# Illness Representations and Adjustment to Dementia

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# Declaration

I declare that this thesis has not been submitted for any other degree or to any other institution.

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## Acknowledgements

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This work is dedicated to my Grandma Amy who sadly died as a result of Alzheimer's disease.

# Abstract

**Literature review:** Studies examining the attitudes, experiences and impact of a dementia diagnosis for people with dementia and their carers were reviewed. The review revealed that there are often delays in people contacting physicians when dementia-related signs are noticed and people with dementia and their carers cite reasons for and against seeking diagnostic disclosure. There is mixed evidence regarding whether those who receive a diagnosis and their carers are satisfied with the diagnostic process and the information provided by clinicians. Initial reactions to the diagnosis include shock and distress, or relief and validation, although emotions alter over time as a process of adjustment takes place. There are a number of methodological limitations to the quantitative and qualitative studies in this review. Conceptual and clinical implications are discussed and recommendations are made for future research.

**Research Report:** The present study assessed the relationship between the Common Sense Model of illness representations (Leventhal et al., 1980) and psychological adjustment in a cross-sectional sample of 49 people diagnosed with dementia. Those who held representations of severe consequences, a strong illness identity and negative emotional representations experienced greater psychological distress. Representations of control, identity, cause and emotional representations were also related to specific coping behaviours. The ‘avoidance or restriction of activities’ as a coping behaviour, was associated with both emotional representations and psychological distress, but did not mediate the relationship between the two. These findings are discussed in relation to the Common Sense Model, previous research and clinical practice.

# Word Count

| | |
|---|---|
| **Literature Review:** | 7,999 excluding references |
| | 9,540 including references |
| **Research Report:** | 11, 114 excluding references |
| | 13, 742 including references |
| **Total:** | 19, 113 excluding references |
| | 23,282 including references |
| | 29,122 including appendices (approx.) |

# Contents

# Literature Review

# Dementia diagnosis: The views and experiences of people with dementia and their carers

## 1. Abstract

**Aim:** Dementia is a progressive condition that can have a severe impact on the lives of people with dementia and their carers. The diagnostic process is a large part of the experience of dementia; however, many people delay diagnosis or go undiagnosed, which can affect treatment options. This literature review aims to increase professional understanding of the attitudes, experiences and impact of diagnostic disclosure for people with dementia and their carers.

**Methods:** A literature review was conducted. PsychINFO, Ovid MEDLINE and Web of Science databases were used to search for articles on the views and experiences of people with dementia and their carers on the diagnosis of dementia. The review included both qualitative and quantitative studies.

**Results**: There is typically a delay from carers noticing the first signs of dementia to seeking diagnostic assessment for their relative, which has been related to uncertainty, normalisation of symptoms and carer responses. There are perceived benefits and barriers to diagnostic disclosure that are largely shared between people with dementia and their carers. The experience of diagnostic disclosure and the information provided varies, with some finding this to be unsatisfactory. Immediate reactions to the disclosure can be negative, e.g., feelings of shock and distress; however, positive emotional and relational responses can also result, e.g., relief and validation. There is a shift in these initial reactions over the days and weeks following a diagnosis, as a process of adjustment takes place.

**Conclusions:** Receiving a diagnosis is a fundamental part of the experience of dementia for many people. It is important to understand the experiences of people with dementia

and their carers in order to increase access to treatment and facilitate adjustment. Theoretical and clinical implications and ideas for future research are discussed.

## 2. Introduction

The term dementia refers to a progressive disease of the brain that affects cognitive functioning, including orientation, memory, language, and judgement (World Health Organisation [WHO], 1992). The main types of dementia are Alzheimer's disease (AD) and Vascular Dementia (VD) (Department of Health [DOH], 2009). Whilst this condition is most common in older people it can affect people at any age. The World Alzheimer Report (2009) indicated an estimated 35.6 million people would have dementia in 2010 with an expected increase to 115.4 million by 2050. Wimo et al. (2010) estimated the worldwide cost of dementia was $422 billion, which includes $142 billion in informal care. In the UK, it has been estimated that 700,000 people (1.1% of the population) currently have dementia with an economic cost of £17 billion (Knapp & Prince, 2007). There is currently no treatment for people with dementia, but cholinesterase inhibitor medication has been developed in recent years, which can delay the progression of symptoms in people who are in the early stages of AD (National Audit Office [NAO], 2007).

Dementia can have a considerable impact on the lives of people with the condition and their carers. Dementia is the second highest contributor to years lived with disability worldwide in people aged 60 and above (WHO, 2008). People can experience changes in mood, behavioural difficulties and psychotic symptoms (WHO, 1992). In many cases it is family members who provide the majority of care for people with dementia. This can have an impact on the physical and mental health of family members (NAO, 2007).

A systematic literature review by Cuijpers (2005) found 22.3% of carers of people with dementia had depressive disorders.

Despite high estimations of the prevalence of dementia and the potential impact on people with the condition and their carers there is a lack of awareness about dementia, particularly in low and middle income countries, which results in people not seeking medical care and limited or no management or support of the condition within health services (Prince et al., 2009). Often people with dementia are cared for by their relatives and caring is associated with high levels of economic disadvantage in developing countries as carers have to seek expensive private medical care (10/66 Dementia Research Group, 2000). Difficulties in providing services to people with dementia are not restricted to low and middle income countries. Moise, Schwarzinger, and Um (2004) compared nine high income countries (including Germany, Japan and USA) and found that large proportions of people with dementia were undiagnosed. It was common across these countries to have Memory Clinics, which provide multi-disciplinary input for people with dementia; however, their function and operation varied. Moreover, there did not appear to be structured national networks of these clinics, which affected their availability to people with dementia.

In the UK only one third of people with dementia receive a formal diagnosis, or are seen by specialist services. Moreover, diagnosis often occurs in the late stages of dementia and/or when a person is in crisis (DOH, 2009). This may be linked, in part, to service delivery. Until 2005, DOH and local commissioners, had given “little priority to dementia” (NAO, 2007, p.11) as there was little political and national focus on the mental health of older adults in general, a focus on other diseases, limited quality research on dementia, and stigma surrounding the condition (NAO, 2007). As a

consequence, dementia care in the UK was inefficient and piecemeal (Knapp & Prince, 2007).

In 2006 the National Institute of Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) produced clinical guidelines for NHS and social care services in the UK on supporting people with dementia and their carers. They indicated there should be a single point of referral to memory assessment services, providing assessment, diagnosis, therapy and rehabilitation for people with dementia and supporting the needs of family members and carers. The National Dementia Strategy was published in 2009 by the DOH, which outlined current difficulties in dementia assessment, diagnosis and care, and highlighted that the limited number of people receiving a diagnosis may be related to a lack of knowledge and understanding of dementia amongst the public and professionals. They also suggested that stigma can make it difficult to discuss the possibility of dementia. The DOH sought to increase awareness, develop specialist services that enable early diagnosis, and improve support for people with dementia and their carers (DOH, 2009).

The diagnostic process has been described as "one of the most fundamental elements in the experience of dementia" (Pratt & Wilkinson, 2003, p. 182). However, there has been much debate on whether it is beneficial to provide a diagnosis of dementia. In a study by Downs, Cibbens, Rae, Cook, and Woods (2002), non-disclosure of the diagnosis to the person with dementia was found to be common practice by GPs. In contrast, carers were often provided with much greater amounts of information. Pratt and Wilkinson (2003) developed a psychosocial model of the experience of dementia. They described both the desire and ability of a person to know their diagnosis and their social context, as two axes of influence on whether people are able to maximise coping strategies, or experience detachment, distress or decline and denial. They indicate it is only beneficial

to withhold a diagnosis if a person's desire and ability to know are low. If this is not the case encouraging denial could lead to distress. They also outlined how the level of support given by medical practitioners at diagnosis can be associated with a person's ability to maximise coping strategies or feelings of distress. Another model of the experiences of people with dementia outlined by Keady and Nolan (1995), situated the 'confirming' of a diagnosis in a nine stage process model of adjusting to dementia, which begins when the first signs are noticed by a person with dementia, 'slipping', and ends with 'death'. The 'maximising' of coping strategies occurs after a diagnosis has been given, according to this model.

The most recent literature review in the area of dementia diagnosis was conducted by Bamford et al. (2004) and incorporated 59 articles published up until September 2003. They examined the attitudes of people with dementia, carers and physicians on disclosure, current practice, and the impact of the disclosure. They found around half of clinicians favoured disclosure, but there were large variations in the opinions of people with dementia and their carers towards diagnosis. There was some evidence that people would rather receive a disclosure themselves than for dementia to be disclosed to a relative. Disclosure was rated as difficult by 28 to 58% of GPs and in practice diagnosis was withheld by approximately 50% of physicians. Common reasons cited for disclosure included psychological benefits, to enable planning, treatment options, and a person's right to know, whereas the possibility of causing psychological distress, the inability of the person with dementia to understand the diagnosis, a sense there were no benefits, lack of a cure and stigma related to dementia were reasons not to disclose. There was variability in carer satisfaction with the information received at diagnosis. Criticisms of the diagnostic process included a reluctance amongst physicians to give a precise diagnosis, not enough information provided, no opportunity to manage emotions and the diagnosis disclosed in an insensitive manner. Disclosure can have a negative

impact for people with dementia and their carers, e.g., shock, fear, and anger and restriction of activities. There are also positive consequences to a diagnosis, such as a sense of relief and an end to uncertainty. Bamford et al. highlight that research on the reaction of adults with dementia to a diagnosis and their experience of the diagnostic process has been sparse. Further research is also needed on people's desire to know a diagnosis and there is a need for more in-depth qualitative research to explore perspectives on disclosure.

The prevalence of dementia, the potential for negative consequences for both people diagnosed with the condition and their carers, and the development of medical treatment to delay the progression of symptoms for those in the early stages of AD, establishes a need for a good understanding of people's attitudes and experiences of diagnostic disclosure. There are several reasons why it is important to update the review by Bamford et al. (2004). First, the Bamford et al. review did not specifically focus on factors leading people to access services for a dementia assessment. However, recent studies have started to focus on these factors and the current review will assess this new research. Second, changes have been made to services that perform the assessment and diagnosis of dementia in the UK (DOH, 2009; NICE & SCIE, 2006) since the previous review and there is a need to review more recent studies. Third, there is a need to draw together more recent evidence on the process and impact of disclosure for people with dementia and their carers, which previous reviews have found to be limited. Considering the perspectives of people with dementia will also help inform and enhance practice (Wilkinson & Milne, 2003). Fourth, the previous review focussed on quantitative research only. The current review will also include qualitative research, which can enable researchers to gain a fuller understanding of a phenomenon (Willig, 2001) and should add to understanding of the processes and impact of dementia diagnosis (Bamford et al., 2004).

Given that research component of this thesis was conducted in the UK, the current review provides details of UK statistics and services. However, the review is not restricted to UK studies. This literature review is an extension of the Bamford et al. review which, although UK based, incorporated international studies. The inclusion of international studies will provide research evidence on the reactions and experiences of people with potential or diagnosed dementia and their carers when confronted with a dementia diagnosis; such information will be valuable to UK services. Where differences between UK and international studies are reported they have been outlined in the review.

The current review therefore focuses on literature relating to people with potential or diagnosed dementia and their carers that has been published since previous reviews on dementia, and considers both quantitative and qualitative research. The review has four aims. First, to review the triggers and barriers to seeking a dementia assessment. Second, to gain an understanding of the perspectives of people with dementia and their carers on receiving a diagnosis. Third, to review their experiences of the process of receiving diagnosis. Fourth, to review psychosocial reactions to the diagnosis for people with dementia and carers, including initial reactions and the initial process of adjustment to a diagnosis.

## 3. Method

The data searches for this review were conducted using PsychINFO, Ovid MEDLINE and Web of Science databases and included articles from September 2003 (the cut-off point from earlier literature reviews) to January 2010. Three search terms were entered at a time: ‘dementia’ and ‘diagnosis’ and one of the following terms reflecting the person’s experiences and reactions to the diagnosis: ‘experience’, ‘process’, ‘reaction’,

‘anxiety’, ‘depression’, ‘distress’, ‘adjustment’. The initial searches were restricted to journal articles written in English language and were combined to eliminate repetitions. In addition, it was possible to limit the PsychINFO and Ovid MEDLINE searches to articles relating to adults 65 and over and refine articles from the Web of Science database so that articles relating specifically to biochemistry, pharmacology and neurology were excluded. The PsychINFO produced 307 articles, Ovid MEDLINE 528 articles and Web of Science 609 articles. The title and abstract from each article was then considered and the inclusion and exclusion criteria were applied. The inclusion criteria were as follows: articles were from peer reviewed journals, used qualitative or quantitative methodology, and directly addressed the decision to seek assessment and diagnostic disclosure, views on the disclosure process, or the immediate impact and adjustment to a dementia diagnosis for the person with dementia and/or their carers. Both international and UK publications were included. Articles were excluded if they were not written in English, related to adults under 65 years, were letters to editors or opinion pieces, or were not peer reviewed. The process of reviewing the abstracts and applying the inclusion and exclusion criteria led to a yield of 23 articles. The references of relevant articles were reviewed and 3 additional studies were located, which met with the inclusion criteria, thereby producing a final selection of 26 articles that were included in the review.

## 4. Results

Eleven of the studies in this literature review included people with dementia (in some studies the type of dementia was specified as Alzheimer ’s disease or vascular dementia), 22 included family members and/or carers of people with dementia, and 2 studies included people with memory complaints and family members of those with neurological problems. A table of the quantitative research studies is included in

appendix A and a table of qualitative research in appendix B. This provides a full summary of the method, participants and key finding for each individual study for reference.

### *4.1. Triggers and barriers to seeking a dementia assessment*

Seven studies examined triggers and barriers to seeking a dementia assessment and they all researched the perspectives of carers. It can be a lengthy process from a carer first noticing changes to their relative and signs of dementia, to seeking professional consultation. The average time has been found to vary from under 47 weeks (Rimmer, Wojciechowska, Stave, Sganga, & O'Connell, 2005) to 1.9 years (Speechly, Bridges-Webb, & Passmore, 2008). Some of the signs of dementia that led carers to seek a diagnosis for their relative were similar across studies. Some researchers have quantified the responses given (Clark et al., 2005; Rimmer et al., 2005; Speechly et al., 2008) and these are outlined as percentages in Table 1 below. Other studies used qualitative methods and whilst comparison with the quantitative studies is difficult due to the in-depth nature of the analysis and terminology used, they have found similar themes (Krull, 2005; Mahoney, Cloutterbuck, Neary, & Zhan, 2005). The main signs of dementia noticed by carers were: changes to their relative's memory, altered personality and behaviour, disorientation or confusion and difficulties with everyday tasks.

*Table 1*. Signs prompting carers to seek a diagnosis

| Signs or symptoms prompting physician contact | No. of studies (N = 5) | % of participants |
|---|---|---|
| **Memory problems** (Clark et al., 2005; Mahoney, 2005; Rimmer et al.; 2005; Speechly et al., 2008) | 4 | 47 -62 |
| **Change in behaviour/ personality** (Clark et al., 2005; Krull, 2005; Rimmer et al.; 2005; Speechly et al., 2008) | 4 | 14 -39 |
| **Disorientation/ confusion** (Clark et al., 2005; Mahoney, 2005; Rimmer et al.; 2005) | 3 | 18-40 |
| **Difficulty with everyday tasks** (Krull, 2005; Rimmer et al.; 2005; Speechly et al., 2008) | 3 | 33 |

Reasons given by carers for the delay in seeking physician contact and a potential diagnosis once symptoms have been identified are outlined in Table 2. When signs of dementia are first noticed carers tend to normalise them, perceiving them as 'normal ageing' (Clark et al., 2005; Krull, 2005; Rimmer et al., 2005), an expected result of stress or a trauma (Krull, 2005), an exacerbation of pre-existing personality traits (Robinson, Clare, & Evans, 2005), or by attributing them to other medical conditions (Rimmer et al., 2005). Mahoney et al. (2005) found reasons for normalisation varied across ethnic groups in the USA. In African Americans it was part of a culture of respect for older people that tolerated behavioural deviance, whereas Latinos did not wish to upset the older person and people of Chinese origin hid the behaviour to avoid social stigma. Other barriers to accessing assessment were carer's awareness about the signs of dementia and whether they were serious, temporary (Rimmer et al., 2005, Robinson et al., 2005), or severe (Clark et al., 2005). In addition, carers reflected on their own difficulty in facing up to the possibility of their relative having dementia (Clark et al., 2005) and responded to it with denial (Rimmer et al., 2005).

*Table 2*. Barriers to seeking physician contact

| Barriers to seeking physician contact | No. of studies (N = 5) | % of participants |
|---|---|---|
| **Normalising**<br>(Clark et al., 2005; Krull, 2005;Mahoney, 2005; Rimmer et al.; 2005; Robinson et al.,2005) | 5 | 57 -58 |
| **Uncertainty about signs**<br>(Clark et al., 2005; Rimmer et al.; 2005; Robinson et al.,2005) | 3 | 50-70 |
| **Carer response**<br>Clark et al., 2005; Rimmer et al.; 2005) | 2 | 42-64 |

Physicians are often contacted by family members when a pivotal event means changes to their relative can no longer be normalised. Ward-Smith and Forred (2005) found the majority of their sample sought medical intervention for their relative after a pivotal event involving automobiles, e.g., driving accidents, losing keys, running out of petrol. Mahoney et al. (2005) identified going on a trip to be the pivotal event in their cross-cultural research sample, leading to problems such as the person wandering off, getting lost, having a car accident. This increased carers' awareness, although family members were consulted before physicians. Krull (2005) argued these events could mean the changes to the person with dementia can no longer be viewed as everyday behaviour. In addition they found carers could be influenced by outsiders' opinions that the person's behaviour is unusual, or through recognition of similarities with others in the family who have had dementia.

### *4.2. Perspectives on disclosure of a diagnosis of dementia*

Seven studies considered the views of people with dementia and their carers on diagnostic disclosure. Of people who attended UK psychiatric services for assessment due to cognitive impairments, the proportion that wished to know if they had dementia ranged from 69% to 92% (Elson, 2006; Pinner & Bouman, 2003). When screening

assessments for dementia have been piloted only 52% of older adults who screened positive for dementia went for further evaluation to confirm a diagnosis. Those who had better screening scores and African Americans aged over 79 were significantly more likely to refuse (Boustani et al., 2006). Studies of carers of people with dementia have found that 58% to 97% are likely to support disclosure of a diagnosis to their relative (Laakkonen et al., 2008; Shimizu, Raicher, Takahashi, Caramelli, & Nitrini, 2008; Lin, Liao, Wang, & Liao, 2005; Pinner & Bouman, 2003).

There was mixed evidence for the impact of experience of being a carer on endorsement of diagnostic disclosure to a relative. Shimizu et al. (2008) found being a carer was associated with reduced support for disclosure compared with controls. However, Lin et al. (2005) found no association between the endorsement of diagnostic disclosure and whether a person had a family member with AD, acted as primary carer or the number of hours they spent caring. There was evidence that for some carers their attitude towards disclosure was dependent on who was being given the diagnosis. Studies have found that 17 to 26% of carers who reported they would want to be told themselves if they developed dementia did not want disclosure to their relative who had dementia (Lin et al., 2005; Pinner & Bouman, 2003). Research investigating whether there were differences in the attitudes of to a diagnosis of cancer versus dementia found comparable levels of endorsement for the different conditions, with only 6% of people with dementia reporting more favourable attitudes to a cancer diagnosis and an equal number of carers desiring to know either diagnosis (Pinner & Bouman, 2003).

Reasons given for seeking diagnostic disclosure for the person with dementia were largely shared by the person receiving a diagnosis and their carers. The main reasons given across studies were: a desire to be informed as to what was wrong with the person, a person's right to know their diagnosis, to consider and have access to

treatment options, and allow them to plan for the future. An additional reason given by carers only was a diagnosis would allow them to get more information about dementia. The most frequent barrier to seeking disclosure indicated by the person receiving a diagnosis and their carers, was a belief that it would lead to psychological distress. Carers also identified that they would not seek a diagnosis as it would not have an impact on their relative's treatment options and because of the stigma and embarrassment attached to having dementia. The percentage of the research samples who endorsed each benefit and barrier to diagnostic disclosure is outlined in Table 3 below. However, the comparability of the percentage rates between people with dementia and carers is affected by differences in the study designs. Two UK studies involving people with dementia asked open ended question on the benefits and barriers of diagnosis, which resulted in single responses (Elson, 2006; Pinner & Bouman, 2003). The two international studies involving carers only, gave the option for participants to choose multiple reasons for and against disclosure from a list of options, leading to higher percentages of participants endorsing each option (Connell, Roberts, McLaughlin, & Carpenter, 2009; Lin et al. 2005).

Cultural views on disclosure were reviewed by Connell et al. (2009) in a study conducted in the USA. Several benefits to gaining a diagnosis were strongly endorsed by Black and White family members. Black family members were significantly more likely to view benefits as informing them what was wrong with their relative, helping their family in case AD is hereditary, helping their relative to be involved in decisions (e.g., writing a will), and enabling them to access drug treatment and community services. The lack of treatment or cure for AD was a frequently reported perceived barrier to seeking diagnostic disclosure and white participants were significantly more likely than black participants to cite this factor.

*Table 3*. Common reasons for wanting a diagnosis

| | **Number of studies (N=4)** | **People with dementia % of respondents** | **Carers % of respondents** |
|---|---|---|---|
| **Common benefits/ reason for wanting diagnosis** | | | |
| **To be informed as to what was wrong** (Elson, 2006; Connell et al., 2009; Lin et al. 2005; Pinner and Bouman, 2003) | 4 | 20-48 | 35-78 |
| **Enabled planning for the future** (Elson, 2006; Connell et al., 2009; Lin et al. 2005; Pinner and Bouman, 2003) | 4 | 15-20 | 27-75 |
| **To consider and gain treatment options** (Elson, 2006; Connell et al., 2009; Lin et al. 2005; Pinner and Bouman, 2003) | 4 | 11-16 | 20-67 |
| **Person's right to know** (Lin et al. 2005; Pinner and Bouman, 2003) | 2 | 24 | 12-72 |
| **To gain information on dementia** (Connell et al., 2009; Lin et al. 2005) | 2 | N/A | 57–81 |
| **Common barriers/ reasons for not wanting diagnosis** | | | |
| **It would lead to psychological distress** (Elson, 2006; Lin et al. 2005; Pinner and Bouman, 2003) | 3 | 50-75 | 100 |
| **Would not impact treatment options** (Connell et al., 2009; Lin et al. 2005) | 2 | N/A | 26-43 |
| **Stigma/ embarrassment** (Connell et al., 2009; Lin et al. 2005) | 2 | N/A | 17-33 |

Note: N/A- not applicable

### *4.3. The process of receiving diagnosis*

Eleven studies examined the perspectives of people with dementia and their carers on the diagnostic process. The timescale from first consultation with a physician, to receiving a diagnosis can be lengthy, with an average timescale between 1.2 years to 2.7 years (Bond et al., 2005; Rimmer et al., 2005; Speechly et al., 2008). Bond et al. (2005) report the average length of time from first noticing symptoms of AD to receiving a diagnosis was 1.7 years across six European countries. The UK had the longest timeframe at 2.7 years. One study found in 84% of cases, GPs were the first health professionals consulted about dementia symptoms (Speechly et al., 2008); however, 43 to 73% of diagnoses are given by specialists, e.g., neurologists (Georges et al., 2008; Rimmer et al.,2005). Diagnosis was disclosed openly to the person with dementia in 64 to 93% of cases (Georges et al., 2008; Laakonen et al., 2008). Rimmer et al. (2005) found 78% of carers in a multi-national survey reported physicians had recommended some form of treatment at diagnosis, including medical treatments (although in the UK this was only 51%).

Research has provided mixed evidence regarding whether people with dementia are satisfied with the diagnostic process. Koppel and Dallos (2007) investigated the views of people with dementia at a UK memory clinic and found whether diagnosis was seen as a positive or negative experience was based on whether they felt they had received an explanation for their memory difficulties and how much they had been involved in the diagnostic process. Feeling uncertain and uninformed as to the explanation for memory difficulties has consequences in terms of a person's sense of self. Robinson et al. (2005) interviewed people with dementia and their spouses together and found after the diagnosis some couples were confused and wanted more information on diagnosis, prognosis and help/treatment.

In terms of carer views, Speechly et al. (2008) found 72% of carers were satisfied with the first consultation, whereas a qualitative study Mahoney et al. (2005) found carers were often disappointed with the first consultation and the diagnostic process. In one study carers reported receiving a diagnosis to be a protracted and disordered process that was frustrating and stressful for them (Robinson et al., 2008). Connell, Boise, Stuckey, Holmes, and Hudson (2004) found many carers felt the way the diagnosis was given was too direct and insensitive, whilst some preferred the direct approach.

Studies have investigated carer satisfaction with the information they are given at diagnosis. Laakkonen et al. (2008) found 71% of carers felt they had received enough information. However, other studies report carers were dissatisfied with the amount of information provided at diagnosis (Bond et al., 2005; Bowes and Wilkinson, 2003; Connell et al., 2004; Georges et al., 2008; Rimmer et al., 2005; Robinson et al., 2005; Speechly et al, 2008). A multinational survey by Georges et al. (2008) found 19% of carers reported receiving no information at diagnosis, 82% said they had no information on the services available, 50% stated they had no information on dementia, its progression (66%), or on available drug treatments (48%). The average level of satisfaction with the information received was highest in the UK. Research has shown carers can find the information provided more useful than people with dementia who often cannot remember their diagnosis (Robinson et al., 2005).

Research has highlighted further difficulties for those from different ethnic backgrounds. In a qualitative study of four South Asian people living in Scotland, families reported no knowledge of dementia prior to the diagnosis and found it difficult gaining this after diagnosis (Bowes & Wilkinson, 2003). Mahoney et al. (2005) reported Chinese carers in the USA expected their physician to talk with them and build a relationship and were disappointed when this did not occur.

### *4.4. Psychosocial reactions to the diagnosis*

#### *4.4.1. Initial reactions*

The impact of a diagnosis for people with dementia and their carers was examined in ten studies. They covered cognitive, emotional and social consequences to a diagnosis. Some studies have reported diagnosis has a negative impact. Aminzadeh, Byszewski, Molnar, and Eisner (2007) found shock and distress were the immediate responses of the majority of people diagnosed with dementia in their study. In another study, 55% of people with dementia developed depressive symptoms after diagnostic disclosure according to their carers (Laakkonen et al., 2008). Carers can have similarly strong negative reactions. Connell et al. (2004) found carers initially reacted with feelings of shock, anger, devastation, and embarrassment at not having known. Many carers also felt grief, anxiety, loneliness and uncertainty about how to deal with after care (Laakkonen et al., 2008).

In contrast, positive reactions to a diagnosis have been reported. Aminzadeh et al. (2007) found a minority of people with dementia felt relieved and validated at knowing their diagnosis. Carpenter et al. (2008) found that there was a significant reduction in symptoms of anxiety for people with dementia and their companions following diagnostic feedback and no significant changes in levels of depression. Carers have also reported that a diagnosis gave them relief and validated their difficulties (Connell et al., 2004). Derksen, Vernooij-Dassen, Gillissen, Olde-Rikkert, and Scheltens (2005, 2006) found carers were able to re-frame the behaviour of their partner with dementia, appreciate their remaining abilities and awareness of good moments in their relationship, and adapt to the carer role following diagnosis. It was an important trigger for thinking about future plans and expressing feelings of grief and loss.

Qualitative research has looked at whether the diagnosis was expected and the impact of expectations on reactions. Ward-Smith and Forred (2005) found that for 11 of the 18 carers in their study the diagnosis was a surprise. They had believed the person was forgetful, depressed or potentially needed a change to their medication. Derksen et al. (2005, 2006) found diagnosis typically confirmed suspicions already held by people with dementia and their partners. For those who did not expect it there was a tendency to feel shocked and threatened initially. Even for those who expected it, diagnosis was an important trigger for thinking about future plans and they were able to express feelings of grief and loss.

Separating the emotional impact of a diagnosis from the consequences of the changes to a person due to their dementia (and hence the burden of care for carers) is problematic. Some statistical evidence for the causal effect of the diagnosis on anxiety reduction was found by Carpenter et al. (2008) who assessed participants pre and post diagnosis. In contrast, Rosness, Ulstein, and Engedal (2009) indicate carer distress was present amongst their sample of spouses of people with cognitive impairment before diagnostic assessment and regardless of whether or not their spouse was ultimately diagnosed with dementia. They found carer distress was associated with their spouse's level of depression, impairment in activities of daily living, and the gender of the carer.

*4.4.2. Adjustment to the diagnosis*

Qualitative research has examined people's adjustment to a diagnosis and found this to be a process that takes place over time. Aminzadeh et al. (2007) identified people with dementia went through stages of awareness and emotional reactions in the days following the diagnosis. Participant responses fell into three categories depending on their appraisal of the diagnosis: lack of insight or denial of diagnosis, grieving or emotional crisis related to actual or anticipated losses (sorrow, fear, guilt, resignation,

hopelessness), and/ or positive coping reactions to maximise outcomes. The researchers hypothesised that over time the response could be either adaptation, or disorganisation and excess disability.

Other studies have described a process of making sense of the diagnosis and adjusting to loss in people with dementia and their carers. Vernooij-Dassen et al. (2006) reported people with dementia struggle to adjust to their losses, particularly their autonomy, and were using coping strategies of minimisation and distraction 12 weeks after the diagnosis. Carers undergo a process of acknowledging the changes to their relationship. They were able to appreciate hope and the remaining capabilities in their partner, but experienced losses of companionship and joy. Robinson et al. (2005) examined the joint experience of 9 married couples and discovered two main themes in adjustment to a diagnosis of dementia: 'not quite the same person, tell me what is actually wrong' and 'everything's changed, we have to go from there'. They identify a cyclical process, whereby couples notice changes in the person with dementia, attempt to deny and minimise what is happening, experience gradual realisation and begin to accept changes as permanent. There is a connected process of acknowledging the losses and focussing on what is left.

## 5. Critique

There are limitations to the research reviewed here on diagnostic disclosure. The varied methodology adds to our understanding of dementia diagnosis; however, it is difficult to compare research findings for qualitative and quantitative literature, and to compare qualitative literature across different epistemologies. The variability in inclusion criteria for participants also leads to difficulties in comparing studies, e.g., categories of participants have included companions, family members and carers. One study included

participants with a family member with neurological problems, some of whom did not have dementia (Lin et al., 2005). Furthermore, the criteria for a 'carer' varied across studies from simply a friend or family member most involved in the assessment for dementia (Aminzadeh et al., 2007) to more defined criteria such as the length of time caring, e.g., they had to be caring for the person for more than one year (Pinner & Bouman, 2003), and the frequency of caring activity, e.g., giving weekly assistance (Mahoney et al., 2005). Some studies did not state inclusion criteria for carers, and their relationship with the person with dementia was not transparent (Shimizu et al., 2008; Bowes & Wilkinson, 2003). Other studies simply labelled a family member of a person with dementia as a carer and did not acknowledge the two may be distinct (e.g., Derkson, 2005, 2006; Rosness, 2009; Vernooij-Dassen et al., 2006).

There are limitations in terms of the generalisability of research findings across different cultures. Studies comparing people from different ethnic backgrounds have found that attitudes and experiences of diagnosis vary (Boustani et al., 2006; Bowes & Wilkinson, 2003; Connell et al., 2009; Mahoney et al., 2005). Diagnostic procedures also vary across countries (Bond et al., 2005; Georges et al., 2008; Rimmer et al., 2005), affecting the generalisability of non-UK findings to the UK. Studies comparing several different countries found that in the UK there was a longer time frame from carers noticing signs of dementia to diagnosis (Bond et al., 2005), people with dementia were less likely to be offered treatment at diagnosis (Rimmer et al., 2005) and they had the highest satisfaction with the information they received (Georges et al., 2008). Furthermore, a systematic difference in research design was found in UK versus non-UK studies when looking at reasons for and against disclosure of a dementia diagnosis, such that UK studies asked open ended questions resulting in single responses (Elson, 2006; Pinner & Bouman, 2003), whereas as non-UK studies allowed participants to choose multiple reasons from a list of options (Connell, Roberts, McLaughlin, & Carpenter, 2009; Lin et

al. 2005). However, typically both UK and international studies used varied methodologies and there were common themes identified across UK and non-UK countries, for example, in carer reaction to a diagnosis (Robinson et al., 2005; Vernooij-Dassen et al., 2006).

It is worth acknowledging that self-reports of service users are not objective accounts of the diagnostic process. Factors such as the strength of a person's emotional response to the diagnosis may interfere with ability to process information given and may impact their reports of this process (Aminzadeh et al., 2007). In addition, the time between diagnosis and data collection in research involving people with dementia. This ranged from an average of 2.7 days to over 2 years (Carpenter et al., 2008; Georges et al., 2008). For this population of people with memory problems issues relating to the diagnosis may be difficult to recall after a period of time (Robinson et al., 2005). Recall bias may also exist for carers, particularly in research considering the triggers to assessment, where researchers have asked carers to reflect on symptoms noticed up to 7 years previously (Clark et al., 2005; Speechly et al., 2008).

### *5.1. Critique of quantitative studies*

The quantitative studies in this literature review were mainly cross-sectional, including surveys (e.g., Speechly et al., 2008) as well as semi-structured (e.g., Pinner & Bouman, 2003) and structured interviews (e.g., Clark et al., 2005). This design has limitations as it provides a snapshot in time only and cannot establish causality, such as whether psychological distress is a result of the diagnosis, or whether mood difficulties pre-dated this and influenced the development of dementia and subsequent diagnosis. Researchers have suggested the possibility that depression could be an early sign of dementia or a risk factor for cognitive decline (Jorm, 2001).

The majority of quantitative studies used convenience samples (e.g., Connell et al., 2009), whereas others selected a random sample registered within an Alzheimer's organisation (Speechly et al., 2008; Georges et al., 2008). Neither method can claim to be representative of the population of people with dementia, as they are not randomly selected from this population. In addition, the sample sizes varied between 36 and 1434 (Elson, 2006; Laakkonen et al., 2008) and this may mean some estimates are more reliable than others. Also, two studies on attitudes to disclosure split the sample so only 5 to 6 participants were questioned about the barriers to diagnosis (Elson, 2006; Pinner & Bouman, 2003). Their attitudes are unlikely to be representative of the population of people refusing a dementia assessment. In many of the studies the majority of participants were female and in some studies females constituted 2/3 or more of the sample (Boustani et al., 2006; Clark et al., 2005; Connell et al. 2009; Georges et al., 2008; Lin et al., 2005; Shimizu et al., 2008; Speechly et al., 2008), which may have led to sample bias. There was a limited response rate in a number of studies, with six studies gaining a response of 50% or less (Clark et al., 2005; Elson, 2006; Koppel& Dallos, 2007; Robinson et al., 2005; Speechly et al., 2008; Ward-Smith & Forred, 2005). There were also a number of studies where the researcher did not specify the response rate (e.g. Rimmer et al., 2005). Few studies assessed whether there were significant differences in the demographic details of responders and non-responders (Aminzadeh et al., 2007; Boustani et al., 2006; Carpenter, 2008; Connell, 2009), although only one study found a significant difference between these two groups with non-responders more likely to be aged over 79 (Boustani et al., 2006).

Of the quantitative studies that directly asked questions of people who have dementia, one study used standardised measures that were found to be valid and reliable with an elderly population, but did not specify their validity for a cognitively impaired population (Carpenter, 2008). Other studies did not specify attempts to establish the

validity of their questions with a cognitively impaired population (Elson, 2006; Pinner & Bouman, 2003).

### *5.2. Critique of qualitative studies*

When assessing the quality of qualitative research, established principles were used (Elliot, Fischer, & Rennie, 1999; Willig, 2001; Yardley, 2000). First, the presentation of the stages of research should be systematic and clear to give transparency and coherence to the data and thus enable the reader to evaluate claims made by the researcher (Yardley, 2000). Second, incorporating verbatim excerpts to illustrate themes adds to the transparency of the findings and grounds the analysis in the data. Third, the rigour of the study, e.g., the appropriateness of the sample and the thoroughness of data analysis, is crucial. Fourth, the reliability of the knowledge generated can be demonstrated through credibility checks (Willig, 2001), e.g., triangulation of analysis through having more than one person coding the data, or through converging different data sources. Fifth, it is important for research to be sensitive to the context for the participant and the researcher, that is, to ground the results in the situation, individual, social, and cultural context. Therefore, qualitative research studies should also address reflexivity, as acknowledging the influence of the researcher's stance and perspective on the research adds to the validity of the findings. The table of qualitative studies in Appendix B incorporates details on whether each study achieved these criteria for quality.

All of the qualitative papers reviewed provided a description of the research methods employed, although some papers gave minimal details on the methods of data analysis, affecting the transparency of the studies (Bond et al., 2005; Bowes & Wilkinson, 2003; Rimmer et al., 2005). The majority of studies grounded their analysis in the data by including excerpts from transcripts. Only one study did not (Robinson et al., 2008). The rigour of the data analysis was improved through data saturation (collecting data until

no new themes emerge) used in some studies working with grounded theory and content analysis approaches (Derksen et al., 2006, 2005; Krull, 2005; Mahoney et al., 2005; Vernooij-Dassen et al., 2006; Ward-Smith & Forred, 2005). Credibility checks were carried out in a number of studies, including triangulating the analysis of different researchers (Derksen et al., 2006, 2005; Connell et al., 2004; Koppel & Dallos, 2007; Robinson et al., 2008, 2005; Vernooij-Dassen et al., 2006), triangulating different sources of data (Aminzadeh et al., 2007) and checking themes with participants (Mahoney et al., 2005; Robinson et al., 2005).

Grounding the data in the context is an important part of interpretative phenomenological analysis, and both studies using this approach discussed the context of participants, including their background, social context and current difficulties (Koppel & Dallos, 2007; Robinson et al., 2005). Case studies also outlined the person's context in detail (Bowes & Wilkinson, 2003; Derksen et al., 2005). All studies gave demographic details of participants and their diagnostic status. Some grounded the findings in the cultural context (Bowes & Wilkinson, 2003; Mahoney et al., 2005). A study by Ward-Smith and Forred (2005) outlined in detail the diagnostic context and the influence of this on participant experience. Few studies reflexively addressed the impact of the researcher. In three studies the possibility of researchers having an impact on participant reports and analysis of data was acknowledged by researchers; however, specific examples from their research were not provided (Koppel & Dallos, 2007; Mahoney et al., 2005; Robinson et al., 2005). One study outlined participant reports of meeting the researcher and the potential effect on their interviews (Vernooij-Dassen et al., 2006).

## 6. Discussion

Despite the limitations of research on dementia diagnosis there are a number of consistent themes across the literature. The thoughts and responses of carers to the initial signs of dementia in a relative can be barriers to seeking assessment. A pivotal event often triggers assessment seeking, leading to increased awareness and reduced possibility of normalisation. Normalising allows people to cope with threat by minimising it and attributing changes to other things. This process has been described as a method of coping used by people with dementia (Clare, Roth, & Pratt, 2005). In Keady and Nolan's (1995) model of adjustment to dementia the first stages of 'slipping' and 'suspecting', reflect recognition of symptoms and attempts to normalise or discount these. They report that these attempts become less successful as symptoms become more frequent or severe. In the next stage people with dementia actively try to 'cover up' these symptoms from family members before 'revealing' them and then 'confirming' them through seeking outside help and getting a diagnosis. Considering the literature in this review, it may be that a parallel process exists for family members in order to manage the threat of dementia.

People who have sought an assessment of their cognitive difficulties may still not wish to be told if they have dementia. People with dementia and their carers cite a number of benefits and barriers to seeking diagnostic disclosure. Some of the benefits were common to the findings of Bamford et al. (2004) in a previous literature review, i.e., to enable planning, treatment and a person's right to know. The anticipation of psychological benefits of knowing a diagnosis was not a theme in this review. The risk of psychological distress and stigma related to dementia were common barriers to seeking a diagnosis outlined in both reviews. This evidence supports the findings of the DOH (2009) that stigma surrounding dementia has an influence on the number of diagnoses given.

Satisfaction with the diagnostic process varies for people with dementia and their carers and this has been linked to factors such as information provision, sensitivity of the physician, and involvement in the diagnostic process. The first two themes were found in the Bamford et al. (2004) review. Pratt and Wilkinson (2003) argue that when people have the desire and ability to know the diagnosis it is detrimental to withhold this, and this may include withholding information on factors such as progression of dementia.

This review found evidence for both positive and negative impacts of a dementia diagnosis for people with dementia and their carers, such as shock and distress or relief and validation, similar to themes identified by Bamford et al. (2004); however, research included in this review in the weeks following the diagnosis has also shown the impact of the diagnosis should be seen as a process of adjustment over time. Keady and Nolan (1995) outline that following the diagnosis the person with dementia goes through a process of 'maximising' coping strategies; however, the results of the current literature review suggest that the process of adjustment to a diagnosis is complex and some people may not use adaptive coping strategies, which could lead to excess disability.

The variability in the impact of a diagnosis, suggests there may be individual differences that affect outcomes. Differences in people's beliefs about dementia may be one explanation, which is supported by a study that found emotional responses varied according to appraisal of the diagnosis (Aminzadeh et al., 2007). The impact of beliefs on emotional and behavioural responses following a health threat, such as a diagnosis, has been reported across a wide variety of health conditions (Hagger & Orbell, 2003). The Common Sense Model (CSM) by Leventhal, Meyer, and Nerenz (1980) indicates people form illness representations or 'lay' illness beliefs in response to health threats, which help them to make sense of their illness and influence coping strategies. Qualitative research has found that in people with dementia the illness representations

of a chronic timeline, severe consequences, and low controllability impact upon the coping strategies they adopt and their sense of self (Harman & Clare, 2006). Clare, Goater, and Woods (2006) also found preliminary evidence of a link between representations of control, the adoption of fewer coping strategies and mood, as those believing "nothing can be done" were more likely to score in the clinical range for depression or anxiety. There is some indication that illness representations are also held by carers of people with dementia (Roberts & Connell, 2000).

### *6.1. Clinical implications*

Considering the length of time typically taken between carers noticing the first signs of dementia and accessing assessment and the fact that medical treatment is only found to be beneficial in the early stages of AD, these findings emphasise the importance of increasing public awareness of the symptoms of dementia to remove some of the barriers to diagnosis such as uncertainty, opportunities to normalise symptoms and stigma. In addition, the perspectives and needs of black and minority ethnic groups in accessing services for dementia assessments and diagnosis should be considered. These findings fit with the recommendations of the DOH (2009) National Dementia Strategy. There are also implications from this review for the disclosure process itself. There is variability amongst people with dementia and their carers as to whether or not they want diagnostic disclosure. This therefore needs to be a choice and should not be assumed. Evidence suggests diagnosing physicians typically need to provide more information to people desiring diagnostic disclosure, such as on dementia, prognosis, treatments and available services. It may be beneficial to assess the beliefs and expectations of people with dementia and their carers before starting the diagnostic process, as these could influence the emotional impact of disclosure.

There are indications that ongoing emotional support may be needed for people with dementia and carers who have difficulty adjusting to the diagnosis. For example, psychological interventions such as cognitive behavioural therapy have been found to improve psychological distress in dementia (Kraus et al., 2008; Walker, 2004) and teaching carers coping strategies can improve psychological health (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007).

### *6.2. Future research*

In order to further our understanding of motivations to seek a dementia diagnosis, the process of disclosure and the impact on people with dementia and their carers, future studies should adopt longitudinal designs. This would be beneficial in establishing the direction of relationships and limiting the effects of recall bias. Using larger sample sizes with people who have dementia and assessing the differences between responders and non-responders is likely to improve the representativeness of the research findings. Research should be clear as to the inclusion criteria for 'carers' to improve the transparency of the findings. In addition, qualitative research on dementia diagnosis could benefit from increased reflexivity.

Further research is needed to specifically evaluate UK memory services and assess whether the diagnostic processes used at these specialist diagnostic services, as recommended by NICE and SCIE (2006), are satisfactory and potentially help to reduce the impact of disclosure on people with dementia and their carers. There have been more studies since the review by Bamford et al. (2004) that have included people with dementia in research; however, this is still a limited area of research. Wilkinson (2002) noted that the voices of people with dementia have typically been excluded and proxies used, which reinforces power imbalances and negative stereotypes relating to the incapacity of people with dementia. More research is needed to gain insight into their

experiences and how the diagnostic process can best meet their needs. In order to develop quantitative research with this client group there is a need to develop measures that are valid and reliable in people with dementia. Finally, it is possible that a person's beliefs about dementia may influence the outcome of a diagnosis on psychological adjustment. Further research could clarify the relationship between individuals' beliefs and the emotional or coping outcomes of receiving a diagnosis.

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# Research Report

# Illness Representations and Adjustment to Dementia

## 1. Abstract

**Aim:** Dementia is a progressive condition that can have a severe impact on people's lives. A quantitative study was conducted to assess whether the Common Sense Model of illness representations (Leventhal, Meyer, & Nerenz, 1980) was related to psychological adjustment to dementia.

**Methods:** Participants (N = 49) were recruited from UK memory services approximately 6 months after being given their diagnosis of dementia. A cross-sectional design was employed. Participants completed questionnaire measures of illness representations, coping behaviours and psychological distress.

**Results:** A regression analysis indicated negative cognitive representations of consequences and identity and negative emotional representations explained large proportions of the variance in anxiety ($R^2$ = .35, p = .001) and depression ($R^2$ = .35, p = .001), with emotional representations making a significant unique contribution to the variance explained in depression. Avoiding or restricting activities was significantly associated with emotional representations and greater psychological distress, but was not found to mediate the relationship between the two.

**Conclusions:** This study has implications for the CSM as a model for understanding people's perception of dementia. It provides a cross-sectional analysis of the cognitive and emotional representations people hold and their association with coping behaviours and psychological distress. There is a need for further research on how clinicians might support people to develop positive representations and adaptive coping behaviours in order to promote psychological adjustment to dementia.

## 2. Introduction

Dementia is a long-term progressive condition that involves a decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal ageing (The Alzheimer's Society, 2008). Symptoms include altered language ability, memory, thinking and judgement (WHO, 1992) as well as psychological and behavioural changes, e.g., psychosis, aggression, wandering (Department of Health, 2009). It has been estimated that 36 million people have dementia worldwide (Wimo, Winbald, & Jonsson, 2009). It is one of the main causes of disability in people aged 60 years and older (WHO, 2008). Risk factors for onset include a person's age, medical history, genetics and lifestyle (Knapp & Prince, 2007). There are several types of dementia. Alzheimer's disease (AD) and Vascular dementia (VD) are the most common types. Others include dementia with Lewy Bodies, Fronto-temporal dementia, and dementia in Parkinson's disease (Department of Health [DOH], 2009).

In the UK, the proportion of the population with the condition has been estimated to be 1.1% (approximately 700,000 people; Knapp & Prince, 2007). It is most common in older people, affecting one in twenty people over 65 years old and one in five people over 80 (Knapp & Prince, 2007). The current cost to the economy has been estimated at £17 billion, of which 41% relates to accommodation costs, 36% to informal care, 15% to social services and 8% to the NHS (Knapp & Prince, 2007). By 2036 the prevalence rates for dementia could potentially double to 1.4 million and the cost treble to over £50 billion.

The recent development of medication that can delay the progression of symptoms in people with Alzheimer's disease (acetylcholinesterase inhibitors; NICE, 2006) has led to an increased need to focus on early assessment and disclosing diagnoses (Bamford et

al., 2004). However, the UK National Audit Office (NAO, 2007) estimated only one third of people with dementia receive a diagnosis and have contact with specialist services; moreover, this typically occurs in the later stages of dementia.

### *2.1. Psychological Distress and Coping with Dementia*

The association between dementia and psychological distress has been found in a number of studies. Depression is often seen co-morbidly with dementia (Lovheim, Sandman, Karlsson, & Gustafson, 2008; Stroud, Steine, & Iwuagwu, 2008) and is more common in older adults with dementia than those without (Lyketsos, 2000). Prevalence rates have varied; for example, one study found clinically significant depressive symptoms in 20% of people with dementia (Arbus et al., 2008), whereas another study found 26% of people with dementia had major depression and 26% minor depression (Starkstein, Jorge, Mizrahi, & Robinson, 2005). The occurrence of depression amongst people with dementia has been associated with increased wandering and behavioural disturbance (Lyketsos et al., 1997), functional impairment and social dysfunction (Starkstein et al., 2005). The possibility that depression could be an early sign of dementia or a risk factor for cognitive decline has been suggested (Jorm, 2000). However, recent research investigating the temporal relationship between the two indicates they are not associated prior to the development of dementia (Becker et al., 2009; Wilson, Arnold, Beck, Bienias, & Bennett, 2008).

Anxiety is also more common in older adults with dementia than those without (Lyketsos, 2000). In a critical review of the literature on anxiety amongst people with dementia, Seignourel, Kunik, Snow, Wilson, and Stanley (2008) found prevalence rates for anxiety symptoms varied from 8 to 71% and for anxiety disorders from 5 to 21%. Common worries following a diagnosis of dementia relate to others finding out they have dementia, social embarrassment and long-term dependency (Husband, 2000).

Anxiety in this population is associated with a lower quality of life (Missotten, 2008), increased dependence (Kraus et al., 2008; Orrel & Bebbington, 1996), problems in the carer relationship (Orrel & Bebbington, 1996) and impairment in activities of daily living (Teri et al., 1999). Anxiety and depression are frequently found to occur co-morbidly in people with dementia (Cairney, Corna, Veldhuizen, Herrmann, & Streiner, 2008; Ferretti, McCurry, Logsdon, Gibbons, & Teri, 2001).

The impact of the severity of dementia on psychological well-being has been investigated in some studies although the relationship is unclear. A study conducted by Zank and Leipold (2001) indicated people with mild dementia reported lower life satisfaction and more depressive symptoms than those with more severe dementia. Other research has offered evidence for higher rates of depression in the middle stages of cognitive deterioration (Lovheim et al., 2008). Bierman, Comijs, Jonker, and Beekman (2007) indicated there is a pattern of increased prevalence of both anxiety and depressive symptoms until the severe stages of dementia where they decrease. One possible explanation for this relationship with severity is due to preserved insight in the early stages of dementia, as an association has been found between awareness of cognitive and functional deficits and increased levels of anxiety and depression (Harwood, Sultzer, & Wheatley, 2000; Seignorel et al., 2008). In contrast, Starkstein et al. (2005) found increased social and functional impairments were associated with more depressive symptoms in people with dementia. Finally, some research has found the severity of cognitive impairment does not relate to depression and anxiety (Carpenter et al., 2008; Cummings, Ross, Absher, Gornbein, & Hadjiaghai, 1995).

Psychological distress in dementia may vary according to age, with one study finding greater anxiety and depression in younger people (Savva et al., 2009). Another study found a gender association such that women were more likely to experience depressive

symptoms than men (Fuhrer, Dufouil, & Dartigues, 2003). However, the majority of evidence suggests both these factors are not significantly related to psychological distress in dementia (Seignorel et al., 2008). There may be a potential link between ethnicity and psychological distress, with anxiety being more prevalent in Hispanics and Asians who have dementia rather than African-Americans and Caucasians with dementia (Seignorel et al., 2008). In terms of differences according to diagnosis, participants with vascular dementia have reported higher rates of depression (Lyketsos, 2000) and higher rates of anxiety (Seignorel et al., 2008) in comparison to those with Alzheimer's disease. It has been hypothesised that this may reflect the areas of the brain affected by the disease as VD affects the subcortical areas of the brain believed to be affected in mood disorders (Lyketsos, 2000).

Adjustment to having dementia, the realisation of what the diagnosis means and the development of strategies to manage the stresses and life changes involved, can be seen as a process that takes place over time (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). Whilst the diagnosis of dementia can result in psychological distress (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Pratt & Wilkinson, 2003), it can also put an end to uncertainty, enable planning of short-term goals (Husband, 2000), allow individuals to access dementia services, and provide people with the opportunity to develop more effective coping strategies (Pratt & Wilkinson, 2003). Aminzadeh et al. (2007) identified three categories of responses people have in the days and weeks following a diagnosis, dependent on their appraisal of the diagnosis: (i) lack of insight or denial of the diagnosis, (ii) grieving or emotional crisis related to actual or anticipated losses (sorrow, fear, guilt, resignation, hopelessness), and (iii) positive coping reactions to maximise the outcome.

A popular model by Lazarus and Folkman (1984) separates the ways people cope when under stress into two types of coping: problem-focussed coping (i.e., being active in altering the source of stress) and emotion focussed coping (i.e., managing emotional distress). Researchers have also made the distinction between active and passive coping (e.g. relinquishing control and avoidance) in chronic health conditions (Brown & Nicassio, 1987; Katz, Ritvo, Irvine and Jackson, 1996). Maes, Leventhal and De Ridder (1996) report the literature on coping and chronic illness is fairly consistent in supporting associations between avoidant emotion-focussed coping with increased difficulty adjusting to chronic illness and active problem-focussed coping and positive adjustment, although they report there is less evidence for the latter. However, there is minimal research on coping and psychological well-being in people with dementia, although coping through problem-solving has been found to have a positive impact on self-confidence (Clare, 2002).

It has been suggested that cognitive functioning has an influence on a person's ability to use adaptive coping strategies in response to stressful events (Rabinowitz & Arnett, 2009). However, research has shown people with dementia can use effective coping strategies to preserve their psychological well-being and self-identity, including problem-solving approaches as well as those that work on an emotional level (Clare, 2002). In a study examining coping behaviours in response to situations that require the use of memory, Oyebode, Motala, Hardy, and Oliver (2009) found that people with Alzheimer's disease were more likely to use active problem-solving and relying on themselves or their carers, rather than concealment and avoidance. Level of cognitive functioning may influence the type of coping behaviour used, with those who have better cognitive functioning using more problem-solving strategies, and those who have worse cognitive functions attempting escape strategies and emotional control (de Souza-Talarico, Chaves, Nitrini, & Caramelli, 2009).

### *2.2. Common Sense Model*

The psychological well-being of people with dementia, as with other chronic health conditions, is affected by people's perceptions of their condition (Clare, Goater, & Woods, 2006). Research in health psychology indicates that when individuals experience symptoms of ill health and are given diagnoses they form beliefs about the illness. These beliefs impact upon their emotional and behavioural responses (Hagger & Orbell, 2003; Petrie, Weinman, Sharpe, & Buckley, 1996). Leventhal et al. (1980) developed the Common Sense Model (CSM) of illness representations to explain people's reactions to health threats. The CSM outlines three stages to how people react/adjust to health threats: first, *representations* of their illness (cognitive and emotional) are formed when individuals experience an internal or external health threat; second, these representations influence *coping* behaviours; and third, a process of *reappraisal* takes place where coping methods are monitored, which feeds back to and influences illness representations.

The CSM proposes the formation of cognitive illness representations or 'lay' illness beliefs is a key component to the process individuals undergo in order to make sense of their symptoms. They are formed when an individual experiences symptoms of the illness and will change as the illness progresses and they attempt to treat or moderate it. Leventhal et al. outlined five dimensions of illness representations: *identity,* the label given to the illness and symptoms; *cause,* beliefs about the reasons for the onset of illness; *timeline,* ideas regarding the duration of the illness and whether it is acute, cyclical, or chronic; c*onsequences* a person's expectations for physical, psychological, social, and economic outcomes (including day-to-day and long-term implications); and *control/cure,* beliefs and expectations regarding recovery or attempts to bring an illness under control. Alongside cognitive representations, there is a parallel process of emotional representations of the illness, (e.g., worry, anger), which can influence coping

and emotional outcomes (Hagger & Orbell, 2003). Subsequent research by Moss-Morris et al. (2002) suggested that the control/cure dimension may be comprised of two dimensions of personal control beliefs and treatment control beliefs. Moss-Morris et al. (2002) also highlighted the importance of whether a person had a coherent understanding of their condition.

Illness representations guide coping efforts, that is, the specific behavioural actions taken by a person, which help them to recover from an illness and improve their health (Leventhal, Leventhal, & Contrada, 1998). For example, the representation of illness as an acute infection may lead to coping behaviours such as a person taking medication to destroy the bacteria causing the infection and rest to recuperate energy levels. A person experiencing colon cancer, which is seen as chronic and caused by internal cell changes, may adopt coping behaviours that may have a longer term impact, such as exercise to strengthen their body or positive thinking to help their immune system. These are common sense health behaviours that are seen as a necessary and appropriate response to their condition as they perceive it (Leventhal, Diefenbach, & Leventhal, 1992).

Many studies have investigated the CSM and links between illness representations, coping, and physical and psychological outcomes have been found in chronic conditions, including allergies (Knibb & Horton, 2008), kidney disease (Fowler & Baas, 2006), Addison's disease (Heijmans, 1999), multiple sclerosis (Vaughan, Morrison, & Miller, 2003) and severe mental illness (Lobban, Barrowclough, & Jones, 2003). A meta-analysis conducted by Hagger and Orbell (2003) reviewed 45 studies on the CSM. Considering the link between illness representations and health outcomes, perceptions of control were associated with greater psychological well-being, vitality and social functioning, less psychological distress and lower scores on objective measures of illness status. Illness identity, timeline and consequences were negatively associated

with psychological well-being, vitality, social and role functioning. Considering the relationship between illness representations and coping behaviours, the meta analysis revealed that a strong illness identity (i.e., regarding the illness as highly symptomatic), a chronic timeline and the perception of serious consequences were associated with avoidance and coping through emotional expression. Belief in the controllability of the illness was associated problem-focussed coping behaviours, cognitive reappraisal and expressing emotions.

The CSM indicates illness representations may both have a direct, and an indirect, impact on health outcomes, via coping behaviours. Thus, people's illness representations may determine the specific coping behaviours they engage in which, in turn, determine psychological adjustment. The evidence to support this mediation hypothesis is mixed. Hagger and Orbell (2003) reported no evidence for a mediation effect in three cross-sectional studies. However, other research has provided some evidence for a meditational effect. For example, Evans and Norman (2009) investigated the CSM with people with Parkinson's disease and found avoidant coping mediated the effect of emotional representations on anxiety and resignation coping mediated the effect of consequences and emotional representations on depression in a cross-sectional analysis. However, no mediation effect was found when prospective analyses were conducted.

### *2.3. Common Sense Model and Dementia*

To date only two qualitative studies have examined illness representations among people with dementia. Illness representations have been viewed as important when adjusting to and coping with early-stage dementia. Harman and Clare (2006) examined illness representations and the lived experience of 9 people with early-stage dementia. Two main themes emerged relating to an understanding of dementia "it will get worse"

and maintenance of identity “I want to be me”. The authors interpreted the first theme to reflect the timeline, consequences, and controllability dimensions of the Common Sense Model and the second theme to reflect the consequences dimension. In addition, they reported that participants were very uncertain as to the identity of their dementia and a range of perceived causes were outlined. They proposed that illness representations enable people with dementia to comprehend their daily experiences and the impact of dementia. Representations are maintained or adapted depending upon day-to-day experiences which further understanding. Illness representations and lived experience impact upon coping and sense of self, as the person attempts to maintain their sense of self whilst experiencing dementia related changes.

Clare et al. (2006) interviewed 22 people with dementia to explore the 5 main dimensions of illness representations outlined by Leventhal et al. (1980) and assessed psychological distress using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Content analysis of the interviews provided evidence to suggest that participants held illness beliefs in line with the CSM. For example, more than half of the participants felt their memory problems had *consequences* for them emotionally and affected their daily life. In addition, the majority of participants described adopting specific coping behaviours to deal with their memory problems, including: writing things down, using specific memory strategies or cues, attempting to maintain a normal routine of activities, relying on others, taking medication, and avoiding or restricting activities to limit the opportunities for them to experience difficulties. There was some preliminary evidence indicating those who believed that “nothing can be done” were more likely to score in the clinical range for depression or anxiety. The authors recommended that further research should be conducted with a larger sample and structured questionnaire specific to people with dementia in order to quantify the illness

representations of people with dementia and to assess the strength of the relationships with other variables, such as coping behaviours and mood.

### *2.4. Present Study*

Receiving a diagnosis of dementia is a difficult process of adjustment. It can cause psychological distress for the person with dementia, the level of which may be influenced by the severity of cognitive symptoms. Illness representations have been shown to influence adjustment to chronic illness and qualitative research has indicated relationships may exist between illness representations, coping behaviours and psychological well-being among people with dementia (Clare et al., 2006; Harman & Clare, 2006). It is important to consider ways to help people to adjust following a diagnosis of dementia and minimise negative outcomes, such as psychological distress and poor quality of life. Research on the CSM may help to inform clinical practice by understanding the illness representations that lead to more successful coping/emotional adjustment (Hale, Treharne, & Kitas, 2007; Wearden & Peters, 2008). It may also assist clinicians when aiming to facilitate the construction of illness representations that lead to positive outcomes for this client group, such as through adding an extra component to cognitive behavioural therapy (CBT; Goodman, Morrissey, Graham, & Bossingham, 2005).

This study was designed to assess whether the CSM is a useful model for understanding people's reactions to dementia where the primary symptoms are cognitive and the condition is likely to deteriorate. The present study will advance the research conducted by Clare et al. (2006) and attempt to quantitatively evaluate the role of illness representations in adjustment to dementia.

The aim of this study is to assess whether illness representations are associated with psychological adjustment to a diagnosis of dementia and the adoption of specific coping behaviours. The study will also evaluate whether the use of specific coping behaviours mediates the impact of illness representations on psychological distress.

## 3. Hypotheses

1. Negative illness representations (e.g., strong illness identity, chronic timeline, serious consequences) will be associated with higher levels of anxiety and depression for people diagnosed with dementia.

2. Positive illness representations (e.g., strong perceptions of personal and treatment control) will be associated with greater use of specific coping behaviours (i.e., practical strategies to deal with memory problems) whereas negative illness representations (e.g., strong illness identity, chronic timeline, serious consequences) will be associated with a greater use of avoidant forms of coping.

3. The use of specific coping behaviours (i.e., practical strategies to deal with memory problems) will be associated with lower levels of anxiety and depression, whereas the use of avoidant forms of coping will be associated with higher levels of anxiety and depression.

4. Coping behaviours will mediate the effect of illness representations on anxiety and depression.

## 4. Method

Ethical approval for this study was gained from the South Yorkshire Research Ethics Committee (see Appendix C).

### *4.1. Participant recruitment and procedure*

The participants were recruited from the two Memory Services, in the North and South of Sheffield, which are part of Sheffield Health and Social Care NHS Foundation Trust. These are multi-disciplinary community assessment centres, which take referrals for adults, 65 years and over, who are showing signs of dementia. The aim of these services is to increase the number of people who receive early assessment and diagnosis of dementias, provide pharmacological treatments for people with Alzheimer's disease (acetylcholinesterase inhibitors) and provide follow-up clinics to assess and manage these. In addition, the services offer support for people with dementia and their carers and talking treatments on a group basis. The services are run in line with NICE (2006) guidelines for the management of dementia. Service users visit the centre initially for a pre-diagnostic counselling session. They may then decide to have a dementia assessment, which may take a few sessions. This is followed by a session where they will receive feedback and possibly a diagnosis of dementia and follow-up monitoring sessions. The length of time between follow up sessions can vary depending on the client's needs, but there is typically a session six months following post-diagnostic feedback where they are given a repeat Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) to assess whether there has been further cognitive decline, or whether their medication may have been effective in reducing this.

The participants were consecutive service users who had a diagnosis of dementia, had not had any recent judgements that they lacked capacity (as identified by the nursing staff) and attended on Thursdays for a six month follow-up session between 29 October 2009 and 1 July 2010. This was the main clinic day for these appointments. Memory Service users were sent a letter informing them that they were going to be asked to take part in a research study at their clinic appointment. The information sheet was included with the letter (Appendix D). After their session at the Memory Clinic the staff member

taking the session asked the patient if they would be interested in taking part in the research. Those who indicated that they would potentially be interested were then introduced to the researcher by the staff member. In order to identify whether patients had insight into their condition, the researcher first asked patients whether they were aware of why they were at the memory clinic and whether they had been given a diagnosis relating to any memory problems. The researcher then went through the information sheet with them, checked they were able to retain and understand the information provided long enough to make the decision to engage in the research and that they could communicate their decision. The researcher asked if they had any questions about the research and requested that they complete the consent form (Appendix D) if they wished to take part in the study. Those who agreed to participate then completed the questionnaires with the researcher.

The inclusion and exclusion criteria were as follows: participants were aged 65 years and older, were given a diagnosis of dementia at the memory service, attended the memory clinic for a follow-up session, had some level of insight into their diagnosis and experience, could understand the questions asked and response options, and were able to provide informed consent. Participants were excluded if they were unable to answer the questions themselves.

A total of 97 potential participants were approached about the study. Of these 23 denied having any type of dementia; 2 did not appear to have capacity and reported they could not understand the information given; 6 decided not to take part; and 17 cancelled their appointment at the memory service. This left a total of 49 participants who completed the questionnaires and formed the final sample for this study.

### *4.2. Measurements*

#### *4.2.1. Illness representations*

The Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) measures five dimensions of Leventhal's (1980) cognitive illness representations as well as emotional representations and illness coherence (see Appendix E). The BIPQ is a generic scale using the word 'illness' to refer to a person's health condition; however, the authors indicate that is can be made more specific by replacing this word with the particular illness or condition being studied. In this study the word 'illness' was replaced with 'dementia'. There are nine items, six of which assess cognitive illness representations: perceived consequences (i.e., *examples removed due to copyright*), timeline (i.e., *examples removed due to copyright*), personal control (i.e., *examples removed due to copyright*), treatment control (i.e., *examples removed due to copyright*), the identity given to the illness (i.e., *examples removed due to copyright*), and perceived cause (i.e., *examples removed due to copyright*). Two items assess emotional representations: concern (i.e., *examples removed due to copyright*), and emotional response (i.e., *examples removed due to copyright*). One item assesses understanding of the condition (i.e., *examples removed due to copyright*). Responses are given on 11-point response scales ranging from 0 (e.g., *examples removed due to copyright*) to 10 (e.g., *examples removed due to copyright*) for all of the items with the exception of the perceived cause item which asks respondents to list potential causes of their condition. Responses on the individual items were scored so that high scores indicated higher levels on each item (e.g., more consequences, longer timeline, and stronger treatment control). However, when combining items to produce a total score on the BIPQ, the personal control, treatment control and understanding items were reverse coded so that high BIPQ total scores indicated more negative illness representations.

In the development of the BIPQ, Broadbent et al. (2006) indicated that the questionnaire was designed to be more suitable to use with the elderly as it is less cognitively demanding and quicker to complete than the full version, the Revised Illness Perception Questionnaire (IPQ-R) developed by Moss-Morris et al. (2002), which has over 80 items. The reliability and validity of the BIPQ has been assessed with adults of varying ages, including adults over 65 years, with a variety of health conditions. Broadbent et al. (2006) report the BIPQ has good concurrent validity when compared with the IPQ-R. It has also been found to have good test-retest reliability amongst renal patients, with significant test-retest correlations at three and six weeks (correlations varied between .42 and .75, $p < .01$). Good predictive validity was found, with the BIPQ demonstrating significant correlations with various outcomes, such as cardiac anxiety and quality of life, in patients with myocardial infarction. In addition, Petricek et al. (2009) found that the BIPQ scale items predicted health outcomes in adults with a mean age of 63 years (SD = 10.9 years).

*4.2.2. Coping behaviours*

A measure of coping behaviours was constructed for the purpose of this study to be specific to the experience of people with dementia. This is in keeping with the Common Sense Model, which indicates people adopt specific coping behaviours to manage a health threat. The use of illness-specific coping measures is also supported in some of the literature on chronic illness. For example, Heijmans (1999) concluded from her research on Addison's disease that the best method for measuring coping may be "in behavioural terms rather than as general strategies" (p147). Generic coping measures have also been criticised for their limited sensitivity when measuring the ways people cope with particular diseases (Maes et al., 1996). In the qualitative research on illness representations and dementia conducted by Clare et al. (2006), people reported adopting a range of specific coping behaviours to help with difficulties experienced following the

development of dementia. The dementia-specific measure developed for the present study was based on the coping behaviours identified by Clare et al. There were six items that asked the extent to which participants used the following specific coping behaviours to help them deal with their condition: writing things down, using specific memory strategies or cues, maintaining a normal routine or activities, relying on others, taking medication, and avoiding or restricting activities. Participants were also asked whether there was anything else they did to cope with their dementia/ memory problems. The frequency of the use of the specific coping behaviours were assessed on 4-point likert scales ranging from 1 = I usually don't do this at all to 4 = I usually do this a lot. Thus high scores on each item indicated high use of the specific coping behaviour.

*4.2.3. Psychological distress*

The Hospital Anxiety and Depression (HAD) Scale (Zigmond & Snaith, 1983), is a standardised assessment tool with 14 items designed to separately assess the severity of anxiety (7 items, e.g., *examples removed due to copyright*) and depression (7 items, e.g., *examples removed due to copyright*) in people with co-morbid health problems. Responses are given on four point (0–3) response categories and the possible scores ranged from 0 to 21 for anxiety and for depression. Cut off scores are 8, 11, and 15 for mild, moderate and severe anxiety and depression respectively. The authors reported good test-retest reliability with correlations of .89 for the anxiety scale and .92 for depression scale. Good internal consistency for the measure was found in a study of 568 people with cancer by Moorey et al. (1991) (Cronbach's alpha was .93 for the anxiety scale and .90 for depression scale). A factor analysis also indicated good construct validity for the two scales.

The HADS, although originally designed to assess anxiety and depression in people aged 16 to 65 in hospital outpatient settings, has been validated across a number of

settings and with elderly samples. Spinhoven et al. (1997) conducted a large scale study and found the reliability of the scale was stable across age groups (including 57 – 65 year olds, and over 65s). It has been validated with a cognitively impaired elderly population who have experienced a stroke (Aben, Verhey, Lousberg, Lodder, & Honig, 2002**)** and researchers have also used the HADS to assess anxiety in people in the early stages of dementia (Clare et al., 2002; Wands et al., 1990).

*4.2.4. Severity of cognitive impairment*

The Memory Clinic nursing staff routinely conduct the MMSE (Folstein et al., 1975) at six-month follow-up appointments to track changes in cognitive impairment and measure the impact of the acetylcholinesterase inhibitors. This 30-item measure is grouped into categories of orientation, registration, attention and calculation, recall, language, and visual construction. Scores from the MMSE were used in this study as a measure of the severity of cognitive impairment. The maximum score is 30 and lower scores indicate greater severity of cognitive impairment. NICE guidance (2006) indicates a score of 21-26 indicates mild cognitive impairment, 11 to 20 moderate impairment and 10 or below severe impairment. An internal consistency reliability score of $\alpha = .81$ for people with Alzheimer's disease was reported in a study by Tombaugh, McDowell, Kristjansson, and Hubley (1996). Tombaugh and McIntyre, (1992) reported test-retest reliability estimates of between .80 and .95 in their review. Research comparing the MMSE with the Clinical Dementia Rating has found high levels of agreement for mild (kappa=0.62, $p<0.001$), moderate (kappa=0.69, $p<0.001$) and severe cognitive impairment (kappa=0.76, $p<0.001$) (Perneczky et al., 2006).

*4.2.5. Demographics*

Demographic and basic clinical details were ascertained, including age, gender, marital status, ethnicity, education and length of time since diagnosis.

### *4.3. Design and Analysis*

This is a cross-sectional study. To assess whether illness representations (as measured by the BIPQ) are related to psychological distress (HADS) and the adoption of coping behaviours and whether coping mediates the effect of illness representations on psychological distress following a diagnosis of dementia, the following analyses were conducted. Illness representations, use of coping behaviours, clinical variables (severity of dementia, time since diagnosis), and demographics (e.g., age, marital status), were firstly correlated with anxiety and depression. Independent sample t tests were used to compare levels of anxiety and depression between groups (e.g., those who did and did not report a cause for their dementia). Variables that correlated significantly were entered into the hierarchical regression analyses to assess the extent to which they explained variance in anxiety and depression. Predictors were entered in blocks using the direct entry method. This approach enables the analysis of the amount of variance explained by sets of predictors over and above others based on theoretical considerations. Any significant demographic or clinical variables were entered in block one of the regression analyses, significant illness representations were entered in block two and significant coping behaviours in block three. It was therefore possible to assess whether illness representations significantly increased the amounts of variance explained in anxiety and depression when demographics were controlled for and whether coping behaviours explained additional variance when demographics and illness representations were controlled for.

To assess whether coping mediated relationships between illness representations and psychological distress (i.e., anxiety and depression) the four step procedure for assessing meditation proposed by Baron and Kenny (1986) was followed. First, illness representations were entered into a regression equation as a predictor, with anxiety/depression as the criterion variable, to assess whether there was an effect to be

mediated. Second, illness representations were entered in the regression equation with coping behaviour as the criterion variable. Third, illness representations and coping behaviours were entered as predictors with anxiety/depression as the criterion variable to establish the effect of coping behaviours on anxiety/depression, whilst controlling for illness representations. Finally, to establish mediation, the effect of illness representations on psychological distress should be non-significant when coping behaviour is controlled for and this is established using the same regression equation as in step three.

*4.3.1. Power Analysis*

Given the small sample size (N = 49), a prospective power analysis was conducted to establish the number of independent variables that could be entered into the regression analyses predicting anxiety and depression. The relationship between illness representations, coping and psychological adjustment to Parkinson's disease was researched by Evans and Norman (2009). They reported illness representations and coping yielded effect sizes of $R^2$ = .49 when explaining variance in anxiety and $R^2$ = .50 when explaining variance in depression for people with Parkinson's disease. These are very large effect sizes and therefore this study assumed a large effect size. With a sample size of 49, a regression analysis with 7 independent variables would be able to detect a large effect size of $R^2$ =.26 (equivalent to $f^2$ = .35), with alpha set at .05 and power set at .80 (Cohen, 1992), As a result, only those variables that correlate significantly with anxiety/depression were entered into the regression analyses in order to reduce the number of independent variables and to ensure that the analyses were adequately powered.

## 5. Results

### *5.1. Data screening*

Data screening was carried out to ensure the study variables were normally distributed. Five measures were found to be significantly skewed. Scores for anxiety on the HADS were moderately positively skewed ($z = 3.93$, $p < .001$). The data was positively skewed on two coping items: the use of memory strategies ($z = 3.29$, $p < .001$), and avoiding or restricting activities ($z = 3.01$, $p < 0.01$). A square root transformation reduced the level of skewness to non-significance on all of these measures. Data was negatively skewed on two of the coping items: maintenance of routine ($z = -3.46$, $p < .001$) and taking medication ($z = 7.37$, $p < .001$). A square root transformation reduced the level of skewness to non-significance on the maintenance of routine. This transformation was multiplied by -1 to ensure the direction of the relationship remained the same in relation to the other variables. It was not possible to reduce the skew on taking medication to a non-significant level. Therefore, a dichotomous transformation was used and the measure was divided into frequent (response 4) and non-frequent use (responses 1 to 3) of medication to assist coping. Transformed variables were used in all subsequent correlation and regression analyses. However, the non-transformed means and standard deviations are presented in Table 2, for clarity of interpretation.

The independent variables were checked for multicollinearity prior to interpreting the regression analyses. Firstly, this was done through examining correlations between the variables. None of the variables were highly correlated ($r < .70$). Secondly, the following collinearity diagnostics were run and examined for all regression analyses: variance inflation factor, tolerance, condition indexes and variance proportions. These tests did not indicate any substantial collinearity between the variables. In addition, the residuals scatterplots for each regression analysis were examined to assess for

normality, linearity and homoscedasticity. The scatterplots indicated that these assumptions were not violated.

### *5.2. Descriptive data*

#### *5.2.1. Sample characteristics*

The sample comprised of 49 individuals (31 women, 18 men) aged between 68 and 91 years old (M = 80.39; SD = 5.42). The majority of the sample were married (n = 28); although a large number were widowed (n = 17) and the remaining participants were either divorced (n = 2) or never married (n = 2). In terms of ethnicity, one participant was Afro-Caribbean and all other participants were White British in origin. Details on the age at which participants left education could not be obtained for all participants; however, the majority for whom this information was available left education prior to 16 (n = 26); others had stayed in education until between 16 and 19 years old (n = 15).

The majority of participants were attending for a follow-up appointment at the Memory Service South (n = 32) versus the Memory Service North (n = 17). Most participants had been diagnosed with Alzheimer's disease (n = 41); some with mixed aetiology, including Alzheimer's disease and Vascular Dementia (n = 6); Dementia with Lewy Bodies (n = 1); and Parkinson's Dementia (n = 1). The average time between the diagnosis and follow-up appointment where they completed the questionnaire was approximately 6 months (M = 195.52 days, SD = 45.00 days); however, time ranged between 3 months and 9 months. All participants had been prescribed acetylcholinesterase inhibitors and one person was having their medication reviewed and not taking it at the time of completing the questionnaire. The severity of cognitive impairment, as measured on the MMSE, ranged between 11 and 28 (mean = 21.90, SD = 3.60). The majority of the sample were in the mild range of cognitive impairment (n = 33), others were in the moderate range (n = 15) and one person's score was above the

cut-off for cognitive impairment, according to NICE (2006). See Table 1 for details of demographic and clinical characteristics of the sample.

*Table 1*. Demographic and clinical characteristics of sample

| Variable | N (%) | | |
|---|---|---|---|
| **Gender** | 31 (63) | | |
| Female | 18 (37) | | |
| Male | | | |
| **Marital status** | | | |
| Married | 28 (57) | | |
| Widowed | 17 (35) | | |
| Never married | 2 ( 4) | | |
| Divorced | 2 ( 4) | | |
| **Ethnicity** | | | |
| White British | 48 (98) | | |
| African American | 1 ( 2) | | |
| **Education** | | | |
| <16 | 26 (58) | | |
| 16-19 | 19 (42) | | |
| **Diagnosis** | | | |
| Alzheimer's disease | 41 (84) | | |
| Mixed aetiology | 6 (12) | | |
| Dementia with Lewy Bodies | 1 ( 2) | | |
| Parkinson's dementia | 1 ( 2) | | |
| | | **M** | **SD** |
| **Age** | | 80.39 | 5.42 |
| **Time since diagnosis (days)** | | 195.52 | 45.00 |
| **Severity (MMSE)** | | 21.90 | 3.60 |

A series of independent samples t-tests and chi-square tests were run to test for differences between the two memory services in terms of demographic variables (gender, marital status, education, diagnosis, age, time since diagnosis, severity) and psychological variables (BIPQ, dementia-specific coping, anxiety and depression).

Significant differences were found for two demographic variables. The mean age of participants recruited from Memory Service North (M = 82.59, SD = 5.08) was significantly higher (t(47) = 2.15, p = .04) than participants from the South (M = 79.22, SD = 5.30). The time since diagnosis for participants recruited from the North (M = 219.35, SD = 51.54) was significantly higher (t(47) = 2.90, p = .006) than the South (M = 182.86, SD = 35.87). No other comparisons were significant.

Associations between the sample characteristics of gender, marital status (grouped into categories of married or single), age at leaving education (pre-16, or 16 and over) and psychological distress were assessed. A series of independent samples t-tests showed participants did not score significantly differently for anxiety and depression based on their gender (t(47) = 0.48, p = .63; t(47) = 1.08, p = .29, respectively); marital status (t(47) = 0.60, p = .55; t(47) = 0.21, p = .84); and age at leaving education (t(39) = 0.25, p = .80; t(39) = 1.26, p = .22). Pearson's correlations were conducted between anxiety and depression and the sample characteristics of age, severity of dementia (as assessed on the MMSE) and time since diagnosis. All correlations were non-significant: age (r = -.23, p = 0.88; r = .16, p = .26); severity (r = 0.24, p = 0.10; r = -0.06, p = 0.69); time since diagnosis (r = -.22, p = .12; r = -.20, p = .17).

*5.2.2. Psychological variables*

Descriptive data for the main variables, including the mean, standard deviation and the alpha coefficients are outlined in Table 2. To ensure good reliability Cronbach's alpha scores should be above .7 (Leech, Barrett, & Morgan, 2005), although Kilne (1999) suggests that for psychological constructs Cronbach's alpha values below this should be considered as such constructs are likely to be diverse.

*Table 2*. Means, standard deviations and alpha coefficients for the psychological measures

| Variable | Mean | SD | Cronbach's Alpha |
|---|---|---|---|
| **BIPQ** | 33.71 | 13.79 | .67 |
| **HADS** | | | |
| **Anxiety** | 2.06 | 0.93 | .83 |
| **Depression** | 3.94 | 3.73 | .80 |

*BIPQ*

The total BIPQ measure was found to have adequate reliability (see Table 2). The mean scores on five of the eight BIPQ scales were above the mid-point. The highest scores were for positive illness representations of treatment control and understanding (see Table 3). A large proportion of participants answered that they did not know the cause of their dementia (n = 22). Of those who did give a possible cause the most frequent answer was age (n = 11). Other responses included bereavement (n = 3), psychological stress (n = 3), biological changes (n = 3), genetics/hereditary (n = 2), an accident/injury (n = 2), limited social contact (n = 2) and early retirement (n = 1).

*Table 3*. Means and standard deviations for BIPQ items

| Variable | Mean | SD |
|---|---|---|
| **consequences** | 3.39 | 2.68 |
| **timeline** | 6.50 | 4.01 |
| **personal control** | 5.92 | 2.87 |
| **treatment control** | 7.10 | 2.62 |
| **identity** | 4.38 | 2.31 |
| **concern** | 5.10 | 3.50 |
| **understanding** | 6.84 | 3.19 |
| **emotional response** | 4.20 | 3.46 |

*HADS*

The measures of anxiety and depression were found to have high levels of internal consistency. The mean score for participants on the HADS was below the cut off for mild anxiety and depression (cut-off score ≤ 8). Six (12.24%) participants met the criteria for mild, three (6.12%) for moderate, and one (2.04%) for severe anxiety. Five (10.20%) participants scored in the mild range for depression and five (10.20%) in the moderate range.

*Coping Behaviours*

The most frequently used method of coping with dementia was taking medication, closely followed by maintaining a routine of activities. The use of specific memory strategies or cues was the least frequently used coping behaviour (see Table 4).

*Table 4*. Means and standard deviations for coping items

| Variable | Mean | SD |
|---|---|---|
| **writing things down** | 2.25 | 1.20 |
| **memory strategies** | 1.67 | 0.99 |
| **maintain routine** | 3.31 | 1.00 |
| **rely on others** | 2.71 | 1.12 |
| **medication** | 3.67 | 0.75 |
| **avoiding activities** | 1.69 | 0.89 |

### *5.3. Associations between illness representations, coping behaviours and psychological distress*

Pearson's correlations were used to assess associations between illness representations, coping behaviours and psychological distress (see Table 5). Given the small sample size it was decided not to apply Bonferroni corrections when conducting multiple (correlation) tests as this would further increase the likelihood of making a type II error. Moreover, there is considerable debate about the appropriateness of using Bonferroni corrections when conducting multiple tests (e.g., Nakagawa, 2004; Pergenger, 1998). The BIPQ total score was significantly correlated with anxiety and depression; such that more negative illness representations were associated with higher levels of anxiety and depression. A number of individual illness representations were also associated with higher levels of anxiety and depression: perceptions of dementia leading to severe consequences, a strong illness identity (attributing many symptoms to dementia), concern about having the condition, and emotional response (regarding the impact of dementia on emotions). In addition, the association between whether or not people named a cause of their dementia and psychological distress was assessed using t-tests. Participants did not score significantly differently for anxiety and depression based on whether they reported a cause ($t(47) = 1.31$, $p = .20$; $t(47) = 0.90$, $p = .38$). Considering

the specific coping behaviours, only avoiding or restricting activities was significantly correlated with higher levels of anxiety and depression.

*Table 5*. Correlation coefficients between illness representations, coping behaviours and anxiety and depression scores (HADs).

| Variable | Anxiety | Depression |
|---|---|---|
| **1. BIPQ** | | |
| **total** | .46** | .43** |
| **consequences** | .44** | .41** |
| **timeline** | .08 | -.06 |
| **personal control** | -.01 | -.14 |
| **treatment control** | -.10 | -.05 |
| **identity** | .36* | .43** |
| **concern** | .48** | .39* |
| **understand** | -.04 | -.07 |
| **emotional response** | .58** | .55** |
| **2. Dementia-specific coping behaviours** | | |
| **writing things down** | .09 | -.07 |
| **memory strategies** | .19 | .08 |
| **maintain routine** | .00 | -.13 |
| **rely on others** | .11 | .16 |
| **medication** | -.02 | -.12 |
| **avoiding activities** | .38** | .38** |

Note: *p< .05, **p< .01

There were significant correlations between some of the BIPQ measures and the coping behaviours (see Table 6). Most notably, of the variables associated with anxiety and depression, it was found that increased concern and emotional responses were associated with greater use of avoiding or restricting activities as a method of coping. In addition, lower perceived personal control and a stronger illness identity were associated with relying on others, and greater perceived treatment control was associated with maintaining a routine. T-tests were used to assess associations between

whether or not people named a cause of their dementia and coping behaviours. Participants who did not report a cause for their dementia were significantly more likely (M = 3.20, SD = 1.01) to rely on others than people who reported a cause (M = 2.33, SD = 1.07) (t(47) = 2.83, p = .007).

*Table 6.* Correlation coefficients for illness representations and coping behaviours.

| Variable | Writing things down | Memory strategies | Maintain routine | Rely on others | Taking medication (a) | Avoiding activities |
|---|---|---|---|---|---|---|
| **BIPQ total** | .14 | -.01 | .01 | .24 | .08 | .23 |
| **consequences** | .09 | .11 | .13 | .10 | .09 | .19 |
| **timeline** | .18 | -.05 | .15 | -.09 | .13 | .13 |
| **personal control** | -.02 | .03 | .07 | -.38** | -.05 | .10 |
| **treatment control** | .12 | .28 | .42** | -.03 | .24 | -.05 |
| **identity** | .21 | .19 | -.14 | .30* | .21 | .25 |
| **concern** | .20 | .03 | .19 | .08 | .07 | .30* |
| **understand** | .15 | .10 | .09 | -.18 | -.01 | .13 |
| **emotional response** | .14 | .10 | .12 | .21 | .00 | .32* |

Note: *p< .05, **p< .01

(a) Non-parametric correlations (Spearman)

*5.3.1. Regression analyses*

A regression analysis was conducted to assess whether the BIPQ and the coping behaviours that correlated significantly with anxiety and depression were able to explain significant amounts of variance. Only those variables that were found to be significantly

associated with anxiety/depression were included in the regression analysis to reduce the number of independent variables. None of the sample characteristics were included in these regression equations as they were not found to be significantly related to anxiety and depression. The illness representations (consequences, identity, concern and emotional responses) were entered into the first block using the direct entry method and the coping behaviour, avoiding or restricting activities, was entered into the second block (Table 7).

*Table 7*. Summary of a regression analysis to assess factors predicting anxiety and depression

| | **Anxiety** | | **Depression** | |
|---|---|---|---|---|
| **Predictor** | **$\Delta R^2$** | **β** | **$\Delta R^2$** | **β** |
| Step 1 | .35* | | .35* | |
| Consequences | . | .07 | | .03 |
| Identity | | .10 | | .25 |
| Concern | | .09 | | -.12 |
| Emotional response | | .41 | | .50* |
| Step 2 | .04 | | .05 | |
| Consequences | | .08 | | .04 |
| Identity | | .08 | | .23 |
| Concern | | .06 | | -.15 |
| Emotional response | | .37 | | .45* |
| Avoiding activities | | .21 | | .24 |

Note: * $p < .05$

The illness representations variables explained 34.9% of the variance in anxiety ($R^2$ = .35, $F(4,44) = 5.89$, $p = .001$); however, none of the illness representations made a significant unique contribution to the regression equation as shown in Table 7, although the unique effect of emotional response was marginally significant ($p = .06$). The avoiding or restricting activities coping measure added in step 2, only explained an additional 4% of the variance in anxiety, which was not a significant increase ($\Delta R^2$ =

.04, F(1,43) = 2.70, p = .11). The amount of variance accounted for by all six predictors in the regression equation was 38.7% ($R^2$ = .39, F (5, 43) = 5.43, p = .001), although none of the variables made a significant unique contribution to the regression equation.

The amount of variance in depression accounted for by the illness representations variables was 34.6% ($R^2$= .35, F(4,44) = 5.81, p = .001), with emotional responses making a significant contribution to the regression equation. The addition of the avoiding or restricting activities coping measure in step 2 explained an additional 5% of the variance; a non-significant increase, ($\Delta R^2$ = .05, F(1,43) = 3.58, p = .07). When all six predictors were included in the final regression equation they accounted for 39.6% of the variance ($R^2$ = .40, F (5,43) = 5.64, p < .001), with emotional responses remaining as the only significant unique predictor (t (43) = 2.13, p = 0.04).

*5.3.2. Mediation analyses*

Mediation analyses were conducted to assess whether any of the coping behaviours mediated the effect of illness representations on psychological distress, in line with the recommendations of Baron and Kenny (1986). Avoiding or restricting activities was the only coping behaviour correlated with both illness representations (concern and emotional responses) and psychological distress measures (anxiety and depression) and was therefore examined to see if it acted as a mediator between these illness representations and anxiety and depression.

Considering the relationship between concern and anxiety, significant relationships were found between concern and activity avoidance (β = 0.30, p = .034), and between activity avoidance and anxiety (β = 0.38, p = .007). However, the relationship between concern and anxiety (β = 0.48, p < .001) remained significant when activity avoidance was controlled for (β = 0.40, p = .003) indicating it did not mediate the relationship

between concern and anxiety. Considering the relationship between emotional responses and anxiety, a significant relationship was found between emotional responses and activity avoidance ($\beta = 0.32$, $p = .03$). , However, a mediation effect was not indicated as the relationship between emotional responses and anxiety ($\beta = 0.58$, $p < .001$) remained highly significant when activity avoidance was controlled for ($\beta = 0.50$, $p < .001$).

Considering the relationship between concern and depression, the relationship between activity avoidance and depression was significant ($\beta = 0.38$, $p = .008$). However, the relationship between concern and depression ($\beta = 0.39$, $p < .006$) remained significant ($\beta = 0.28$, $p = .04$) when activity avoidance was controlled, suggesting activity avoidance did not mediate the relationship between concern and depression. Finally, the relationship between emotional responses and depression ($\beta = 0.54$, $p < .001$) also remained highly significant when activity avoidance was controlled for ($\beta = 0.54$, $p < .001$), indicating activity avoidance did not mediate this relationship.

## 6. Discussion

The findings of this study provide evidence for the relevance of the CSM for people with dementia, supporting the small-scale qualitative research by Clare et al. (2002) and Harman and Clare (2006). In line with the first hypothesis, those who held negative cognitive illness representations on the dimensions of consequences and identity (i.e., believing the consequences and symptoms of dementia were more severe), and negative emotional representations (i.e., experiencing greater concern and emotional reactions in relation to having dementia), experienced greater psychological distress. When these were entered into a regression analysis they explained 35% of the variance in anxiety and depression. In particular, the emotional response item of emotional representations

independently predicted elevated levels of depression. The association between emotional representations and psychological distress has been found in previous studies with health conditions. Fowler and Baas (2006) found emotional representations were linked to reduced psychological well-being in people with kidney disease and Knibb and Horton (2008) found them to be linked with severe depression amongst allergy sufferers. In addition, the correlation between the measures of psychological distress and higher perceived consequences and a stronger illness identity is consistent with Hagger and Orbell's (2003) meta-analysis of CSM research. Contrary to expectations, the illness representations of timeline, control, cause and understanding were not associated with levels of psychological distress.

There were some associations between illness representations and coping behaviours, offering partial support for the second research hypothesis. Positive illness representations of treatment control were found to be related to a greater use of maintenance of a routine as a coping behaviour. This method of managing the changes associated with dementia might be considered a problem-focussed coping strategy as it is a way of helping people with memory problems to remember to do certain things during the day (Alzheimer's Society, 2011). As such it would be consistent with the findings of the meta-analysis conducted by Hagger and Orbell (2003) that found that perceptions of controllability were associated with problem-focussed coping. Negative illness representations of lower personal control, stronger illness identity and uncertainty about the cause of dementia were related to greater reliance on others. Relying on others may be viewed as a passive coping behaviour. Katz et al. (1996) described passive coping as "withdrawal or giving up and relinquishing control to something or someone else" (p 258). Previous health research has found links between viewing an illness as uncontrollable and passive coping strategies (Hagger & Orbell, 2003). The association between a strong illness identity and seeking social support has

been found in previous research into diabetes (Edgar & Skinner, 2003). Strong emotional representations were also associated with the avoidance or restriction of activities in order to cope, which is in line with previous research by Evans and Norman (2009) in Parkinson's disease.

In assessing the impact of coping behaviours on psychological well-being, correlation analyses showed the use of avoiding or restricting activities as a coping behaviour was the only measure that correlated with anxiety and depression offering limited support for the third research hypothesis. The correlations were positive, such that increased use of activity avoidance was related to greater psychological distress. This finding is consistent with chronic illness research by Maes et al. (1996), Rabinowitz and Arnett (2009), and Heijmans (1998) who have related avoidant coping to poor mental health. Carver, Scheier, and Weintraub (1989) suggest that when people reduce their attempts to deal with a situation causing stress this can reflect an expectation that coping strategies would not be useful and a sense of helplessness. The lack of association between the other coping methods and psychological distress is not consistent with a body of literature on adjustment to chronic illness and mental health outcomes (Heijmans, 1998; Maes et al., 1996). This may relate to the limitations of the coping measure used in the present study (see section 6.1 for a discussion of this issue). However, some studies have also found a lack of relationship between problem-focussed coping and psychological well-being in chronic illness (Edgar & Skinner, 2003; Heijmans, 1999), therefore further research may be needed to assess whether such strategies do help psychological adjustment to dementia.

The present study also examined activity avoidance as a mediator of the effect of illness representations on psychological distress. It was correlated with both emotional representations and anxiety and depression, however, contrary to the fourth hypothesis,

no mediation effect was found. This parallels the research findings in a review by Hagger and Orbell (2003) that reported little evidence for mediation effects among people with physical health conditions, but contrasts with research by Evans and Norman (2009) that found partial evidence that avoidant coping mediated the effect of emotional representations on anxiety in people with Parkinson's disease.

The results broadly reflect the qualitative findings of Clare et al. (2006) on the relevance of illness representations in dementia. However, Clare et al.'s study included people who were not aware that they had a condition or illness, most seeing themselves as having memory difficulties relating to ageing, whereas the present study only included participants who were aware they had a type of dementia. The lack of awareness is likely to affect representations, such as the identity of the condition and perceptions of the consequences and may reflect why reduced awareness has been associated with lower levels of anxiety and depression (Harwood et al., 2000; Seignourel et al., 2008).

This study is of theoretical importance as it is the first piece of research to use quantitative methods to assess whether the CSM is associated with psychological adjustment in people with dementia. The results indicate that perceived consequences and identity of dementia, as well as emotional representations, are associated with psychological distress. It is important to acknowledge, however, that whereas four illness representations were related to psychological distress and explained a large amount of the variance, other CSM variables did not. If these findings are replicated in future research these results could place into question the predictive validity of the CSM model taken in its entirety for people with dementia.

### *6.1. Limitations of the present study*

There are several limitations to this study, which mean the above findings are interpreted with caution. Whilst illness representations explained approximately 35% of anxiety and depression, this means that 65% of the variance remains unexplained. Other factors that may have an impact on psychological distress in this population include social support (Cooper, Bebbington, & Livingston, in press), life events (Waite, Bebbington, Skelton-Robinson, & Orrell, 2004), and chronic medical conditions (Bird & Parslow, 2002). Investigating the impact of these factors was beyond the scope of this study, however.

Only a limited number of associations were found between coping and psychological distress, which is inconsistent with a body of literature on coping with chronic illness (e.g., Maes et al., 1996). This may have been related to the operationalisation of coping as specific dementia-related behaviours (in line with the CSM), which were assessed with single items. Adopting this approach meant that broader coping strategies or styles, and their impact on psychological distress, were not assessed. In addition, it was not possible to assess and the internal consistency of the coping behaviour measures due to the use of single items. Single-item measures typically have lower reliability when compared to multi-item measures (Nunnally, 1978). A meta-analysis by Sverke, Hellgren and Naswall (2002) in occupational psychology has also found that multiple-item measures have stronger associations between variables than single-item measures, which may explain the limited associations in this study between coping and distress. However, generic coping measures have been criticised for being too general (Coyne & Racioppo, 2000) The items used to assess dementia-specific coping behaviours in the present study are likely to have high face/content validity as they were derived from the qualitative work of Clare et al. (2006).

The study used a cross-sectional design and therefore there are difficulties in establishing the causal relationships between illness representations, coping and distress. For example, individuals who experience elevated levels of psychological distress may be more likely to want to avoid activities and have more negative illness representations, than vice versa. In addition, the study did not control for participants' pre-dementia experience of anxiety and depression. It is therefore not possible to ascertain whether the measures of psychological distress were assessing the psychological effects of the diagnosis of dementia or pre-existing mood disturbances.

The sample size for this research was relatively small and consequently there is a risk of the study being under powered. This meant that it was necessary to limit the number of independent variables in the regression analysis and only those that were found to correlate with anxiety and depression were included. It is important for future research to replicate these results with larger samples. Almost half of potential participants were not included in the research, mainly due to lack of awareness. This was a necessary requisite for people being able to reflect on their beliefs about having dementia; however, as a result this study is unlikely to be generalisable to people who do not have awareness of their condition. Future research could also focus on illness representations among people who are aware of their memory problems, but not of dementia. Moreover, those who declined to take part in the study may differ systematically from participants. For example, they may have increased levels of distress, which may make it difficult for them to discuss their diagnosis.

The specificity of the sample recruitment may affect the external validity of the results. The study included participants from two NHS memory services in Sheffield. The specialities involved and the exact procedures for assessing and giving a diagnosis of dementia may vary in NHS Trusts across the country. This may play a part in the

adjustment process (Koppel & Dallos, 2007), affecting the generalisability of these results to older people diagnosed with dementia in different services. All but one of the sample were white British and research has found adjustment to dementia can vary according to ethnic background. This affects our ability to generalise these results to populations from different ethnic backgrounds. The participants used in this study were largely diagnosed with Alzheimer's disease, or mixed Alzheimer's disease and vascular dementia. Research has found psychological distress following diagnosis can be influenced by the type of dementia diagnosed, i.e., those who are told they have VD can experience greater psychological distress (Lyketsos, 2000; Seignourel, 2008); however, there were no differences between the different diagnostic groups in terms of psychological distress in the present study.

This study gained data from the person with dementia only. Research has suggested that people with dementia may minimise difficulties with mood and therefore a collateral source of information should be gained from carers to provide a clearer picture of symptoms (Rubin, Veiel, Kinscherf, Morris, & Storandt, 2001). However, the participants in this study had awareness of their condition and it was felt they were best placed to know their own beliefs, coping behaviours and mood. Proxy reports are not able to provide a full understanding of the experience of living with dementia (Wilkinson, 2002). Research has shown self-reports of depression in people with mild to moderate dementia have good concordance rates with medical clinicians (Arlt et al., 2008). Wilkinson (2002) highlights greater inclusion of people with dementia is needed in research. The exclusion of their perspectives reinforces power imbalances in research and negative stereotypes about the level of incapacity of this population.

The severity of cognitive impairment varied from mild to moderate. Bedard et al. (2003) suggested that with increased cognitive impairment self-reports may become less

accurate and display an increased positive response set bias; however, the correlation analysis did not find an association between severity and levels of psychological distress. Other researchers have reported scores of severity on the MMSE do not reflect a person's ability to reflect on their experiences (Pratt & Wilkinson, 2003). In addition, Mills (1997) found people with moderate to severe levels of dementia could recall emotional memories, suggesting these global cognitive measures may not be indicative of all areas of functioning.

The researcher was present and assisted participants to complete the questionnaires. This enabled the researcher to observe whether the questionnaires were understood and were completed by the person with dementia and not their carers. However, it may have led to some level of inconsistency in the level of support that was provided, e.g., when explaining the scoring system. The MMSE was completed by one of eight nurses from the memory services. Variability in administration style may have led to reliability issues on this measure.

### *6.2. Clinical Implications*

It has been suggested that clinical practice can be improved when there is an increased understanding of perceptions of illness (Roberts & Connell, 2000). This study highlights the need for assessment and facilitation of certain illness representations in clinical practice to aid psychological adjustment to a diagnosis of dementia. Targets for interventions could include altering perceptions of the consequences, identity and negative emotions associated with dementia. In addition, psycho-education on the potential negative effect of avoiding activities on mood may be beneficial for people with dementia. One way in which this may be facilitated is through using a CBT approach. CBT, which includes an illness-representations-change component, has been piloted for people experiencing lupus (a chronic auto-immune illness) and was found to

be effective in changing beliefs about control of treatment, emotional representations and stress (Goodman et al. 2005). Research has shown CBT can also improve psychological distress in dementia (Kraus et al., 2008; Walker, 2004).

### *6.3. Recommendations for further research*

Further research should employ longitudinal designs to examine the course of psychological adjustment to a dementia diagnosis in relation to illness representations in order to establish the direction of the relationships found in the present study. Such a design would also enable researchers to assess the stability of illness representations over time. Standardised measures of coping could also be used to assess whether more global coping strategies or styles are related to illness representations and psychological adjustment to dementia. Research using a larger sample would enable researchers to enter all CSM variables into a regression analysis and gain a fuller picture of their influence. Also, future research could compare the illness representations and coping behaviours of those who are aware they have dementia with those who are aware they have memory problems, but not that these are related to dementia, in order to assess the relative impact of awareness of the diagnosis on psychological adjustment. Gaining the opinion of carers as well as the person with dementia in future research may act as a collateral source of information on factors such as coping strategies (Rubin et al, 2001). In addition, it is important to investigate the ways therapeutic interventions (such as adapted CBT approaches) might address illness representations in dementia populations and the outcomes of these interventions in aiding the adjustment process.

## 7. Conclusion

This study provides a cross-sectional analysis of the cognitive and emotional representations people hold about their dementia and their association with coping and

psychological distress. Negative cognitive representations of consequences and identity and negative emotional representations were associated with greater anxiety and depression. Avoiding activities was associated with emotional representations and greater psychological distress, but was not found to mediate the relationship between the two. These findings support the small-scale qualitative research by Clare et al. (2002) and Harman and Clare (2006) that suggests the CSM is relevant for people with dementia. There is a need for further research on how clinicians might support people to develop positive representations and adaptive coping behaviours to support psychological adjustment to dementia.

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# Appendices

# Appendix A:

# A summary of the quantitative research studies included in the literature review

| References | Country of study | Methodology | Sample | Summary of key findings |
|---|---|---|---|---|
| Boustani et al. (2006) | USA | Recorded demographic details/ prescription medications. | 434/434 people aged 65 and over screening positive for dementia. | 48% of participants refused diagnostic assessment. Older age and a better screening score were associated with refusal. African Americans over 79 were more likely to refuse. |
| Carpenter et al. (2008) | USA | Pre and post survey design. | 90/136 people diagnosed with AD or Mild Cognitive Impairment and their companions (relatives/friends). | A decrease in anxiety was found after diagnostic feedback. No significant changes in depression scores. No association between depression scores and diagnostic outcome/ dementia severity. |
| Clark et al. (2005) | USA | Structured interviews, questionnaires. | 79/163 carers of African Americans diagnosed with AD. | Main reasons for delays in seeking consultation regarding dementia symptoms: belief it was normal ageing (57%); carer not sure of the severity of the problem (55.7%); and difficulty discussing concerns with person with AD (53.2%). |
| Connell et al. (2009) | USA | Telephone survey. | 178/222 Black and White family members and carers of people with AD. | Family members endorsed several benefits to gaining a diagnosis, e.g., finding a cause (78%), gaining information (81%), being able to make plans (75%). The most frequent barriers were: believing there is no cure (36%) and not much can be done to help someone with AD (26%). There were some significant differences in the endorsements of black and white family members. |
| Elson (2006) | UK | Structured interviews pre and post diagnosis. | 36/95 people over 65 with memory complaints. | 86% of participants wished to know the cause of their memory problems. 69% would wish to know if it was dementia. Reasons for wanting the diagnosis: to enable planning, keep informed, consider treatment, facilitate psychological adjustment. Most common reason for not wanting diagnosis: source of anxiety/ distress. |

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|---|---|---|---|---|
| Georges et al. (2008) | UK, France, Germany, Italy, Poland, Spain | Questionnaire. | 1,181 carers of people with AD (UK sample: 334/1000) | Reports on the diagnostic process and satisfaction with services are outlined. Inadequate information provided for 46% of sample.19% reported receiving no information at diagnosis. |
| Laakkonen et al. (2008) | Finland | Postal survey-demographic (Smaller qualitative study outlined in Appendix B) | 1434/1943 spousal carers of people with AD. 63 carers in qualitative study. | At diagnosis, 71% were satisfied with the information they had received on dementia. After diagnosis disclosure 55% of carers developed depressive symptoms. Many experienced grief, anxiety, loneliness and uncertainty. |
| Lin et al. (2005) | Taiwan | Questionnaire. | 150/? family members of people with neurological problems (74% had a family member with AD) | Family member's views on diagnostic disclosure: if they developed AD themselves, 93% would like disclosure. Only 76% would want disclosure to a family member who developed AD. |
| Pinner & Bouman (2003) | UK | Semi-structured questionnaire. Retrospective case note study after 1 year. | 50/? people with mild dementia and their carers. | 92% of participants with dementia would want disclosure of a dementia diagnosis, compared with 98% who would wish to know if hypothetically diagnosed with cancer. 98% of carers would wish to know either diagnosis. 26% of carers did not want the dementia diagnosis disclosing to their relative. After 1 year 6% of people with a dementia diagnosis were on anti-depressants. |
| Rimmer et al. (2005) and Bond et al. (2005). Reviewed data from the same survey. | UK, France, Germany, Italy, Poland, Spain | Questionnaire. | 600 carers for people with AD; 1200 members of the general public. | Carers frequently delay seeking physician involvement regarding signs of dementia and cite several reasons e.g. uncertainty about symptoms. Reports on the process of dementia diagnosis are outlined. The consequences of dementia on carers and the person with AD in the long term are also discussed. |

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| Rosness et al. (2009) | Norway | Questionnaire. | 413/? - spousal carers of people with a dementia, or cognitive impairment no dementia (CIND). | 20.3% carers of people with CIND, compared to 42.2% of carers for people with dementia had moderate to severe levels of distress. Distress was associated with impaired activities of daily living, the gender of the carer, level of depression observed in patients, and not the dementia diagnosis. |
| Shimizu et al. (2008) | Brazil | Structured questionnaire. | 50/? carers of people with AD and 50 controls who were not carers. | Carers were less likely to support disclosure of an AD diagnosis (58%) compared with controls (88%). This was associated with the experience of being a carer. |
| Speechly et al. (2008) | Australia | Postal survey. | 209/ 415 family carers of people with dementia | The first signs of dementia noticed by carers were memory impairments (47%), followed by problems with everyday tasks (33%). Symptoms were noticed an average 1.9 years before professional consultation. 72% of carers satisfied with first consultation. |

## Appendix B:

# A summary of the qualitative research studies included in the literature review

| References | Country of study | Methodology | Sample | Summary of key findings | Quality control |
|---|---|---|---|---|---|
| Aminzadeh et al. (2007) | Canada | Audio-tapes of diagnostic feedback; in-depth interviews; focus-groups with carers. Qualitative analysis based on grounded theory approach. | 30/38 people with AD or VD and their carers. | Responses to diagnosis included: lack of insight or denial of diagnosis; grieving or emotional crisis related to actual/ anticipated losses; positive coping reactions. Emotional response to diagnosis occurred in stages. | *CC:* triangulation of data sources<br>*Reflexivity:* NR |
| Bowes & Wilkinson (2003) | UK | Case studies, semi-structured interviews. Thematic analysis. | 4/? South Asian people with dementia and their families/ carers. 11 professionals. | South Asian people reported solely negative experiences of dementia, isolation from community and family, need for support. Case studies showed poor knowledge of dementia and limited access to appropriate services. | *CC:* NR<br>*Reflexivity:* NR |
| Connell et al. (2004) | USA | Focus groups. Qualitative analysis NR- assisted by qualitative software programme. | 52/? carers and 39 physicians. | Carers reported some advantages knowing the dementia diagnosis, in terms of their perceptions of the person and role in the relationship. Negative emotions were felt following diagnostic disclosure e.g. shock, anger. Experienced relief and validation also. Carers expressed varying preferences for the process of diagnostic disclosure. | *CC:* triangulation of analysis by 2 researchers<br>*Reflexivity:* NR |

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|---|---|---|---|---|---|
| Derksen et al. (2006, 2005) | Netherlands | (2006) Semi-structured interviews post-diagnosis.<br>(2005) Case study from the same sample.<br>Grounded theory. | (2006)18/? adults with dementia and partners/ carers.<br>(2005) 1 patient and partner. | Examined reaction to diagnosis. At 2 weeks those who did not expect the diagnosis felt threatened and shocked. For most it confirmed their suspicions. Diagnosis acted as a trigger for future planning. Families adjusted to becoming carers. People with dementia attempted to hold on to their roles. 12-week follow-up discussed in Vernooij-Dassen et al. (2006) article. | *Rigour:* data saturation<br>*CC:* triangulation of analysis by 2 researchers<br>*Reflexivity:* NR |
| Koppel & Dallos (2007) | UK | Interviewed pre and post diagnosis. Interpretative phenomenological analysis. | 3/6 cognitively impaired sample assessed for dementia. Partners interviewed to gain interpretive context. | Investigated diagnostic process. Participants desired to gain an explanation for memory problems. Satisfaction with explanations depended on whether they felt informed. Uncertainty impacted on their sense of self. | *CC:* triangulation of analysis of one transcript.<br>*Reflexivity:* reflective journal kept to monitor researcher responses/biases. |
| Krull (2005) | USA | Semi-structured interviews.<br>Grounded theory. | 13/? family carers of people with AD | Carers who recognise the first signs of AD attempt to normalise these. Only when this fails do they seek a diagnosis e.g. through a pivotal event, outsider's opinions, recognition of similarities with others who have had dementia. | *Rigour:* Data saturation<br>*CC:* NR<br>*Reflexivity:* NR |
| Laakkonen et al. (2008) | Finland | Semi-structured interviews. Content analysis (plus survey - details outlined in Appendix A) | 63/? carers | As outlined in Appendix A. | *CC:* NR<br>*Reflexivity:* NR |

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|---|---|---|---|---|---|
| Mahoney et al. (2005) | USA | Meta-synthesis of 3 qualitative studies using focus groups and interviews. Content analysis. | 22/? family carers of people with AD from African American, Latino and Chinese origin. | Cognitive changes in person with dementia were normalised by all groups until a critical event led to increased awareness. Limited knowledge of AD was a barrier to seeking assessment. There were cultural differences in concerns as dementia symptoms progress. | *Rigour:* data saturation<br>*CC:* Triangulation with original investigator's themes. Validated themes with participants and the wider community.<br>*Reflexivity:* General description of researcher influence |
| Rimmer et al. (2005) and Bond et al. (2005). | UK, France, Germany, Italy, Poland, Spain | Qualitative interviews. | 96/? people with AD | Person with AD responded to diagnosis with a belief difficulties were linked to old age, lack of acceptance or fatalistic attitude. | *CC:* NR<br>*Reflexivity:* NR |
| Robinson et al. (2008) | Australia | Focus groups. Content and thematic analysis. | 101/? family carers, health professionals/care staff | A long diagnostic process creates stress for carers. Without diagnosis access to services was reduced. | *CC:* triangulation of themes with 4 researchers<br>*Reflexivity:* NR |
| Robinson et al. (2005) | UK | Joint semi-structured interview. Interpretative Phenomenological Analysis. | 9/23 married couples– one with a diagnosis of AD or VD. | Reactions to the diagnosis were under two headings: 'not quite the same person, tell me what is actually wrong' and 'everything's changed, we have to go from there'. Participants tried to make sense of diagnosis and adjust to loss. The authors developed a model of understanding this process. | *CC:* triangulation of analysis by 3 researchers. Consultations with the participants to refine themes. Examined researcher memos for potential biases.<br>*Reflexivity:* Influence of researcher was discussed |

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| Vernooij-Dassen et al. (2006) | Netherlands | Semi-structured interviews 12 weeks post-diagnosis. Grounded Theory analysis. | 18/? adults with a dementia diagnosis and their partners/carers. | Formation of meaning of diagnosis is a gradual process. Themes at 2- weeks (Derksen et al., 2006) remained at 12-weeks with small changes in understandings of dementia and relationships. | *Rigour:* data saturation<br>*CC:* triangulation of analysis by 2 researchers<br>*Reflexivity:* discussed potential researcher influence on results. |
| Ward-Smith and Forred (2005) | USA | Semi-structured interviews. Analysed using qualitative software programme/ content analysis. | 18/47 family carers of people diagnosed with AD | Pivotal events, mainly involving automobiles, led to carers seek medical intervention. 11 participants were surprised by the dementia diagnosis. | *Rigour:* data saturation<br>*CC:* NR<br>*Reflexivity:* NR |

Note: *CC* - credibility checks

NR - not reported.

# Appendix C:

# Ethics approval letter from the South Yorkshire Research Ethics Committee

**South Yorkshire Research Ethics Committee**
1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Telephone: 0114 226 9153
Facsimile: 0114 256 2469
Email: joan.brown@sth.nhs.uk

19 August 2009

Miss Catherine Leeming
Trainee Clinical Psychologist
Sheffield Health& Social Care NHS Foundation Trust
Clinical Psychology Unit
University of Sheffield
Western Bank
S10 2TP

Dear Miss Leeming

**Study Title:** **Illness Representations and Adjustment to Dementia**
**REC reference number:** **09/H1310/50**
**Protocol number:** **3**

Thank you for your letter of 21 July 2009, 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. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance 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* |
|---|---|---|
| Supervisor CV - Paul Norman | | |
| Questionnaire: Hospital Anxiety & Depression Scale (HADS) | 2 | 29 January 2009 |
| Questionnaire: The Brief Illness Perception | 2 | 29 January 2009 |
| Peer Review | | 09 April 2009 |
| Investigator CV | | |
| REC application | | 09 June 2009 |
| Letter from Sponsor | | 23 April 2009 |
| GP Letter | 3 | 21 July 2009 |
| Response to Request for Further Information | | 21 July 2009 |
| Participant Consent Form | 3 | 21 July 2009 |
| Participant Information Sheet | 3 | 21 July 2009 |
| Protocol | 3 | 21 July 2009 |
| Covering letter addressing points raised in provisional opinion letter | | 21 July 2009 |

**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.

| **09/H1310/50** | **Please quote this number on all correspondence** |
|---|---|

Yours sincerely

**Miss Jo Abbott**
**Chair**

Email: joan.brown@sth.nhs.uk

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Mr Richard Hudson, University of Sheffield, New Spring House, 231 Glossop Road, Sheffield, S10 2GW

R&D Consortium

# Appendix D:

# Information sheet and consent form

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

**Clinical Psychology Unit**
**Department of Psychology**
**University of Sheffield**
**Western Bank**
**Sheffield S10 2TN UK**

Email: pcp07cml@sheffield.ac.uk

**Information Sheet**

**Project:** **Influences on adjustment to a dementia diagnosis**
**Researcher:** **Catherine Leeming, Trainee Clinical Psychologist, University of Sheffield.**

**You are being invited to take part in a research study.** This study is being conducted as part of my training to be a Clinical Psychologist. Please take time to read this information sheet and discuss it with a friend or family member if you wish. Please ask me if you have any questions.

**What is the purpose of the study?**
When a person receives a diagnosis of dementia it can be difficult and may lead to changes in the way a person lives their life. This study will look at the ways people think about their dementia and how these can influence coping and well-being.

**Who is taking part?**
Adults who have recently received a diagnosis of dementia at the memory clinic.

**What does it involve?**
After you have finished your follow-up meeting at the memory clinic, I will come and ask you a number of questions on your thoughts, feelings and things you do to help you cope with your dementia. This should take up to 30 minutes. I will also ask the memory clinic to provide me with the score you achieved on a short cognitive assessment they conducted with you to help them make your diagnosis of dementia.
You can bring someone with you for support whilst you complete the questionnaire if you wish.

**Do I have to take part?**
No. It is up to you to decide if you want to take part. Your treatment at the memory clinic will not be affected, whether or not you take part in the study.

**What are the benefits of taking part?**
There are no direct benefits to taking part in this study. However, it is hoped that the results of this research will inform therapeutic interventions to help people who are struggling to adjust to having dementia.

**What if I feel worried or upset?**
Some people find talking about their experiences helpful, however if you find the questions upsetting you do not have to answer them and can ask to stop at any time. Please talk to Catherine Leeming if you feel upset when answering the

questions. You could also contact your key-worker at the Memory Clinic or your GP

**Can I withdraw from the study at any time?**
Yes, you can withdraw at any time without having to give a reason. If you wish to withdraw please let me know. I can be contacted at the address and telephone number on the top of this sheet. I will then remove all record of your details and the information you have given.

**Will the information I give be confidential?**
Yes, all the information you give will be kept in confidence. In my report, there will be no mention of your name or any other details that would identify you.

**What will happen to the results of the study?**
The results will be written up as a report. This will form part of my Doctorate in Clinical Psychology.

**What if I have questions of concerns the study?**
If you have any questions or concerns about any aspect of the study, please contact me. A message can be left for me by telephoning Christie Harrison, Research Support Officer on (0114) 222 6650. Christie can only relay messages and cannot answer queries herself. I will return your call as soon as possible.

If you wish to complain about any aspect of the way in which the study has been run, please also contact me or my research supervisor, Paul Norman on 0114 2226505. Formal complaints on behalf of the university of Sheffield are handled by: Dr David Fletcher, University Registrar & Secretary, Registrar & Secretaries Office, Firth Court, Weston Bank, S10 2TN. Tel: (0114) 222 1100.

Formal complaints can also be made using the NHS complaints procedure. You can contact the Complaints & Litigation Lead, Sheffield Health and Social Care NHS Foundation Trust, Fulwood House, Old Fulwood Road, Sheffield, S10 3TH. Tel: (0114) 2718956.

**Independent advice**
If you have a concern that you do not want to raise directly with myself, my supervisor, or through formal complaints procedures, you can contact the Patients Advisory Liaison Service at NHS Sheffield, 722 Prince of Wales Road, Sheffield, S9 4EU. Tel: 0800 085 7539.

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

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**CONSENT FORM**

**Title of the Project:** Influences on adjustment to a dementia diagnosis

**Name of Researcher:** Catherine Leeming

| | Please initial boxes |
|---|---|
| 1. I confirm that I have read and understand the information sheet dated…….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, without my medical care or legal rights being affected. | ☐ |
| 3. I understand that the data collected during the study may be looked at by regulatory authorities or by the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | ☐ |
| 4. I agree to let the researcher have access to my medical records for the purpose of gaining demographic details and formal assessment scores relevant to this study. | ☐ |
| 5. I agree to my GP being informed of my participation in the study. | ☐ |
| 6. I agree to take part in the above study. | ☐ |

| _____ | _____ | _____ |
|---|---|---|
| Name (printed) | Date | Signature |
| _____ | _____ | _____ |
| Name of researcher | Date | Signature |

# Appendix E:

# Research Questionnaires

## Brief Illness Perception Questionnaire

(Removed due to copyright)

## Dementia Specific Coping Measure

**These items deal with ways you've been coping with any stress in your life since you were told you had dementia. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it.**

**1. Do you write things down to help you cope with your condition?**

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**2. Do you use specific memory strategies or cues to help you cope with your condition?**
1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**3. Do you try to maintain your normal routine or activities to help you cope with your condition?**
1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**4. Do you rely on others to help you cope with your condition?**

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**5. Do you take your medication to help you cope with your condition?**

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**6. Do you avoid or restrict activities to help you cope with your condition?**

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

**7. Is there anything else you do to help you cope with your condition?**

**How often do you do this?**
1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

# Appendix F:

# Guidelines for submission to Clinical Psychology Review

## Clinical Psychology Review: Guide for authors

### Use of wordprocessing software

It is important that the file be saved in the native format of the wordprocessor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the wordprocessor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Do not embed "graphically designed" equations or tables, but prepare these using the wordprocessor's facility. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Do not import the figures into the text file but, instead, indicate their approximate locations directly in the electronic text and on the manuscript. See also the section on Electronic illustrations.
To avoid unnecessary errors you are strongly advised to use the "spell-check" and "grammar-check" functions of your wordprocessor.

### Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009).
Manuscripts should ordinarily not exceed 50 pages. Exceptions may be made with prior approval of the Editor in Chief for manuscripts including extensive tabular or graphic material, or appendices.

### Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on.

### Essential title page information

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.
*Author names and affiliations.* Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.
*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.
*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address"' (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

**Abstract**
A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

**Research highlights**
Research highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate file in the online submission system. Please use 'Research highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters per bullet point including spaces). See http://www.elsevier.com/researchhighlights for examples.

**Keywords**
Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, "and", "of"). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

**Abbreviations**
Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

**Acknowledgements**
Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

**Footnotes**
Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.
*Table footnotes*
Indicate each footnote in a table with a superscript lowercase letter.

**Tables**
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

**References**
Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American

Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from http://books.apa.org/books.cfm?id=4200067 or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html

**Citation in text**
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either "Unpublished results" or "Personal communication" Citation of a reference as "in press" implies that the item has been accepted for publication.

**Web references**
As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

**References in a special issue**
Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

**Reference style**
References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).
*Examples:* Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.
Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).
Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

# Appendix G:

# Guidelines for submission to Psychology and Aging

## Psychology and Aging: Instructions to Authors

### Length

Manuscripts should not exceed 8,000 words (approximately 27 double-spaced pages in 12-point Times New Roman font). Shorter manuscripts are equally welcomed.
The word count does not include references, tables, and figures. If you feel that you need extra space, please contact the editor. For example, you may have a complex methodology or statistical approach or a new theoretical framework that requires more text.
Please include the word count for the main text below the keywords.

### Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).
Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.
If your manuscript was mask reviewed, please ensure that the final version for production includes a byline and full author note for typesetting.
Review APA's Checklist for Manuscript Submission before submitting your article.

### Submitting Supplemental Materials

APA can now place supplementary materials online, available via the published article in the PsycARTICLES database. Please see Supplementing Your Article With Online Material for more details.

### Abstract and Keywords

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

### References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.
Examples of basic reference formats:

**Journal Article:**
Herbst-Damm, K. L., & Kulik, J. A. (2005). Volunteer support, marital status, and the survival times of terminally ill patients. *Health Psychology, 24*, 225–229. doi: 10.1037/0278-6133.24.2.225

**Authored Book:**
Mitchell, T. R., & Larson, J. R., Jr. (1987). *People in organizations: An introduction to organizational behavior* (3rd ed.). New York, NY: McGraw-Hill.

**Chapter in an Edited Book:**
Bjork, R. A. (1989). Retrieval inhibition as an adaptive mechanism in human memory. In H. L. Roediger III & F. I. M. Craik (Eds.), *Varieties of memory & consciousness* (pp. 309–330). Hillsdale, NJ: Erlbaum.

### Figures

Graphics files are welcome if supplied as Tiff, EPS, or PowerPoint files. The minimum line weight for line art is 0.5 point for optimal printing.
When possible, please place symbol legends below the figure instead of to the side.
Original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay

# Appendix H:

# Letter of approval of the specified journals from the Research Tutor

Blue

17 December 2009

**Part 2. Thesis Submission**

A. The literature review

Please nominate a target journal Psychology and Ageing

I confirm that this journal:

- Is peer reviewed Yes No
- Is included in the Social Science or Science Citation Index Yes No
- Is potentially of interest to psychologists Yes No

You are required to confirm all of the above to fulfil course criteria.

Please attach the journal's *Instructions to Authors* to this form.

Trainee's signature C. Hung Date 21/1/10

I approve the choice of journal as specified:
Lead academic supervisor's signature Paul Date 19/1/10

B. The research report.

Please nominate a target journal Clinical Psychology Review

I confirm that this journal:

- Is peer reviewed Yes No
- Is included in the Social Science or Science Citation Index Yes No
- Is potentially of interest to psychologists Yes No

You are required to confirm all of the above to fulfil course criteria.

Please attach the journal's *Instructions to Authors* to this form.

Trainee's signature C. Hung Date 21/1/10

I approve the choice of journal as specified:
Lead academic supervisor's signature Paul Date 19/1/10

Please hand this form in to Christie Harrison before 31st January 2010.