.000	2.575	.655	1.275	3.875
	Equal variances not assumed			3.829	76.113	.000	2.575	.673	1.236	3.914

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SHS1	Equal variances assumed	7.477	.007	1.336	98	.185	.450	.337	-218	1.118
	Equal variances not assumed			1.420	97.064	.159	.450	.317	-.179	1.079

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SHS2	Equal variances assumed	11.640	.001	5.195	98	.000	2.075	.399	1.282	2.868
	Equal variances not assumed			4.680	55.742	.000	2.075	.443	1.187	2.963

Regression

Correlations

		HHTotal	SISTotal
Pearson Correlation	HHTotal	1.000	-.276
	SISTotal	-.276	1.000
Sig. (1-tailed)	HHTotal	.	.042
	SISTotal	.042	.
N	HHTotal	40	40
	SISTotal	40	40

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.276 ^a	.076	.052	2.966

a. Predictors: (Constant), SISTotal

b. Dependent Variable: HHTotal

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients		95% Confidence Interval for B		Correlations			Collinearity Statistics		
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	43.739	4.675		9.356	.000	34.274	53.203					
	SISTotal	-.191	.108	-.276	-1.771	.085	-.409	.027	-.276	-.276	-.276	1.000	1.000

a. Dependent Variable: HHTotal

Correlations

		QOLTotal	SISTotal
Pearson Correlation	QOLTotal	1.000	-.227
	SISTotal	-.227	1.000
Sig. (1-tailed)	QOLTotal	.	.080
	SISTotal	.080	.
N	QOLTotal	40	40
	SISTotal	40	40

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.227 ^a	.051	.027	4.095

a. Predictors: (Constant), SISTotal

b. Dependent Variable: QOLTotal

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients		95% Confidence Interval for B		Correlations			Collinearity Statistics		
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	46.772	6.454		7.247	.000	33.706	59.838					
	SISTotal	-.214	.149	-.227	-1.436	.159	-.515	.088	-.227	-.227	-.227	1.000	1.000

a. Dependent Variable: QOLTotal

Correlations

		QOLTotal	HHTotal
Pearson Correlation	QOLTotal	1.000	.487
	HHTotal	.487	1.000
Sig. (1-tailed)	QOLTotal	.	.001
	HHTotal	.001	.
N	QOLTotal	40	40
	HHTotal	40	40

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.487 ^a	.237	.217	3.673

a. Predictors: (Constant), HHTotal

b. Dependent Variable: QOLTotal

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.487 ^a	.237	.217	3.673

a. Predictors: (Constant), HHTotal

b. Dependent Variable: QOLTotal