

COHERENCE OF ILLNESS REPRESENTATIONS IN EARLY-STAGE DEMENTIA:  
AN EXPLORATORY STUDY USING THE FRAMEWORK OF LEVENTHAL'S COMMON SENSE SELF-  
REGULATION MODEL

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others.

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**ABSTRACT**

The Common Sense Model of Self-Regulation of Health and Illness has previously been applied to people with early-stage dementia. This suggests that people hold 'illness representations' of cognitive perceptions of their health condition. Illness representations develop from lay knowledge, current experience and information from external sources. Recent studies have highlighted that people with early-stage dementia have unmet information needs and require individually tailored information about aspects of dementia which are important to them. Professionals require a way to identify what people with early-stage dementia feel they do not understand about their dementia. Thus, the current study investigated whether illness representations might provide a mechanism for identifying the information needs of eight people with early-stage Alzheimer's or mixed dementia attending a National Health Service memory clinic.

An important feature of illness representations is whether they allow someone to form a coherent understanding of their condition, the 'coherence' of their illness representation. For the current study, the definition of coherence was adapted to match research aims, allowing the investigation of particular aspects of dementia people felt they did not understand using semi-structured interviews. A novel feature of this approach was using explicit prompts about what participants felt they understood or did not understand about each area of their illness representation to help illustrate how lack of understanding could contribute to absence of coherence. Interview transcripts were subject to framework analysis which showed that participants could identify things which they did not understand about their dementia and aspects of dementia they would like to know more about. Broad areas of dementia were identified which several people wanted to know about, along with idiosyncratic information needs. For some participants, illness representations, informed by medical stereotypes, appeared to limit their awareness of possible psychosocial support. Strengths, limitations and recommendations for research and practice were discussed.

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**ABBREVIATIONS**

ADL	Activities of Daily Living
CS-SRM	Common Sense Model of Self-Regulation of Health and Illness
CT	Computerised Tomography
DoH	Department of Health
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders - IV text revision
DSM-5	Diagnostic and Statistical Manual of Mental Disorders - fifth edition
FAQ	Frequently Asked Questions
GP	General Practitioner
ICD-10	International Statistical Classification of Diseases - 10
IPA	Interpretative Phenomenological Analysis
IPQ	Illness Perception Questionnaire
IPQ-M	Illness Perception Questionnaire - Memory
IPQ-MCI	Illness Perception Questionnaire - Mild Cognitive Impairment
IPQ-R	Illness Perception Questionnaire - Revised
IR	Illness Representation
MCI	Mild Cognitive Impairment
MMSE	Mini–Mental State Examination
NHS	National Health Service
NIHR	National Institute for Health Research
WHO	World Health Organization

## INTRODUCTION

### **My Interest in This Topic**

I have a longstanding interest in all types of developmental and acquired cognitive impairment, which I initially pursued through focusing on experimental cognitive psychology during my undergraduate studies and psychometric assessment of cognitive function when working within a neuropsychology service. I later became involved in assessment and care planning for people with learning disability and dementia, a role which also involved providing psycho-education regarding dementia to clients, families and professional carers. I found this a more holistic process than cognitive assessment in isolation, but was aware that the perceptions of my clients were not fully taken into account. Reflecting on my own experience of having family members with dementia and the above work made me keen to explore further the ways in which people may make sense of their dementia and whether they feel they lack information on particular aspects of their condition. I believe that such insights could have been of some benefit in my past professional and caring roles in helping to tailor the information I conveyed to be compatible with the beliefs of individual people with dementia.

### **Literature search strategy**

As a systematic review was beyond the scope of the current study, a thorough literature search using a number of approaches described below was used to identify relevant articles. Several structured searches were conducted: OvidSP was used to search the 'Medline' and 'PsycINFO' databases, and some Google scholar literature searches were also performed. These searches were repeated periodically throughout the research process to identify new papers. Article titles and/or abstracts of all publications identified by the searches described below were screened by the author and articles which appeared relevant to the aims of the study were retrieved for further consideration.

Searches of Medline and PsycINFO conducted using Ovid SP

- An advanced search was performed for articles containing the keyword 'dementia' and any of the following phrases as a keyword: 'illness perception', 'illness representation', 'illness cognition', 'common sense + self regulation'. *This identified 10 articles.*

- An advanced search was performed for articles published since 2002 containing the keyword 'coherence' and any of the following phrases as a keyword: 'illness perception', 'illness representation', 'illness cognition', 'common sense + self regulation'. *This identified 68 articles.*
- An advanced search was performed for the term 'illness representation\*' occurring in the article title, limited to articles published since 1980. *This identified 154 articles.*
- An advanced search was performed for any publications since 1980 where one of the authors was 'Leventhal, Howard'. *This identified 165 articles.*

#### Searches completed using Google Scholar

- An advanced search was performed for the word 'dementia' and the phrase 'illness representation\*' occurring anywhere in the article. *This identified 215 publications.*
- An advanced search was performed for the phrase 'illness representation\*' in the article title. *This identified 90 publications.*

The above structured searches were augmented by pursuing a number of other approaches to identifying relevant literature. For key articles, in particular all original qualitative studies using illness representations to investigate dementia, Web of Knowledge and Google Scholar were used to identify articles which had cited these papers. The titles and abstracts of these citing articles were then reviewed by the author and relevant articles retrieved for further consideration. Original studies that were referenced by publications identified during literature searches and which appeared relevant to the current study were retrieved for further consideration. Where literature searches had identified relevant books that were held by the University of Leeds library, adjacent books on the library shelf were browsed for other publications of interest. Recent issues of the journal 'Dementia: International Journal of Social Research and Practice' were browsed for relevant articles. A Google search was also performed for webpages containing the word 'guideline\*' along with either of the words 'dementia' or 'Alzheimer\*', and a Google search for the word 'report' along with either of the words 'dementia' or 'Alzheimer\*'. Finally, the Alzheimer's Society's website <http://www.alzheimers.org.uk> was browsed for recent reports and publications of interest.

There are some limitations to the approach adopted to reviewing the literature. This approach may have missed some studies which used models other than the illness representation framework to investigate people's understanding of their dementia. Also, it may have been overly inclusive of studies from a health psychology perspective and not as effectively identified literature from other disciplines, such as those with a more medical focus. Furthermore, the search strategy may have resulted in excess weight being given to findings from studies identified through unstructured methods that resonated with the researcher's views.

## **Dementia**

Dementia is, in most instances, a term used to refer to a variety of progressive conditions where predominantly memory and other cognitive functions are impaired; it also involves changes in how people engage with day-to-day tasks and social relationships (Department of Health, 2009; Kitwood, 1997). Although traditionally defined in terms of medical and cognitive factors, it can be better understood by considering both medical and social perspectives. Dementia affects an estimated 35,600,000 people worldwide (Alzheimer's Disease International, 2009); a prevalence study (Luengo-Fernandez, Leal, & Gray, 2010) gave an estimate of over 800,000 cases in the UK, and in 2012 there were estimated to be 8400 people with dementia within the city where the current study was conducted (Leeds City Council & National Health Service Leeds, 2012). The number of people with a diagnosis of dementia is expected to rise yearly due to factors such as improved early detection and the increasing number of older people in the UK population (Albanese et al., 2007). The prevalence of dementia is expected to double in the next 20 years (Alzheimer's Disease International, 2009).

### **Medical model of dementia**

From a medical perspective, the symptoms observed in dementia are generally attributed to neuropathological changes. The World Health Organization (WHO) describes dementia as an umbrella term referring to conditions affecting cerebral structures, which are typically progressive and which disrupt thinking, memory and higher cognitive functions, such as language and attention, in the absence of impaired consciousness to such a degree that social behaviour, emotional regulation or motivation are liable to deteriorate (WHO, 1992). In addition to impairment of memory, criteria from the Diagnostic and Statistical Manual of Mental Disorders-IV text revision (DSM-IV-TR) requires impairment of at least one other area

of cognitive function and requires symptoms to have a significant impact on activities of daily living (ADL) (American Psychiatric Association, 2000). The International Statistical Classification of Diseases-10 (ICD-10) stipulates a cognitive decline sufficient to impact upon ADL, however observed change in such activities is not required due to cultural variation in social roles (WHO, 1992). Within the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5) “dementia is subsumed under the newly named entity major neurocognitive disorder” (American Psychiatric Association, 2013, p. 591). This is a broader entity than dementia with the requirement for substantial decline in only one of the following cognitive domains: complex attention, executive function, learning and memory, language, perceptual-motor or social cognition with the additional criteria of interfering with ADL and independence (American Psychiatric Association, 2013).

Numerous subtypes of dementia have been defined with varying or unknown aetiology, among the more common are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies (Alzheimer's Society, 2011; Robillard, 2007). Symptoms and pathology common to particular subtypes of dementia can co-occur (Robillard, 2007) and dementia often has multiple aetiologies, the most common being Alzheimer's mixed with other pathologies (Gauthier et al., 2012). Diagnosis of dementia remains a clinical exercise based on symptom description as biological markers have only been established for certain types of dementia and these are generally limited to research use (Downs, Clare, & Anderson, 2008; Naylor et al., 2012; Robillard, 2007; Visser, Vos, van Rossum, & Scheltens, 2012). Since our understanding of dementia is evolving, diagnostic criteria are liable to undergo continual revision (Rockwood, Bouchard, Camicioli, & Léger, 2007).

It can be seen that there remains a degree of uncertainty among professionals regarding the nature and identity of what constitutes dementia. Furthermore, the recent publication of DSM-5 has questioned the utility of dementia as a diagnostic category by replacing it with a distinction between mild and major neurocognitive disorders (American Psychiatric Association, 2013; Ganguli et al., 2011). However, this has been criticised for placing too great an emphasis on a dichotomous distinction between major and mild severity of neurocognitive disorder (Snelgrove & Hasnain, 2012). In addition to debate around appropriate nosology, the same neuropathological changes can result in a variety of different symptoms and cognitive changes, suggesting that aetiology is multifactorial and not purely biological (Rockwood et al., 2007). Also, symptoms of dementia can exist without any observable neuropathological

changes, while the neuropathological changes commonly associated with dementia have been identified in people who do not exhibit symptoms of dementia (Cheston & Bender, 1999; Davis, Schmitt, Wekstein, & Markesbery, 1999). These observations highlight the need to consider wider environmental and social factors to better understand how these influence the symptoms perceived by individuals with dementia.

### **Social perspectives on dementia**

Some authors have questioned the validity of a purely medical description of dementia (Cheston & Bender, 1999; Kitwood, 1997). Recently, a biopsychosocial view of dementia has received wider acceptance (Downs et al., 2008) and this is now reflected in current guidelines and policy documents which encompass both medical and social perspectives (Department of Health, 2009; National Institute for Health and Care Excellence & Social Care Institute for Excellence, 2007; Scottish Intercollegiate Guidelines Network, 2006). Kitwood (1997) refers to the medical view of dementia as the 'standard paradigm' and suggests that its emphasis on neuropathological causes can restrict people's awareness of the ways in which the impact of dementia can be managed. The degree to which someone's social environment can be adapted in order to facilitate maintenance of participation in everyday activities greatly impacts the way people experience dementia and factors such as anxiety and hypervigilance can amplify the impact of cognitive changes (Kitwood, 1997).

A view of dementia based on the standard medical paradigm may lead to a greater level of dependency and functional impairment than would be expected for a given degree of cognitive impairment, so that engagement in activities and relationships may wane before cognitive changes necessitate this (Cheston & Bender, 1999; Downs et al., 2008). People with dementia may describe the changes they notice in a way that helps them make sense of their experience (Pearce, Clare, & Pistrang, 2002; Van Dijkhuizen, Clare, & Pearce, 2006) and this will be affected by their prior perception of how medical and social factors influence dementia. Cheston and Bender (1999) observe that receiving a diagnosis of dementia may be disempowering when medical stereotypes have been internalised, if such stereotypes suggest that dementia leads to a steady inevitable decline caused by biological changes which the individual and those around them can do little to address. However, a diagnosis can provide a way for people to conceptualise and make sense of memory difficulties in the context of prior knowledge and experience (Pearce et al., 2002). Negative impacts of dementia may be due to how people internalise expectations about their condition in a way that makes sense to them

in addition to the current degree of cognitive changes (Rockwood et al., 2007). Cheston and Bender (1999) suggest that people with dementia need to be helped to understand their condition in a way that enables them to do as much as they can to manage the impact of dementia. This suggests that there may be aspects of dementia where individuals feel that they lack information or where they feel that they do not know enough, indicating unmet information needs. For instance, someone with dementia who has a degree of awareness that their memory has changed may not feel fully informed about how to control the social or personal impacts of such changes.

### **Stages of dementia**

As dementia is generally progressive, various methods of describing the degree of impairment in terms of stages are in use. The WHO (1993) defines mild dementia as being characterised by primarily anterograde memory difficulties which interfere with everyday tasks, but are not incompatible with living independently. In moderate dementia, memory difficulties pose a serious handicap to living independently and severe dementia is characterised by a lack of any anterograde memory abilities and substantial difficulty in accessing any retrograde information such as recognition of close family (WHO, 1993). A variety of instruments are available which are used as one component of the process of clinically diagnosing the early, mid and later stages of dementia. The Mini-Mental State Examination (MMSE) is widely used due to its brevity where a score of 20-26 is usually consistent with a diagnosis of early-stage dementia and a score of less than 20 consistent with more advanced stages of dementia (Alzheimer's Society, 2013; Folstein, 1997).

Prince, Bryce, and Ferri (2011) emphasise that a key purpose of diagnosing people with dementia while in the early stages of the disease is that it can enable them to access information about their condition in a timely manner. Assisting people with dementia to find personally relevant information about their condition may be particularly beneficial during the early stages of dementia, as at this time they typically still possess a sufficient degree of cognitive ability to engage with support to help them adjust to the changes experienced as a result of their dementia (Sullivan, Muscat, & Mulgrew, 2007). The National Dementia Declaration was recently published by the Dementia Action Alliance, a collaboration of organisations including the Department of Health (DoH), Alzheimer's Society and British Association for Counselling and Psychotherapy (Dementia Action Alliance, 2010). This aimed to describe important changes that people with dementia wish to see in their lives and one of the

main desires highlighted was to have sufficient advice and information about their dementia to help them plan how best to manage their condition. In addition, the 2011 World Alzheimer Report advocates that early diagnosis of dementia can make it easier for people with dementia to develop a personal framework for understanding their condition which may provide relief through validation of concerns (Prince et al., 2011).

### **Self-Regulation**

Maes and Gebhardt (2000) suggest that self-regulation can be seen as a set of actions carried out with the intention of reaching personal goals; the process of self-regulation involves an individual directing or changing how they behave in order to achieve these goals in response to new events, for instance finding out they have a particular illness. Models specifically addressing the process of self-regulation have been developed since traditional models of health behaviour, such as Bandura's (1977) social learning theory and behavioural theories such as Dollard and Miller's (1950) Fear-Drive model were not sufficient to encapsulate all the processes involved in the self-regulation of health behaviours (Maes & Gebhardt, 2000).

### **Common Sense Model of Self-Regulation of Health and Illness (CS-SRM)**

A variety of self-regulation models have been proposed, the most widely established of which is the CS-SRM (Leventhal et al., 1997; Leventhal, Brissette, & Leventhal, 2003; Leventhal, Musumeci, & Contrada, 2007; Leventhal, Nerenz, & Steele, 1984), though other self-regulation models such as the Health Behaviour Goal Model (Maes & Gebhardt, 2000) have also been proposed. The CS-SRM proposes that an individual's cognitive perceptions of their health condition, which are termed Illness Representations (IRs), exist in parallel to an emotional reaction to the illness and that these IRs and emotional reaction guide the process of self-regulation (Leventhal et al., 2003). IRs are generated when new experiences are compared to and integrated with prototypes or schema which people are thought to hold about types of illness; these cognitively held IRs may lead to the development of procedures to control or prevent the identified illness or health threat and plans for how and when to act upon these procedures (Leventhal et al., 2012).

Changes in day-to-day function, symptoms, other external information and abstract information such as thoughts are processed by heuristics or rules, which are used to compare

new information with the underlying prototypes of known illnesses in order to construct IRs (Leventhal et al., 2003). Heuristics elaborate on and ascribe meaning to information in the context of past experience of life with and without illness (Leventhal, Forster, & Leventhal, 2007). For example, the symmetry rule or heuristic implies that when symptoms are experienced, this will initiate a search for labels for these symptoms, and that when labels such as a diagnosis are present this will lead to searching for symptoms (Leventhal et al., 2012). The age-illness heuristic suggests that symptoms with a gradual onset might be ascribed to ageing rather than a pathogen while the novelty heuristic suggests that unusual symptoms need to be checked as they may be more serious (Leventhal, Forster, et al., 2007).

In comparison to other theories of self-regulation and health behaviour, the CS-SRM has been applied to a wide variety of conditions, including chronic conditions and mental health conditions (Lobban, Barrowclough, & Jones, 2003; Petrie & Weinman, 1997). The CS-SRM has recently been applied to the study of dementia, as outlined below. An advantage of the CS-SRM over other health and illness behaviour theories is its ability to identify the content of what each individual believes about their illness and how this informs the problem-solving processes involved in addressing these concerns (Leventhal et al., 2012). The CS-SRM was originally developed inductively from exploratory qualitative research which was based on open-ended interviews (Leventhal et al., 2012; Leventhal et al., 1984). Meta-analysis of data from studies using the CS-SRM has identified that the way participants' responses cluster together during factor analysis is consistent with the IR domains proposed by the CS-SRM; this provides further support for the construct and discriminant validity of these domains (Hagger & Orbell, 2003). As the CS-SRM is now a well established and validated model, it is also used as an *a priori* framework to inform top-down research via use of questionnaires (Moss-Morris et al., 2002; Weinman, Petrie, & Moss-Morris, 1996) and semi-structured interviews. These interviews utilise questions to explore the various domains within the CS-SRM along with open-ended prompts to facilitate elaboration.

### **Illness representations (IRs)**

According to Leventhal (Leventhal et al., 1997; Leventhal, Forster, et al., 2007; Leventhal et al., 1984), IRs describe the way people think about illnesses or other potential threats to their health in terms of a set of cognitive domains which encompass areas that people are likely to consider in relation to health problems. IRs are comprised of both abstract verbal representations of the illness and perceptual representations of how people believe the illness

may affect them, and these IRs exist alongside a parallel emotional reaction to the illness, such as anger or fear (Leventhal et al., 2003). The cluster of views a person holds within these domains, encompassing their acquired knowledge and beliefs about an illness as represented in their memory and conscious awareness at a particular point in time, constitutes their current IR. As IRs are variable and result from an individual's personal understanding at that particular point in time, they do not necessarily include biologically accurate information about aetiology or accurate information about applicable medical, social and environmental management approaches (Leventhal et al., 2012). The development and revision of an individual's IR is thought to be informed by three main sources of information: lay knowledge about the illness, current experience of the illness, and knowledge received from external sources such as information from health professionals (Leventhal, Meyer, & Nerenz, 1980; Leventhal et al., 1984). These IRs influence how a person will respond to, and cope with, a particular illness or threat to their health (Weinman & Petrie, 1997).

In terms of the cognitive components of an individual's IR, Leventhal et al. (1984) initially proposed four IR domains of *Identity, Cause, Timeline and Consequences* with Lau and Hartman (1983) proposing a fifth IR domain of *Cure-Control*. Horne (1997) argued that within the domain of *Cure-Control* a distinction could be made between *Personal Control* efforts and *Treatment Control* offered by others, such as health professionals. Moss-Morris et al. (2002) found further evidence in support of this *Personal Control / Treatment Control* distinction. Moss-Morris also proposed that for some health conditions, the *Timeline* domain might be viewed as cyclical as opposed to chronic or acute, but a cyclical view of *Timeline* is likely to be most applicable to hormonal or relapsing-remitting conditions (Moss-Morris et al., 2002) rather than conditions such as dementia.

In earlier papers, Leventhal outlined IR domains but with minimal clarification of how they might be defined (Leventhal et al., 1997; Leventhal et al., 1984). Recently, Leventhal has provided more expansive descriptions of the five primary domains within an IR (Leventhal, Breland, Mora, & Leventhal, 2010; Leventhal, Forster, et al., 2007). The content of an individual's IRs consists of information represented within these five domains, along with the construct of coherence and a parallel emotional reaction. The five primary IR domains are summarised below.

- Identity
  - *The terms people use to refer to their illness and the changes or symptoms they attribute to it*

- Cause
  - *The events and factors people see as responsible for their illness*
- Timeline
  - *How long they expect their illness to last and how quickly they think it may change*
- Consequences
  - *Areas which people perceive as being affected by their illness and areas they expect to be affected*
- Cure-Control
  - *People's personal expectations and experiences of what they or other people can do to manage the impact of their illness, including whether they believe a cure may be possible and their views about the range of treatments which they know about*

### **Coherence**

Elliott, Fischer, and Rennie (1999) note that in qualitative research, the researcher's interpretation of their data is presented in such a way that the themes from their interpretation fit together without redundancy or overlap so as to achieve a coherent interpretation of their data. Other psychological models, such as Antonovsky's Sense of Coherence model, see coherence in terms of an individual's enduring sense of being able to predict and explain internal and external stimuli, while also having sufficient resources available to meet demands imposed by the stimuli (Antonovsky, 1993). However, in the context of the CS-SRM, the term 'coherence' is used in a different manner and different researchers have used the term to describe different aspects of the model. Furthermore, some researchers have specified an adapted definition of coherence particular to their study or recommended adaptations to how the construct of coherence is applied in studies utilising the CS-SRM (French, Cooper, & Weinman, 2006; Hall, Weinman, & Marteau, 2004). Within the CS-SRM, the construct of coherence was initially proposed by Moss-Morris et al. (2002), who defined coherence as "the extent to which a patient's illness representation provided a coherent understanding of the illness" (Moss-Morris et al., 2002, p. 2) or "how the illness 'makes sense' as a whole to the patient" (Moss-Morris et al., 2002, p. 13). Moss-Morris' original definition of coherence relates to a holistic overview of whether all aspects of someone's IR provide a sufficient basis for that person to make sense of their illness. It is important to emphasise that when Moss-Morris defines coherence, it is the participant or patient rather

than a researcher who is asked to make a judgement about whether they feel their illness makes sense to them.

Subsequent publications by different authors have adopted an alternative view of the construct of coherence within someone's IR. Leventhal and his colleagues define coherence as occurring when there is a close link between elements of an individual's IR and the action plans and procedures that are being used by that individual to manage their condition (Horowitz, Rein, & Leventhal, 2004; Leventhal, Benyamini, & Shafer, 2007). A common element between how coherence has been defined by Moss-Morris and by Leventhal is that coherence is described as a property of a system, in that someone's IR is coherent when the knowledge they hold about their condition within each IR domain is consistent with their beliefs about their condition contained within other IR domains. Therefore, if someone's beliefs about their condition in terms of one IR domain conflicts with their beliefs about their condition within any of the other IR domains, their illness representation as a whole will not be coherent.

Leventhal also describes a concept of 'illness schema' (Leventhal et al., 1984) in which certain patterns of IRs can be seen as consistent with a particular illness schema held by individuals, such as acute or chronic. For example, an IR in which someone reports intermittent symptoms where consequences are only present when symptoms occur could be seen as making sense in terms of an acute schema. The concept of illness schema is described as a distinct component of the CS-SRM, which operates at an early stage during the process of forming an IR from perceived symptoms (Bishop, 1991; Leventhal et al., 2012). However, there appear to be some similarities between illness schema and the construct of coherence in that if the symptoms someone experiences are a good fit with a schema they may feel that their IR is coherent.

A key distinction between how Moss-Morris describes coherence and how Leventhal describes it is that for Moss-Morris it is the person with the illness who makes a judgment about whether their IR is coherent (Hall et al., 2004; Moss-Morris et al., 2002), whereas for Leventhal the judgment as to whether or not IRs fit coherently with action plans and procedures is made by a third party, such as a researcher or health professional. Similarly, for Leventhal's concept of illness schema, although the process of matching symptoms to an underlying schema or prototype is thought to be predominantly unconscious and automatic (Leventhal et al., 2012),

descriptions of what schema consist of are commonly reported from the perspective of the researcher.

Although Moss-Morris defined coherence of IRs for the purpose of a questionnaire measure, the Illness Perception Questionnaire – Revised (IPQ-R), an advantage of drawing from Moss-Morris' view of coherence for the purposes of qualitative research is its focus on how individuals see their illness not a researcher's judgment of how people see their illness. However, it is harder to define coherence of IRs than to define other IR domains (Farquharson, Johnston, & Bugge, 2011; Hall et al., 2004; Horowitz et al., 2004). Farquharson et al. (2011) applied Moss-Morris' definition of coherence to their qualitative investigation of how people present to health services. As a quality check for their study, Farquharson et al. (2011) had another researcher code their data in order to assess inter-rater reliability, which was acceptable for all IR domains with the exception of coherence. Furthermore, in a study which looked at adapting the IPQ-R to construct a measure of memory complaints, Hurt, Burns, Brown, and Barrowclough (2010) found that questionnaire items designed to measure coherence had lower inter-item correlations compared to questions used to measure other IR domains. Hall et al. (2004) adopted Moss-Morris' definition of coherence of IRs in a study exploring how coherence is affected by receiving information about the link between cervical cancer and smoking. Hall et al. clarified how they had interpreted Moss-Morris' definition of coherence by stating more explicitly how they intended to apply this definition of coherence in the context of the aims of their study. These findings indicate that qualitative studies investigating people's understanding of their condition using the construct of coherence may benefit from providing a more explicit definition of what constitutes coherence of IRs for each study.

Leventhal does not see the CS-SRM as a finished system but as a 'work in progress' to be built upon by further "conceptual elaboration and empirical work" (Leventhal et al., 2012, p. 4) with studies that utilise the CS-SRM commenting on the potential merits of refining or adapting the model. French et al. (2006) applied the CS-SRM to an investigation of another chronic condition, coronary heart disease, adopting Moss-Morris' definition of coherence. They noted that a limitation of this view of coherence was that it did not help to identify which particular aspects of an illness people see as not making sense to them. They recommended that future research involving the construct of coherence should aim to investigate which particular features of their illness people feel they do not have a clear understanding of, rather than just

whether or not people feel that they have a clear understanding of their illness as a whole. Enquiring about someone's overall understanding of their illness does not help to explain why some people do not have a coherent understanding of their condition. One possible approach to investigating why people may or may not feel they have a coherent overall understanding of their condition would be to investigate what it is about a particular IR domain or domains people feel that they do not understand or does not make sense to them. Knowledge of which features of their illness people feel they do not understand, by investigating whether individuals feel they understand enough about each IR domain, might help to show where beliefs within one IR domain are not consistent with beliefs held in other IR domains. This would then give an indication of which features of their condition someone has not been able to link together in order to form a coherent understanding of their condition as a whole.

A recent report from the National Institute for Health Research (NIHR), highlights that professionals need to be able to tailor information to the individual needs of people with dementia, and that professionals will be better able to do this if they have a mechanism for eliciting information needs based on the perspective of the person with dementia (Manthorpe et al., 2010). In addition, Miranda-Castillo, Woods, and Orrell (2013) recently investigated how people with dementia living in the community perceived their needs and emphasised the "importance of assessing the needs of people with dementia by considering their own views" (Miranda-Castillo et al., 2013, p. 9). Therefore, in order to enable a detailed and person-centred analysis of the information needs of people with early-stage dementia, the current study chose to investigate whether a lack of knowledge or understanding about particular aspects of dementia might make it more challenging for people to form a coherent overall understanding of their condition. More specifically, it will focus on whether a lack of understanding within particular IR domains leads to instances where the elements within someone's IR do not fit comfortably with each other in a way which makes sense as a whole to the individual. This will allow some interpretative observations to be made regarding how lack of knowledge within individual domains may have impacted upon someone's ability to form a coherent understanding of their condition.

See Appendix 1 for details of how interview transcripts were coded for instances where participants talked about understanding or lack of understanding of particular aspects of their dementia.

There are a number of advantages and difficulties to approaching the study of coherence by investigating what people say they don't understand about particular IR domains, as opposed to investigating whether people say they have a coherent understanding of their illness as a whole. Enquiring about understanding of individual IR domains would be better suited to identifying specific information needs which may contribute to a lack of a coherent understanding than investigating whether people feel they have a coherent overall understanding of their condition. This approach could aid consideration of coherence of someone's condition as a whole by highlighting particular aspects of their illness which might be impeding the formation of a coherent understanding, for example helping to identify areas where a person feels their understanding of their condition conflicts with each other or areas which are incomplete. However, a more direct approach to assessing overall coherence might be to ask people whether they have a coherent understanding of their condition as a whole; investigating understanding of individual IR domains may not always show whether someone has a coherent understanding. For instance someone may still feel they have a coherent understanding of their condition if it is not important to them to know more about aspects of their condition which they do not feel they understand. Although investigating understanding of individual IR domains could help to highlight gaps in knowledge that people want to acquire about their condition, this would not necessarily show whether providing them with such knowledge would definitely impact upon the coherence of their IRs as there may also be aspects of their condition which people do not feel they sufficiently understand, but they may choose not to disclose these to a researcher. However, being able to identify information which people have stated they do or do not want to know more about may have other uses in addition to helping to explain why some people may find it hard to form a coherent understanding of their condition. Such knowledge could inform provision of a manageable amount of information to people about their condition which was more personally relevant and therefore potentially more likely to be retained. This approach may also help identify aspects of their condition which people would prefer not to know more about.

#### **Other components of the CS-SRM: procedures and action plans**

In addition to the formation of an individual's IR, including their parallel emotional reaction, an additional component of the CS-SRM involves an individual developing procedures for controlling or preventing the illness in question, and action plans for how, where and when to implement these procedures (Leventhal et al., 2012). Rules, called heuristics, are the mechanism by which coping procedures and action plans are developed from IRs, and are also the mechanism by which IRs are formed and revised (Leventhal et al., 2003; Leventhal, Forster,

et al., 2007). The procedures which are specified by heuristics define ways of detecting, preventing, controlling or eliminating health threats; these vary greatly in form and may include choosing to take no action, using natural remedies, medication or other types of professional intervention or seeking support from others (Cameron & Leventhal, 2003; Leventhal et al., 2010). As procedures are informed by IRs, they are closely related to them and can also be classified according to the five primary IR domains (Brownlee, Leventhal, & Leventhal, 2000; Cameron & Leventhal, 2003). Procedures specify an action class, for instance taking a painkiller or seeking professional support, along with a detailed choice within this class such as a specific medication or a specific type of support such as attending a rehabilitation programme (Cameron & Leventhal, 2003; French et al., 2006). Procedures are thought of as valuable if there is an obvious means by which change may be affected such as attacking the health threat at a particular location or causing observable change in a symptom (Cameron & Leventhal, 2003; Leventhal et al., 2010). A procedure will be less appealing if evidence of its action is delayed or it has less face validity to an individual because its mechanism of action does not obviously fit with their IR (Leventhal et al., 2010). For instance, there is no obvious link between cervical cancer and smoking, so unless female smokers believe that smoking is a risk factor they are unlikely to consider changing their smoking behaviour in order to affect their risk of this cancer (Hall et al., 2004).

Action plans then describe a specific place and time to initiate and complete the procedure (Leventhal et al., 1997), e.g. 'I'll go to the rehabilitation group at the hospital on Tuesday'. The experience of implementing these coping procedures via action plans contributes to the parallel emotional reaction and the outcome of implementing procedures is evaluated (Leventhal, Forster, et al., 2007). Evaluation may result in current IRs, action plans, and procedures being maintained or revised in a way that the individual believes will be more effective (Leventhal, Forster, et al., 2007). The process of evaluating and deciding whether to revise IRs is ongoing so IRs vary over time for individuals. This separation of action plans and procedures from the IRs and emotional reaction from which they are derived is a central feature of the CS-SRM as an IR is not sufficient on its own to result in health-related behaviour change (Leventhal et al., 2012). In order to allow a focused topic of investigation, the current study aims to utilise the first stage of the CS-SRM, i.e. an individual's IR and their emotional reaction, and will therefore not explicitly aim to elicit coping procedures or action plans.

### **Application of the CS-SRM to Dementia**

To date, a small number of published studies have looked at how the CS-SRM might aid our understanding of dementia from a variety of perspectives; some have used quantitative questionnaires (Hamilton-West, Milne, Chenery, & Tilbrook, 2010; Roberts & Connell, 2000) though the majority have used qualitative interviews. Qualitative studies have investigated how people with dementia think about their condition while going through the process of diagnostic assessment (Moniz-Cook, Manthorpe, Carr, Gibson, & Vernooij-Dassen, 2006) and how people with a recent diagnosis of dementia think about their condition (Clare, Goater, & Woods, 2006; Glidewell, Johnston, & Thomas, 2012; Harman & Clare, 2006). Research has also looked at how lay people perceive dementia (Hamilton-West et al., 2010) and how family members of people with dementia conceptualise this condition (Glidewell et al., 2012; Moniz-Cook et al., 2006; Roberts & Connell, 2000). The majority of family members in Roberts and Connell's study had cared for a relative with dementia, and Glidewell et al. (2012) investigated how a family caregiver and health professional conceptualised an individual's experience of dementia using the CS-SRM. The degree to which the CS-SRM was used as a framework to assist with generating and interpreting data has varied in previous studies.

Moniz-Cook et al. (2006) were interested in what dementia means to people undergoing diagnosis and their families. They utilised a semi-structured interview with open-ended questions based on IR domains to elicit participants' perception of symptoms, but do not provide details of how explicitly their interview schedule related to IR domains. Moniz-Cook et al. (2006) utilised Interpretative Phenomenological Analysis (IPA) to look for emergent themes from their data and found that IR domains were reflected in the content of their themes of *losing control, inevitable future dependency* and *loss of pleasure*. Descriptions consistent with illness identity included an awareness of symptoms of memory impairment, causes of dementia included not using your memory or keeping active, the time course of dementia was described as chronic and degenerative, cure-control strategies included seeking professional advice, considering medication and a belief that little could be done and the consequences mentioned included diminishing self-identity and family stress (Moniz-Cook et al., 2006).

Harman and Clare (2006) were keen to explore the relevance of the CS-SRM for understanding individuals' expressed experience of their dementia, current coping strategies and information about their condition they had retained from previous contact with services or prior lay perceptions. They used a semi-structured interview with some initial probes based on CS-SRM

domains, after which interviews used open questions directed by participant narratives. During analysis, Harman and Clare (2006, p. 488) “applied IPA to investigate the elements of an existing structural model”, the CS-SRM, rather than using IPA as a purely exploratory method. They note how the results of their IPA analysis were comparable with the domains of the CS-SRM: their theme of *‘it will get worse’* reflected insight into potential causes, the chronic time course of dementia and the consequence of declining abilities and their theme of *‘I want to be me’* reflected insight into the consequences of dementia on self-identity. They then conducted an additional content analysis which identified the frequency with which responses consistent with IR domains occurred in each participant’s account.

Clare et al. (2006) investigated the viability of using the CS-SRM to systematically explore how people with early-stage dementia describe their experience of this condition, its implications and the way they address these. They utilised a semi-structured interview schedule based on IR domains which aimed to elicit: changes that had prompted contact with services, attributions and explanations for these changes, the repercussions of changes, coping strategies and perceptions of their future with dementia. Content analysis was used to identify statements from any participant which related to one or more IR domain (Clare et al., 2006). Their analysis reports the relevant themes identified within each IR domain, indicating how many participants made statements that supported each theme, and providing illustrative examples of data used to support prominent themes. However, it is difficult to tell from the examples how their understanding developed from the data. Clare et al. (2006) note that forgetfulness was the most commonly identified symptom, while normalising their experience as part of the ageing process was the most prevalent causal process identified, with genetic factors, life stress and traumatic injury also being considered. Time course was viewed as either stable or degenerative by different participants in their study.

Glidewell et al. (2012) report a case study which investigated whether a patient with early-stage dementia, a family caregiver and a general practitioner (GP) described dementia using IRs along with considering whether the GP and caregiver understood how the individual with dementia represented their condition. Their study used a semi-structured interview using open questions to elicit participants’ identity labels, followed by prompted questions that explored whether participants talked about dementia using IR domains. Glidewell et al.’s semi-structured interview prompted participants to talk about their emotional reaction and coherence of their IRs in addition to the five primary IR domains. Glidewell et al. (2012) coded

and analysed interview data using the framework of the CS-SRM. They found that participants spontaneously talked about dementia using some CS-SRM domains, but that prompting people to talk about particular domains allowed a more systematic and detailed exploration of their understanding of dementia. Glidewell et al. identified that the GP was not aware of how the person with dementia thought about their condition. For example, the GP felt that their patient was satisfied with their current knowledge about dementia, whereas both the patient and carer stated that the patient would like to know more about their condition.

### **Overall findings regarding CS-SRM domains from dementia studies**

The above studies provide evidence for the presence of IR domains in the narratives of people with dementia from both exploratory analysis (Harman & Clare, 2006; Moniz-Cook et al., 2006) and analysis using the CS-SRM as an *a priori* framework (Clare et al., 2006; Glidewell et al., 2012; Harman & Clare, 2006). However, not all participants in these studies used the term 'dementia' or diagnostic labels such as 'Alzheimer's' to refer to their symptoms, some choosing alternative labels to refer to their illness identity. Clare et al. (2006) suggest that although there is variability in the terminology used to refer to their illness identity, with some people not using a dementia label, this does not suggest a problem in applying the framework of the CS-SRM to people with dementia, but rather reflects a difficulty with the title of the CS-SRM as a model. Other studies (Glidewell et al., 2012; Moniz-Cook et al., 2006) have also adopted the practice of not priming participants with the use of diagnostic language by the researcher. This approach is an important way to gain insight into the language individuals use to describe their illness identity label. By enquiring about the language used to refer to the condition of dementia at the start of a research interview, it is possible to use the participants' own words during subsequent questioning so as not to prompt them with terminology they would not otherwise have used. Even for participants who did use terms such as dementia or Alzheimer's, Harman and Clare (2006) noted that there was uncertainty as to the appropriate use and meaning of these terms. Clare et al. (2006) conclude that the IR domains proposed by the CS-SRM can provide a useful framework to help people with early-stage dementia talk about their condition.

The participant with dementia studied by Glidewell et al. (2012) was unsure about what specifically he or others could do to improve or slow the progression of his dementia, but he was eager to learn about anything that would help control his condition. He felt that medical professionals would be able to advise him about what else could be done, and already utilised

help from his family and strategies such as noting appointments in his diary. Harman and Clare (2006) noted that some participants reported no descriptions consistent with the cure-control IR domain. Also, Clare et al. (2006) found little evidence that their participants were planning for the future. There were, however, some instances where positive personal control strategies or treatments were talked about, in particular only one of the participants interviewed by Clare et al. (2006) did not report some sort of control strategy, with other participants remaining active, using familiar routines, seeking support from others and restricting activities. It is worth noting that although representations consistent with the cure-control domain were not always disclosed in previous studies, these may have been present but other factors could have inhibited participants from disclosing these in the interview. Only one study to date (Glidewell et al., 2012) has included investigation of the coherence of IRs in early-stage dementia and further research with coherence as a primary focus of investigation may be relevant, particularly given the observation that some participants in previous studies did not talk about their IRs in terms of all the CS-SRM domains that were prompted.

### **Application of the CS-SRM to Other Conditions Involving Memory Changes**

The CS-SRM has also been applied to the investigation of Mild Cognitive Impairment (MCI) using both qualitative interviews (Lingler et al., 2006) and questionnaire measures (Lin, Gleason, & Heidrich, 2012). Lingler et al. (2006) used semi-structured interviews to elicit how people with an MCI diagnosis experienced living with this condition. Although they adopted grounded theory as a method of analysis, Lingler et al. found similarities between their grounded theory analysis and IR domains with evidence of a parallel emotional reaction, providing additional cross validation to the application of IRs to the study of conditions involving memory changes. The literature reviewed so far suggests that people with early-stage dementia and other similar memory difficulties do think about their condition in terms of IRs and that the CS-SRM provides a useful framework for investigating how people understand dementia and memory changes in more depth. However, previous research has not investigated the coherence of individual IR domains for people with early-stage dementia.

### **Relevance of National Strategic and Service-User Perspectives**

Traditionally, research into dementia has paid little attention to the perspective of the person with dementia, however recent government policies recommend taking a person-centred approach (Department of Health, 2009). A literature review of patients' perspectives on their

dementia (Boer et al., 2007) found that literature on patients' experience of dementia focused on insights into the consequences of dementia and coping strategies used, but not whether people feel that they have enough information to come to a personally clear understanding of their condition.

The DoH recommends that people with early-stage dementia receive assistance in finding relevant information about their condition which is tailored to what the person with dementia wants to know and that they are supported to understand this information (Department of Health, 2009). The World Alzheimer Report 2011 into the benefits of early diagnosis and intervention highlights the important role professionals play when providing people who have early-stage dementia with information about their condition (Prince et al., 2011) and the Alzheimer's Society's Dementia 2012 report also highlights that people should receive assistance to understand information about dementia (Alzheimer's Society, 2012). Therefore, the CS-SRM could have the potential to address these needs if prompting people to talk about their dementia in terms of IRs is able to elucidate the specific aspects of their dementia where people feel they would like further information.

An effective way of identifying personally relevant information to be given to people with dementia is necessary as the DoH, local council and local National Health Service (NHS) Trust are committed to providing such information in a timely manner (Department of Health, 2009; Leeds City Council & National Health Service Leeds, 2012). There is also a clear desire for this type of information from people with dementia as highlighted by several recent national service-user focused reports. The National Dementia Declaration highlights that following a diagnosis of dementia, the majority of people do not have a sufficient understanding of their condition and "many people with dementia and carers report receiving no information about their condition" (Dementia Action Alliance, 2010, p. 3). In addition, the Alzheimer's Society's 2012 national report found that 38% of the people with early-stage dementia surveyed did not think they knew enough about dementia. Furthermore, the National Dementia Declaration highlights several key outcomes which people with dementia wish to experience in their lives, including to "know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me" and having sufficient relevant information to make decisions about management of their condition (Dementia Action Alliance, 2010, p. 5).

### **The Need for Tailored Patient Information**

Leventhal suggests that IRs should be borne in mind when planning the delivery of interventions and that IRs can provide a helpful starting point when working with patients (Leventhal et al., 2012; Leventhal et al., 2010). The CS-SRM proposes that people may make sense of a health threat in ways that, although personally meaningful to them, would not fit with a clinical understanding of their condition. The CS-SRM suggests that IRs provide a framework for making sense of new information from health professionals and that new information people receive about their condition is less likely to be rejected if an individual sees the information they are provided with as personally relevant, as well as commensurate with their IRs (Leventhal et al., 2003).

Lin et al. (2012) investigated people's beliefs about their diagnosis of MCI using a version of the IPQ which had been adapted for MCI (IPQ-MCI). They noted that, although the people in their study had received psychoeducational information about MCI from their memory clinic, approximately half of their participants reported feeling that their understanding of MCI was not coherent. Consequently, Lin, et al., recommended that "further efforts to tailor patient education about MCI to patients' knowledge and cognitive levels may need to be addressed in clinical practice" (Lin et al., 2012, p. 203). This recommendation may be applicable to people with early-stage dementia as between a third and half of those diagnosed with MCI are expected to progress to early-stage dementia (Busse, Angermeyer, & Riedel-Heller, 2006; Mitchell & Shiri-Feshki, 2009). Furthermore, the NIHR also highlights that communicating information to people about their dementia needs to be improved and "tailored to an individual's needs" (Manthorpe et al., 2010, p. 27). It may therefore be relevant for research to investigate potential mechanisms for identifying individually tailored information for people with early-stage dementia which take into account their current beliefs and knowledge about their condition. Further research into the aspects of dementia which people feel they do not sufficiently understand, may indicate whether the construct of coherence could provide a mechanism for identifying unmet individual information needs for people with early-stage dementia.

### **Summary**

This review has highlighted that there are a range of professional views regarding what constitutes dementia, indicating the role played by both physiological and environmental

factors in the genesis of symptoms. Previous research has established the applicability of the CS-SRM to people with early-stage dementia and it can be seen that national policies highlight the importance of facilitating opportunities for people with dementia to find out relevant information about their condition during the early stages. Service-user reports from people with early-stage dementia have indicated that many do not feel they have been told enough about their condition and that they desire to be provided with relevant information about their dementia. These factors indicate a need to investigate potential mechanisms that may facilitate the identification of what people with early-stage dementia feel they do not understand about their condition. Therefore, the current study proposes to investigate what people with early-stage dementia feel they do not understand about their condition, by utilising the CS-SRM, with an adapted definition of coherence of IRs, to address the following research question.

### **Research Question**

- When using illness representations as a framework, how do people talk about their condition and how coherent are their understandings?

In addressing the above research question, this study aims to offer some insights into the following areas:

- *What participants themselves feel they do not understand about their dementia*
- *Aspects of dementia that participants say they would like to know more about*
- *Aspects of dementia which participants feel they have sufficient knowledge about at the time of the research interview*

## METHOD

### Context

The current study was based within the memory service of a local NHS trust in the North of England. The memory service consists of clinics covering five areas of a large city receiving approximately 1500 referrals a year, the majority of whom receive a diagnosis of dementia. One memory clinic, serving the largest area of the city, assisted with recruitment. Memory service staff include psychiatrists, memory nurses and occupational therapists who offer assessment, diagnosis and, where appropriate, monitoring and support for people with dementia. Referrals to this service are predominantly from GPs with some from liaison psychiatry and other secondary care services, however there are no explicit referral criteria. People referred to this service receive a standardised pre-diagnostic assessment from a memory nurse or occupational therapist, which is then reviewed by the multidisciplinary team who may request further necessary investigations such as a computerised tomography (CT) scan. Following this, patients are offered an appointment with a psychiatrist at the memory clinic where they are informed of the outcome of their assessment and whether they have a diagnosis of dementia. At this point in the service pathway, many patients with vascular dementia, who cannot benefit from medication for cognitive changes, are discharged back to their GP. Patients with Alzheimer's or other dementias where medication such as an acetylcholinesterase inhibitor or other support may be beneficial are then reviewed by a psychiatrist at the memory clinic between four and twelve weeks after their diagnostic appointment. In this memory service, once patients who have chosen to accept prescribed medication for their dementia are satisfactorily established on their medication, monitoring of their dementia is transferred from a psychiatrist to a memory nurse. When this research was designed, the local NHS Trust offered a separate service for people under 65 where more intensive support was provided.

### Design

The current study adopted a cross-sectional design employing qualitative methods with a single face-to-face semi-structured interview with each participant with early-stage dementia. *For the purposes of this study, people who had received a clinical diagnosis of dementia and where their Mini Mental State Examination (MMSE) score had been recorded as 20 or above within the previous six months were considered to have early-stage dementia.* Interviews were audio recorded with consent, transcribed, coded, and subject to framework analysis along with measures of inter-rater reliability. The decision was taken not to use any form of psychometric

measure to help contextualise the sample's level of cognitive impairment as this might convey the impression that participation was in some way evaluative in nature, which could affect the way participants responded to the research interview.

Quantitative measures, such as various versions of the Illness Perception Questionnaire (IPQ) are more suited to evaluating strength or quality of IRs, rather than specific beliefs within someone's IR (van Oort, Schroder, & French, 2011). The IPQ (Weinman et al., 1996) and IPQ-R (Moss-Morris et al., 2002) more explicitly prompt participants to think in particular ways and restrict descriptions to agreement with predetermined statements in comparison to qualitative methods. Qualitative methods allow a broader and more individualised range of IRs to be elicited in early-stage dementia (Clare et al., 2006; Glidewell et al., 2012; Harman & Clare, 2006) and are better able to explore the range of ways in which participants describe and understand their IRs compared to investigation of IRs using quantitative questionnaires. Therefore, qualitative research methods were adopted as they are more appropriate than quantitative methods to investigating participants' idiosyncratic perceptions of how well they understand their dementia.

Semi-structured interviews are a commonly used technique for obtaining participants' views on *a priori* areas (Britten, 2006) which have the advantage of being able to focus on a limited range of topic areas, therefore allowing the researcher to systematically collect information on the same topic areas from all participants (Berger, 2013). Previous studies using exploratory methods such as IPA (Harman & Clare, 2006) have established that people with early-stage dementia do conceptualise their condition within the domains of the CS-SRM. In addition, other studies have used a semi-structured interview method to investigate IRs in dementia (Clare et al., 2006; Glidewell et al., 2012; Moniz-Cook et al., 2006). Using a semi-structured interview was thought to provide an appropriate balance between covering all the broad topics thought to be present within IRs while allowing space to explore participants' own understanding within these. A narrative interview would not have been focused enough to elicit sufficient detail in a consistent manner and a structured interview would have restricted exploration of individual experience in a similar manner to a questionnaire-based study.

### **Public consultation**

The Alzheimer's Society research network was invited to comment and provide feedback on the interview topic guide. This network is facilitated by a research coordinator from the Alzheimer's Society who circulated the topic guide to its members for comment. Research network members consist of interested members of the public, including past and present carers of people with dementia, along with people with early-stage dementia. Five carers commented on the topic guide and interview process but no-one with early-stage dementia chose to respond. Their feedback was supportive of not prompting people with the term 'dementia' or other diagnostic labels and highlighted that carers felt the current study had identified an important research topic which might help the views of people with dementia to be valued and considered. Feedback also led to specific changes to the wording used to introduce some interview topics in a more sensitive manner and research network members offered many helpful comments for the author to bear in mind in order to facilitate interpersonal engagement and make the interview process as meaningful as possible for participants.

### **Ethical approval**

A favourable ethical opinion for the current study was granted by the Bradford National Research Ethics Service, Research Ethics Committee on October 15<sup>th</sup> 2012. This committee also granted approval to three protocol amendments: one amendment to allow for recruitment by memory nurses as well as psychiatrists to address slow recruitment, one to allow memory nurses to post study information sheets to eligible patients following a telephone consultation and one in response to feedback giving participants the option to request the presence of a carer during the research interview. NHS permission for the current study and study amendments was also granted by the Trust's Research and Innovation Department. See *Appendix 2* for copies of ethical approval letters.

### **Participants**

In order to provide a sufficiently focused topic for the scale of the current study, the decision was made to focus purely on the views of people with early-stage dementia rather than also including a carer's perception of the views of the person with dementia. Furthermore, Sullivan et al. (2007) highlight that self-reported information from people with dementia may be more

reliable than the views of their carers, as they found that carers underestimated what the person they cared for knew.

It was felt to be most appropriate to recruit people with early-stage dementia through a memory clinic for a number of reasons. It was possible to ensure that all those approached were still in the early stages of dementia, which would have been impractical in a non-NHS setting. Recruiting through other agencies, such as the Alzheimer's Society, would have necessitated open use of diagnostic labels, which could have unintentionally primed participants with diagnostic terms such as 'dementia' or 'Alzheimer's'. This was undesirable as the research design involved eliciting participants' IRs of dementia, which include the labels they use to refer to their condition and whether they choose to use terms such as dementia or not. Also, such a strategy might have resulted in a skewed sample of people who had sought support from an organisation such as the Alzheimer's Society and therefore be less representative of all people who had received a dementia diagnosis from a memory service.

Recruiting from a single memory service clinic covering one sector of the city was judged suitable to provide a sufficient number of participants. Neighbourhood Index data from the local city council (Leeds City Council, 2012) suggested that the area covered by the clinic involved in recruitment encompassed a more socioeconomically diverse population than areas covered by other memory clinics. It is preferable to recruit from a socioeconomically diverse population as this factor has been shown to impact upon IRs in other conditions (Anagnostopoulos & Spanea, 2005; Baumann, 2003). When the study began only people who were attending a review appointment with the psychiatrist were considered for eligibility and offered a study information sheet. After two months, this was expanded to also encompass patients being reviewed by a memory nurse, to facilitate recruitment.

### **Inclusion and exclusion criteria**

The following criteria were applied when identifying suitable participants

#### *Inclusion criteria*

- Aged 65 or over.
  - *At the time this research was designed, the memory service offered a separate pathway for younger people with dementia under the age of 65 where service*

*provision was significantly different with most clients receiving more intensive individualised one-to-one support rather than routine reviews. This difference in service provision would be liable to influence how people think about their dementia. Therefore, a sample with a more homogeneous range of experiences could be obtained by only recruiting people over 65, which ensured that all participants had come through the same memory service pathway.*

- Clinical diagnosis of Alzheimer's or mixed dementia according to ICD-10 criteria; where the patient had previously been informed of this diagnosis.
  - *It would have been hard to recruit people with pure vascular dementia as due to the structure of the memory service that was assisting with recruitment many of these people were discharged back to their GP soon after diagnosis. Including a small number of people with pure vascular dementia would have been liable to skew results from other participants. Gauthier et al. (2012) highlight that many cases of dementia have multiple aetiologies, the most common being Alzheimer's combined with other brain pathologies. Therefore purposively sampling for Alzheimer's or mixed dementia could help to enable recruitment of a sufficient number of comparatively homogeneous participants; this might not have been possible if also trying to identify people with other types of dementia.*
  
- MMSE score of 20 or above, consistent with early-stage dementia, identifiable from their most recent memory clinic assessment.

#### Exclusion criteria

- Cases where clinicians identifying potential participants deemed that individuals would struggle to tolerate a research interview of approximately one hour.
- Dementias associated with a primary diagnosis of movement disorder including Huntington's disease, Parkinson's disease or Motor Neurone Disease.
  - *Dementias associated with these conditions were excluded as the current study was trying to elicit IRs of dementia, and for these conditions IRs of dementia and the associated movement disorder may have been enmeshed; this could have led to results that might not relate to dementia but to the other primary health condition.*

- People not fluent in English.
  - *There were insufficient resources to allow for translation and use of interpreters due to the scale and limited budget of this research.*
- Inability to give informed consent to the research interview.
  - *This was determined by researcher prior to beginning the research interview.*

## **Materials and Equipment**

The materials detailed below were designed for the current study in accordance with National Patient Safety Agency ethical guidelines. All of the materials below, with the exception of the coding frame, were approved by the ethics committee. Equipment consisted of an Olympus DM-450 digital voice recorder, which was used with consent to take an audio recording of the research interview for later transcription.

- 1) Information Sheet for Health Care Professionals (*Appendix 3*)
 

*A brief information sheet outlining the study aims, inclusion and exclusion criteria and recruitment procedures was created to act as an aide-mémoire for memory service clinicians in order to help them identify potential participants and verbally discuss whether they would be interested in receiving a participant information sheet.*
- 2) Research process diagram (*Appendix 4*)
 

*This consisted of a concise flowchart of inclusion and exclusion criteria to help clinicians identify potential participants.*
- 3) Background details table (*Appendix 5*)
 

*This was used by memory service clinicians to record details on MMSE score, type of dementia, medication and age, to be passed to the author in an anonymous form to characterise those approached in the form of descriptive statistics.*
- 4) Participant Information Sheet (*Appendix 6*)
- 5) Participant Consent form (*Appendix 7*)
 

*The participant information sheet and consent form used accessible language where possible so that people had to retain and weigh up the minimum amount of information necessary when deciding whether to take part. Feedback from memory service staff was sought during the design of these forms. The final page of the information sheet contained a reply slip to be returned to the author's university*

*address by people who wished to find out more about the study or take part. A freepost reply envelope was also included with the information sheet for this purpose.*

6) Interview topic guide (Appendix 8)

*The construction of the topic guide drew from that used by Langston et al. (2006) and from a version of this which had been adapted by the author's research supervisor, Dr Glidewell, for a previous project. Before beginning the study, this topic guide was piloted on two age-matched non-clinical volunteers.*

7) Patient participation letter (Appendix 9)

*This was a brief letter sent to the participant's psychiatrist informing them that their patient had taken part in the research but with no other details about their responses.*

8) Coding frame

*A coding frame was constructed and revised during data collection and coding to aid the framework analysis process. See Table 2 in the results section for a copy of the coding frame. The framework analysis section below gives more details of how the coding frame was employed.*

### **Topic guide design**

The topic guide was split into two sections, beginning with non-directive questions and then moving on to questions based upon the areas of the CS-SRM. This was done in order to allow a degree of comparison between what participants reported before and after being prompted to talk about their IRs of dementia. These two types of questions were referred to as 'open questions' and 'CS-SRM questions' and this terminology is used when discussing the results of the study. The CS-SRM questions covered the five primary IR domains beginning with 'identity'. Terms such as 'dementia' or other diagnostic labels were not introduced during the interview unless first used by participants so as not to unintentionally prime them with these terms and because not all people may acknowledge or be comfortable using such terms; this is in line with methodology adopted by previous studies (Clare et al., 2006; Glidewell et al., 2012; Moniz-Cook et al., 2006). Participants' own identity terms were then used to refer to their dementia during subsequent sections of the topic guide. Coherence and emotional reaction were prompted for at the end of exploring each IR domain using CS-SRM questions, rather than being explored at only one point during the interview. The topic guide was not adapted during the course of this research to ensure that the same areas were covered with all participants. However, after exploring the domain of identity, the order in which other

elements of participants' IRs were discussed varied slightly in order to follow areas introduced by participant's responses.

## **Procedure**

### **Recruitment**

Psychiatrists and memory nurses from the memory clinic were asked to hand out participant information sheets to anyone they saw who met the study criteria. Once potential participants had had time to consider the information sheet, they could choose to contact the author. This ensured that participants had had at least 24 hours to consider whether they wished to take part, that only those participants expressing an interest chose to supply their contact details and provided an extra stage where they could have questions addressed before meeting to complete the research interview. Once people had been in touch to express interest, the author contacted them to answer any questions they had about this research and to arrange a time to visit participants to conduct the research interview for those who were interested. Memory nurses assisted by sending reminders to people who had not responded within two weeks and recruitment took place over a period of six months.

### **Informed consent**

When meeting with participants prior to the research interview, the author followed the principles of the Mental Capacity Act 2005 while talking through the information sheet and consent form with participants. This included allowing further time to respond to questions, exploring their understanding of what was involved in the study and whether they still wished to take part and allowing them an opportunity to communicate a decision to take part if they wished to and were able to communicate this decision.

### **Semi-structured research interview**

- i Individual face-to-face interviews between the author and the participant lasting approximately one hour took place at the participant's home; interview duration varied from 32 minutes to 1 hour 35 minutes. Each participant took part in only one interview and interviews were audio recorded with consent. The author used the topic guide as a flexible aide memoire during all interviews to provide a degree of consistency and facilitated the interview by

prompting participants to elaborate on a particular point or clarify their understanding where necessary.

- ii Prior to beginning the research interview, participants were made aware of the subject area for this research, reminded that they could stop the interview at any time, that they did not have to answer questions that they did not wish to and could withdraw without giving a reason. During the research interviews, the author was sensitive to whether overly emotive material was being covered so that the material could be adjusted appropriately. There was a procedure in place so that if a participant became distressed at any point during the interview, the author could pause the interview and check whether they would like to continue, reminding them that they did not have to answer questions they did not wish to. The author would also have terminated the interview if a participant became overly distressed yet wished to continue, however this was never necessary. If a participant had wished to withdraw, all identifiable data collected would have been removed. Participants were informed that they could ask for their answers to be removed from the study for up to two weeks after the interview. At the end of the research interview the author checked whether participants were interested in receiving information on where to enquire about possible sources of support. There was also a procedure in place so that if a participant disclosed information during the interview, which indicated active plans for harm to self or others the author could have stopped the interview, discussed the need to break confidentiality and informed the duty psychiatrist from the memory service.
- iii The original research design involved the interview taking place with only the author and participant present. However, feedback from people approached about the study indicated that at least two of those approached would have been happy to take part but felt uncomfortable being interviewed on their own. When reviewing this study the ethics committee had also suggested that the author might wish to allow a relative or carer to be present during the interview if this would make some participants feel more comfortable, though this was not a condition of ethical approval. Therefore, the design was amended after recruiting the first six participants to allow subsequent participants the option of having a relative present as a silent observer if they felt this was necessary. One participant took up this option.

## **Ethical Considerations**

Recruitment proceeded prospectively in that people were informed about the study during routine contact with their memory service clinicians as it was not felt appropriate to contact people retrospectively who had had an appointment in the past few months. Participants were consulted about whether they were happy for their psychiatrist from the memory clinic to be informed that they had participated in the current study. Participants were assured of the confidentiality of their responses during the research interview and that their doctor from the memory clinic would only be informed of their participation, not their responses. Consent was also sought for the use of anonymised quotations from participant interviews when writing up the current study, and when reporting quotations during analysis, the minimum amount of material necessary was used to illustrate a point. One participant was happy to consent to all aspects of the study apart from the use of verbatim quotations. In order to respect this participant's wishes, alternative quotations from other participants were used instead where possible or responses from this participant were paraphrased. Following transcription of interview audio recordings, the author ensured that all identifiable information such as names, places, occupations and dates were removed from the transcripts. Participants' interview responses are referred to using a randomly generated letter that does not relate to the order in which they were interviewed. This step was taken as memory clinic staff may have had some idea of the order in which participants were interviewed.

## **Analysis**

### **Transcription and familiarisation**

Following research interviews, the author listened back to interview recordings to begin the process of familiarisation and to note down thoughts and ideas for use in later stages of analysis. Following this, all audio recordings were transcribed. In comparison to other methods of analysis such as direct coding of an audio recording, transcription allows a greater degree of transparency of how coding proceeded and allows for measures of inter-rater reliability of coding to be performed more easily. It was not possible for the author to transcribe interviews due to his dyslexia and the amount of qualitative data produced during each interview. All audio recordings of research interviews were transcribed verbatim by third party transcribers who had been asked to sign a confidentiality statement and were accustomed to working with confidential data. Three different transcribers were used due to time constraints. A potential advantage of outsourcing transcription is that the third party will not hold the same

preconceptions as the researcher when punctuating the text and punctuation may affect the researcher's interpretation of interview transcripts.

On receipt of each transcript, the author listened back to the audio recording of that interview while reading through the transcript making corrections where necessary. Proofreading the transcript while listening to the recording served two main functions. It improved the author's familiarisation with the data, which is an integral part of the method of qualitative analysis adopted (Pope, Ziebland, & Mays, 2000), helping the author to note down potential themes and associations within the data. This process also allowed the author to monitor the accuracy of transcription and make corrections where transcribers had not been able to make out what was being said at points during the interview. Poland (2002) highlights that where a researcher has not transcribed their own recordings this creates greater potential for ruptures in understanding, however it is highly unlikely that third party transcription will result in no errors of interpretation. Therefore, as transcription quality may vary greatly, researcher review of transcripts can be highly beneficial, although seldom done in full due to time constraints (Mays & Pope, 2006).

### **Use of computer software**

Computer assisted qualitative data analysis software (QRS NVivo10) was used to help manage data. Audio Notetaker 3.0 software was used to assist with reviewing interview recordings.

### **Framework analysis**

The framework analysis approach (Ritchie & Spencer, 1994) was adopted to analyse data from interview transcripts. Framework analysis provides a way of coding or organising interview data into themes which facilitate the researcher in interpreting their findings (Lacey & Luff, 2007). Within framework analysis, coding of data is also referred to as indexing (Pope et al., 2000). Framework analysis is not a mechanical process and the researcher's creativity and judgment are necessary during all stages (Ritchie & Spencer, 1994). Framework analysis is both inductive and deductive in its approach. In common with other inductive qualitative methods, it builds from original participant accounts (Pope et al., 2000), however coding of data is based deductively on themes defined by *a priori* theoretical constructs and other emergent themes

that become apparent from participants' narratives (Ritchie & Spencer, 1994). In the current study the areas within the CS-SRM were used as an *a priori* theoretical framework.

Framework analysis proceeded according to the following five recommended stages (Pope et al., 2000; Ritchie & Spencer, 1994):

1) Familiarisation

*In this stage the researcher immerses themselves by listening to, and reading through, transcripts of interviews to familiarise themselves with the data and look for any emergent themes which could be used in the thematic framework.*

2) Identifying a thematic framework

*A framework of key themes and concepts to be identified within the data is defined. This is referred to as the 'coding frame'. This takes into account the research question and objectives, a priori theory and emergent themes. This coding frame is then used to index or code the data, and refined during subsequent steps of the analysis.*

3) Indexing (also referred to as coding)

*The coding frame is then applied to interview transcript data, by tagging all sections of the text that refer to a particular theme with a code or brief description to identify that theme.*

4) Charting

*Charting involves turning the data into a more accessible form by creating charts, similar to a large table, with participants represented by rows and themes represented by columns or vice versa. Rather than copying verbatim sections of transcript as lengthy quotations, charting involves synthesising the data by paraphrasing key issues alongside important quotations, which act as a reminder to the researcher. These are entered into the appropriate cell in the chart along with a reference to the location of the original data. Each cell in a chart therefore represents a summary of what one participant said about one particular sub-theme.*

5) Mapping and interpretation

*This involves using charts to facilitate the construction of explanations from research findings by identifying patterns and associations within participants or across themes to describe the range and nature of the phenomenon under investigation. This process is guided by the research question and additional themes which may have emerged during*

*the research. This can be a visual process where diagrams are used to help conceptualise and test various interpretations of the data.*

### ***Merits of framework analysis***

Framework analysis was selected as it allows the use of a previously established theoretical model to apply a broad structure to the data, facilitating the identification of sub-themes within the structure provided by the *a priori* theoretical framework selected. A strength of the framework approach is that it allows specific questions to be investigated in greater detail than more exploratory approaches such as IPA (Britten, 2006) and the structure it provides allows the researcher to proceed in a systematic way when trying to interpret large volumes of qualitative data (Ritchie & Spencer, 1994). Framework analysis also facilitates the proposal of recommendations along with addressing specific research questions (Ritchie & Spencer, 1994). In contrast to similar methods such as thematic analysis (Braun & Clarke, 2006), which can also use the structure of a previously established theory (N. Hayes, 1997), framework analysis allows for transparency by being explicit about the stages of the analytic process conducted. This ensures that all data is methodically treated in the same manner so that the reader, and not just the researcher, can see how results were obtained from the data (Lacey & Luff, 2007; Ritchie & Spencer, 1994).

A potential criticism of using framework analysis with the CS-SRM as an *a priori* framework is that it may offer fewer opportunities for themes to emerge from participants' narratives. However, framework analysis was felt to be appropriate as past research using more exploratory qualitative methods has established that all IR domains are present within narratives of people with early-stage dementia (Clare et al., 2006; Harman & Clare, 2006; Moniz-Cook et al., 2006; Pope, Ziebland, & Mays, 2006) and framework analysis has previously been applied to qualitative interview data from people with early-stage dementia (Glidewell et al., 2012; Spector, Gardner, & Orrell, 2011). Furthermore, when using framework analysis with an *a priori* model it may be possible to identify a greater degree of detail in terms of emergent themes within the *a priori* areas identified by the model, which in the current study are the IR domains proposed by the CS-SRM.

### ***Application of framework analysis***

There were two main phases to the coding of interview data, firstly coding to *a priori* themes taken from the CS-SRM: *identity, cause, consequences, timeline, cure-control, emotional reaction* and *coherence* (referred to as CS-SRM themes) and secondly coding to sub-themes within each CS-SRM theme. Coding proceeded concurrently with interviewing participants. When coding interviews to CS-SRM themes, data from the entire interview was considered for coding to each CS-SRM theme not just data from questions that asked about that area of the CS-SRM. Initially, meaningful units (phrases, sentences or paragraphs conveying a discrete unit of information) from all interview transcripts were coded to CS-SRM themes. The definitions used for coding to CS-SRM themes and an example excerpt from a coded transcript are shown in *Appendix 1*.

Ritchie and Spencer (1994) recommend that during framework analysis the process of defining and revising the coding frame occurs once data collection has begun. The second phase of coding to sub-themes began with reading through all the data coded to each CS-SRM theme while making research notes summarising the issues talked about within that CS-SRM theme. These summary notes were then re-ordered in conjunction with notes made during previous reflection and grouped together in order to identify potential sub-themes within each CS-SRM theme. This process was used to refine the coding frame, which is shown in *Table 2* in the results section. The researcher then read through all data within each CS-SRM theme in conjunction with the coding frame in order to code data from each CS-SRM theme to sub-themes.

This was an iterative process with the researcher revising how data was coded to CS-SRM themes and sub-themes while applying the coding frame to each CS-SRM theme. Once the coding frame had been applied to all CS-SRM themes, sub-themes that appeared to cover similar areas, or themes that contained a minimal amount of data, were reviewed in order to consider whether they could be amalgamated or re-coded to other themes. Once the first interview had been coded to CS-SRM themes this coding was reviewed with the researcher's supervisors who offered feedback; this and subsequent feedback from the researcher's supervisors was utilised at various points to help focus the process of analysis. The initial application of the coding framework to identify sub-themes within the CS-SRM theme for coherence was also discussed with the researcher's supervisors. These discussions helped to focus the refinement and application of the final coding frame.

The *charting* phase and *mapping and interpretation* phase of framework analysis proceeded by creating one very large chart with every sub-theme represented by a column and two rows representing each participant, one row for each participant's answers to open questions and one row for each participant's answers to CS-SRM questions. This was used to summarise what each participant said about each sub-theme while allowing a distinction to be made between their answers to open questions and CS-SRM questions. Numerous smaller charts were then created to assist with the analysis of CS-SRM themes. Individual charts were created for each sub-theme, with the exception of coherence sub-themes. These charts showed the sub-theme in question as one column alongside a column which indicated which meaningful units within that sub-theme had also been coded to any of the coherence sub-themes. Additional charts based upon observations recorded in research notes were also created to aid mapping and interpretation. These allowed the researcher to explore hypotheses about potential links between multiple sub-themes and coherence sub-themes by displaying a summary of the relevant sub-themes next to each other in order to facilitate comparison.

### **Inter-rater reliability**

A colleague of the chief investigator assisted by coding a selection of interview data in order to assess inter-rater reliability. This colleague was a clinical psychologist with experience of working with memory disorders and research experience in using the CS-SRM in another chronic condition, people who have had a stroke. To ensure that all elements of the CS-SRM were represented within the data selected for inter-rater coding, 70 meaningful units were used. This second rater assisted by coding the units according to the presence or absence of CS-SRM themes, within each meaningful unit using the same set of definitions as those used by the author (see *Appendix 1*). Reliability of the author's coding in comparison to this second rater was evaluated using Krippendorff's  $\alpha$ ; this measure differs from other reliability measures in that it calculates disagreement rather than corrected percentage agreement (Krippendorff, 2013). Krippendorff's  $\alpha$  was chosen over other measures of reliability as it can be calculated independently of the number of observers or level of measurement and can also be calculated when there is missing data (A. F. Hayes & Krippendorff, 2007).

### **Saturation**

The concept of thematic saturation, the point at which new themes or theoretical concepts cease to become apparent from new interviews, is often used as a standard by which

qualitative research is evaluated (O'Reilly & Parker, 2013; Ritchie, Lewis, & Elam, 2003) and differs from the concept of theoretical saturation used in Grounded Theory, originally proposed by Glaser and Strauss (1967). Guest, Bunce, and Johnson (2006) note that although saturation is considered by some to be a gold standard in health science research, the concept is poorly operationalised with no guidance available on how to determine whether saturation has been achieved. Consequently, relying on the researcher's sense that similar instances have begun to recur could be seen as a slightly arbitrary and subjective judgement. O'Reilly and Parker (2013) argue that there are difficulties with the blanket application of thematic saturation as a criterion for quality in qualitative research due to the wide variety of qualitative methods available. Caelli, Ray, and Mill (2003) advocate that different qualitative approaches should be evaluated against standards which are in line with their epistemology by providing an explanation of the meaning of saturation in the context of that study. O'Reilly and Parker (2013) also call for studies to transparently describe how saturation was judged to be achieved.

Francis et al. (2009) have proposed two principles for use in determining thematic saturation for studies utilising interviews based upon an *a priori* theory. Firstly, they advocate specifying a minimum number of interviews in order to ensure that unexpected homogeneity early on in data collection does not result in the researcher coming to premature conclusions regarding saturation, referred to as the '*initial analysis sample*'. Francis et al. (2009) then propose that researchers specify a number of additional interviews to be carried out where no new themes emerge in order to be confident that no further important novel ideas would be likely to be mentioned if further participants were to be interviewed, referred to as the '*stopping criterion*'. With this approach, saturation can be assessed by constructing a summary table for each theoretical construct of interest and a corresponding cumulative frequency graph to illustrate when the number of novel themes within that construct plateaus (Francis et al., 2009). In their study, Francis et al. found that a '*stopping criterion*' of three additional interviews where no new themes emerged was sufficient to determine when saturation had been reached. They have found their proposed approach to be robust and replicable for similar studies utilising interviews based upon *a priori* theory. This proposal was adopted in order to provide a method of determining thematic saturation consistent with the current study's epistemology. This approach had the additional advantage of making the process by which saturation was determined transparent and replicable.

O'Reilly and Parker (2013) note that thematic saturation could be seen to be adequate at a point where it allows the research question to be sufficiently answered and Francis et al. (2009) suggest that their proposed method is applicable both at a study-wide level and at the level of individual theoretical constructs. Therefore, for the current study, the point at which thematic saturation had been achieved was assessed for sub-themes of the CS-SRM construct of coherence rather than at a study-wide level as coherence was the focus of the research. During the study, five interviews were completed as an *initial analysis sample* with three additional interviews with no new themes completed in order to reach the *stopping criterion*. Although attention was paid to thematic saturation, time constraints also had an impact and it was not possible to extend recruitment of participants beyond a period of six months.

### **Reflexivity**

Researcher reflexivity can be seen as a process of internal self-evaluative appraisal where the researcher considers how their own views and background may differ from and interact with the area of research under investigation (Berger, 2013). Elliott et al. (1999) advocate that providing an acknowledgement to the researcher's theoretical views, personal expectations and values prior to and during the research can assist the reader in interpreting and understanding how the researcher's position may have influenced their interpretation of the data. In addition to outlining the researcher's personal and professional connection with the research topic at the start of the thesis, a reflective diary was also kept throughout the research process, including after each research interview. Mays and Pope (2006) advocate keeping a reflective research diary in parallel with collecting and analysing data in order to facilitate reflexivity. During this study, the author's reflective diary was used to help monitor the research process and moderate undue personal influence by enabling a more conscious process of decision making about how the researcher's perspective may have affected analysis.

## **RESULTS**

*This section begins with descriptive background information to give an overview of all those who were eligible to participate, then anonymised descriptive portraits are included to help characterise all the individuals who took part and finally an in-depth account of the analysis is presented.*

## Participant Characteristics

During the recruitment period, fifteen patients from the memory service were identified as being eligible to participate. All of these people were given a study information sheet to consider by their doctor or nurse from the memory clinic; five were given an information sheet by their psychiatrist and ten by their memory nurse. Eight of those eligible to participate gave informed consent and completed the research interview giving a response rate of 53%. Everyone who took part in the study was of white British ethnicity. All participants lived in the community, as opposed to residential care; five were living with their spouse and three were living on their own. Of the eight who took part, one person was informed of the study by their psychiatrist and the rest by their memory nurse. Of those who were eligible to participate but did not take part, one person declined to consent having met the researcher to discuss the study further as they were not comfortable being interviewed without a family member present, one informed their memory nurse that that they were interested in the study but not comfortable being interviewed alone and psychiatrists reported that one person was interested but was encouraged not to take part by a family member. For the other people who were eligible but did not take part, factors influencing this decision were not known. All of the fifteen people eligible to take part in the study had been prescribed medication to help with the symptoms of dementia and of those who participated six were prescribed Donepezil, one Galantamine and one Memantine. Six of the eight participants had a diagnosis of Alzheimer's type dementia and two had a diagnosis of mixed dementia. Further details of the sample are shown in *Table 1*.

*Table 1 Descriptive statistics for study sample*

	Mean	Standard deviation	Minimum	Maximum	Range
MMSE score participants	24.75	2.38	21	28	7
MMSE score Eligible but did not take part	25	2.52	21	28	7
Age years; months participants	79;4	5;4	70	86	16
Age years; months Eligible but did not take part	78;3	7;5	69	92	23
Interview duration (hh:mm:ss)	00:52:08	00:19:43	00:32:35	01:35:15	01:02:40

## **Pen Portraits of Participants**

### Mrs A

Mrs A was in her early 80s with a MMSE score of 23 and lived with her husband in their house in a suburban area on the edge of the city. She did not choose to talk about her memory changes in terms of dementia and felt that memory changes had made no difference to her life as she did not actually think there had been any changes. A family member had encouraged her to make contact with the memory clinic, however she felt that she had never had a good memory and did not expect anything to be able to change that. She described accepting that her memory had always been the way that it was, but felt that it would have been very upsetting to have had a good memory and then lost it. She talked about a limited number of strategies for managing having a poor memory but appeared to be adopting a more passive approach than some participants in that she felt that someone would have already told her of anything that could be done to aid her memory. I was particularly struck by a comment made towards the end of the interview where Mrs A conveyed that she had found the research interview a lot more accepting as an experience in comparison to most visits from professionals, which I found helped me be mindful of how to maintain rapport in subsequent interviews.

### Mr B

Mr B was in his mid 80s with a MMSE score of 23 and lived with his wife in a flat on a council estate in the city centre. He voiced frustration that he could not be certain whether anything had changed about his memory. He wanted to understand more about what might have changed if possible but felt that this would be difficult. He described trouble fetching information from the back of his mind and was unclear about whether anything could be done to help him with this. He thought that any difficulty with his memory was brought about by contact with people or circumstances outside of his regular routine; he found that this challenged him to recall things that he then found he could not remember. I got the impression that he had reduced his day-to-day activities so that he was less likely to encounter unfamiliar or less predictable circumstances. In terms of what he felt he might be able to do himself to aid memory, he talked about trying harder to recall things but did not know how to work out whether this was making a difference for him. Mr B felt that his memory would change but was very unclear about what he might expect to happen in the future. He wanted to know more about which aspects of memory might be affected and wanted someone to help him work out what had changed about his memory. He relied heavily on support from his wife;

describing her as acting as a memory box for him. As well as the support from his wife, he described having been to a reminiscence group. Although he found that prompts from other people during this group helped him recall older memories, he felt bothered by why he seemed able to hold onto these memories during the group but would forget them soon after he left as this did not fit with what he would expect to happen. However, one thing he felt particularly positive about was that going to a reminiscence group had made him a lot more outgoing socially and increased his confidence, whereas before beginning this group he described himself as being very reclusive. During the interview with Mr B I noticed myself being tentative about probing for further information as a way of helping maintain rapport.

### Mrs C

Mrs C was in her late 70s and had a MMSE score of 27. She lived on her own on a council estate and although her children lived in other parts of the country her daughter was regularly in touch to offer support over the telephone. She described first suspecting difficulties with her memory approximately eight months ago, being diagnosed with dementia within the last few of months and feeling comfortable talking about the diagnosis to friends and family. Although she described feeling confused about the specific causes of her dementia, she was happy with what she knew and did not appear to have a desire to find out more. She talked about it having to happen to somebody so why not her and described not wanting to dwell on why it happened as it would get her 'in a stew' and would not be of any benefit. She felt that her dementia was not currently having a large impact on what she felt able to do day-to-day but had noticed her mind going blank frequently during conversations and becoming more forgetful. During the interview she talked about several strategies she had developed to help prompt her memory, both those she employed herself and by using help from others. For instance, when we talked to arrange the research interview she had asked me to telephone her the night before as a reminder. She gave the impression that doing this came naturally to her and she could judge how to make just enough changes to manage things that she felt were a current issue such as remembering appointments. She also discussed the impact of several other co-morbid chronic health conditions, which she felt were more of a pressing concern for her at present than her dementia, and described having had to manage life-threatening health conditions in the past. She was clear that she wanted to know more about how to manage her dementia but was also able to articulately convey why she felt she would benefit from developing her knowledge gradually as new symptoms became apparent. She described being certain that she would deteriorate over time, but that too much knowledge too soon would make her mind work overtime and therefore she would not find it beneficial to know what

might help until it was necessary. This gave the impression that the desire to only find out more about her dementia as her symptoms increased was related to having to manage physical health concerns in conjunction with dementia.

### Mr D

Mr D was in his early 70s with a MMSE score of 28. He lived alone in a house on a council estate near the city centre. As well as dementia, he had to deal with several other chronic physical health conditions, which he often felt were a more pressing concern. He had noticed himself misplacing things, forgetting what he was doing or where he was going and some word finding difficulties. He was uncertain as to how much a recent bereavement, other health conditions or illnesses that run in his family had contributed to his dementia. However, this did not overly concern him as he saw little benefit in trying to change what had happened or worry about it and he felt that dementia affected everybody differently anyway. His experience was that dementia just seemed to come out of the blue but that he had put off going to the doctor to get his memory checked out. Throughout the interview he showed a keen interest in how he might find out more about many aspects of his dementia, while also pausing to reflect aloud on whether furthering his knowledge would be helpful or unhelpful to him. For example, he voiced his uncertainty about how long he could continue to care for himself in the future but then commented that knowing too much about this could be scary and a better approach might be to deal with changes as they occurred. He still found that how much he would be able to do for himself in the future was the main thing he worried about because he had always been a caregiver rather than a care recipient and did not know how he could manage adjusting to such a change. As well as describing some practical strategies which he used to help with his memory, Mr D felt that there were some areas of his dementia where medical expertise would be incredibly unlikely to be able to provide an answer for things that he remained unsure of, such as how long he had had dementia for or how it could be cured. He commented that the brain was too complex for science to understand in this much detail and that only God had the ability to fix everything about him. He believed that keeping going with some physical activity and tasks that kept his mind active would help his dementia and that keeping his mind active was of primary importance as he felt his mind looked after his body. He had also stopped drinking and smoking, and was trying to get more rest, but was uncertain whether he would be able to manage if there came a time when he could no longer be given medication to help with his dementia. I was particularly struck during this interview by his capacity to openly reflect on how he evaluated whether to trust new information from different sources such as professionals or the media, and noticed myself feeling humbled by

how he appeared able to accept everything that had happened to his health without questioning or begrudging it.

### Mr E

Mr E was in his mid 80s with a MMSE score of 21 and lived in his own home where he received regular visits from family and carers to provide support for his dementia and other chronic physical health difficulties. He reported experiencing memories rushing back then disappearing again without warning, that many of his current memories related to earlier life experiences and that it took him a lot more effort to try and recall things. He spoke a little about how other people could prompt him to help his memory and described strategies that he could use personally. However, he felt unclear about whether anything else could be done to help his memory but commented that he had begun to do less for himself and rely on others more. The way he talked gave the impression that this increased reliance on others was due in part to other aspects of his physical health which had made him more dependent, not just changes due to dementia, and he spoke about being unsure about how the support he was receiving was connected to his memory or other health difficulties. Although he felt a need to accept support from other people, he commented that he did not wish to expect too much from them and wondered whether this support sometimes led to him making less effort than he felt he should to try and recall things. He wondered whether there might be some things that could be done to improve his memory but commented that he did not wish to pursue more knowledge as he felt his upbringing had taught him not to ask for more support than was offered. It struck me during this interview how allowing someone the opportunity to express that they did not wish to further their knowledge about dementia might be an empowering experience. This was later mirrored in some positive feedback about Mr E's experience of the interview that I received from his family a few days later.

### Mrs F

Mrs F lived with her husband in their house in a suburban area of the city; she was in her mid 70s and had a MMSE score of 26. She had been concerned at the first sign of changes to her memory, sought help from her doctor straightaway after noticing herself being unable to find familiar objects in her home, and described feeling rattled by this experience. Mrs F contrasted her approach to seeking diagnosis with how friends had advised against talking to her doctor as her friends had commented that she was the same as them and their forgetfulness was just

due to age. She found herself leaving things partly done and felt she had been forgetting what she was doing. She also discussed difficulty recalling words and names and sometimes felt awful when she could not find what to say. Mrs F described how she benefited from the support of her husband and close friends who would gently prompt her to help her work out what she was trying to say. However, she also found the adjustment to relying more on her husband challenging as she felt their relationship had often been the other way round. She described feeling unclear about what was meant by terms such as dementia and Alzheimer's, wondering which was worse and talked about wanting to know whether there were different stages with different names or if dementia or Alzheimer's progressed differently. Although Mrs F was unclear about what might have caused her dementia and about whether specialists might be able to tell her, she did not describe a wish to find out more and commented that it might be largely due to chance. She had been encouraged to use labels to identify where things were kept around the house but she described feeling very uncomfortable with doing this as she expected this only to be necessary for people whose dementia was much worse than hers. Mrs F chose to raise the term 'Alzheimer's' during the interview and used it throughout, but described feeling more comfortable referring to 'memory loss' when with her friends as she felt this would be less frightening for other people to hear. Although she talked about not knowing enough about what the future might hold, she felt it could be too overwhelming to find too much out just now given some of her current concerns such as how to keep actively socialising with her friends. She described managing this by going to see people during the day when she still felt confident enough to drive and developing meaningful word associations to help with reminding her what to say.

### Mr G

Mr G was in his early 80s with a MMSE score of 24. He talked about having trouble with his memory for the previous 12 months and had recently moved with his wife to a retirement flat close to their old house. The most salient changes he reported noticing were a very poor memory for recent and future events along with word finding difficulties for names of people. His dementia appeared to be having a strong emotional impact. He found himself only able to engage in superficial conversation with people; his difficulty for names in particular was upsetting and he could feel embarrassed talking about memory difficulties to other people. As well as finding that he had less to say for himself in social situations, Mr G had noticed other people talking to him less, which was reducing his opportunities to socialise. He felt that his wife's support in reminding him about what was happening that day was invaluable and believed that he would feel 'like a lost soul' without her. Mr G told me about some strategies

that he found helpful such as keeping a notebook with his grandchildren's names in his shirt pocket. He wanted to understand more about why his memory had changed but found this very confusing because he could not identify any tangible factors such as a bang on the head which he felt would account for the changes. It did not appear logical to him that he could remember some things such as past holidays but could not remember what was happening day-to-day. Mr G talked about how several things in his past should have helped him to maintain a good memory such as good school exam results and running his own business. He wondered whether his memory would have changed had he still been working. The impression this gave during the interview was that not being able to identify a cause for his difficulties which he felt was plausible and consistent with his other beliefs was impacting upon his ability to adjust to the changes he was experiencing to his memory.

### Mr H

Mr H was in his late 70s with a MMSE score of 26. He was living in a complex of retirement flats with his wife who was his main carer. The most prominently reported feature of his dementia was forgetfulness for what he saw as 'everyday things' such as where he was meant to be going or for recalling recent events. He felt that these were things that he should have 'automatically remembered'. The cognitive dissonance experienced when his expectations regarding what he should remember clashed with the experience of changes to his memory appeared to be puzzling and frustrating for him. His belief that recalling these things should be automatic appeared to make it hard for him to find a meaningful way to understand why this was happening to him. He attributed the onset of his memory changes to removal of all his managerial responsibilities at work when his workplace was taken over by a new company; this appeared to be a very disempowering experience. He frequently referred to changes to his memory as an inevitable part of ageing and the impression this gave was that by normalising changes he was able to give himself permission to accept these changes and get on with activities he was still able to actively enjoy in a way that helped to minimise the degree of frustration experienced. A predominant coping mechanism appeared to be remaining as active as possible in maintaining activities he was able to enjoy, however there was evidence of meta-reflection whereby he would pause and question whether his assertions were accurate, or whether there might be some other underlying cause or means of support. This gave the impression that he was willing to question and re-evaluate his beliefs as he did not want to miss out on anything that might be helpful. It appeared that the activities which he felt helped his memory such as general knowledge quizzes and playing sports were likely to be dependent on older and more frequently rehearsed procedural and declarative knowledge.

### Summary of Themes and Sub-Themes

*Table 2* summarises the themes used during analysis. The first cell in each column indicates *a priori* themes based on areas of the CS-SRM with subsequent cells in that column indicating sub-themes within that domain or construct. The relative contributions of ‘*open questions*’ and ‘*CS-SRM questions*’ are indicated by the numbers below the name of each theme or sub-theme. The first number indicates the number of interviews where answers to CS-SRM questions contributed to the theme, and the second number in brackets indicates the number of interviews where answers to open questions contributed to this theme. These numbers are for illustrative purposes only and are not statistically meaningful.

It can be seen from the second last column in *Table 2* (the CS-SRM theme of coherence) that using questions based on the CS-SRM, in comparison to open questions, helped structure discussions allowing a wider variety of information to be captured regarding what people did not understand about their dementia. Open questions were able to elicit information about other areas of that CS-SRM, and elicit some information about coherence. However, it appears that it may be more challenging to elicit information about coherence without using IRs to help structure discussions as participants only spoke a little about what they did not understand about their dementia spontaneously and never talked about their rationale for how much they wanted to know about their condition without prompting. Further details about what people did not understand about their dementia and the use of IRs to help elicit this information are reported towards the end of the results section after results from other themes to help contextualise study findings.

Table 2 Summary of themes and coding frame

CS-SRM Theme	Identity 8 (7)	Cause 8 (5)	Consequences 8 (5)	Cure-control 8 (7)	Timeline 8 (6)	Emotional reaction 8 (5)	Coherence 8 (7)	Other (Not captured by the CS-SRM) 5 (3)
Sub-themes	Labels & names 6 (5)	Growing older 6 (3)	Adjusting expectations & opportunities 3 (1)	Self-help 8 (1) I don't think so but ... 8 (3)	It just won't stop but I wish it would 6 (2)	Self-critical 7 (2)	I'll find out as I go along 3 (0)	Interaction of dementia with other health difficulties 3 (2)
	Memories - hard to hang on to 4 (4)	Circumstances & incidents 5 (2)	Changing relationships 4 (2)	Strategies & advice 7 (1)	Sometimes I know when ... but it's hard to be sure 4 (6)	Frightened & uncomfortable 7 (2)	I can't find out because nobody knows 4 (0)	
	Slowing down & going blank 4 (2)	Bodily changes & poor health 4 (3)	Trying & getting started 3 (1) Being cared for & going daft 4 (2)	A helping hand 8 (6)	Variable speed 5 (2)	Thankfulness & acceptance 7 (1)	I think I know enough about that 4 (0) I want to know more about ... 8 (2)	Credibility of advice (what to trust) 2 (0)
	Finding what to say 1 (2)	How you are born & family history 4 (0)	Just the same 5 (1) Something's missing & it just won't click 5 (2)	Approach to their dementia (hide or seek) 7 (2)				
	Nothing noticed 4 (2)					Loss & adjustment 5 (2)	This doesn't make sense & it really gets to me 6 (3)	

Results are reported below in the form of summaries of each CS-SRM sub-theme alongside quotations to illustrate participants' perceptions of their dementia in terms of these themes. Links between each sub-theme and coherence are also reported to give an indication of how talking to people about their dementia using the structure provided by IRs may have helped elucidate what participants felt they did not understand about particular aspects of their dementia. Some interpretation is also provided regarding participants' appraisal of how relevant they felt it was to address gaps in their knowledge.

Although some of the sub-themes reported below mirror elements of CS-SRM constructs or other psychological models, the author reflected upon whether this was the most appropriate way to portray the findings. Alternatives were actively considered before deciding to use sub-themes informed by established psychological theories. For instance, during initial coding the author noticed a tendency to try and categorise responses according to areas of memory such as procedural or episodic memory, however the use of a reflective diary helped in evaluating and rejecting this idea as it did not fit with participants' narratives or the objectives of this research. The names given to sub-themes were revised during the research process in order to achieve a balance between basing sub-theme names on words used by participants and finding a name that conveyed the content of each theme.

## **Summary of Analysis by IR Domain**

### **Identity sub-themes**

#### *Labels and names*

Over half the participants made reference to names they used to refer to their dementia, using both medical terms "*It ... it's Alzheimer's*" (Mrs F) and colloquial phrases "*Having senior moments*" (Mrs C). Participants indicated that terms used varied over the course of their dementia and social context. In the early period when finding out about their dementia participants tended to avoid medical terms.

*"I just thought, 'I'm going mad,' you know or I've, well, 'I've lost it'" (Mrs F)*

Some participants also expressed uncertainty about the meaning of, and difference between, terms such as Alzheimer's or dementia.

*"There's an X in it. I couldn't .. think of the name ..Anyway, something like dementia*

*but another name for it. I don't know if it's higher than dementia or the other dementia, I don't know ..it's nearly the same as dementia" (Mr D)*

**“Researcher - You said you'd starting using Alzheimer's and you used memory loss; do you know, do you think you know enough about those words?**

*Participant - No, No. 'cause I think there's a lot of variations of Alzheimer's from years ago and hearing about it 'cause you never used to hear about it, did ya? I mean my grandma, she just went daft.” (Mrs F)*

Participants such as Mrs F indicated that uncertainty about what Alzheimer's actually was made it more challenging to picture in enough detail what was likely to happen to her as her condition progressed. For Mrs F, she was not sure if such knowledge would be helpful but felt that she would be better off knowing than not knowing. She did not suggest that knowing more about what Alzheimer's was would necessarily help her manage her condition better but gave the impression that such knowledge might help her to feel less uneasy because of a clearer overall understanding.

Several people described becoming more comfortable with using medical terms personally, but then moving away from using these with friends.

*“Participant - I've got the early onset of Alzheimer's*

**Researcher - So Alzheimer's or early onset of Alzheimer's, is that a kind of term that you would use or?**

*Participant - Well I have used it, you know to friends I've said that's what I've got but that's only the once. I don't use it whenever I see them” (Mrs C)*

*“I'm not going to kid to them that I . . . I've not um, I've not got, I've got problems. But I've gone back to saying memory, you know I've got memory loss. And it's better for people who don't know me; and it's better for me friends 'cause Alzheimer's is a word that everybody's frightened of, I think” (Mrs F)*

However, some participants spoke about being unclear about which term was most appropriate to use to refer to their memory changes in different social contexts. *“Well I might, I might say, 'Well I'm losing it.' I don't really know!” (Mrs F)*. In some cases it was apparent that people were not at all comfortable with medical terms *“Senile dementia's a rotten - rot silly word” (Mr H)*, and one participant was struggling to find an acceptable way to talk about his

memory changes to other people *"I wouldn't like to say to somebody 'You'll have to excuse me I'm very forgetful and I can't remember things'. I'd feel embarrassed then."* (Mr G).

### Memories - hard to hang on to

This sub-theme related to participants' experiences of forgetfulness *"I put something down and I forgot where I'd put it. And then I just left it, just left it."* (Mr D) and their evaluation of this experience *"This is just memory not being as good as it was, and it's just gone another point down or something. Yeah, and that's the best way I can describe it"* (Mrs F). This also included their reliance on islands of older memory with most other things slipping away and the extra effort required making it harder to hang onto the memories they did have left.

Participants such as Mr B also talked about being particularly bothered by their experience of memories being easier to hold onto in some contexts than others.

*"I can't, I don't understand all the things. What can I say? See I am really bothered about the .... the memory while we're all gathered but once I get away from the meeting and back to, back into ordinary, ordinary living. And they, it's it goes!"* (Mr B)

For Mr B, it appeared that this experience of being able to recall memories better in some contexts than others was hard to understand as it conflicted with how he expected his memory to function. It is possible that this experience was difficult to understand if it was not sufficiently similar to his underlying schema of what conditions such as dementia or age-related memory changes should look like. Therefore, difficulty in identifying a plausible explanation for his memory changes is likely to have made it hard for Mr B to come to a coherent overall understanding of these experiences.

Participants also expressed some uncertainty about whether their experiences of forgetting things were normal, as opposed to being related to dementia, and whether or not they had to accept symptoms such as forgetfulness.

*"I'll go to the shop and I'll forget maybe one or two items but again .. a lot of people do that. Yes, so I don't know. I don't know."* (Mr D)

*"Sometimes it's a bit frustrating when, when you can't just remember things and do things but, you've got to accept it, haven't you really?" (Mr H)*

In comparison to other conditions, where symptoms bear little relation to everyday experiences, symptoms experienced in dementia such as forgetfulness also occur in everyday life, albeit to a lesser extent. It is possible that this makes it more challenging for people with dementia to make sense of whether their experiences are of sufficient intensity to be part of dementia or not. For some participants, having a way to judge what might have caused their symptoms appeared to play an important role in helping them to appraise their experiences in order to consider whether they felt they had dementia.

#### Slowing down and going blank

This sub-theme captured participants' experiences of many things taking longer since the onset of their dementia.

*"I'm think me more of what I'm doing, than that than what I used to" (Mr B).*

*"I sometimes sort of stand in the bathroom and, 'What am I doing?' I don't just go in to get a shower. I sort of stand and not doing anything; just sort of standing and looking round and then, 'Oh right, yeah.' Yeah. It's all just not closing down. It's just takes longer." (Mrs F)*

Mrs F felt that this was related to her observation that *"When I'm trying to think what am I supposed to be doing ... I can't un-jumble me head"* (Mrs F)

#### Finding what to say

Only a couple of participants chose to talk about word finding difficulties

*"I just have two or three words to sort of cover it" (Mr B)*

#### Nothing noticed

Half of the participants in the study began by saying that they had not noticed any changes or symptoms

*"As I say as I am at the moment I don't feel any different to what I did before I knew I*

*had it" (Mrs C).*

*"This is the thing about it, I don't realise that I've been, that I've had any changes." (Mr B)*

For most people, further interview questions allowed them to elaborate on changes they had noticed but did not initially mention. However, one participant's view throughout the interview was that

*"I've just accepted that it's the way it is. It isn't as though I've had a good memory and then lost it!" (Mrs A).*

Although Mrs A felt that she had always had a poor memory, further prompting during the interview identified that she did not feel she knew enough about what might be able to help it.

*"I'd be very interested if there was somebody that had something that could bring it back! ... Because then I never had a good memory, as I say, to be brought back" (Mrs A)*

Mrs A's interest in whether somebody could do something to help her memory is explored further during discussion of cure-control sub-themes below.

### **Cause sub-themes**

#### *Growing older*

The majority of participants spoke about ageing playing at least some part in bringing about their dementia. *"All I can put it down to is my age" (Mr G)* but some participants talked about being uncertain whether ageing was a causal factor related to the changes they were experiencing to their memory.

*"Should I put it down to my age, should I put it down to this and that. I don't know. I don't know what to say. I don't know". (Mr D)*

When prompted to elaborate on this point later in the interview, Mr D talked about having some difficulty in understanding which factors and experiences might have contributed to his dementia, and how much might be due to factors such as aging.

*"You know what I mean ... I don't know, I put it down to.. I don't put it ... I put it down to ... one per cent, I say, one per cent I put it down to my age, naught percent is ... is it because I've got dementia? I don't know what's going ... I don't know" (Mr D).*

However, this lack of knowledge did not appear particularly important to him, or to have a large impact upon his overall understanding, as he also went on to indicate that his strategies for trying to manage his dementia were based more on his experiences of symptoms than his knowledge of cause as he believed dementia affected everybody differently anyway.

Although some participants felt that age was the only factor responsible, others felt that ageing revealed susceptibility to memory difficulties inherent from birth.

*“Everybody’s different from being born and then as you get older things come out, I think!” (Mrs F).*

For one participant, attributing the cause of his dementia to ageing appeared to allow him to justify the changes he was experiencing to himself.

*“Well, I’ve got to bloomin’ 80 year old. If I can’t, if I start forgetting a few things now it’s, you know. That’s why I put most of it down to my age” (Mr H)*

but at the same time he questioned whether this was the right thing to do.

*“I can’t expect to be same as what I was at 21 or 22, can I really?” (Mr H).*

This seems to suggest that ageing was the most plausible explanation Mr H could identify for his memory changes. However, he seemed to struggle to form a coherent understanding of all his experiences as it appeared that his belief about ageing as a cause did not fit with his observation that recent memories were more difficult to recall than older memories.

### Circumstances and incidents

This sub-theme encompassed a variety of external factors which participants felt may have contributed to their dementia. Without prompting, one participant expressed uncertainty as to whether a recent bereavement had played any role in causing his dementia but he did not indicate that he wanted to find out any more about this.

*“I mean I don’t know if losing my partner didn’t help a lot. But I don’t know.” (Mr D)*

When prompted to talk explicitly about the causes of their memory changes, participants talked about a variety of circumstances and events that they felt had contributed to their dementia, such as time of day and amount of rest *“Maybe I’m tired or not getting enough sleep on a night.” (Mr D)* alongside changing circumstances which placed different demands on

their memory. Changes in day-to-day environment, shock and stressful circumstances were also seen as having a causal role.

*"I had a bit of a traumatic do and all like that leaving work ... they brought this bloke into the office and all of a sudden I went from being the sort of office manager to the office boy! To put it quite bluntly. And I finished up going to work every day as usual but having nothing to do. ... I'm sure that's what caused most of this." (Mr H)*

#### Bodily changes and poor health

Views about the role of physiological factors in causing dementia ranged from general comments about health being implicated as a cause *"It can be your health and things you see can't it"* (Mrs F) to being uncertain about whether previous health conditions or treatments had anything to do with it.

*"There was, I could be wrong on this, but when I had cancer I was having this specific chemo and they were write up in paper once and they said that this particular chemo could cause I'm not sure whether they said Alzheimer's or the other one, ... So whether that had anything to do with it?" (Mrs C)*

For participants with mixed dementia, they talked about finding it easier to identify a concrete explanation which made sense to them for the vascular component of their dementia in comparison to Alzheimer's.

*"Well apart from the vascular one which as I say they've told me that's the veins in my head, but the Alzheimer's no I've no idea at all what caused it." (Mrs C)*

However for Mrs C, not understanding the causes of the Alzheimer's component of her dementia did not appear to be important to her or impacting upon her overall understanding.

*"As I say I don't know how I've got it or why, but I mean you could say why me but then again you could say why not me? ... Well I don't think about the causes. It's there and that's it." (Mrs C)*

In relation to coherence, Mr D viewed a shrinking brain as one cause of his dementia and appeared to link this understanding of cause to a belief that nobody would be able to tell him how to cure his dementia.

*"I don't know how can they .. they won't never find a cure for it, I don't think. So it's like a lot of things, they won't find a cure for. Because ... the brain goes down, shrinks down, Doctor's told me, my brain is going smaller. And that's what caused a lot of dementia." (Mr D)*

Although such views may have limited his awareness of ways to manage his condition, his overall understanding could be seen as coherent to the extent that his belief about cause was compatible with his belief that this cause was too complicated to be cured. Comments such as this suggested that some people may find it easier to maintain a coherent understanding of their condition if they adopt a view that 'I can't find out because nobody knows', and choose to accept that what they don't understand cannot be answered. However Mrs F expressed uncertainty about whether anyone would be able to tell her what caused her dementia, but still indicated that she was keen to find out more about why she had got it.

*"I mean who knows what causes it?" (Mrs F)*

*"I just happen to want to really know more about it and why," (Mrs F)*

She appeared to hold a view that it was important for her to know as much as possible about why she had got dementia along with a belief that there might be some things about causes which she could not find out because nobody knows the answer. In this instance Mrs F's understanding of her dementia may not be coherent because she appears to be indicating that she does not know enough about her dementia, including why it happened. However, this absence of coherence may be encouraging Mrs F to increase her awareness of her condition.

#### How you are born and family history

The sub-theme reflects how some people evaluated the likelihood of their genetic make up playing a part in their dementia.

*"I think it does run in families because me grandma ended up living with my mum and dad for a while, and then they had to put her in somewhere" (Mrs F)*

Some felt they did not have enough knowledge to know whether their dementia could be related to their family background

*"I don't know whether it's anybody else in the family or you know back in the family have ever had it because I don't know my family enough" (Mrs C)*

and some alluded to a genetic cause without mention of things running in their family.

*“As I say, it, I was born with it! ... I've just accepted that some people ... are like this and ... we're not all the same, are we?” (Mrs A)*

### **Consequences sub-themes**

#### Adjusting expectations and opportunities

Some participants talked about having to adjust their activities or expectations because of their dementia. These varied from expecting not to live as long as they hoped to more practical adjustments to what they chose to do or were able to do.

*“I had about three months when I couldn't - supposed to drive ... you've got to rely on other people again” (Mrs F)*

*“So I just thought I can't get into the conversation with anybody.” (Mr G)*

#### Changing relationships

Around half the people in the study felt that there had been some degree of change in their relationships with friends and family, particularly their relationship with their spouse. Some people spoke about changes they were currently experiencing.

*“I think I'm not putting the same input into the ... into the family as what I should be doing ... I used to be the one who did the organising and now, now it's turned the opposite way round now; sort of ... reliant on [partner] all ... [partner] all the time now. Remembering where we're going, telling me what to do” (Mr H)*

Mrs F voiced uncertainty about how much consequences, such as finding cooking more challenging, were impacting on her daily life but she also mentioned that presuming that the consequences she was currently experiencing were typical of dementia helped her make sense of her condition.

*“Well I don't know about things. It's just . . . I suppose I just presume that this is what happens. Yeah, that'd make, that'd make sense, don't it.” (Mrs F)*

However, an ability to accept what was happening as normal was not shared by some other participants where a conflict between their experience of symptoms and expectations of their condition appeared to make it more challenging for them to come to a coherent understanding of their overall condition.

Some participants spoke about changes to relationships which they expected to occur as a result of their dementia including uncertainty about how family members might cope with consequences the participant might experience.

*"I've stopped going to see her because it worried me ... I hope my friends won't abandon me if I go totally doolally, you know if"* (Mrs F)

*"Not knowing my family. You know when you get visitors and you don't know who's there. I know I won't know anything about it, but it's just the thought of it that upsets me because I know the effects it'll have on them."* (Mrs C)

*"Well my daughter's, she's in [name of county]. She's [description of daughter's health difficulties] and I don't know how she'll cope because she's way down there."* (Mrs C)

Uncertainty about how her daughter would manage as the consequences of Mrs C's dementia changed appeared to be a concern for her. However, it was unclear what knowledge could address this concern; one possibility is that helping Mrs C identify alternative support for her daughter in the future might be more beneficial than furthering her understanding of future consequences.

#### *Trying and getting started*

A few participants described that since having dementia they had noticed increased difficulty in initiating things they wanted to do. *"Sometimes ... like I say to myself ... I'll go on and write a letter today. I didn't get round to it"* (Mr D). Participants also reported a desire to try to take their share of what it was possible for them to do but found it difficult to make the effort to try to recall things. *"It gets to a pitch where I try and try and I don't get anywhere with it so I just leave it."* (Mr G)

Being cared for and going daft

This sub-theme related to the way participants described the expected consequences of their dementia as it continued to progress. Almost half the participants expressed a view about this and none of them spoke positively about the possibility of moving to a care home.

*“I’ll get dafter but never mind ... So I’d rather not go in a home. I’m alright going down to [name of sheltered housing] because that’s my own flat.” (Mrs C)*

*“I think it would be better to die than have to be in care” (Mrs F)*

Mr D expressed uncertainty about future consequences that he might expect, but was clear that there were some things that were important for him to know, such as how much he could keep doing for himself, and other things such as how long he might live for which he would prefer not to know because they would be too frightening.

*“As long as I can look after myself, I’ll be alright. Feed myself, look after myself.. medical ..washing, showered, shave.. look after my cat, look after my house. But then again see, I don’t know. I don’t know.” (Mr D)*

*“I don’t want to know because... if you know what’s going to happen, you know you’re going to die in two days time, you don’t want to know that. You run me?” (Mr D)*

This gave the impression that for Mr D, knowing about the future was important to him if it related to things he could have control over which might help him to maintain independence but a lack of understanding for things outside of his control might be less likely to impede the formation of a coherent understanding if they are seen as unimportant as they cannot be changed. Therefore, for some people, absence of knowledge may be more likely to affect overall coherence, and be important for people to address, if it relates to issues which they have the possibility of exerting some degree of control over.

Other participants such as Mrs F were aware that there were likely to be additional future consequences of their dementia but did not feel it would be helpful to know any more about what might happen to them.

**“Researcher - Are there any things that you expect to be different in the future because of memory loss?”**

*Participant - Yes, I am sure there will be, and I don't really want to go ... I don't really want to go searching anymore.” (Mrs F)*

In this instance, Mrs F had already described previous experiences of observing how dementia affected people as it continued to progress so she may have already felt she had a clear enough picture of what to expect and did not feel it was important to further her understanding of specific future consequences.

### Just the same

Half of the participants initially expressed that they did not think there had been any consequences to their dementia but these participants later elaborated on changes that they had noticed.

*“No nothing’s changed. It’s just that I get annoyed with myself and I don’t remember”  
(Mr G)*

*“No, I don't think ... my patience has gone, quite a bit! I don't seem as patient now” (Mr H)*

However, some participants who felt that their dementia did not currently have any noticeable consequences did not see this as a static situation. Mrs C expected uncertainty about her condition to increase as changes due to dementia began to have more of a day-to-day impact. It appeared that finding out more about new changes as she went along was a strategy which she hoped would help her to maintain a coherent overall understanding of her dementia.

*“As things change I want to know more ... I’ve just got on day to day and it hasn’t made a great deal of difference to what I was doing before I knew I had it.” (Mrs C)*

### Something’s missing and it just won’t click

This sub-theme encompassed times when participants talked about being aware that there was something they felt they should know but they could not quite manage to bring it to mind. This was apparent in the narratives of half of the participants.

*“Coming home it started raining and it was awful 'cause I couldn’t get the windscreen wiper on all the time, and I was just doing it every bit as I was driving. ... It was after I’d*

*left [friend] and I'd dropped her at home, and it suddenly clicked, you know. I was just having them going intermittent; you know when you just do it with your finger. I'd just not turned it far enough." (Mrs F)*

*"I'm going down there and coming half way back and I forgot this item, I mean, maybe a little thing and I say, I forget that." (Mr D)*

Some participants felt that their memory changes had made some difference day-to-day but they did not know exactly what had changed.

*"What difference does a memory change mean. Does it, how about, does it come to a, bring you to a point that's..., I don't know. That's the question, I can't go far enough into it." (Mr B)*

**"Researcher - So how do you think that's affected you just now?"**

*Participant - I don't know, I can't, I don't think it's made a lot of difference to me. Can't be sure." (Mr B)*

For Mr B, difficulty in finding identifiable consequences of his memory changes appeared to coincide with experiencing symptoms which he did not expect. This suggested that it may have been hard for him to decide whether or not he was experiencing dementia, giving the impression of a more general confusion about what was happening to his memory.

**Cure-control sub-themes**

**Approach to their dementia (hide or seek)**

The majority of participants made reference to the ethos with which they approached trying to manage their dementia and this appeared to vary between participants. Some participants appeared to adopt a predominantly optimistic approach to trying to control their dementia, not dwelling on why things had happened, looking to make the most of what they could still do, and availing themselves of anything they felt that might help.

*"I just take each day as it comes basically ... it's just what you're meant to cope with. I'll have to get on with it." (Mrs C)*

*"I like to know things ... I want to know how it affects other people if everybody sort of starts with this kind of thing ... I don't know whether it will be useful or not, I just want to know." (Mrs F)*

Other participants appeared to approach things with an attitude that could be considered avoidant

*"I don't think about it." (Mrs A)*

Some participants also talked about trying to revise approaches to coping with dementia that they felt were not helping, or viewed their methods of coping as positive in comparison to alternative approaches.

*"I've got so used to it now. I get upset. I say to myself what is the use in worrying about it? It'll only make matters worse." (Mr G)*

*"I think it depends on people's personality and what they . . . they don't . . . like I say, my best friend just don't want to know. So she'll end up totally bonkers, and she won't have done anything about it, will she? Least I'm trying - taking the tablets!" (Mrs F)*

#### *I don't think so but ...*

This sub-theme reflected participants expressing that they felt nothing much could be done about their dementia, or a tentative hope that something might be possible but only in the future. A common perception appeared to be that the interviewer was enquiring about the possibility of completely curing dementia even when questions such as **"Is there anything that can be done to improve how it affects you day-to-day?"** had intended to enquire about managing the day-to-day impacts of dementia.

*"Participant - I can't do anything about it*

**Researcher - I guess I'm just curious as to why you feel you can't do anything about it**

*Participant - Well, maybe someday there'll be something that can do something about it! But there isn't so ... It might come when they find something that would help, but I don't think it's around at the time ... Well I think it might be when I've gone!" (Mrs A)*

Some participants did not think they understood how it would be possible for anything to cure their dementia and were not inclined to investigate whether anything could be done because

they felt they could not find out any more because nobody knew, as it was too complex to understand.

*"I don't know about that because .. they .. I don't think so, don't think so. I mean, when you break your arm they can put it in a sling or set it or things like that but not your brain, no ... they won't find a cure for. Because .. the brain goes down, shrinks down ... they never will find one. But say five years down the line they find a drug or an operation can help ..., say if it's a little bit of trouble, take that bit of trouble away .. then I might say well, alright, I'll do that but .." (Mr D)*

This type of belief, that they can't find out because nobody knows, appeared to allow people to minimise the importance of finding out about cure-control strategies, perhaps helping them to maintain a coherent understanding of their condition by allowing them to accept that their current understanding was sufficient, given what they believed was currently known about dementia.

### Self-help

All participants contributed to this sub-theme, which was only mentioned once during open questions at the start of the interview in relation to adapting patterns of socialising with friends *"I've put my head in the sand and just don't get involved with [friend]," (Mrs F)*. This sub-theme encompassed things which only individuals with dementia themselves had done or felt they could have done to try and help their dementia such as applying more effort, keeping their body or mind active and healthy and asking or enquiring about things.

*"I keep trying when we go to the [reminiscence group name] to remember what's happened" (Mr B)*

*"Keep your mind active, your mind looks after your body, not the other way around because your mind is like this ... your mind tells you, you pick that cup up. Your mind says you put the TV on ... your body doesn't tell you that. Your mind says you walk, you run, you cry, you laugh, you make love." (Mr D)*

*"I often think, 'I'll have to pull myself together a bit more ... you know I keep saying to myself, you know, 'get a grip,' and, you know, 'try a bit harder', if that's the simple expression to use. ... Do a bit of dancing ... it's ... it helps; and I go playing bowls and all that .. all I think is that I've got to keep trying to do as much as I possibly can in, you*

*know in every direction: exercise, going to quizzes and doing all these things, and trying to keep going as long as I possibly can” (Mr H)*

For some participants, normalising their view that many people with Alzheimer’s would not have a clear idea of how they were going to manage it may have provided a mechanism for giving themselves permission to limit furthering their knowledge about their dementia.

**“Researcher - Do you feel you have a clear enough understanding of what you might be able to do to manage any changes because of Alzheimer’s or vascular dementia?**

*Participant - No I suppose not, but then I don’t think many people will have much of an idea how they are going to manage Alzheimer’s.” (Mrs C)*

### A helping hand

All participants talked about this sub-theme which encompassed occasions when participants referred to help they had received or help they thought they might find beneficial, from family, friends, professionals, the wider community, or God.

*“Yes we go to [location of reminiscence group] ... They ask us questions just to give us a start and they’re quite interesting really ... the kind of question they ask, they always seem to be things that I haven’t known until ... You get, well how can I say, how can I put it you get, jolts to me what I did, so many years ago ... and .. it’s, it comes to me as we speak” (Mr B)*

*“A bloke in the apartment is absolutely excellent. He arranges quiz nights. It’s not rocket science and things like that. It’s reasonably ... they’re simple, they’re simple questions that you should know, if you know what I mean? And er, that’s doing us a bit of good really,” (Mr H)*

*“Once you get in the system and have got the label of ... Like when I ... I thought probably the doctor would, my own doctor, would see me but, no, you go to the memory clinic ... you see very different like my own doctor didn’t know anything about this drug I was on and the patches, yeah. So it is very specialist.” (Mrs F)*

A prominent and highly valued source of support was their spouse. However, some participants did not always find this support helpful and some felt they could be doing more themselves.

*"I take quite a lot of tablets each day and each day my wife gets them all out and puts them down for me. Otherwise I wouldn't know which tablets to take" (Mr G)*

*"Sometimes I get very, very upset about it because I'm just a spare part. As I say I get very upset and it doesn't help having a conversation with my wife" (Mr G)*

*"Well, I rely on [spouse] a hell of a lot. I'll say that. In fact, I get a bit complacent about things and er, not let her take over but let her, you know ... you know I don't know where the hell I'd be without her, to tell you the truth." (Mr H)*

On some occasions participants talked about being uncertain how effective methods of controlling their dementia were, about not finding the support that had been offered helpful, or giving examples of how they had benefited from help.

*"They've put me on tablets but they made me ill because I'm on that many tablets anyway. Then I've had them for a fortnight and I rang up and asked to be taken off them and I've never done that before ... so they took me off them and they can't give me anything else." (Mrs C)*

*"Participant - My daughter's very good ... She's in [county] but she's got all my appointments down on her calendar so I don't forget them.*

**Researcher - Ok and do you find that makes a difference at all?**

*Participant - Well it does because I do have a notice board out there, but I haven't got anything with your name on so I told her and she put it down. You rang me last night and she rang me first thing this morning to tell me that you were coming." (Mrs C)*

As mentioned earlier, some participants adopted a view that they couldn't find out more about certain aspects of their dementia because nobody knew the answer. This view was most prominently expressed in relation to what other people might be able to do to help their dementia. Mrs A commented that if somebody knew something that would help she would have already been told.

**“Researcher - Is there anything at all that you can think of that might be able to be done to help with not having a good memory?”**

*Participant - Well I hope there is but I don't know of anything.” (Mrs A)*

*“I think if . . . if you had that knowledge people would be trying to find the way out! Wouldn't you? ... Thinking, trying to find if there was something that could help ... I haven't heard of anybody who was working on this and, and er, they would be ... spreading the news, wouldn't they if they were doing that?” (Mrs A)*

Mrs C appeared to draw a parallel between her dementia and physical health difficulties but felt that changes to the brain were too complex to address in a similar manner.

**“Researcher - what might be done to manage the effects of Alzheimer's or vascular dementia?”**

*Participant - Give me a new brain? No, I don't know” (Mrs C)*

When directly asked, some participants, such as Mrs F found it difficult to consider how other people might be able to assist them in the difficulties they were experiencing because of their dementia.

**“Researcher - Is there anything you think other people can do to help you manage with memory loss?”**

*Participant - Not really. Well, no, I mean in what way could they help you?” (Mrs F)*

By adopting the view that what they wanted to know about was unavailable, this appeared to allow some participants to be comfortable holding two potentially conflicting views at the same time; hoping that something could be done to improve their memory while believing that they couldn't find out anymore about things that could be done. For participants who expressed both these views this did not appear to impact upon the overall coherence of how they understood their condition as although they hoped something could be done they did not believe this hope could be realistically addressed.

### Strategies and advice

This sub-theme encompassed strategies and advice, which had the potential to be either self-generated or suggested by other people. Some participants also commented on whether they found these strategies helpful.

*“I say to, I've forgotten his name or I've forgotten her name. So I have done and I've*

*written all their names down in my diary ... so I'll have a quick look if I'm going somewhere to visit someone." (Mr G)*

*"Participant - I just make sure I always, when I go out, that I've got a pencil and some paper and so that if I need to remember something that comes across, I would write it down*

**Researcher - And do you find, does that make a difference for you at all?**

*Participant - Not really, no" (Mrs A)*

**Researcher - Is there anything else like you were saying about the notice board ... that you think might help?**

*Participant - If I've got any hospital appointments, I stick it on there and then it will hit me in the eye when I come down the steps. That way you know I've more chance of seeing them than anywhere else.*

**Researcher - So it sounds like there's maybe something about where you put the notice board or?**

*Participant - Yes at the bottom of the stairs so I can see it" (Mrs C)*

### **Timeline sub-themes**

In relation to the time course of their dementia, some participants spoke about dementia progressing at different rates and some did not feel they understood how the rate at which their dementia progressed might vary and what might affect the rate at which it changed.

**Researcher - Do you feel you know enough about how your memory loss might change over time?**

*Participant - No, I don't ... I don't think it's a set thing, quite honestly from the bits people that you know about" (Mrs F)*

*"I don't know because if ... how what this tablet does for me. They tell me it's slows it down a bit, but how bit ... I don't know. How fast it'll go, I don't know." (Mr D)*

Although participants expressed uncertainty about the rate at which their dementia might change, this uncertainty often appeared to sit comfortably with their other beliefs as they expected this aspect of their condition to be individual and variable between people.

There were two other timeline sub-themes that captured participants' views. One encompassed varying degrees of certainty regarding when events had taken place, '*Sometimes I know when ... but it's hard to be sure*'.

*"I think there might be some changes and I'm relating now to just a few months back"*  
(Mr B)

*"Last year, I collapsed at the end of June I think and after that I seem to forget things"*  
(Mrs C)

Another timeline sub-theme encompassed a view held by the majority of participants that their dementia was unlikely to stop, but with some also mentioning a hope that it would, '*It just won't stop but I wish it would*'.

**"Researcher - How long do you think your dementia might last for?"**

*Participant - Rest of my days." (Mr D)*

For some participants, normalising their experiences appeared to allow them to accept a view that their memory would not improve or would continued to deteriorate without feeling that it was important to find out how to prevent this from happening.

*"I'm just hoping it doesn't get a lot worse! ... I just assume that as you get older you're gonna get worse. I assume that's a reasonable assumption to have, isn't it really?" (Mr H)*

### **Emotional reaction sub-themes**

Participants described a variety of emotional reactions alongside their IRs. It was common for participants to feel self-critical to some degree but there was a range of experiences within this. Some participants talked about being mildly annoyed or frustrated with themselves. "*Bit frustrating at times ... but it's nothing really terrible, I can live with it, you know*" (Mr H). "*It's annoying when there's things in the back of your mind*" (Mr B). However, others had a stronger self-critical reaction.

*"I get upset about it, I get annoyed with myself ... I just get angry and I shouldn't get angry ... It's awful it is. Terrible it is. I was never like this. Never"* (Mr G)

A sense of fear and being uncomfortable about what was happening was also apparent for some people.

*“Sometimes it doesn’t help you to know what’s round the corner because if people think they know what they’re .. going to happen to you, it scares you, it scares you” (Mr D)*

*“I tried to do Sudoku and really struggled and that I find that, that is awful.” (Mrs F)*

Feeling embarrassed was also an issue for some participants.

*“I wouldn’t like to say to somebody ‘you’ll have to excuse me I’m very forgetful and I can’t remember things’. I’d feel embarrassed then.” (Mr G)*

Participants also spoke about having to adjust to or manage feelings of loss.

*“So, so I’ve just forgotten how to cook I think ... and that’s, it’s, that to me is sad” (Mrs F)*

*“I just go on as I did before I knew what they’d diagnosed me with. As I say I had about four bad days and that was about a fortnight ago was that so it just suddenly hit me one morning and that, but since then I’ve just ... I’ve just taken each day as it comes” (Mrs C)*

However, some people found a way of seeing a positive side to things, expressing a degree of acceptance and thankfulness for this.

*“I console myself by thinking, well, I look round and I think, ‘Well, I’m not doing so bad,’ when I look round and see, comparatively speaking; see people my age, I think, ‘Well, I haven’t got a lot to moan about!’” (Mr H)*

*“I’m bound to deteriorate at some point. As I say if I live long enough I’ll deteriorate so it’s, but it’s no good getting myself into a spin over it because if I start getting into a spin about things it’s just, I get the family all upset then and they’ve shouldn’t have that worry about me getting into a spin” (Mrs C)*

*“No, it’s not got any worse ... no and I’m thankful for that” (Mrs A)*

When there were experiences that did not fit with participants' beliefs about what they expected to happen to their memory, this appeared to particularly get to them and could elicit a strong negative emotional reaction.

*"So as I say I'm a bit of a lost soul at the moment and I don't know why it's started!"  
(Mr G)*

Comments such as this indicated that finding a plausible explanation for things that did not make sense may also have a role in helping to regulate emotional distress.

Other participants indicated that choosing to limit which things were important for them to find out more about might play a role in regulating the emotional impact of their dementia.

**"Researcher - does talking about, thinking about the consequences of memory loss, does that kinda raise any feelings or emotions for you?"**

*Participant - Not emotions 'cause like I say I don't really want to know. I suppose I don't want to know any more now! Because I know it's ongoing."*

### **Coherence – an individual's overall understanding of their condition**

Interview prompts focused on what participants felt they did or did not understand about individual IR domains, however some participants also made more general comments about their overall understanding of their condition or made comments that could indicate how their degree of understanding about one aspect of their dementia related to their overall understanding. In order to explore this area further, a number of participants' quotations are reported along with some of the author's observations about how participants' comments may relate to their overall understanding of their condition and general observations about participant overall understanding. This includes instances where participants indicated a lack of coherence in terms of their overall understanding and instances where participants appeared to be content with their current degree of understanding of their overall condition.

Some participants made comments that appeared to relate more to their overall understanding of their condition than to whether there was anything they did not know about individual IR domains. Mr D commented that he felt that doctors did not even know what dementia really was and it affected everybody differently. However Mr B made a number of

comments suggesting that he could not work out what had changed and how it might affect him.

*"I don't know. I mean... dementia, I mean I know it's a thing that... even the top doctors don't know really what it is." (Mr D)*

*"I mean everybody's dementia different, I know. But if they say to me, your dementia is this and it will go that fast or that slow, then I would know. But like I said, nobody knows. Everybody's different" (Mr D)*

*"What else, what ... how much memory change do you have? Does it go on forever?" (Mr B)*

*"**Researcher** - Is there anything about kind of the causes for memory changes that you don't feel that you know enough about?"*

*Participant – I don't know enough about all of it." (Mr B)*

*"There have, there must be some things about .. What can I say? I'm lost. I'm lost, really" (Mr B)*

Mr B indicated that he did not think he was sufficiently aware of what was happening to his memory or how it affected him. On other occasions he also mentioned wanting people to tell him what had changed about his memory, perhaps believing that this might help him identify what the changes to his memory were or if he could do anything to address them. In contrast, Mr D appeared to be aware of several aspects of his memory that had changed and how they were affecting him but did not think it was possible to understand what dementia really was, so he may have been less inclined to try and find out more about his dementia even though he would like to have known more. Both of these views could be seen as consistent with a lack of overall coherence. However, it appears that other factors may affect idiosyncratic responses to lack of coherence including someone's belief about the availability of additional knowledge and whether they see things they do not understand as personally relevant to address. These may influence whether they feel it is relevant to further their understanding of their condition.

Some participants indicated that they currently felt they had a sufficient overall understanding of their condition or did not want any additional knowledge about their dementia. It appeared that it was possible for this to occur even when they were aware that there was more that they could find out about dementia, if this information was not important for them to know.

**“Researcher - You were saying that you didn’t feel that you wanted to know more now, can you tell me anymore about that?”**

*Participant - No because the trouble with me is as I always say a little knowledge is dangerous. If you get to know too much, if you get to know so much, my mind works overtime and I can imagine all sorts of things.” (Mrs C)*

**“Researcher - You were saying that sometimes a little knowledge is dangerous. I guess I’m wondering how much knowledge is right for you?”**

*Participant - So I think I’d rather know more about it as it goes further on and there are changes. You know get the knowledge as it as I change.” (Mrs C)*

Also, Mrs A had not considered trying to find out any more, as she did not expect her memory to change. *“I don't expect it to change. So I haven't really thought about that”* whereas it appeared that taking part in the research interview may have caused Mrs F to become more consciously aware that she took her experiences for granted as being typical for dementia. *“Well I don't know ... about things. It's just ... I suppose I just presume that this is what happens”.*

It can be seen that a coherent understanding may in some instances limit someone’s awareness of their condition if they do not see a need to further their knowledge about their condition. Also, for some people acquiring too much knowledge about their condition may make it harder to maintain a coherent understanding as participants such as Mrs C indicated that they would find it more manageable to find out more about their dementia as they went along.

In some instances, participants’ narratives regarding what they did not sufficiently understand about individual IR domains appeared to be related to a broader sense of puzzlement about their dementia as a whole. This was particularly apparent within the IR domains of cause and identity. Mr H appeared to be struggling to form a coherent understanding of his condition as his experience of symptoms didn’t fit with his expectations. *“Things that I should really automatically know and I keep forgetting don't !! ... It's very difficult talking about it really” (Mr H).* His experience of things that he found himself forgetting more frequently may have conflicted with beliefs and expectations about potential causes for memory difficulties. Comments about forgetting things which Mr H felt he should automatically know recurred

throughout his interview. This suggests that he may have been perplexed by this experience, and slightly fixated on it, which may have inhibited his ability to expand his understanding of memory changes in other domains. Mr D appeared to be confused about whether there might be another name for the changes he was experiencing to his memory in addition to dementia. *“Now you’ve got dementia then you’ve got this other memory loss. I don’t know what you call the other memory loss. I don’t what you call it” (Mr D)*. It is likely that this may have made it harder for him to come to a coherent understanding of all of the changes he was experiencing to his memory.

For some participants, uncertainty about cause, in combination with identity in terms of symptoms experienced, appeared to lead to a general sense of confusion. For instance Mr G struggled to identify a cause which he felt was a plausible explanation for the things he found difficult to recall.

*“I’ve not had no bangs on my head, I have had no accidents so why should it happen?”*  
(Mr G)

*“So as I say I’m a bit of a lost soul at the moment and I don’t know why it’s started”*  
(Mr G)

On a number of occasions throughout the interview Mr G returned to this issue and expressed his frustration at not being able to identify a plausible cause. While it was important for him to find out what had caused these memory changes, focusing on this issue may have made it challenging for Mr G to understand other aspects of his memory difficulties, and consider how to address these difficulties, because he remained unclear about what exactly he would be trying to control.

Although difficulty understanding particular areas of a condition can be seen to impact on someone’s overall understanding, it may be possible for someone to believe there are things that they do not fully understand in one or more IR domains without this having an impact upon overall coherence if they do not feel it is important to know about these areas. This may also be the case if they do not feel that additional knowledge would impact upon their ability to manage their condition. In contrast to Mr G’s approach to the cause of his memory difficulties discussed above, for some participants such as Mrs C, knowledge of cause was unimportant as they felt it would not impact on how they managed their condition.

*"I know how it affects people and you know the effects but the cause of it I've no idea."  
(Mrs C)*

*"Well I don't think about the causes. It's there and that's it. I mean stewing myself over it won't do me any good" (Mrs C).*

Therefore, the level of detail about individual IR domains required to reach a personally sufficient overall understanding of their condition is likely to vary between people and impact upon whether or not they are able to form a coherent understanding.

It was also apparent that other conditions and life events could have an impact upon participants' overall understanding of their dementia. Mrs C expressed uncertainty about whether her family, or prior mental health difficulties, might have influenced her dementia. *"You worry about your families and family problems and that but I don't think that has anything to do with it, but so I had nervous breakdowns when I was younger but I don't know".* Mr D appeared to be experiencing more general confusion about whether all of his symptoms were due to dementia, or if some might be due to age or to his other health conditions.

*"Like I say, lot of things going berserk at the moment because I [description of bereavement], I'm getting a lot of complaints, plus my .. [significant physical health event] and this time of year and a lot of things going berserk. Everything's going daft. I don't know what .. what to sort of put it down to" (Mr D)*

*"what's going on with me? you know what I mean .. I don't know. I put it down to.. I don't put it .. I put it down to .. one per cent, I say, one per cent I put it down to my age. nought percent is.. is it because I've got dementia? I don't know what's going .. I don't know." Mr D*

Mr E had been experiencing sensory changes which were impacting upon his independence. He believed that these sensory changes were related to his memory difficulties but did not understand how his dementia might be connected to these sensory changes and vice versa.

The above observations highlight the importance of also considering the context of someone's dementia in relation to other health difficulties and significant life events, such as bereavement or family difficulties, as such factors may also impact upon someone's ability to form a coherent overall understanding of their condition.

## Other Themes

There were some issues raised by participants that were not captured by the CS-SRM but appeared to be related to coherence of IRs. These were the *'Interaction of dementia with other health difficulties'* and *'Credibility of advice, deciding what to trust'*. In terms of deciding what to trust, some participants questioned whether professionals had believed them, whereas others had a more unquestioning acceptance of health professionals' advice.

*"Other people seem to ... to think um, other ... other way, I just get, I don't say they've said anything about it but they've sort of looked as if they couldn't understand that, you know" (Mrs A)*

*"I only go by what the doctors tell me. But then again, I'm not a medical person but I know a little bit, not that much." (Mr D)*

Regarding *'Interaction of dementia with other health difficulties'*, for some participants a change in medication for other conditions meant they might no longer be able to be prescribed medication for dementia, and some felt there was a connection between their dementia and another condition but did not feel they understood what this was. Also, some people did not feel they understood whether the changes they were experiencing were definitely due to dementia, and some felt that physical chronic health difficulties were more of a pressing concern to deal with.

*"I'm getting a lot of complaints, plus my ... heart attack and this time of year and a lot of things going berserk. Everything's going daft. I don't know what ... what to sort of put it down to" (Mr D)*

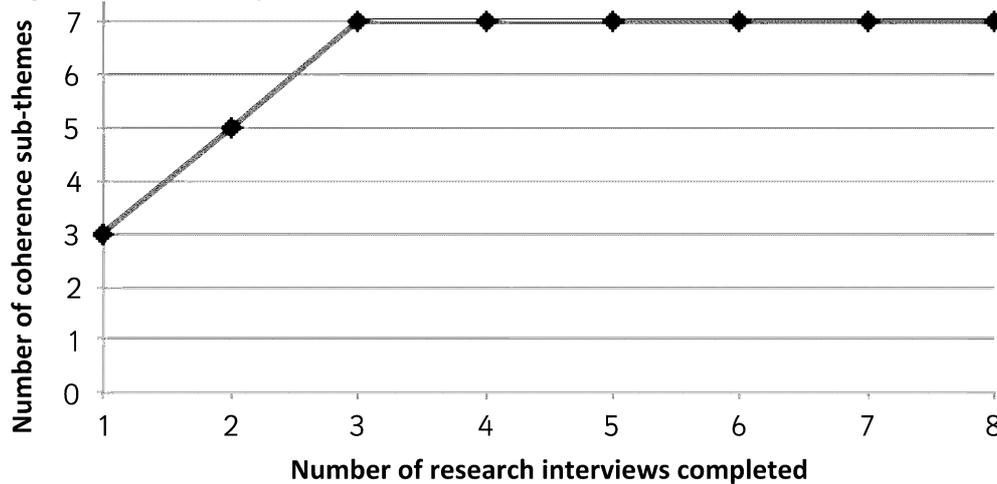
*"I have more problems with the physical ailments than I have with my head at the moment ... I mean it might change, but at the moment, it's my physical health because I get so much pain the [health condition] makes you feel really drained, as if somebody's turned a tap on and taken all your energy and all you want to do is lay down. So that takes more coping with at the moment than Alzheimer's" (Mrs C)*

## Saturation

Thematic saturation was determined for sub-themes of the CS-SRM theme of coherence using the method proposed by Francis et al. (2009) using a minimum initial analysis sample of five

interviews and a stopping criterion of three interviews. *Figure 1* below shows that all coherence sub-themes describing what people felt they did or did not understand about their dementia were apparent by the end of the third interview, and that no new coherence sub-themes became apparent during interviews four to eight. As the three interviews following interview five did not add any novel coherence sub-themes, stopping after eight interviews was felt to provide a sufficient breadth and depth of information to achieve thematic saturation for the CS-SRM construct of coherence.

*Figure 1 Saturation of coherence sub-themes*



### **Inter-Rater Reliability**

A comparison of the reliability of the author's coding of 70 meaningful units with those of a second rater was calculated using Krippendorff's  $\alpha$ , where  $\alpha$  is a measure of the extent to which independent observers agree (A. F. Hayes & Krippendorff, 2007). When interpreting Krippendorff's  $\alpha$ , an  $\alpha$  value of 1 denotes perfect agreement, 0 indicates that agreement between raters is equivalent to what would be expected due to chance, and an  $\alpha$  value of less than 0 indicates that agreement is lower than that which would be expected by chance; therefore the closer  $\alpha$  is to 1 the stronger the degree of agreement between raters (Krippendorff, 2013). Krippendorff's  $\alpha$  was calculated separately for each CS-SRM theme with the value for levels of measurement set to 1 (nominal).  $\alpha$  values for each CS-SRM theme are reported in *Table 3*.

*Table 3 Krippendorff's  $\alpha$ : Assessment of inter-rater reliability*

CS-SRM theme	Krippendorff's $\alpha$	Lower 95% confidence interval	Upper 95% confidence interval
Identity	0.20	- 0.15	0.50
Cause	0.72	0.44	0.93
Consequences	0.67	0.49	0.85
Cure - Control	0.80	0.61	0.96
Timeline	0.78	0.48	1.00
Emotional reaction	0.85	0.64	1.00
Coherence	0.50	0.23	0.77

Previous studies which have applied Krippendorff's  $\alpha$  to assessing inter-rater reliability for coding of qualitative data using the CS-SRM have adopted a value of  $\alpha > 0.7$  to indicate adequate reliability (Farquharson et al., 2011). It can be seen that the degree of agreement between raters for the coding of coherence, identity and consequences themes was lower than 0.7. Potential explanations for these low  $\alpha$  values will be covered in the strengths and limitations section of the discussion and recommendations regarding how the reliability of coding could be improved during future research will be made.

## DISCUSSION

### Key Findings

The current study explored whether IRs could provide a structure for talking to people with early-stage dementia to facilitate the identification of what they felt they did not understand about their dementia. Previous research has established that the concept of IRs from the CS-SRM is applicable to people with early-stage dementia, and that qualitative semi-structured interviews are an appropriate methodology for investigating IRs in early-stage dementia (Clare et al., 2006; Glidewell et al., 2012; Harman & Clare, 2006).

To help identify what participants felt they did not understand about their dementia, the current study employed a semi-structured interview including questions which aimed to elicit participants' views about their dementia in relation to all areas encompassed by their IR, referred to as 'CS-SRM questions', and non-directive questions referred to as 'open questions'. A novel feature of the semi-structured interview design was the use of explicit 'coherence prompts' which were employed at the end of exploring participants' understanding of each of the five primary IR domains. Coherence prompts enquired whether participants were satisfied with what they currently knew about each area of their dementia. This approach for assessing whether participants felt they had a coherent understanding of each area of their dementia drew from a study by French et al. (2006) which highlighted the need for further empirical and theoretical research into which particular features of their condition people feel do not make sense to them.

### **Study Aims**

The current study aimed to offer some insights into what participants themselves felt they did not understand about their dementia, aspects of dementia that participants said they would like to know more about and aspects of dementia which participants felt they had sufficient knowledge about. In comparison to open questions, the CS-SRM interview questions were able to facilitate the identification of a wider variety of participants' views about what they felt they did not know about, or wanted to know more about. In addition, framework analysis highlighted some unique contributions of using IRs to structure discussions with people with early-stage dementia. This approach helped participants to indicate that there were several aspects of their dementia which they felt they knew enough about and to talk about their rationale for how much they wanted to know for particular areas of their dementia. Furthermore, framework analysis highlighted that there is a continuing need to revisit whether people with early-stage dementia feel they understand enough about their condition, as people reported wanting to choose what they find out about depending on their current experience of symptoms and the current impact of their dementia on their day-to-day lives. Specific findings from the current study are summarised below.

*Italicised text* indicates material only elicited by CS-SRM questions. Un-italicised text indicates material elicited by both CS-SRM questions and open questions, or material only elicited during open questions.

### What participants felt they did not understand about their dementia

During the current study, all participants expressed views indicating that they did not understand about some of the following aspects of their dementia, but without indicating whether they wished to know more about these areas. The aspects of dementia that participants felt they did not understand are listed below.

- *The meaning of terms such as 'Alzheimer's'*
- *If Alzheimer's and dementia were the same thing or different things*
- *How to talk to friends about their dementia*
- *How and how much their memory might change in the future*
- *Whether memory strategies or medication were making any difference*
- *If they could believe what they had been told about things to help their dementia*
- *Why everyday things were harder to recall than older memories*
- *How their dementia would affect their family*
- *What the symptoms of their dementia actually were*
- *Whether their dementia had caused anything to change about their day-to-day lives*
- *Whether particular life events might have contributed to causing dementia*
- *Whether physiological changes, environmental changes, ageing or mental health difficulties might have contributed to causing their dementia*

It was also apparent that participants were more likely to feel that they did not understand what had caused their Alzheimer's type dementia than the vascular component of mixed dementia as the explanations that they had been given for the cause of vascular dementia, such as 'mini strokes', were seen as being tangibly plausible.

Framework analysis also helped to identify that the majority of participants spoke about confusing aspects of their dementia which evoked a particularly strong reaction, captured by the coherence sub-theme '*This doesn't make sense and it really gets to me*'. These emotive aspects of dementia are listed below.

- *Why some memories are more difficult to recall than others*
  - *Predominantly, why they frequently forgot more recent 'everyday memories' but were still able to recall memories from longer ago.*
- *Whether they would be able to continue looking after themselves without support from paid carers*
- *Why they had got dementia*

- *In particular, being unable to identify tangible causes for their Alzheimer's type dementia*

### **What participants would like to know more about**

During the study, all participants specifically indicated a desire to know more about some of the aspects of their dementia listed below. These can be seen to overlap with what participants said they did not understand about their dementia. Some participants said they did not understand about a particular aspect of their dementia and did not go on to say that they wanted to know more, whereas others stated they did not understand about something and then went on to say they also wanted to know more about it.

- What caused their dementia
  - *If a particular event or factor was likely have caused their dementia*
- *How their dementia might be connected to other health conditions*
- *If it would be helpful to know more about their dementia*
- *How their dementia might impact upon their lives*
- *How quickly their dementia would progress*
- *The meaning of terms such as 'Alzheimer's' and 'dementia' and if they were different*
- *What, if anything, could help their dementia*
- *What sources of advice about dementia they could trust*

A few participants also indicated a preference for only finding out certain things about their dementia in the future, when they would find this information more relevant. This distinction was only elicited during CS-SRM questions. Aspects of dementia which participants wanted to find out about as they went along are listed below.

- *If there were different types of dementia or stages to dementia*
- *The types of memories that could be affected by dementia*
- *How much worse their memory was likely to get*
- *What difference having dementia would make to them in the future*
- *How quickly their memory might change*
- *Why they had got dementia*
- *Whether their family background might have contributed to causing their dementia*
- *If medication or anything else might be able to aid their memory*

### **What participants felt they knew enough about**

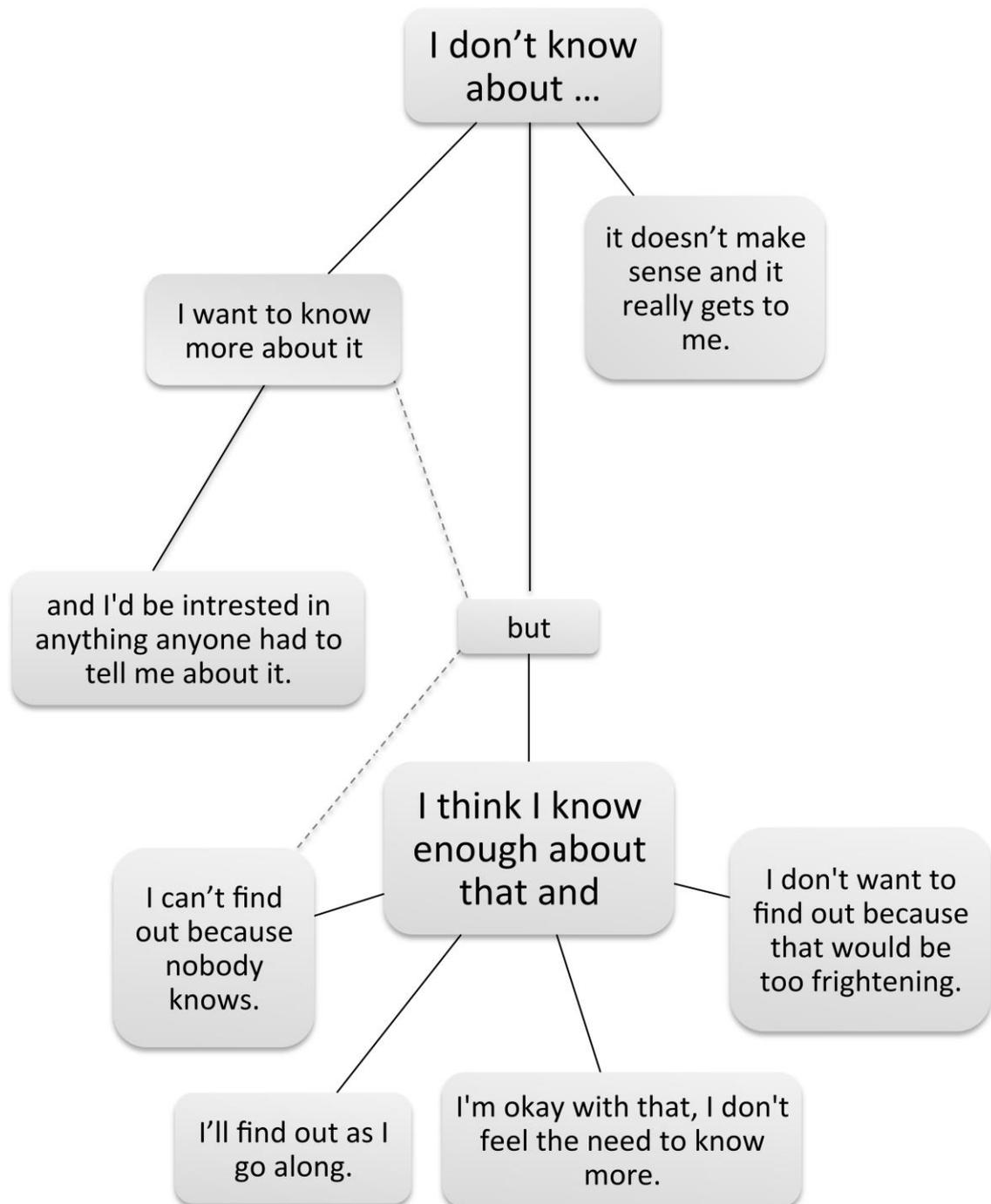
In response to CS-SRM questions, half of the participants were able to convey that they did not want to know any more about their dementia in general, about the rate at which it might progress, or about changes that could occur in the future. CS-SRM questions also helped identify participants' rationale for feeling they did not want to find out more about their dementia. A few participants reported that they felt they knew enough because too much knowledge would be too frightening to deal with. Some participants particularly highlighted that information about how they would change because of their dementia in the future, or when they might be likely to die, would be too much to deal with. However, an observation that may have a more direct clinical application was that half the participants reported a strong desire and motivation to find out more about their dementia, but had not acted upon this, as they felt no one would be able to provide them with the information they wanted to know. Participants reported that no one would be able to inform them about the following aspects of their dementia:

- *What caused their dementia*
- *The nature of dementia; what it was*
- *How they might change over time*
- *What could be done to help their dementia*

Some people reported believing nothing could be done or nobody could help, as they appeared to interpret questions such as *"Is there anything in particular about things that could be done to manage your dementia that you don't feel you know enough about?"* as relating to whether it was possible to wholly or partly reverse the changes to the brain which had caused their dementia, rather than whether it was possible to do anything to help moderate the impact of dementia. These findings highlight the importance of seeking further clarification if people with early-stage dementia report that they feel they know enough about a particular area of their dementia, as some people may feel content with what they know, some may want to know more but believe they cannot find out and some people may feel that certain things would be too distressing to find out.

In order to capture the above findings, a preliminary model (*Figure 2*) was developed during the mapping and interpretation phase of framework analysis to illustrate some of the potential cognitive processes in operation when people with early-stage dementia are prompted to consider whether they feel they know enough about their dementia.

Figure 2 Preliminary model of coherence reasoning in early-stage dementia



#### Interaction of dementia with other health conditions

Another interesting feature of the data, which became apparent while constructing and reviewing framework charts, was a potential link between the coherence sub-theme '*This doesn't make sense and it really gets to me*', experience of managing other chronic health conditions and an unresolved sense of loss. The majority of participants who reported

experience of managing and adjusting to other chronic health conditions did not talk about aspects of their dementia that they felt were incongruent with their expectations and reported no persistent feelings of loss or difficulty in adjusting to having received a diagnosis of dementia. Conversely, participants who did not mention experience of managing other chronic conditions reported struggling to move on from feelings of what they had lost because of their dementia. The majority of the participants who did not mention experience of managing other chronic conditions talked about areas of their dementia which they did not understand, and also described struggling with this experience as the things that did not make sense to them were contrary to their expectations. For example, participants' descriptions of memory changes often reflected a temporal gradient where they reported a greater difficulty recalling more recent events than older memories, such as childhood holidays. Many participants talked about not understanding why this was the case, but participants without prior experience of managing other chronic conditions were more likely to mention feeling particularly perturbed by this experience. It was also apparent that for some participants their dementia, and finding out more about their dementia, was a less pressing concern than their other health conditions, which they felt had a more significant day-to-day impact on their lives.

There are some commonalities between dementia and other chronic conditions, such as type 2 diabetes and heart disease, which participants in the current study reported. For example, they are all more likely to occur with increased age, disrupt day-to-day life, and people may need to change some of the things they do in order to accommodate to the new health condition. One possible explanation for the observation that participants without previous experience of managing chronic health conditions may be more likely to have an unresolved sense of loss, is that participants may have been able to draw on skills which they developed while adapting to their other conditions, and apply these skills to help them adjust to and manage their dementia. Having experience of dealing emotionally with other chronic health conditions might also moderate some of the negative emotional impact from dementia.

## **Relationship of Findings to Previous Research**

### **The views of people with dementia**

A recent questionnaire survey, which included the views of 280 patients in the early stages of dementia attending UK memory services (Hodge, Doncaster, Moniz-Cook, Purandare, & Orrell, 2013), identified that some of the people surveyed felt that they did not know enough about

certain areas of their dementia. Several of the areas which Hodge et al. (2013) felt people did not know enough about could be seen as comparable with IR domains which participants in the current study also felt they did not know enough about. For example, 'signs and symptoms of dementia' might be comparable with the domain of identity and 'options for care and treatment' with cure-control (Hodge et al., 2013, p. 277). Furthermore, in a recent systematic review of qualitative studies investigating the experiences of people with dementia, von Kutzleben, Schmid, Halek, Holle, and Bartholomeyczik (2012) noted that many people with dementia actively sought to find out more information about their condition and were likely to be searching for idiosyncratic answers. The findings of the current study are in line with von Kutzleben et al.'s findings in that the majority of participants in the current study identified specific aspects of dementia about which they wished to know more. Hodge et al. (2013, p. 277) noted that "there is a dearth of empirical research on what may be helpful information in memory clinic settings". The current study has identified a range of aspects of dementia which patients in a memory clinic setting felt they would like to be better informed about. Furthermore, the current study indicates that exploring whether people with early-stage dementia feel they have a coherent understanding of each area of their IR can help to identify individual preferences regarding information needs.

In a recent survey investigating the needs of people with dementia from multiple perspectives, Miranda-Castillo et al. (2013, p. 8) reported that "people with dementia highly value the reception of continuous information during the progress of the disease". Hodge et al. (2013) also queried whether some memory service patients might wish to receive information about their dementia progressively as the condition develops. A similar finding in the current study can be seen from the coherence sub-theme '*I'll find out as I go along*', which indicated that some participants had a desire to pace receiving information about their dementia as their condition progressed. However, the current study also highlighted the importance of being aware of individual variation in the aspects of dementia which people may be happy to receive more information about and which aspects they do not want to know more about until later on in their condition. For example, some participants expressed a current desire to know more about how their dementia would affect them in the future, whereas other participants reported that they would find it frightening to have too much information about future changes at present and would prefer to find out more as and when their symptoms increased.

### Elements of the CS-SRM

Leventhal et al. (1980) introduced the concept of illness schema to the CS-SRM, describing these as implicit disease models in which an illness and its symptoms reciprocally define each other. Bishop (1991) elaborated this concept of disease schema by incorporating it into his prototype model of disease representations; he proposed that schema can be thought of as idealised prototypical representations of different diseases, where each disease prototype encompasses the symptoms and other attributes which a person believes is associated with that disease. People are thought to compare symptoms they experience to the range of underlying prototypes they hold and the prototype which is the closest match to the symptoms they currently experience is used to help them identify which disease or illness they think they have (Bishop, 1991). For people to identify which illness they have, the symptoms do not have to perfectly match a prototype, but just have to be a good enough fit to be plausible (Bishop, 1991). In the current study, participants' narratives within the coherence sub-theme of *'This doesn't make sense and it really gets to me'* indicated that participants were having difficulty making sense of certain experiences. An explanation for this might be found from Bishop's model of disease prototypes within the CS-SRM, as participants may not have been able to make sense of experiences where there was not a close enough fit with one of the underlying prototypes they held, for example, if their experiences did not match expectations of either age-related memory difficulties or dementia.

Participants' narratives indicated an interaction of their dementia with other chronic health difficulties which has already been referred to in the context of managing the emotional impact of their dementia. Previous research that investigated the impact of multi-morbidity of chronic health conditions on IRs found that people often prioritise one health condition as comparatively more important than another depending on their evaluation of consequences (Bower et al., 2012). Bower et al. found that some people placed a greater emphasis on conditions that had a more immediate functional impact, whereas others placed a greater emphasis on conditions with more distant but threatening consequences. There were similar findings in the current study as some participants with chronic conditions in addition to dementia reported prioritising conditions such as chronic pain, because they felt this had a greater day-to-day functional impact, whereas others reported prioritising dementia over diabetes as they felt their diabetes was well managed.

### Using the CS-SRM with people with early-stage dementia

In line with previous research which utilised the CS-SRM with people with early-stage dementia (Clare et al., 2006; Glidewell et al., 2012; Harman & Clare, 2006; Moniz-Cook et al., 2006), the current study found that people with early-stage dementia were able to talk about their condition in terms of all the areas encompassed by IRs, and similarly found that semi-structured interviews were an appropriate methodology for prompting participants to talk about all areas of their IRs. Glidewell et al. (2012) used the CS-SRM to investigate early-stage dementia, and is the only previous study which included assessment of coherence of IRs. Glidewell et al. found that the person with dementia in their study wanted to understand more about their dementia and, in particular, why it had happened to them. The current study was able to replicate this finding in a different context, showing that all participants wanted to understand more about their dementia and identified areas of dementia which each participant wanted to know more about. Furthermore, an additional finding of the current study, which the author does not believe has been previously reported in the literature, was that some participants described their rationale for wanting to know more or not wanting to know more about areas of their dementia.

The design of the current study incorporated the practice of not introducing diagnostic terms such as 'dementia' during the research interview, unless first raised by participants. This practice had also been adopted by some of the previous studies, which had used the CS-SRM with people with early-stage dementia (Glidewell et al., 2012; Moniz-Cook et al., 2006). Findings from the current study add further support to the use of this practice for a number of reasons. Several participants commented on negative associations with diagnostic terms used for dementia, which the author was unaware that the participants held at the start of their interview, for example, Mr H commented that "*Senile dementia's a rotten - rot silly word*". As diagnostic terms were not raised by the researcher, participants used this opportunity to speak about their own personal words and labels that they chose to use in place of 'dementia'. Some participants also spoke about why they chose to use the term 'dementia' in some contexts but not others.

In a previous clinical psychology thesis which used the CS-SRM to investigate the perspective of people with early-stage dementia, Harman (2004) noted that cure-control descriptions from his participants reflected a predominantly physiological understanding of dementia with limited reference to psychosocial mechanisms for managing dementia. Harman (2004)

suggested that this finding may indicate an absence of knowledge in people with early-stage dementia about the range of psychosocial interventions available. A similar pattern was also observed in the current study. The narratives of several participants suggested that they may have internalised medical stereotypes regarding the aetiology and nature of dementia and these participants were less likely to report considering the possibility of psychosocial cure-control mechanisms. The following quote from Mrs C could be interpreted as indicating that she felt that little could be done because it was not possible to have a brain transplant in a similar way to how organ transplants can help other conditions. *“Researcher - what might be done to manage the effects of Alzheimer’s or vascular dementia? Participant - Give me a new brain? No, I don’t know”*. Therefore, for some people with early-stage dementia there may be a gap in their awareness of the potential range of psychosocial interventions available. It is interesting to note that in the current study, such participants often expressed a strong desire to know more about anything which could possibly help their dementia. However, they had not considered investigating the possibility of psychosocial support mechanisms, as they did not feel psychosocial interventions would have any impact upon the neurological changes caused by Alzheimer’s disease. This finding also fits with the observation of Kitwood (1997) that a view of dementia which focuses on neuropathological causes may restrict someone’s awareness of the wider range of options for managing their condition.

### **Awareness in dementia**

Clare (2002) posits that apparent lack of awareness in the early stages of dementia should not be viewed as a purely neurobiological symptom, but wholly or partly as a product of a psychologically adaptive response to an individual’s social situation. In an interview study on how people with dementia and their partners view awareness, Clare (2003) proposes a preliminary model of how people develop a conscious awareness of the impact of their dementia. Clare suggests that apparent dismissal of memory difficulties may serve protective psychological functions or be related to comparing dementia with other health difficulties, which reframes the importance of dementia as minor in comparison. Recent systematic reviews and studies, including an international population-based study by Mograbi et al. (2012), also endorse the view of awareness advocated by Clare that a psychologically constructed element to awareness in dementia needs to be taken into account (Bunn et al., 2012; Orfei et al., 2010; von Kutzleben et al., 2012).

In line with the findings of Clare (2003), the current study identified that some participants actively chose to limit the amount of information they wished to find out about their dementia because they perceived their other health conditions as having a more immediate and pressing impact than dementia. Furthermore, the current study identified a variety of potential explanations that participants gave for deciding to limit what they wanted to find out about their dementia. These choices would therefore impact upon the extent to which they might expand their awareness of their dementia. In line with the findings of Clare (2003), some participants in the current study described that choosing not to find out more about their dementia, or choosing to pace the rate at which they found out new information, allowed them to minimise the fear which such information might evoke. However, within the coherence sub-theme of '*I can't find out because nobody knows*', participants referred to areas of dementia such as how they might change over time and what could be done to help their dementia, which they believed they were sufficiently aware of. For these participants, it is likely that their awareness of these areas of dementia was constrained by their belief that nobody would be able to provide them with further information.

The Johari window model (Luft, 1969), is traditionally used in organisational and personality psychology but in this instance can provide a useful perspective on participants' awareness of the potential for psychosocial ways of managing their dementia. Luft (1969) proposes that knowledge about the self and knowledge about other people, including knowledge about how other people can help an individual, can be divided into four areas: things that are known to the individual and also known to other people, things that are known to the individual but not disclosed to other people, a unknown area of things not known to the individual or to other people, and finally an area which is someone's blind spot, things that an individual does not know about but that other people do know about. For participants in the current study, knowledge about psychosocial mechanisms which could help the management of dementia could be seen as a blind spot, as professionals working in settings such as memory services do have knowledge of psychosocial support mechanisms for dementia but the people with dementia may be unaware that they could know about mechanisms of psychosocial support. It would be unrealistic to expect people with early-stage dementia to express an interest in finding more about things they are unaware that they could know.

### **Study Strengths and Limitations**

The structure provided by the interview topic guide appeared to be directive enough to allow a sufficient level of detail to be captured regarding the research topic while enabling participants to express a range of views within this area of investigation. However, it is possible that there may have been some aspects of dementia which participants wished to know more about but chose not to talk about during the research interview. Although the topic guide could be perceived as being overly directive, a less structured interview would have carried a greater risk of skewing the data by the researcher unintentionally introducing views that they felt were particularly relevant. The decision to focus on participants' views of what they did not understand about their dementia is liable to make any recommendations from the current study more patient-centred than if the author himself had been making a judgement about aspects of dementia that participants did not know enough about. In addition, choosing to adapt how coherence of IRs was defined to fit with research aims allowed a more nuanced description of what participants felt they did not understand about their dementia than would have been possible from investigating the construct of coherence as it had previously been defined. Adopting IRs as a framework for the semi-structured interview may have led to both barriers and benefits in terms of the breadth of participant's views about their dementia or memory changes that were sampled. In contrast to open-ended narrative interviews, all semi-structured interviews will shape and direct the interview process to some degree. Using the domains within the IR framework to structure the topic guide presupposes that participants' thoughts and views about their dementia or memory changes can be captured within the confines of an illness-based understanding of dementia. It is possible that this approach may not be best suited to capturing the views of people who perceive the symptoms and experiences which are encompassed by a diagnosis of dementia, not as a distinct interrelated entity, but as linked to a variety of illness, non-illness, environmental and social factors. However, the interview topic guide was able to elicit detailed information about all of the areas encompassed by IRs and in addition to this information, some participants also chose to talk about broader social consequences such as how their engagement with social support and opportunities had been either expanded or restricted following diagnosis of dementia. Family circumstances and environmental context were also mentioned to varying degrees by participants.

Models such as Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1994) emphasise the importance of considering the context in which human experience and interaction takes place in order to better understand how people adapt to and manage

challenges, including health conditions. Information on social context identified during the interview may have been incomplete and discussed to different degrees as it was only obtained when participants chose to disclose it and not explicitly elicited by the topic guide. Therefore, a more complete understanding of how social context may have impacted upon how people understood their dementia and whether they felt they were able to make sense of their experiences may have been elicited if participants had been directly prompted to talk about the social context of their experiences, not just about their IRs. It would have been useful to gather more detailed information on social and environmental context as this may have impacted upon how people make sense of their dementia. For instance, some participants saw their experience of dementia not as an illness, but as a result of social causes such as changes in employment or age-related changes comparable to their peers. Also, basing interviews on the IR framework may not have been the most appropriate approach for people who felt that symptoms which could be ascribed to dementia were due to multiple conditions.

In spite of the small sample size, analysis of saturation of coherence sub-themes (*Figure 1*) suggests that the range of views regarding coherence of IRs in early-stage dementia was adequately sampled. The current study was also able to build on previous theory and suggests a potential mechanism (*Figure 2*) which might describe some of the cognitive processes involved in how people with early-stage dementia decide whether they wish to know more about aspects of their dementia. Quinn, Clare, McGuinness, and Woods (2012) highlight that, in comparison to conducting research interviews in a formal setting, interviewing in participants' homes can provide a comparatively neutral space which is less likely to elicit answers based on participants' perceptions of the researcher's agenda. Therefore, interviewing participants in their own home may have helped them to be more open about their views.

Several factors may have influenced who participated in this study, and these factors may limit the degree to which study findings can be generalised to other contexts. For ethical reasons it was necessary for study exclusion criteria to enable clinicians to decide whether participating in the research interview would be too much for some patients to tolerate. However, this may have limited the range of people with early-stage dementia who were judged eligible. In order to minimise demands placed upon clinicians' time, only one memory clinic was involved in the recruitment process. Referral patterns may have differed to other memory clinics in the city and patients in other areas may hold different views regarding what they wish to know about

their dementia or what they feel they do not understand. In addition, there may be factors that influenced why some people who received the study information sheet chose to take part and some declined; this could have had an effect on the views participants expressed regarding what they did not understand about their dementia.

It is also possible that participants' views could have been influenced by the length of time between receiving their diagnosis and participating in the research interview. Initially, the study design anticipated recruiting enough participants through psychiatrists' clinics and, due to the nature of the service structure, this would have resulted in all participants being between three and six months post-diagnosis. Therefore, the research protocol had not incorporated collecting data on time since diagnosis. Due to recruitment difficulties, it became necessary to expand recruitment to patients who were being seen by one of the memory nurses from the clinic involved in the study. Consequently, this resulted in a larger range of time between diagnosis and interview than originally anticipated, with some participants being over a year post-diagnosis. However, participants' responses in the current study suggest that time since diagnosis may bear little relation to the length of time that people have had dementia. Some participants spoke about going to their GP when they first noticed very subtle changes to their memory, whereas others indicated that they had waited a year or more since they first noticed memory changes. Manthorpe et al. (2010) identified that the information needs of people with dementia are likely to be different for people who present to services at the first sign of memory changes than for people who delay seeking support until memory changes are more evident. Therefore, it may be that time since onset of dementia symptoms, which is challenging to assess accurately, may have a greater impact on coherence of IRs and information needs than time since diagnosis. It is likely that someone whose symptoms of dementia had been progressing gradually for a few years would have different views about their condition and different gaps in what they felt they understood than someone with the same symptoms that had become apparent over a period of months. The degree to which this may have affected results is unknown as no data was collected on time since onset of dementia or time since diagnosis. However, it would not have been possible to identify precisely how long participants had been experiencing dementia as people may have been experiencing a sufficient degree of symptoms to be able to receive a diagnosis for a variable and unknown length of time before they were formally diagnosed.

It was hoped that only recruiting participants with Alzheimer's type dementia, or mixed Alzheimer's/vascular dementia, would allow findings to be more applicable to other people in the early stages of Alzheimer's type dementia than if a broader range of aetiologies had been sampled. Also, all participants were receiving support from a memory clinic and the views of people with early-stage dementia not receiving support from NHS services may differ. However, by recruiting through an NHS memory service it was possible to purposively select for a variety of characteristics in order to ensure that there was a degree of homogeneity between participants. It is hoped that by being as transparent as possible about the characteristics of study participants and striving to ensure completeness in reporting study methods, this will help others make a judgement about how closely participants in this study resemble people with early-stage dementia seen in other services. Consequently, readers may be better able to judge how applicable the current study's findings may be to other contexts.

One limitation of the semi-structured interview is that the 'open questions' and 'CS-SRM questions' are not directly comparable. The section of the interview devoted to open questions was substantially shorter than the CS-SRM questions section. Therefore, participants may have had less opportunity to voice their views during open questions. It is also possible that participants may have been more reticent in what they chose to say during open questions as these came at the start of the interview, when the author was beginning to build rapport. However, methodological and ethical considerations made it hard to address these issues in the study design. The interview had to begin with open questions so that participants' answers to open questions were not influenced by having been previously primed by CS-SRM questions. In addition, a number of factors meant it was not possible to devote comparable time to both open questions and CS-SRM questions. It might have been hard for many participants to tolerate a substantially longer research interview and it was not felt to be ethically justifiable to spend longer than necessary interviewing participants using non-directive questions, which were not expected to meet the objectives of this research. Therefore, it may not be possible to be certain whether discussions that use IRs as a structure are superior to less directive discussions at eliciting people's views about their dementia. However, as the majority of coherence sub-themes were only present during CS-SRM questions, people may be less likely to talk spontaneously about coherence than other aspects of their IRs.

Allowing participants the option of having a carer present during the research interview may have impacted upon what some participants chose to say. However, it was felt necessary to introduce this adjustment both to facilitate recruitment and in response to feedback from people who were approached to take part and the ethics committee regarding the potential emotional impact of completing the research interview alone. It is not possible to be certain what might have been influenced by the presence or absence of a carer during the research interviews. The presence of a carer could make some participants refrain from sharing certain information. For example, before discussing how their dementia had made them more dependent on their spouse, one participant said, "She's not listening is she?" However, the presence of a carer could also have a positive impact. For example, one participant's carer decided to make a brief comment regarding a potential cause for the participant's dementia that the participant knew about but had not yet mentioned. This appeared to help that participant talk about their rationale for believing that this event had influenced their dementia.

When calculating inter-rater reliability using Krippendorff's  $\alpha$ ,  $\alpha$  was found to be less than 0.7 for the CS-SRM themes of 'identity' ( $\alpha=0.20$ ), 'consequences' ( $\alpha=0.67$ ) and 'coherence' ( $\alpha=0.50$ ). It is likely that ambiguity as to whether to code certain items as either identity or consequences can account for the observed  $\alpha$  values for these themes. The psychologist who assisted with coding to assess inter-rater reliability had experience of using the CS-SRM for research in another condition, people who had had a stroke. In this condition, cognitive changes such as difficulties with memory or language would be seen as a consequence of the stroke whereas, for people with dementia, these experiences could be interpreted as being symptoms of dementia. It became apparent that the majority of meaningful units that the author had coded as 'identity' the other psychologist had coded as 'consequences'. In order to minimise the possibility of such confusion in future studies, a more explicit definition of how to code these IR domains could be provided along with detailed practical examples to illustrate coding. Previous studies that have assessed inter-rater reliability for coding of qualitative material using the CS-SRM have found lower values of Krippendorff's  $\alpha$  for the construct of coherence in comparison to other areas of the CS-SRM (Farquharson et al., 2011). Also, in their report on the construction of a questionnaire measure which utilised the CS-SRM to assess memory difficulties, Hurt et al. (2010) found lower inter-item correlations for questions designed to assess coherence than questions to assess other areas of IRs. These observations suggest that the construct of coherence maybe harder to define and more challenging to consistently code than other areas of IRs.

### Implications for Future Research

To the best of the author's knowledge, the current study is the first to investigate the application of the CS-SRM to elicit information about what people with early-stage dementia do not understand about their dementia by adapting how the construct of coherence was defined in order to provide a detailed insight into the information needs of people with dementia. A preliminary model (*Figure 2*) was proposed which may account for some of the cognitive processes involved in how people with early-stage dementia evaluate expanding their understanding of their condition. However, further research would be necessary in order to validate whether this is replicable or applicable in other contexts. The current study focused on participants with Alzheimer's or mixed dementia in a memory clinic setting, and although recruitment criteria did not focus on any particular ethnic group, all participants were of white British origin. Future studies might consider using a similar methodology to the current study in order to investigate whether the information needs expressed by people with early-stage dementia differ for other cultural groups, for people not in contact with memory services, or for other types of dementia.

It was also beyond the scope of the current study to investigate what carers of people with early-stage dementia felt the person with dementia did not understand about their condition and this area might benefit from further study using a similar methodology to the current study. Several participants spoke about wanting to know more about broad areas of their dementia, such as things that might help their dementia, in addition to indicating that they wished to know more about idiosyncratic aspects of their dementia. Therefore, it might be possible for future studies to look into adapting a questionnaire measure, such as the Illness Perception Questionnaire – Memory (IPQ-M) (Hurt et al., 2010) to elicit information regarding whether people with early-stage dementia wish to know more about certain areas of dementia. Such a measure might prove to be a more time-efficient clinical tool for sampling information needs of people with early-stage dementia than individual interviews.

Scott and Clare (2003) suggest that research should pay attention to individual factors that may impact upon engagement with psychosocial interventions for dementia and whether a particular individual sees such intervention as relevant. In addition, previous studies (Hodge et al., 2013; Manthorpe et al., 2010) have highlighted that it may be more appropriate to provide people with dementia with written information about their condition, rather than verbal information, which they may be liable to forget. Future research might consider whether

providing people with early-stage dementia with written information for their expressed information needs has an impact on the coherence of their IRs. During research using the CS-SRM to investigate another chronic condition, Glattacker, Heyduck, and Meffert (2010, p. 292) note that “patients have a great need for information that is often not satisfied by providing ‘standard’ information. In order to reach the patients better, it is increasingly necessary to tailor patient information to the individual needs of patients and make stronger use of patients’ ‘common sense’ models”. However, the author is not aware of any previous research using the CS-SRM for people with dementia that has investigated whether an effective psychosocial intervention can be provided by basing individually tailored information on aspects of their condition where people do not feel they have a sufficient understanding.

Several participants in the current study reported having to manage multiple chronic conditions in addition to dementia. Some of these participants chose to speak about the interaction between their dementia and their other health conditions. However, the interaction between dementia and other co-morbid chronic conditions was not the focus of this research. In addition, there is a complex relationship between depression and Alzheimer’s type dementia (Korczyń & Halperin, 2009), and IRs of memory complaints in older adults have been shown to be predictive of depression (Hurt, Burns, & Barrowclough, 2011). Sufficient resources were not available to allow the current study to investigate the impact which mental health difficulties may have had on the coherence of participants’ IRs. Future research into the coherence of IRs in early-stage dementia should therefore consider the impact which comorbid chronic health conditions or mental health difficulties may have on IRs as the way in which people choose to prioritise the management of multiple health conditions may impact upon what they wish to know about their dementia.

### **Implications for Clinical Practice**

The findings of the current study may be of some benefit to professionals working with people with early-stage dementia in helping increase their awareness of a range of aspects of dementia which people may wish to know more about. It may also be beneficial for professionals to be aware that confusion about certain aspects of dementia may cause distress if people are unable to find a personally meaningful explanation for particular experiences. Consequently, several areas of enquiry are recommended which professionals may wish to consider when working with people with early-stage dementia. It is hoped that these may help

facilitate the provision of individually tailored information which has a greater face validity and relevance to individuals than generic sources of information.

Leventhal et al. (2012) suggest that even a cursory recognition of an individual's IR can provide an effective way to begin communicating with patients. An awareness of patients' IRs of dementia may allow health professionals to consider how their own understanding of dementia differs from how individual patients understand dementia. Knowledge of patients' IRs may help professionals appreciate why some patients talk about choosing to manage their condition in ways which may appear to be sub-optimal or counterproductive by helping professionals see why the patient may feel certain management approaches are useful. For instance someone may appear to be adopting an avoidant approach to their dementia if they believe their symptoms are not having a big impact and are not likely to progress quickly. Knowledge of patients' IRs may also help professionals to be mindful of whether what they are planning to say is likely to challenge beliefs that are helping a patient to maintain a coherent understanding of their condition. Therefore, this knowledge could help professionals encourage patients to develop alternative functional coping strategies before challenging beliefs or behaviours which patients currently find helpful. As the degree of difference between health professionals' IRs of dementia and each patient's IR of dementia will vary, knowing about patients' IRs may help professionals to adopt a more graded approach to introducing new ideas for patients whose understanding of dementia may be very different from the issues health professionals wish to discuss.

Furthermore, in chronic conditions other than dementia, providing people with written information about their condition based on IR domains has been shown to help them to develop an increased understanding of their condition, improving the coherence of their IRs (van Ittersum, van Wilgen, Groothoff, & van der Schans, 2011; Vollmann, Kalkouskaya, Langguth, & Scharloo, 2012). However, van Ittersum et al. (2011) found that people's coherence of their IRs only improved after receiving information when they felt the information they were provided with was relevant. Also, applying the findings of the current study to help meet the information needs of people with dementia is important as Miranda-Castillo et al. (2013) were concerned that people with dementia expressed a need for more information which was not being met by clinical services, and highlighted that "a better provision of information might help people appraise their needs more accurately and help them to cope with the dementia in a more adaptive way" (Miranda-Castillo et al., 2013, p. 8).

In addition, Clare (2002) has noted that, in dementia, a reduced awareness of the condition may be related to a lack of personally relevant information rather than psychological or neurological causes and suggests that sensitively providing appropriate information to people with dementia may therefore help them to further develop their awareness of their condition.

The following recommendations are provided in the hope that they may help professionals identify appropriate and personally relevant information to be given to individuals with early-stage dementia with whom they are working which may, in turn, help the individual to increase their understanding of their dementia in ways that are important or meaningful to them.

- People with early-stage dementia are able to identify and describe aspects of their condition which they would like to know more about and aspects where they feel they have a sufficient understanding.
- Without prompting, people with early-stage dementia are less likely to talk about what they wish to know more about, or why they want to know more about some things but not others.
- Asking people with early-stage dementia whether they feel they know enough about each of the areas encompassed by the concept of illness representations may help professionals to identify particular aspects of dementia which a person wishes to be better informed about, or which they have reasons for not wishing to know more about.
- The following prompts may be helpful for exploring such areas:
  - Is there anything in particular that's unclear to you about ... ?
  - Is there anything about ... that you don't feel you know enough about?
- If people's experience of having dementia does not tally with their expectations and beliefs, they may be liable to become upset or strongly frustrated by this.
  - Prompts such as "Is there anything that doesn't make sense to you about ... that makes you feel particularly upset or frustrated?" may be helpful when exploring whether this is the case.
- There is a need to regularly enquire about what people with dementia feel they would like to know about their condition as what people want to know is likely to change

over time depending on their current experience of symptoms and the current impact of dementia on their day-to-day lives.

- Professionals working with people with early-stage dementia should be aware that questions which are intended to enquire about what someone knows about managing the day-to-day impact of dementia might be interpreted as asking if anything can be done to completely cure dementia.
- If people say that they feel they know enough about certain areas of their dementia it is important to clarify what they mean by this as some people may want more information but believe that there is no point in asking because no one would be able to provide an answer.
- It is important to be aware that some people with early-stage dementia may actively choose to limit the amount of information they find out about particular areas of their dementia. Marzanski (2000) highlights that people with dementia, irrespective of their level of impairment, ought to be asked whether they want more information about their dementia and their preference respected. Therefore, in order to respect their wishes, it is important for professionals not to presume that all people with dementia will be happy to receive information about all areas of their condition.
- The current study observed that managing other health conditions could have an impact on how people manage their dementia, therefore professionals should enquire about other health conditions that people with dementia may have.

The current study highlighted that the way people with dementia think about their condition may still be heavily informed by a biomedical perspective. However, many of the concerns participants talked about were psychosocial in nature and could not be addressed by medical intervention, for example how to find an acceptable way to talk to their friends about having dementia. It has been the author's experience that memory services sometimes offer information about medication such as acetylcholinesterase inhibitors during or soon after diagnostic appointments but without emphasising the benefits of psychosocial intervention. Such an approach might reinforce the biomedical and physiological aspects of dementia over psychosocial aspects. Ensuring that people with early-stage dementia are informed of psychosocial methods for managing dementia soon after diagnosis, alongside discussion of medical interventions, could provide people with an opportunity to develop a more balanced view of the range of management options available.

During public consultation, the Alzheimer's Society research network suggested that findings from the current study might help to inform a 'frequently asked questions' (FAQ) style information leaflet. A study by Mosleh, Kiger, and Campbell (2009) has indicated that information leaflets can prove to be an economical and effective intervention if theoretically worded and based upon the CS-SRM. There were a number of areas which became apparent during analysis where either multiple participants indicated that they would like to know more about a particular issue or where uncertainty about a particular aspect or area of their dementia was distressing for several participants. In addition, participants talked about idiosyncratic information needs particular to each individual. In order to efficiently provide individually tailored information leaflets, template paragraphs could be constructed which provide accessible summaries of the areas which people with early-stage dementia commonly want to know about. It would then be possible to quickly adapt these for an individual's situation in combination with addressing idiosyncratic information needs. Incorporating clarification on the following issues into an information leaflet might be particularly beneficial as it may help some people with early-stage dementia to come to a more coherent understanding of these issues.

- Many participants wanted to know more about why they had developed Alzheimer's type dementia. Some expected to be able to identify a concrete and tangible cause, and were distressed because they could not identify one. It might be helpful to clarify that Alzheimer's is a name for one type of dementia, and highlight that while there has been some research on risk factors, that for the vast majority of cases, nobody knows exactly why some people develop Alzheimer's.
- A temporal gradient is often observed in Alzheimer's where older memories are easier to recall than more recent memories (Bright & Kopelman, 2004). Several participants in the current study reported finding it difficult to understand why this happened as it was contrary to their expectations. Therefore, an accessible description of why this can happen may be useful.

## **Conclusion**

The current study found that people with early-stage dementia were able to identify things about dementia which they did not understand. In addition, people with early-stage dementia were more likely to talk about what they did not understand if illness representations were used to inform the areas discussed. When prompted about the coherence of each illness

representation domain, participants were able to identify specific aspects of dementia they wanted to know more about. The types of information people wanted to know about can be divided into two categories: information about broad areas of dementia, such as possible causes, which multiple people with dementia wanted to know about and idiosyncratic information about particular aspects of their dementia which were pertinent to them. In spite of a greater emphasis on person-centred care for people with dementia, predominantly medical interpretations still heavily informed how people thought about their condition. However, people with this view also expressed the desire to know more about aspects of their dementia which could be addressed by psychosocial support. This shows that there is a need for professionals to provide tailored information about things which people with early-stage dementia want to know and sources of support which they are not aware might be beneficial. Therefore, enquiring about whether people have a coherent understanding of each area of their dementia could provide a mechanism for identifying the information required to meet these needs.

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## APPENDICES

**Appendix 1: Illness Representation Definitions used for Coding and a Transcript Excerpt**

*Examples in italics were added to help facilitate inter-rater coding*

**Identity**

- “Refers to the category, name or label, and the experience of **symptoms, changes in function, and visible signs**. The combination of abstract and concrete experiential features ‘defines’ or identifies the disease.” (Leventhal, Forster, et al., 2007, p. 352).

*Within the domain of identity, personal names and labels can include other words, terms or phrases people may use in place of dementia.*

**Cause**

- “Reflects the perception of the single or complex set of events perceived to be responsible for disease onset.” (Leventhal, Forster, et al., 2007, p. 352)
- “Causes of the threat, which may involve external agents (e.g., bacteria, viruses, job stress, or even bewitchment), internal susceptibilities (e.g., genetic factors), and behaviours.” (Leventhal et al., 2012, p. 7)

**Consequences**

- “Anticipated and experienced consequences of the disease” (Leventhal et al., 2012, p. 7)
- “Are the set of expected and perceived physical/functional, personal, and social and economic factors impacted by the illness.” (Leventhal, Forster, et al., 2007, p. 352)

*Consequences encompass how the symptoms of dementia affect someone. e.g. poorer memory for names would be a symptom but changing who you socialise with because you can't remember their name would be a consequence. A symptom might be forgetfulness but a possible consequence could be having too much stuff because they kept buying the same thing at the shops, thinking they did not think they had it. Consequences might also include things like stopping or reducing activities.*

### **Cure-Control**

- “Refers to the expectation that a specific disease can be cured or controlled by the body's own defences and/or in conjunction with expert intervention, and the actual experience of the effects of these interventions on specific features (symptoms and/or test results) of disease.” (Leventhal, Forster, et al., 2007, p. 352)
- “One component was concerned with personal control and self efficacy beliefs, whereas the other assessed belief in the treatment or recommended advice” (Moss-Morris et al., 2002, p. 2)

*This would include professional help, e.g. asking their doctor, and what their doctor tells them to do, including taking medication; help from others, e.g. things their partner, friends, or relatives may do to help their memory and things which they do themselves, including strategies such as use of lists.*

### **Timeline**

- “Timelines, including perceptions and beliefs respecting the onset, duration, and rate of decline with and/or without a home-based or medical intervention, as well as the time from disease onset to death when no treatment is possible” (Leventhal et al., 2012, p. 7)
- “Cyclical timeline beliefs.” (Moss-Morris et al., 2002, p. 2)

*Timeline would include any reference to how long they have had their dementia, how long they think it might last, whether they see it as chronic (always there) or acute (only there sometimes). Timeline would also encompass if they think their dementia will progress quickly or slowly.*

### **Emotional reaction**

- “Emotional reactions (fear, depression, anger, etc.) are elicited by the representation of the threat.” (Leventhal, Benyamini, et al., 2007, p. 353)

### **Coherence**

Instances where participants talked about understanding or not understanding particular aspects of dementia were coded within the domain of coherence. It is not that such instances of understanding or lack of understanding in themselves constitute coherence, but that these

may inform a broader interpretation regarding whether lack of understanding about particular aspects of dementia may lead to instances where someone's knowledge about elements of their IRs do not fit comfortably with each other in a way which makes sense to them as a whole.

- For the purpose of the current study, phrases, sentences or other meaningful units within a transcript will be coded to the IR domain of coherence when they suggest that:
  - A participant is indicating that there is something about a particular area of their IR (e.g. identity, cause, consequences, cure-control, timeline or emotional reaction) that they feel they do not know about or do not understand.

*e.g. when they just say they do not know without indicating that they want to know more.*

- A participant is expressing that their understanding of a particular area of their IR (e.g. identity, cause, consequences, cure-control, timeline or emotional reaction) is not as clear to them as they wish it to be.

*e.g. as well as being something they do not understand, indicating that they want to know more about a particular aspect or area of their dementia.*

- A participant is expressing that there is something within a particular area of their IR (e.g. identity, cause, consequences, cure-control, timeline or emotional reaction) that they feel they do not know enough about, or that remains unclear to them.

*e.g. as well as being something they do not understand, indicating that they want to know more about a particular aspect or area of their dementia.*

- A participant indicates that they are satisfied with their current knowledge regarding a particular area of their IR (e.g. identity, cause, consequences, cure-control, timeline or emotional reaction) or satisfied with what they know about a particular aspect of their dementia within a particular area of their IR.

*e.g. saying they do not feel they want or need to know any more about it just now*

This definition of coherence draws from the work of Moss-Morris et al. (2002, pp. 2, 4-5 & 13) but was adapted to fit the research aims of the current study in line with observations of French et al. (2006, p. 765).

Excerpt from coded transcript

**Researcher [20.30]**  
**And I guess I was also wondering how long do you think these changes to your memory might last; or how fast your memory might change at all?**

**Participant [20.40]**  
Well, I don't seem to thin--I think things have. Not in a rush or anything like that; changing rapidly, but, no, I don't, I don't think, I don't think, you know thinking about it, I think it's a gradual process and that. I put it all down to 'I'm 80 year old and I can't expect to be doing and thinking and ...' or should I be thinking along those lines? Should I be expecting to be the same as I was 20 years ago? I can't be, can I? So ...

**Researcher [21.14]**  
**Okay. Do you expect that your memory will change over time at all from now or ... ?**

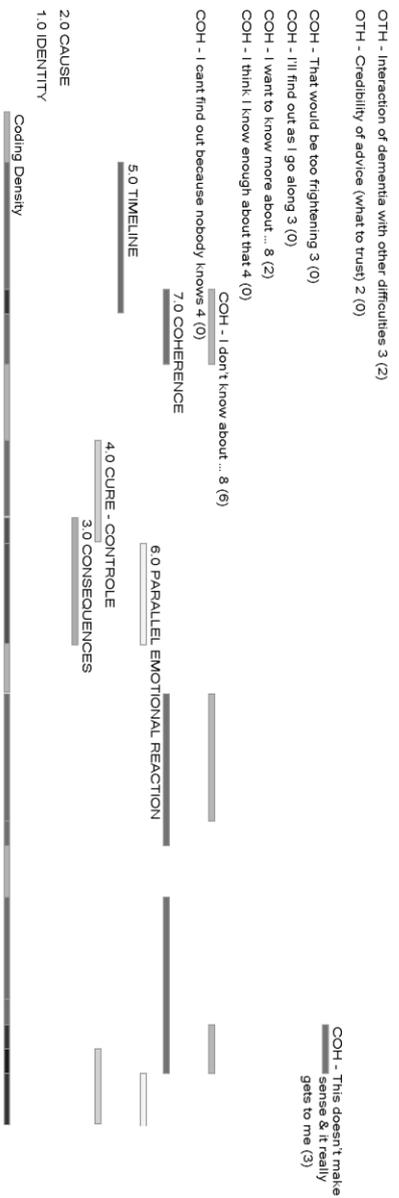
**Participant [21.21]**  
Well, I don't expect it to be improving a right lot! But er, I'm not ... I'm ... I'm all right in most things. I can ... *{partner}* might not agree with me here, but I can go to quizzes and things like that. They have quizzes in the ... apartments and that and er, we go to these quizzes and I look around me and I can hold me own with most of the people my age; and I know, know the answers to most of the things that they're asking but er, it's just ... I get a bit frustrated with other things

**Researcher [22.02]**  
**Okay then. And do you feel that these changes you've noticed to your memory, are they there all the time or ... ?**

**Participant [22.10]**  
Well, I don't really know that er, no, I think I can remember some things very well and other things I can't remember very well so ...

**Researcher [22.18]**  
**Okay. Can you tell me any more about that or ... so, what sort of things are trickier or easier to remember?**

**Participant [22.27]**  
Well I can remember things I did ages ago, and years ago, and this, that and the other; and then sometimes I can forget that that I've done last week, which ... I don't know whether I'm being right or wrong, but I put it all down to that I'm 80 year old and I can't expect to be like I'm 15 year old! So ... I mean you've got, I've got to accept these things. That's the way I look at it. That I can't expect to be the same as what I was years ago



Researcher [22.57]

Okay. And do you feel that you ...

Participant [23.00]

And sometimes it is a bit frustrating and I'll admit that

Researcher [23.04]

Yeah. I mean I think you said about being frustrated a few times. I just wondered in particular about how your memory might be changing over time. Does that raise any other emotions for you ... ?

Participant [23.17]

Well ...

Researcher [23.18]

... or feelings?

Participant [23.19]

... not really. I, you know it's ... sometimes when you forget things that you should know automatically it's ... I think it's enough to frustrate anybody really!

Researcher [23.31]

And is there anything about your memory that you feels unclear or puzzling to you just now, thinking about how it might change over time?

Participant [23.45]

No, not really. I'm just hoping it doesn't get a lot worse! But er ...

Researcher [23.48 ]

Okay. Do you feel you know enough about whether it might get worse or not?

Participant [23.55]

Er, not really, no, but, as I, I keep, I keep repeating myself with this – I just assume that as you get older you're gonna get worse. I assume that's a reasonable assumption to have, isn't it really?

Researcher [24.15]

Is there anything in particular about how your memory might change over time that's unclear to you, that you feel you'd like to know more about or ... ?

Participant [24.24]

Well, no. I think now ... I don't think it's anything. I don't think it's getting a lot worse now than what it, what it's been, I... I... and sometimes I can remember things just like that: years and years ago. And other times things that I probably should remember I'm tending to forget, you know it's ... and it's just a little bit frustrating at times but, as you say, I mean what the hell, you know it's ... nobody gets better as they're getting older, do they really?!

	OTH - Interaction of dementia with other difficulties 3 (2)
	OTH - Credibility of advice (what to trust) 2 (0)
	COH - That would be too frightening 3 (0)
	COH - I'll find out as I go along 3 (0)
	COH - I can't find out because nobody knows 4 (0)
6.0 PARALLEL EMOTIONAL REACTION	
4.0 CURE - CONTROL	
3.0 CONSEQUENCES	
2.0 CAUSE	
1.0 IDENTITY	
Coding Density	
	COH - This doesn't make sense & it really gets to me (3)
	COH - I think I know enough about that 4 (0)
	COH - I want to know more about ... 8 (2)
	COH - I don't know about ... 8 (6)
7.0 COHERENCE	
5.0 TIMELINE	

## Appendix 2: Ethical Approval Letters

the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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.reforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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
Covering Letter		23 August 2012
Evidence of insurance or indemnity		28 September 2011
GP/Consultant Information Sheets	1.0	29 August 2012
GP/Consultant Information Sheets	1.0	20 August 2012
GP/Consultant Information Sheets	1.0	
Interview Schedules/Topic Guides	1.0	20 August 2012
Investigator CV		20 August 2012
Other: CV- Dr Liz Glidewell- 1st Academic Supervisor		21 June 2012
Other: CV- Dr Gary Latchford- 2nd Academic Supervisor		22 June 2012
Other: Letter to Doctor Regarding Patient Participation	1	28 August 2012
Other: Information Letter About Trainee Clinical Psychology Research		01 January 2012
Other: Research Process Diagram	1.1	30 September 2012
Participant Consent Form	1.1	30 September 2012
Participant Information Sheet	1.1	30 September 2012
Protocol	1.0	20 August 2012
REC application		23 August 2012
Response to Request for Further Information		02 October 2012

### Statement of compliance

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

### After ethical review



## Health Research Authority

NRES Committee Yorkshire & The Humber - Bradford

Yorkshire & Humber REC Office  
Mill Pond Lane  
Millside  
Leeds  
Meanwood  
LS6 4RA

Telephone: 0113 3050128

15 October 2012

Mr Ewan McNeill  
University of Leeds

Dear Mr McNeill

### Study title:

Coherence of Illness Representations in early stage dementia: an exploratory study using the framework of Leventhal's Common Sense Self-Regulation Model  
12/YH/0432  
100464

REC reference:  
IRAS Project Number:

Thank you for your letter of 02 October 2012, 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

NHS 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).

Non-NHS sites

### 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

Reporting requirements

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
- Notification of serious breaches of the protocol
- 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.

Feedback

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.

Further information is available at National Research Ethics Service website > After Review

**12/YH/0432** **Please quote this number on all correspondence**

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

Yours sincerely



**Pp Dr Ian Woodlands**  
Chair

Email: nrescommittee.yorkandhumber-bradford@nhs.net

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Faculty Research Ethics and Governance Administrator  
Alison Thompson, Leeds and York Partnership NHS Foundation Trust

04 December 2012

Mr Ewan McNeill  
 University of Leeds

Dear Mr McNeill

**Study title:** Coherence of Illness Representations in early stage dementia: an exploratory study using the framework of Leventhal's Common Sense Self-Regulation Model  
**REC reference:** 12/YH/0432  
**Amendment number:** 03 December 2012  
**Amendment date:** 03 December 2012

Thank you for your letter of 03 December 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Protocol	1.1	03 December 2012
Notification of a Minor Amendment		03 December 2012

**Statement of compliance**

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

**12/YH/0432:** Please quote this number on all correspondence

Yours sincerely



**Linsey Anderson**  
 Assistant Committee Co-ordinator

E-mail: [nrescommittee.yorkandhumber-bradford@nhs.net](mailto:nrescommittee.yorkandhumber-bradford@nhs.net)

Copy to:

Alison Thompson, Leeds and York Partnership NHS Foundation Trust

12 February 2013

Mr Ewan McNeill  
 University of Leeds

Dear Mr McNeill

**Study title:** Coherence of Illness Representations in early stage dementia: an exploratory study using the framework of Leventhal's Common Sense Self-Regulation Model

**REC reference:** 12/YH/0432

**Amendment number:** 2

**Amendment date:** 06 February 2013

**IRAS project ID:** 100464

Thank you for your letter of 06 February 2013, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Protocol	1.2	18 January 2013
Notification of a Minor Amendment	2	06 February 2013

**Statement of compliance**

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

**12/YH/0432:** Please quote this number on all correspondence

Yours sincerely



**Linsey Anderson**  
 Assistant Committee Co-ordinator

E-mail: nrescommittee.yorkandhumber-sheffield@nhs.net

Copy to:

*Alison Thompson, Leeds and York Partnership NHS Foundation Trust*  
 Faculty Research Ethics and Governance Administrator

12 February 2013  
 Mr Ewan McNeill  
 University of Leeds

Dear Mr McNeill

**Study title:**

**Coherence of Illness Representations in early stage dementia: an exploratory study using the framework of Leventhal's Common Sense Self-Regulation Model**

**12YH/0432**

**3**

**06 February 2013**

**100464**

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**Documents received**

The documents received were as follows:

Document	Version	Date
Participant Consent Form	1.2	06 February 2013
Participant Information Sheet	1.2	06 February 2013
Protocol	1.3	06 February 2013
Notification of a Minor Amendment	3	06 February 2013

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

**12YH/0432: Please quote this number on all correspondence**

Yours sincerely



**Linsey Anderson**  
**Assistant Committee Co-ordinator**

E-mail: [nrescommittee.yorkandhumber-sheffield@nhs.net](mailto:nrescommittee.yorkandhumber-sheffield@nhs.net)

Copy to:

*Alison Thompson, Leeds and York Partnership NHS Foundation Trust*  
*Faculty Research Ethics and Governance Administrator*

## Appendix 3: Information Sheet for Health Care Professionals

'Making sense of memory changes' was used as a short title for study material so that participants were not primed with the term dementia

this study may be of use in the future in helping those supporting people with early stage dementia to provide information that is tailored to help people find out more about what they feel is important for them to know about their dementia.

### Possible Disadvantages

Patients taking part in the research will be asked to give some of their time. Professionals will also be asked to spend a little time identifying potential participants and handing out information packs as described above and in the attached flowchart. Some people may see this as a disadvantage. If patients are upset by anything during the research interview, it can be paused or stopped. My current programme of study has covered identifying and responding to distress within the context of my role as a researcher. After the interview, patients will be offered the opportunity to speak to Mary Page, a senior memory nurse from the Leeds memory service, if they have any questions about what support the memory clinic can offer for memory changes and all participants would be given a leaflet from the Patient Advice and Liaison Service who they could contact for more information about other services that are available.

### Confidentiality

All participant responses will be anonymised for use in the study report. With their consent, you will be provided with a copy of the signed consent form for inclusion in the medical records for all of your patients who chose to take part but their answers will remain confidential. However you would be informed if any risk of harm to self or others becomes apparent during the research interview.

### What will happen to the results of the research study?

The results of this study will be written up in a thesis as part of my training at the University of Leeds. I will also provide a summary report to the memory service and would be happy to come and present my findings. Results may also be published in an academic journal to share findings more widely.

In addition to the details above, the participant information sheet also explains to patients who are considering taking part that their research interview would be audio recorded with their consent, how this recording would be used, how any questions, concerns or complaints would be addressed, and offers them the opportunity to receive a summary of the results.

### What if I have more questions?

Please contact the researcher, Ewan McNeill, at the University of Leeds who will be happy to answer any questions you have about this study.

**E-mail:** ewan.mcneill@nhs.net

**Mobile number:**

**Thank you ever so much for your help with this study**



## Information Sheet for Health Care Professionals

*Research Study title: Making sense of memory changes*

This study is being carried out by Ewan McNeill, a research student from the University of Leeds. I am interested in recruiting older people with early stage dementia for this study which hopes to investigate the variety of individual ways in which they understand their dementia and what is puzzling to them about it. Study documentation for patients uses the term 'memory changes' as not all participants may be comfortable using the term 'dementia'. This study has been reviewed by Bradford Research Ethics Committee and given a favourable opinion.

I hope to recruit approximately 12 people with Alzheimer's or mixed dementia after they have been told their diagnosis of dementia when they next see their psychiatrist for a review appointment, to understand how people make sense of their dementia at this time.

### What help is being asked from professionals?

- To hand out an information sheet to people who meet the criteria in the attached flowchart
- Log some background details about these people while using the flowchart  
(so anonymous contextual information about those approached can be passed to the researcher)
- To let people know that their usual care will not be affected and they do not have to participate

### What will happen to patients who choose to take part?

Patients who take part will complete a research interview of approximately 1 hour where they will be asked to talk about how they view their memory changes. The interview will be informed by the concept of Illness Representations. An Illness Representation provides an outline of how someone understands a threat to their health at a particular point in time; this covers various aspects they are likely to think about in relation to their health threat, including its consequences and perceived cause. I will arrange a convenient time to visit participants at home to complete the interview. They can ask to withdraw at any time during the interview or ask for their answers to be removed for up to two weeks after the interview.

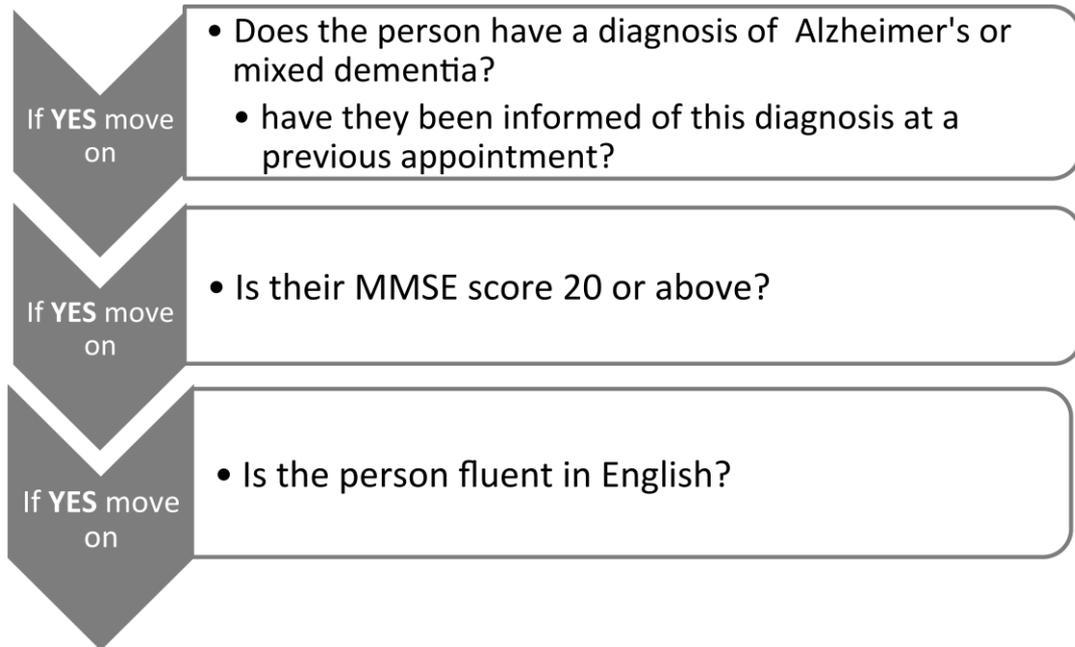
### Potential Benefits

Talking with the researcher may be of interest as it could give people space to consider the experiences and values they draw on when trying to make sense of memory changes. Findings from

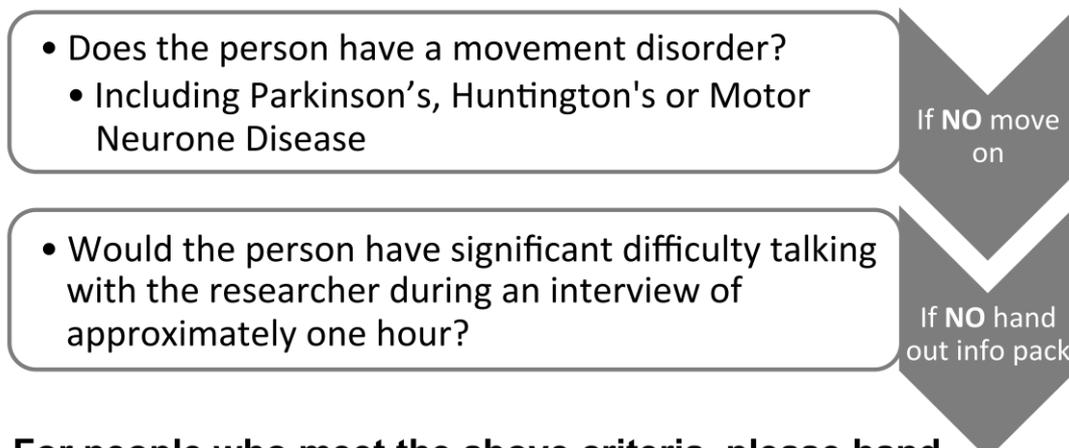
## Appendix 4: Research Process Diagram

*Making sense of memory changes***Process diagram for identification of potential participants**

*If you can answer **YES** look to the next box,  
If **NO** then the person is not appropriate to the study*



*If you can answer **NO** look to the next box,  
If **YES** then the person is not appropriate to the study*



**For people who meet the above criteria, please hand out information pack for 'Making sense of memory changes' study and complete background details table.**

Appendix 5: Background Details Table

**Background details for patients approached**

Pack No.	Date pack given	MMSE Score (20 or above)	Diagnosed type of dementia (Alzheimer's or mixed)	Name of medication for dementia	Age (65 & up)	Name and Date of birth
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						

 Please remove shaded column with name and date of birth when giving a copy of this form to the researcher

## Appendix 6: Participant Information Sheet

### Participant Information Sheet

Research Study title: **Making sense of memory changes**

You are invited to take part in this research study. Reading this sheet before you decide will tell you why the research is being done and what would be asked of you. The researcher will go through the sheet with you and answer any questions. Talk to others about the study if you wish.

- **Part 1** tells you the reason for this study and what would be asked of you.
- **Part 2** provides more detail about the conduct of the study. Please ask if anything is not clear.

#### Part 1

##### What is the purpose of this study?

This study is being conducted to find out about how people make sense of changes to their memory and whether any aspects of memory changes they have experienced are puzzling to them. Your answers could be helpful as not much is known about how people like you view memory changes.

##### Why have I been invited?

We are asking approximately 12 people who have been to the memory clinic to take part in this study. We are interested in talking to people to find more about the variety of individual ways in which they understand changes to their memory.

##### Do I have to take part?

No, it is entirely up to you if you want to take part. If you decide to take part and then want to withdraw from the study you can do this at any point while meeting with the researcher, or you can ask for your answers not to be used in the study for up to two weeks after meeting with the researcher and you do not have to give a reason. If you choose not to take part, or choose to withdraw, the standard of your care or treatment will not be affected. If you choose to take part, you will be asked to sign a consent form.

##### What will happen if I choose to take part?

You will be asked to take part in an interview at your home; this is a conversation where the researcher would meet with you and ask you to talk about how you view your memory changes, lasting approximately one hour. Some people may find it easier if only you and the researcher are present during this interview as having someone else in the room during the interview might affect what you choose to say. But for other people having a relative or friend present can help them feel more comfortable so this would also be okay. As we are particularly interested in your views about memory changes, anyone else present during the interview would be asked just to observe and not to answer any questions. With your consent, an audio recording of this interview will be taken. A typed copy of this recording will then be made for use during this research; your name and any other details which could be used to identify you will be removed so that what you say remains confidential. Your doctor from the memory clinic will provide the researcher with some basic background details about you, which will be recorded in an anonymous form and used to describe the range of people who take part. If you wish, you can receive a summary of the report from this study.

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##### What will I have to do?

When you have read this information sheet, if you would like to take part in the study or have any questions, please return the reply slip at the end of this form or contact the researcher by telephone. The researcher will then contact you to answer any questions and if you wish to take part arrange a convenient time to visit you at your home. This visit would involve an interview with the researcher about memory changes. After the interview, you could speak to Mary Page, a memory nurse from the Leeds memory service who can tell you about what the memory clinic can offer to support memory changes (Tel: 0113 295 2489). You would also be given a leaflet from the Patient Advice and Liaison Service who you could contact for more information about other services that are available.

##### Are there benefits or disadvantages to taking part?

###### Benefits

Talking with the researcher about any changes you have noticed to your memory may be of interest as it could give you space to consider the experiences and values you draw on when trying to make sense of these changes. Taking part in this study may result in you having new questions about any memory changes. It may also be of interest to find out how a range of other people with similar memory changes make sense of these changes through a summary of study findings that will be offered to everyone who takes part. Although not a direct benefit to you, this study may allow us to learn more about how people view their memory changes which could help people like you to be supported in the future.

###### Disadvantages

You will be asked to give some of your time which some people may see as a disadvantage. If you are upset by anything during the research interview you can ask for it to be paused or stopped. If you have any questions or concerns please contact the researcher, details below.

##### What happens when the research study stops?

Taking part in the research interview will not affect your care which will continue as normal after this study.

##### Will my answers be kept confidential?

**Yes.** Everything you talk about will remain confidential and care will be taken to remove anything that could identify you. Your name will not be used anywhere in the study and a number will be used to refer to each person so that your answers are anonymous. With your consent, your memory clinic doctor will be told you are taking part but not your answers, unless the researcher is concerned about your safety or another person's safety. Your information will be held securely at the University of Leeds. After a report for this study has been written, all extra information will be kept securely for 3 years and then destroyed. This is standard practice for this sort of study.

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## **Part 2**

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

If you don't want to carry on with this study during the interview, the interview will be stopped, and if you wish, your answers to the interview questions so far will not be included in this study. You can let us know up to two weeks after the interview if you don't want some or any of your answers used and these will be removed from the study.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do his best to answer your questions (details below). If you remain unhappy and wish to complain formally through the University complaints procedures you can do this by contacting Clare Skinner, Faculty Head of Research Support, Faculty of Medicine and Health Research Office, Room 10.110, Level 10, Worsley Building, University of Leeds, Clarendon Road, Leeds, LS2 9NL, Telephone: 0113 343 4897.

### **Involvement of the General Practitioner/Family doctor (GP)**

Your GP will not be informed about you taking part in this research. With your consent the doctor that you see from the memory clinic will be told that you are taking part in this study, but they won't be told about any of the things you talk about with the researcher.

### **What will happen to the results of the research study?**

The results of this study will be written up in a thesis as part of the researcher's training at the University of Leeds. Results may also be published in an academic journal to share findings more widely. This will help make other people who provide support for people who experience memory changes aware of the variety of individual ways in which people try and make sense of changes to their memory. Findings of this study will also be given to the memory clinic and may aid them in planning how services are offered in the future. You will not be identified in any report or publication. We can send you some information on the results of this study. Please let us know by ticking the relevant box on the consent form.

### **Who has reviewed the study?**

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

**If you choose to take part in this study, you will be given a copy of this information sheet and a signed consent form to keep.**

### **What if I have more questions?**

This study is being carried out by Ewan McNeill, a postgraduate research student at the University of Leeds who will be happy to answer any questions you have about this study.

**Telephone number:** 0113 343 0815 **E-mail:** [umerwrm@leeds.ac.uk](mailto:umerwrm@leeds.ac.uk)

**Address:** Ewan McNeill  
Room G04  
Leeds Institute of Health Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Woodhouse  
Leeds  
LS2 9LJ

The national advisory group for public involvement in NHS research (INVOLVE) can be contacted by telephone on 0238 065 1088 for independent generic advice on choosing whether to participate in research.

**If you would like to take part, or find out more about this study please return the reply slip on the next page, or contact Ewan McNeill on 0113 343 0815**

*We will send you a reminder letter if we have not heard from you after 2 weeks*

**Reply slip**

**If you would like to take part, or find out more about this study please return this slip using the enclosed Freepost envelope.**

*I have read the above information sheet and am happy to be contacted about this study*

**PLEASE COMPLETE IN BLOCK CAPITALS**

Name: \_\_\_\_\_

Contact telephone number: \_\_\_\_\_

**Appendix 7: Participant Consent Form**

Participant Identification Number:

**CONSENT FORM****Research Study title:** Making sense of memory changes**Name of Researcher:** Mr Ewan McNeill**Please PUT YOUR INITIALS in each of the boxes if you agree to these statements**

1. I confirm that I have read and understood the information sheet dated 06/02/2013 (version 1.2) for this study. I have been able to consider this information, ask questions and have had these answered satisfactorily.
2. I understand that I do not have to take part or answer questions that I do not wish to, that I can withdraw at any time without giving a reason and my care will not be affected.
3. I understand that my answers will remain confidential, and that my name and any details which could be used to identify me will be removed from all information and study reports.
4. I agree to take part in the above study.
5. I consent to an audio recording of the interview being made for this study
6. I consent to the use of brief anonymous interview quotes to help illustrate study results
7. I consent to my doctor at the memory clinic being informed of my participation in the study, with a copy of this consent form to be kept in my medical notes.
8. I give permission for staff from the University of Leeds, the NHS Trust or regulatory authorities to look at some of my data relevant to this research to check whether the study has been conducted appropriately.

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Name of researcher Ewan McNeill \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

*To be dated and signed with researcher and participant present.*If you have agreed to take part please tick **one** of these boxes to let us know if you wish to receive a summary of results of this study.

- I would like a summary of the results of this study.
- I would not like to receive summary of the results of this study.

*When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes*

## Appendix 8: Interview Topic Guide

### “Making sense of memory changes” - Study topic guide

..... = personal terms for their memory changes

**Initial open questions** - *You've been to the memory clinic at (name of clinic), is that right?*

- Ask their thoughts about any changes to their memory & what lead them to go to the memory clinic
  - What changes they may have noticed to their memory
  - Their views about any changes to their memory,
    - what they say they know about these changes
  - How they think going to this clinic / memory changes has affected their life

#### **First topic area**

**Establish identity terminology** - *Clarify how they refer to their memory changes*

- Their description for their memory changes in their own words
  - terms & labels used by each individual

**Other topic areas to explore.** *The order may vary if some areas are first raised by participants*

**Identity** - *How they think their ..... displays itself*

- signs which they understand to be linked to their memory changes
  - how they experience these changes

**Cause** - *what they think started their .....*

- Event, set of events or factors that they see as responsible for starting their .....
  - things outside their control & things that they have done or could have done

**Consequences** - *what they think is influenced by their .....*

- how they think their ..... currently affects them
- what they expect to be different because of *their .....in the future*

**Curability / Control** - *what they think can be done about their .....*

- whether they think their ..... can be reversed
- what they think they can do to manage the effects of their .....
- what they think other people can do to help manage the effects of their .....
  - *Whether they think help they have had to manage the effects of their ..... has made a difference*

**Timeline** - *how long they think ..... will last and how fast it will change*

- do they think they have ..... all the time
- how long they think ..... will last
- if they think their ..... changes over time
  - how quickly they think their ..... has changed / may change in the future
    - *with & without doing things to try and manage their .....*

**Constructs / topic areas to be explored in parallel with other topic areas**

**XXX** = current aspect of construct being discussed

**Emotional reaction** - how their ..... *makes them feel*

- what emotions may be raised for them by [XXX]

**Coherence Prompts** - whether people feel they do/don't understand enough about .....

- do you feel you have a clear understanding of [XXX]?
- is there anything about [XXX] that's unclear or puzzling to you?
  - what in particular about [XXX] is still puzzling / unclear for you?
- is there anything about [XXX] that you don't feel you know enough about?

**General prompts**

**Clarification**

- can I just check what you mean by [*participants comment*]
- what does [*participants comment*] mean for you

**Depth / refocus**

- do you have an example of [*participants comment*]
- we've been talking about [*current construct*] can I just ask if there's anything else

**Elaborate / broaden focus**

- are there any other [*question about alternative views*]
- is there anything else that [*question about alternative views*]
- how come you see things like that

**Appendix 9: Patient Participation Letter**

**UNIVERSITY OF LEEDS**  
**FACULTY OF MEDICINE AND HEALTH**

Programme in Clinical Psychology  
Leeds Institute of Health Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Woodhouse  
Leeds  
LS2 9LJ

*Dr. Name*  
*Address of memory clinic*

**Research Study title:** Making sense of memory changes

Dear *Dr. Name*

I am writing to inform you that the following patient has taken part in the making sense of memory changes research study. This involved completing a research interview of approximately 1 hour where they were asked to talk about how they view their memory changes. It is hoped that their participation will help us find out more about the variety of individual ways in which people with early stage dementia understand their condition. A summary report for the Memory Service will be made available following completion of this study.

*Name of patient* \_\_\_\_\_

Yours Sincerely

Ewan McNeill  
*Psychologist in Clinical Training*  
*University of Leeds*