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The Impact of Information on Illness

Representations and Coping in Early Dementia

from the Perspective of the Person with Dementia-

A Phenomenological Approach

Guy Harman

D.Clin.Psy

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ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

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Abstract

The onset of chronic illness often leads to threats to perceptions of self identity and challenges to prior ways of living. The self-regulation model of illness behaviour of Leventhal, Nerenz & Steele (1984) has provided a framework for understanding how people may manage these threats to self. To date this has been applied predominantly to physical illnesses and a few chronic neurological illnesses including Motor Neurone Disease. Whilst there have been several studies which have looked at the experience of people with early dementia, none has used the self-regulation model as a framework. A semi-structured interview methodology was used to explore the following questions.

1. What representations do people with early-stage dementia have following diagnosis?

2. How do people's representations relate to the experience of early-stage dementia and how they manage it?

3. What are the implications for theory from what people tell us about their experience?

Interpretative Phenomenological Analysis (IPA) was used to analyse the data from the interview transcripts. This approach attempts to understand people's beliefs about a given topic through the assumption that there is an indirect link between what people report and underlying cognitions. IPA is a phenomenological approach in that it is concerned with individual subjective accounts and beliefs about objects or events and interpretive in that these accounts are elicited through a dynamic process in which the researcher's own beliefs play a part as they interpret data.

Two overarching themes emerged from the analysis. These themes are 'Understanding Dementia: It Will Get Worse', which represents the individual's knowledge and representations of dementia, and 'I Want To Be Me', which represents the lived experience of adapting to dementia. The first of these themes is constructed from a number of sub-themes. 'I Want To Be Me' has two components of 'Personal Dilemmas: Where Do I Stand' and 'Interpersonal Dilemmas: The Line Is Crossed', each of which is also constructed of further sub-themes.

The results were discussed in relation to each of the research questions in turn. It was then considered how the results add to the understanding of the experience of early dementia. A tentative model of how illness representations contribute to the lived experience is suggested. Areas for future research in the field that emerged from the study were discussed including the potential of exploring and comparing the representations of different groups of people. Possible methodological limitations of the study were explored in the context of the implications these may have had for the wider applicability of the results and how the researcher's assumptions and experience may have influenced the outcome of the study. Finally, implications for clinical practice arising from the study were discussed. These included the need to recognise the importance of directly involving people with dementia in the diagnosis sharing process, if they so choose and how people with early stage-dementia may be helped in maintaining their sense-of-self whilst adjusting to dementia related changes.

Acknowledgements

Introduction

Overview

This phenomenological study will investigate how people describe the perceptions that they hold of dementia after diagnosis, and will explore the impact that the information they receive has on their understanding of their difficulties and how they cope with them. The study will use the self-regulation model (Leventhal et al., 1984) as a framework for exploring representation formation and the impact that information received at diagnosis has on this process. This area is considered to be of importance in adding to the currently limited literature related to how people with early-stage dementia construct an understanding of their experience. It is hoped that the findings will help to inform clinical practice in helping people to understand their difficulties and address some of the issues related to how to share information and diagnoses with people with early-stage dementia. This introductory chapter will begin with an examination of how chronic illnesses, including dementia, can be regarded as a threat to a person's sense-of-self. It will then review the self-regulation model (SRM) and its development. Subsequent sections will discuss the relevant areas of the dementia literature that relate to the components of the SRM. The chapter will conclude with a discussion of the aims of the current study.

Illness as a Threat to Self

Illness is often defined in terms of personal experience, contrasting with the concept of disease as a bodily disorder which reflects an agreed-upon set of symptoms (Charmaz, 2000). This differentiates the perspectives of individuals from the disease model perspective of practitioners which dominates medicine and social scientific research (Mischler, 1994). Charmaz (2000) suggests that developing our

understanding of people's experience of illness can help to further our knowledge at three levels: individual assumptions and attitudes about health and illness; the interaction between the individual and the health care system; and health policy and institutional provision.

The experiences of people with chronic illness differ from those with acute illness primarily because chronic illness lasts longer and therefore poses more difficulties for the individual in terms of, for example, social and existential problems. However, notions of acute illness have been found to pervade how society understands and reacts to chronic illness. This stems mainly from the idea of the 'sick role' (Parsons, 1964), which assumes that recovery will take place, patients are passive in this process, and active physicians decide a regimen of treatment based upon scientifically-derived diagnostic criteria. This role temporarily exempts the 'sick person' from the responsibilities of adult life, instead obliging them to seek medical help and comply with any treatment offered by the physician. However, this model of the experience of illness was found not to explain how individuals with chronic illness manage their lives. For example, Roth (1963) studied the experience of individuals in a tuberculosis hospital and found that rather than passively accepting treatments offered, patients actively negotiated their roles. Roth described being ill as being akin to a career with direction, goals and turning points.

Chronic illness has a significant impact upon the previous continuity of an individual's life as they have to make sense of developing symptoms, attempt to reconstruct order and maintain control over life (Charmaz, 2000). These threats posed by chronic illness are not only related to physical symptoms, acceptance and care, but also challenge meanings of self and identity. Taken-for-granted ways of understanding self, ways of living and sources of personal meaning are challenged,

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and life becomes uncertain. The vulnerability of self is also derived from potential devaluation and disapproval by society, which Charmaz (2000) describes as 'the moral cast' of continuing illness. Others (Das, 1994; Kleinman, 1994; Williams, 1993) describe how these moral meanings of chronic illness are developed through people's interactions in their social contact with, among others, friends, family and health care professionals.

People learn about their illness through day-to-day experience. Practically, this is the result of recognising changes in performance on everyday tasks while functioning as the person with a chronic illness compared to the old, healthy self. There are also cultural, historical and social contexts within which discovering about illness occurs, so that the chronically-ill individual learns to take on the role that society expects (Waxler, 1981, as cited in Charmaz, 2000). One way in which people manage the threat and disruption of chronic illness is to normalise the changes to life in order to render them routine. This adaptation may involve accepting changes and adapting perspectives to suit, or alternatively, struggling on and attempting to, as much as possible, maintain pre-illness life. Management strategies may range from innovation in finding ways to adapt, through to withdrawal. There is also an element of social negotiation in balancing the development of desired levels of social support with maintaining existing relationships. For some this may become problematic when expectations of support exceed those available within existing relationships. Finally, management of chronic illness by the individual is not limited to the physical, practical and social domains, but includes the emotional impact of the threat of chronic illness, which may fluctuate with changing threat and successful management (Charmaz, 2000).

The work of Charmaz (2000) and others provides an outline for understanding the experience of people facing the threat of chronic illness and how this is dependent on the social context in which the illness is experienced. However, whilst this work provides an explanation it lacks a framework in which to understand everyday experience.

One illness that has been conceptualised as a threat-to-self is early-stage dementia (Pearce, Clare, & Pistrang, 2002; Clare, 2003). The literature indicating how the experience of early-stage dementia has been explored to date will be reviewed later in this chapter. Prior to this, the self-regulation model will be reviewed as a framework of how people make sense of and manage the threat-to-self that is posed by the experience of illness.

The Self-Regulation Model

The Self-Regulation Model (SRM) aims to explain how people interpret and manage threats to self through the onset of illness or disability. It was developed from the drive reduction model of Dollard and Miller (1950) which suggested that if behaviour planned to reduce the fear of health threats did not actually reduce the fear, then active denial would be employed to reduce fear with the threat remaining intact. Later studies (Leventhal & Niles, 1965; Leventhal & Watts, 1966) found, to the contrary, that fear produced by health threats had some effect upon attitudinal and behavioural change, but these effects were short-lived.

Studies of how long-lasting behavioural and attitudinal change occurred (Leventhal, Singer, & Jones, 1965; Leventhal, Watts, & Pagano, 1967) indicated that if threat messages were coupled with an identified action plan, then more durable change would occur. However, the findings also suggest that an action plan requires

the presence of fear, via the threat message, for it to be carried through, but changes in behaviour and attitude were found to outlast the fear associated with the threat. It was therefore proposed that there is another underlying mechanism that was termed the cognitive representation of a health threat. This gave rise to the Parallel Response Model (Leventhal, 1970), which delineates the response to the emotional component of threats to health (fear) and the processing of cognitive representations, and also separates the illness representation from the plan to cope with the threat. Figure 1 illustrates this model. In addition to the links between fear, attitudinal and behavioural change and cognitive representations, Johnson and Leventhal (1974) have indicated the need for clear, concrete information in coping with illness threat, demonstrating that this enabled individuals to reduce levels of anxiety and develop clearer representations and action plans.

Figure 1: The Parallel Response Model (Leventhal, 1970)
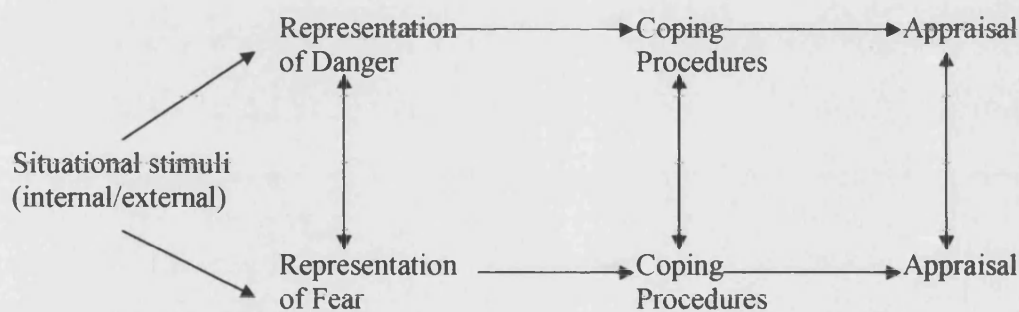
Leventhal, Meyer, and Nerenz (1980) described what they called 'common-sense representations of illness danger'. They propose a framework in which people regulate illness behaviour that is based on empirical evidence from many related studies. Firstly, in a similar way to Roth (1963), they propose that people are active participants in their medical treatment. They take in and interpret information and

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use this to cope with difficulties as they arise. There is a symmetrical relationship between symptoms and illness, where people use symptoms or body states to define labels, and conversely, people will search for symptoms and sensations to represent an illness label. Using concrete symptoms to represent illness is seen as advantageous to individuals, as they provide an available cue that can be experienced immediately without the need for any complex measuring device, and give feedback about the progress of health threats that is both instantaneous and continuous.

Leventhal et al. (1980) suggest that individual theories of illness are based on three basic sources of information available to individuals. These are bodily experiences, information and interactions with the social environment (including health professionals, carers, family, and media) and past experiences of illness. They propose that initial representations are based mainly on semantic factors. They use the example of people who are told that they are hypertensive often reporting it to mean that they are 'emotionally tense' as opposed to having high blood pressure, resulting in a possible focus on physical tension as an indicator of disease. However, as more information is gathered by the individual, such as them having high blood pressure when they are not particularly tense, then there is a shift towards other symptoms as an explanation of illness. It is also suggested that people understand their illness in terms of three different models. These are an acute model of sudden onset of symptoms that will subside after an appropriate short period of time, a cyclical model where symptoms repeatedly come and go over time, and a chronic model where there is often no simple explanation to the symptoms and there is a "susceptibility" to the problem, with symptoms being expected to last.

The formation of representations provides a guide to coping. Representing illnesses as available, tangible symptoms allows for the ongoing formation and

evaluation of targeted coping mechanisms. More concrete representations are reported to provide more specific goals for action, which in turn provide a clear indicator of the effectiveness, or not, of coping strategies. Conversely, those that are more abstract and remote are seen to generate uncertainty and distress.

Representations are also seen as being used by individuals to regulate treatment. Leventhal et al. (1980) reported how symptoms were used as cues to re-enter treatment, indicating a need for further intervention. They were also used to regulate medication taking, in that those people who saw treatment as ameliorating symptoms were more likely to take medication as prescribed, while those who reported little or no effect on symptoms were less likely to be engaged in treatment or to adapt a prescribed treatment themselves to fit with their representation.

Leventhal and colleagues also suggest that representations lend themselves to the construction of strategies for managing illness threats which are additional to more formal interventions. They give the example of individuals with cancer who have a mechanical understanding of their illness in terms of, for example, bad cells. It is reported how these people may engage in management or coping strategies such as intensive exercise or adapting diet, which strengthen the body against the illness threat. In this way, representations provide a focus for individuals to develop self-regulating behaviours that may increase self-determination and control over emotional experiences and quality of life.

Finally, Leventhal et al. (1980) describe how the effects of treatment can have an impact upon representations. They describe how people can often adapt to even the most noxious side effects, for example those related to chemotherapy used in the treatment of cancer, using representations of side-effects and their change to develop emotional and practical coping strategies. However, when the effects of

treatment are represented as being unpredictable (e.g. lacking a regular pattern), vague, or uncontrollable, then they can result in difficulties in forming coping strategies and lead to increased distress.

Since this framework of illness representations was first described, there has been a great deal of work in refining the understanding of exactly what is involved in their formation. Leventhal et al. (1997) summarise the dynamics and content of representations. In terms of dynamics they describe how representations have a 'bi-level' coding, in that there are concrete, perceptual codes which represent the experience of symptoms, and more abstract, linguistic codes which are symptom labels used to describe health threats. These levels are linked, with perceptual events leading to a need for a linguistic 'label', and labels generating the search for confirmatory perceptual events. Regarding the content, or attributes, of illness representations, Leventhal et al. (1997) report that this can be summarised, to date, in terms of five elements. These are disease identity (symptoms and label), time line (time to develop and duration, i.e. chronic, acute or cyclical), consequences of the health threat, causes and controllability. These attributes may form an explicit representation of illness threat, in that they are reported by individuals, or implicit, identified by inference from an individual's behaviour.

Leventhal and colleagues incorporated the work on illness representations and the earlier 'Parallel Response Model' (Leventhal, 1970) to produce the 'Self-Regulation Model' of illness behaviour (Leventhal et al., 1984; see figure 2, below). At the early, 'pre-attentive' stages, individuals are receiving messages from symptoms and social messages. The latter, as described above, include information from the media, health professionals, and friends and relatives. The information from

Figure 2: Self-Regulation Model (Leventhal et al., 1984)

Feedback Loop

Representation of illness in conscious awareness

Coping with objective features of illness

Evaluation of objective impact

Pre-attentive Stages

Perception	Integration of Perceptions with memory	Awareness	Coping		Evaluation of coping
			Planning of response	Executing of responses	

Emotional reactions to illness

Coping with emotional reaction

Evaluation of change in distress

Feedback Loop

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initial perceptions is then compared with and integrated into the individual's existing models and ideas of health threats based on personal past experiences and interactions with health systems and others. A current health threat is a threat to the individual's homeostasis, both physically and psychologically, in that it threatens emotional well-being and sense-of-self. The typical response, according to problem-solving theory, is for people to be motivated to re-establish the status quo through the assignment of meaning to the problem and the formation of problem solving and coping strategies (Ogden, 1996). In the SRM this involves two parallel processes. The first of these is the formation of the illness representation, from perceptual, symptomatic information and social messages, constructed along to the five attributes discussed above of identity, time-line, consequences, causes and controllability.

The representation provides the goals which, if achieved, would be an indicator of management of the threat. From these goals individuals develop and execute procedures to manage the illness threat. At a very basic level this may be either approach coping or avoidance coping. Following the execution of management strategies, a process of evaluation takes place, where individuals appraise how coping strategies may have brought them closer to, or taken them further from, the goals specified by the representation. Information from appraisal is fed back into the process of representation formation and coping, and has the effect of maintaining existing representations, goals and strategies, or alternatively, leading to a process of adaptation, depending on the perceived effectiveness of current representations, goals and strategies. The second process is the parallel processing of emotional reactions to the health threat. This involves the formation of an emotional response, such as, for example, fear or anxiety, and the development of a coping plan for the management

of emotion. Just as in the illness representation process, an appraisal and feedback process is in operation, whereby emotional reactions and coping are maintained or adapted depending on the perceived effectiveness of current coping. The two processes do not operate discretely; rather they interact as the individual adapts to health threats and the changes that may take place as this adaptation evolves. Finally, self-regulation is hierarchically organised, operating at both concrete and abstract levels, whereby, for example, when coping with back pain, representations, coping and appraisal are influenced by the concrete features of processing the pain, and also by abstract features such as thinking that a nerve has become trapped. Leventhal et al. (1984) describe how studies have shown that discrepancies can arise between abstract and concrete levels, where abstract information, such as medical reports that one's condition is measurably improving, does not tally with concrete perceptions, such as feeling worse. It is suggested that this reflects the difference between abstract-information-driven 'problem-focused' representations and coping, and concrete-experience-driven emotional responses and 'emotion-focused' coping.

The main aim of the process described by the Leventhal et al model is the regulation of self following the perception of a health threat in a drive to maintain the 'healthy', pre-threat status quo. The process of self-regulation involves the interaction of the three main processes, described above, of representation formation, coping and evaluation in an ongoing dynamic fashion. Concrete symptom perception may influence emotional reactions, possibly increasing anxiety and heightening the intensity and frequency of symptoms experienced. Alternatively, abstract labels applied by others may also increase symptom perception. Both of these may promote goals for symptom reduction in an attempt to regulate the self. Denial as a coping strategy may lead to a reduction in symptom perception, which in turn may lead to

less fear and anxiety as an emotional response. This could lead to a change in the illness representation, as having less severe consequences and possibly being shorter in duration. Evaluation of such a coping mechanism as being successful may change the controllability aspect of representations, and may lead to its continuation as a way of managing the threat and maintaining self. It must be noted here that with conditions involving cognitive impairment or brain damage, for example dementia, some kinds of stroke, and some types of head injury, neurologically based unawareness (anosognosia) may have an impact upon the process of representation formation, coping, and evaluation.

The SRM has some advantages over other models that have been developed to try to understand health related behaviour. Its advantage over The Theory of Planned Behaviour (TPB; Ajzen, 1985) is that, unlike the TPB, it includes constructs of cognitive and emotional representations of the disease threat. Neither does the TPB include a temporal element, as does the SRM with its feedback loop.

In comparison to the Health Belief Model (HBM; Rosenstock, 1966, as cited in Ogden, 1996), the SRM has the advantage that it includes an emotional component to the illness experience. The HBM can also be said to be rather simplistic in that its focus is on the rational processing of information, or weighing up the pros and cons of a particular behaviour, whereas the SRM places an emphasis on processes of representation formation, emotional and practical coping and monitoring of coping. The lack of monitoring in the HBM leaves it rather static with no room for development or change.

However, the SRM has not avoided criticism itself. Ogden (1995) suggested that the model, like the HBM before it, is too individualistic and 'remains within the head of the individual', ignoring the surrounding context. Leventhal et al. (1997)

dispute this, emphasising how the model focuses on the person's way of construing contacts with the environment, in that illness representations are based on perceptions and conceptions extracted from the reality of experience. This is also supported by Croyle and Hunt (1991) and Croyle (1992) who, using the SRM, suggest that the opinions and health characteristics of others have an impact upon how people form their own cognitive, emotional and behavioural responses to health threats.

There has been limited attention to testing of the proposed causal links between beliefs and outcomes (Lobban, Barrowclough, & Jones, 2003). However, the evidence to support the link between beliefs and outcomes is growing. Examples include Yardley, Beech, and Weinman (2001) who looked at the relationship between beliefs about the consequences of dizziness and resulting handicap and the impact of therapy on beliefs. They found that negative beliefs led to sustained long-term restriction of activity and that therapy helped to modify negative beliefs. In another study (Hunter, Grunfeld, & Ramirez, 2003) it was found that intention to seek help in women with breast-cancer symptoms was mediated by representations of the identity and consequences of the illness. A study investigating the psychosocial impact of multiple sclerosis (Vaughan, Morrison, & Miller, 2003) suggested that representations of an acute time-course, low controllability and more serious consequences contribute to higher levels of depression.

Finally, Lobban et al (2003) suggest that using cognitive models of illness threat is not appropriate when exploring the experience of people with mental health problems as the very nature of their problems may impair their ability to reflect upon their experience and form mental models. They do go on to suggest how this implies a clear distinction between physical and mental experiences, whereas in reality there

are many diseases that are regarded as physical, such as diabetes, which can have a significant impact upon cognitive processes. Conversely there are problems considered by many to be psychological in origin, such as chronic fatigue syndrome, which have an identifiable physical symptomology. Another, related potential difficulty is that of neurologically based unawareness, a difficulty that can arise in some dementias. This may impact upon the individual's ability to reflect upon and form cognitive models of illness. To date, as far as can be ascertained, the SRM has not been used to consider conditions where this may be an issue.

The self-regulation model has been applied to many different health threats in attempts to understand how individuals manage them. In addition to the studies of Leventhal and colleagues that examined hypertension and cancer these include coronary artery by-pass graft surgery (Gump et al., 2001), cardiac rehabilitation (Whitmarsh, Koutantji, & Sidell, 2003), angina (Haugbølle, Sørensen, & Henriksen, 2002), Addison's disease (Heijmans, 1999) and schizophrenia (Barrowclough, Lobban, Hatton, & Quinn, 2001).

Others have used the model to look at the management of threats posed by neurological illness (Earll, 1994), and more specifically, motor neurone disease (Earll, Johnston, & Mitchell, 1993) and Huntington's disease (Helder et al., 2002). Earll (1994) found that self-regulation is a useful framework for understanding how people with chronic neurological illness with no cure or effective palliative treatment options cope with the threats these conditions present. She looked at the perceptions of people with multiple sclerosis and motor neurone disease, and found that people's representations of their condition and their assessment of coping strategies were predictive of outcome in terms of increased social support, greater satisfaction with

support, improved self esteem, better emotional well being and less severe levels of disability.

However, to date, the self-regulation model has not been used as a framework to advance our understanding of the experience of the person with early-stage dementia in managing the threat it presents, but it may be a useful tool to do so. However, as has been mentioned already, there is a need to consider how the model can deal with the issues of cognitive impairment and unawareness. The following sections of this chapter will look at how the current dementia literature relates to the components of the SRM.

Awareness

Leventhal et al (1984) propose that the first stage in the development of an individual's understanding of illness and the threat it presents is the development of awareness. The SRM describes as developing through the perception of illness related changes and the integration and comparison of these changes with past experiences of well-being and illness.

In the field of dementia, awareness has predominantly been considered in terms of reduced awareness, often seen as a symptom of the illness. There have been many different terms used to refer to the construct of diminished awareness (Clare, 2004), including anosognosia, lack of awareness, lack of insight and denial. Clare indicates how this reflects the varying constructions of awareness that have been drawn from different disciplines including neuropsychological, psychiatric, and psychosocial perspectives. Bond, Corner, Lilley, and Ellwood (2002) report the findings of a content analysis of psychiatric and psychological texts where they found a lack of clarity in the defining of awareness and in the operationalisation of definitions. In general they found awareness as being seen as the ability to

understand one's own problems, suggesting that lack of awareness or insight is a professional judgement in the context of medicalised definitions of dementia. In other words, impaired awareness is seen as a symptom of dementia. Bond et al. (2002) go further to suggest that this medicalisation of awareness in dementia may lead to increased depersonalisation and marginalisation and reduced independence as behaviour is individualised. This suggests the need for a clearer more coherent understanding of awareness in dementia.

Clare (2004) reviewed publications from the past 30 years relating to the concept of awareness from the neuropsychological, psychiatric, and psychosocial fields and considered their relevance to understanding the concept of awareness and variations in awareness among people with early-stage AD. From this review a biopsychosocial model was developed to integrate the models from these domains and create a framework of the experience of awareness in AD that takes into account person-centred approaches to dementia, research and clinical practice.

The model proposes that there is a "unifying context for experience" that is provided by a person's sense-of-self. Self is represented at the three levels by different concepts. At the biological level, there are cognitive representations of self as images, schema, prototypes and goals or tasks. At the psychosocial level, self is a socially constructed concept represented by three aspects; self[1], the personal identity; self[2], personal characteristics (including personality, coping styles, beliefs and experience); and self[3], the different presentations of self used in different social settings (Sabat & Harré, 1992; Harré, 1998).

When considering AD, changes in cognitive functioning, including memory and executive functions, may result in an altered level of awareness at the biological

level. The model also accounts for how changes in cognitive function may impact the ability to understand and apply information regarding the illness threat.

At a psychological level, awareness can be considered at three levels: awareness of change; awareness of symptoms; and the awareness of the meaning and impact of these (Marková, 1997, as cited in Clare, 2004). It is in response to these that an individual's personal characteristics, such as coping style, personality, and beliefs, play a role as he or she reacts to the threat-to-self. In their responses, people move through a cyclical process of registering, reacting, explaining, experiencing and adjusting, with individual coping responses falling on the continuum between self-maintaining and self-adjusting responses (Clare, 2003). Clare (2004) suggests that processes of denial may limit awareness at an explicit level, but that it may still be present at an implicit level.

The social component of the model introduces interactions with friends, family, services and professionals and the impact that these different interactions are likely to have on the expression of awareness. This is particularly pertinent to the idea of the self[3] level, where people present different versions of self dependent upon the social situation they are in. Within the social level, expressed awareness is also influenced by social role valorisation, the presence of malignant social psychology (Kitwood, 1997), social representations and cultural narratives of AD and the impact they have on services.

Information also plays an important role in this framework. Social interactions and biological changes are seen to contribute to the development of knowledge and understanding about dementia and the ability to apply that knowledge. This knowledge and understanding is in turn seen as impacting upon the psychological processes of developing awareness of change, symptom presence and

the meaning and impact of change; self maintaining or adjusting styles of coping; and denial, minimisation or avoidance.

What has been presented here is a brief summary of a complex model of awareness in AD that incorporates biological and psychosocial models in a move away from past expressions of diminished levels of awareness being seen as a symptom of AD. Clare (2004) is clear to point out that this model is tentative and that further exploration of the component parts is needed. However, this model does offer an initial explanation of the mechanics of awareness in AD that takes into account the ideas of AD posing a threat-to-self, through changes in cognitive functioning and social interactions and how different people may respond in different ways to that threat, that have emerged from exploration of the experience of people with early dementia. This explanation of awareness may also help to expand and improve the self-regulation model in terms of the process of illness representation development that is referred to as being a process of developing 'conscious awareness' of the illness threat.

The idea that awareness is not simply a symptom of dementia, but more of an interplay between social constructions, neurological and cognitive and psychological components with self as the context of experience over time is supported by Phinney (2002). This qualitative study explored the fluctuating nature of awareness over the course of dementia with respect to how this impacts upon the illness narrative. Results indicated that people with dementia may experience symptoms as being salient, vague, and inconspicuous and that some symptoms may be forgotten or absent. It is suggested that this variability in the experience of symptoms leads to difficulties for individuals in expressing a coherent illness narrative, and that in order to overcome this problem the narrative becomes one that is shared as others become

involved in its telling. This challenges the notion that constructs of self are dependent upon self awareness as an individual characteristic, as it suggests interplay between individuals and others in the development of illness narratives and constructs.

The SRM proposes that as individuals begin to make sense of the illness threat through perceiving changes and making comparisons to past experience they begin to develop cognitive models of the illness referred to in the model as 'illness representations'. These are based on information from perceptual, symptomatic information, and social messages, constructed along to the five attributes of identity, time-line, consequences, causes and controllability, which develop through individual experience and interaction with others. An important source of information for the person with dementia is his or her interactions with health professionals through the process of diagnosis. This can provide important social feedback and concrete information about the illness threat. The question of diagnosis disclosure remains, however, a somewhat controversial topic with some researchers and clinicians proposing that the sharing of diagnoses as being beneficial to the person with dementia and others believe that it can be detrimental. The next section of this chapter will focus on the issue of diagnosis disclosure in the dementia literature.

Diagnosis Disclosure

To date there has generally been a reluctance to disclose diagnoses to people with early dementia. One study found that only 48% of people with dementia were told of their diagnosis (Heal & Husband, 1998). This figure is reflected in other studies of psychiatrist behaviour when sharing dementia diagnoses with the person with dementia (Rice & Warner, 1994) where 38 to 44% described it as normal

practice to do so. Rice and Warner went on to describe how this figure fell dramatically for people at a moderate and severe stage, respectively, where only 13 and 6% of those professionals polled "nearly always" gave a diagnosis. Similar patterns have been reported among other health professionals such as geriatricians (Rice, Warner, Tye, & Bayer, 1997) and GPs (Vassilas & Donaldson, 1998). In the latter study it was also reported that, in comparison to dementia, 95% of GPs were "always or often" willing to share a diagnosis of terminal cancer. Other studies have looked at the willingness of heath professionals to share a diagnosis of dementia with carers. For example, Rao (1997) found that in 63% of cases, the diagnosis was shared with the carer only, with 39% of carers going on to share the diagnosis with the person with dementia. This issue is important to consider in terms of the formation of illness representations and the consequences of them as information is needed to develop representations. A paucity of information could lead to difficulties in forming representations and subsequently in developing approaches to manage threats to sense-of-self.

In considering the sharing of diagnoses with people with dementia, some workers have drawn upon the field of cancer care for comparisons. There are striking similarities in the current situation with dementia and that of sharing cancer diagnoses 20-30 years ago. In the late 1970s Novack et al. (1979) reported a significant shift in the behaviour of health professionals in the disclosure of cancer diagnoses. They found that 97% of hospital-based medical staff were in favour of disclosure compared to the earlier finding of 90% being against disclosure reported by Oken (1961). This change in attitude was attributed to increased knowledge about cancer, treatment and patient wishes. Meredith et al. (1996) looked at the information needs of cancer patients and found that the majority of sufferers wanted to know

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their diagnosis and information about their prognosis, treatment options and possible treatment side effects. It was suggested that this information is important in the development of patients' representations of their difficulties, and assists in adaptation to their circumstances and the development of coping strategies. Vassilas and Donaldson (1998) found that health professionals are more likely to disclose this information to people with cancer than people with dementia.

The practice of health care professionals illustrated in those studies reported above does not relate well to the findings of studies that have examined what people report they would hope to experience in terms of the sharing of dementia diagnoses. One study comparing the wishes of people with dementia and depression in their desire to know their diagnoses (Jha, Tabet, & Orrell, 2001) found that over 75% of people with dementia wanted to know. This study also reported that people with severe dementia (as measured by MMSE score less than 15) preferred to be told of their diagnosis, even if this meant some degree of distress. In samples of people without dementia, it has been reported that 92% of people would want to be told of their diagnosis (Erde, Nadal, & Scholl, 1988). This figure was more recently replicated with a sample of undergraduate students, with a mean age of 26 (Sullivan & O'Conor, 2001), of whom 93% reported that they would like to be told. Whilst these samples may not be reflective of people at risk of developing dementia at the time of being asked about their preferences, some studies have looked at more 'risk aware' groups. For example, in a sample with a mean age of 78 years, the figure was still high, with 79.5% of participants reporting that they would like to be told of a diagnosis of dementia (Holroyd, Snustad, & Chalifouk, 1996). A study of people with first-degree relatives who have been diagnosed as having AD (Maguire et al.,

1996) found that 72% of this sample would reportedly wish to know of a similar diagnosis for themselves.

There is little clarity regarding carers' views of sharing the diagnosis with the person with dementia. Some studies have suggested that they are more aligned with the views of professionals, with numbers of carers who think that the person with dementia should not have their diagnosis shared with them ranging from 60.6% (Pucci, Belardinelli, Borsetti, & Giuliani, 2003) to 83% (Maguire et al., 1996). More recently, Wilkinson and Milne (2003) reported 54% of carers expressing a wish for the person with dementia to be told. A study by Holroyd, Turnbull, and Wolf (2002) reported that nearly 72% of carers believed that people with "a disease affecting their memory" should be told of their diagnosis and what symptoms to expect. This is significant in relation to people with dementia developing representations of their condition, as carers may be an important source of information and social feedback.

The development of an understanding of the reported reluctance of some professionals to share diagnoses of dementia with people with dementia has focused on their perceptions related to the advantages and disadvantages of disclosure. One often reported disadvantage is that the sharing of a diagnosis of dementia with the person with dementia will have a significant negative impact on his or her psychological well-being (Clafferty, 1999; Ahuja & Williams, 2000; Drickamer & Lachs, 1992), with depression and increased cognitive decline often being cited. There is evidence to suggest that this fear is shared by carers (Maguire et al., 1996). It has been suggested that in extreme cases, sharing a diagnosis of dementia may lead to suicide (Rhode, Peskind, & Raskind, 1995). However, in a survey of suicide in 100 older adults, (Cattell & Jolley, 1995), only 1% had a diagnosis of dementia, suggesting that risk of suicide is not elevated in people with dementia. However,

whilst a diagnosis of dementia was reported, it is not clear if the individual with dementia had been told of her or his diagnosis. There have also been concerns expressed over the stigma attached to the diagnosis of dementia (Clafferty, 1999; Rao, 1997; Goldsmith, 1996). This is in relation to its impact on areas of social interaction and functioning; financial considerations including pensions, mortgages and insurance; and access to health care due to the prejudices of other professionals (Drickamer & Lachs, 1992).

Professionals also report a reluctance to share the diagnosis since there is typically a degree of uncertainty in its accuracy and also regarding the prognosis (Clafferty, 1999; Drickamer & Lachs, 1992; Goldsmith, 1996). Concern here is again in adding to the distress of the person with dementia through uncertainty, and beliefs around the potential impact an incorrect diagnosis may have on a person's life (Drickamer & Lachs, 1992; Clafferty, 1999; Goldsmith, 1996). This is reported in the context of perceived inaccuracies regarding the detection of dementia, stemming from the use of diagnostic prefixes such as 'probable' and 'possible', which in turn arise from the majority of dementia diagnoses being confirmable only at post mortem. With regards to the prognosis, Drickamer and Lachs (1992) describe how limited understanding of the process and inaccurate descriptions of the course and duration of the dementias may lead to increased uncertainty and anxiety in those people with dementia being told of their diagnosis.

Drickamer and Lachs (1992), Heal and Husband (1998), and Rao (1997) suggest that poor insight and impaired memory in the person with dementia is another reason given for the withholding of diagnoses of dementia from people with dementia. However, this relates back to the model of awareness proposed by Clare (2004). If people do not have the information they need to understand their condition,

then what chance have they of developing awareness? Whilst the poor insight and memory argument may be the case for people who are diagnosed at a late stage in the dementia process, there are many more who are given a diagnosis at an earlier stage when cognitive impairments are more circumscribed. The assumption that there is no point in telling people with dementia of their diagnosis as they will not remember it also contradicts the other reasons for not telling discussed above. If people with dementia are not able to remember being told then they are unlikely to become distressed, depressed or suicidal. Additionally, the sharing of a diagnosis can be an emotional experience for the person with dementia. Evidence from studies of people with dementia who experienced an earthquake (Ikeda et al., 1998) and follow up experimental evidence (Kazui et al., 2000; Boller et al., 2002) suggests that information that has a high emotional significance may be better retained by people with early-stage dementia than information that is low in emotional significance. This has been demonstrated to be the case for both positively and negatively emotionally-charged information (Hamann, Cahill, & Squire, 1997). Therefore, whereas many unexceptional everyday events may not be recalled, this significant and unusual event with emotional implications is more likely to be registered in episodic memory and recalled later on.

Some studies have reported that some health professionals are against the sharing of dementia diagnoses with people with dementia as they perceive that there is little that can be done in terms of effective treatment after a diagnosis has been given (Drickamer & Lachs, 1992; Clafferty, 1999; Goldsmith, 1996; Milne, Woolford, Mason, & Hatzidimitriadou, 2000; Olafsdottir, Skoog, & Marcusson, 2000). However, for people with AD, there is now increasing access to acetylcholinesteraise-inhibiting medication. With vascular dementia there is some

evidence that treatment of hypertension, one of the risk factors for initial onset and decline (Skoog, 1998), can slow the onset of decline (Devine & Rands, 2003). With vascular dementia (VaD), a more holistic therapeutic approach including medication, relaxation, family intervention and cognitive rehabilitation can have a significant benefit in terms of level of functioning over controls (Kruglov, 2003). Further evidence for benefits of treatment includes the use of memory training groups with people with AD (Moore, Sandman, McGrady, & Kesslak, 2001) to improve memory functioning and mood. Another study (Clare, Wilson, Carter, Hodges, & Adams, 2001) demonstrated how gains from individualised cognitive rehabilitation interventions can be maintained over periods of years. However, evidence for the effectiveness of these interventions is still lacking in terms of controlled, randomised studies (Graesel, Wiltfang, & Kornhuber, 2003). This is supported by Clare, Woods, Moniz Cook, Orrell, & Spector (2004) who conducted a Cochrane systematic review of studies of cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia. They found no randomised controlled trials (RCTs) of cognitive rehabilitation, while of six studies investigating cognitive training, none reported statistically significant effects. However, there was some evidence of some modest non-significant effects in individual areas of cognitive functioning. Clare et al (2004) suggest that these findings should be regarded with a degree of caution due to the limited number of RCTs available that have explored this area, and also because some of the studies that have been conducted have methodological limitations. The review also concludes that it is currently not possible to evaluate the effectiveness of individualised cognitive rehabilitation approaches as to date there have been no RCTs looking at this area.

The reasons for not sharing a diagnosis of dementia with people with dementia presented in the literature tend to be from a stance of protecting the individual from the perceived pain and suffering of receiving such a diagnosis. Wilkinson and Milne (2003) also suggest that there continue to be myths of dementia that persist in health care. These include beliefs of there being no benefit in sharing dementia diagnoses and a risk of misdiagnosis. This is reflected in another recent qualitative study exploring the factors that influence professionals when deciding to sharing diagnoses (Keightley & Mitchell, 2004). The main influence on making decisions is reported to be uncertainty about whether the person with dementia would want to know their diagnosis or not, driven by anxiety that sharing a diagnosis with an individual who did not want to know would cause harm. Keightley and Mitchell also found that professionals report a strong sense of hopelessness and helplessness when confronted with dementia. They go on to suggest that these feelings are projected onto the person with dementia, resulting in the adoption of the protectionist stance many professionals take. Whilst studies have revealed this protectionist stance taken by many professionals as a key driver in not sharing diagnoses, the literature presents many arguments for the sharing of dementia diagnoses.

Many of the advantages of sharing a diagnosis of dementia described in the literature can be seen as having practical value to the person with dementia. These include: planning for the future (Pinner, 2000; Clafferty, 1999; Sullivan & O'Conor, 2001) in terms of finances, 'living wills', and care needs; settling family matters (Sullivan & O'Conor, 2001); and even taking the opportunity to "take that holiday of a life time" (Pinner, 2000) whilst the individual is still able to. There is also a need to be aware of limitations and consider when to adapt behaviour. One often-cited example of this is driving behaviour (Johnson & Bouman, 1997).

Other arguments for sharing diagnoses are based around ethical considerations including the 'right to know' (Pinner, 2000) and the maintenance of autonomy (Drickamer & Lachs, 1992; Marzanski, 2000). The key argument here is considering how, in collaboration with the person with dementia, to establish the conditions for them to continue living their lives as fully as possible and as close to how they lived prior to the influences of dementia. This is the essence of the positive approach to maintaining personhood as described by Kitwood (1997).

Others have described how sharing a diagnosis can help with adjustment to the changes experienced in dementia. Often, people with dementia are aware of their symptoms, and without a label may experience heightened anxiety in the search for possible explanations for what is happening to them (Clafferty, 1999). There is some evidence (Gilliard 1995, as cited in Downs, Cribbens, Rae, Cook, & Woods, 2002) that people with dementia who know their diagnosis are less troubled than those who do not, as they have had more of an opportunity to make sense of what is happening to them. However, this adjustment may be related to how the process of sharing the diagnosis is dealt with, to individual coping style or to the reactions of others to the diagnosis, as others may not make such a positive adjustment and experience psychological distress including depression and anxiety (Teri & Gallagher-Thompson, 1991; Thompson, Wenger, Zeuss, & Gallagher, 1990; Jha et al., 2001; Husband, 2000). Husband (2000) reports how these reactions can often be related to fears of social embarrassment, anxiety about dependency on others and not being listened to. Sharing a diagnosis of dementia is seen as advantageous in terms of providing a potential opportunity to offer psychological interventions as an aid to adjustment.

Whilst there have been those who support and those who oppose the sharing of dementia diagnoses with people with dementia, the body of evidence has grown in favour of sharing (Meyers, 1997; Clafferty, 1999; Pinner, 2000; Rice et al., 1997; Post, 2000). This has been supported at a national policy level through advice given in the National Service Framework (NSF) for Older people (Department of Health, 2001) which states that the treatment of dementia 'always involves explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support' (NSF, page 98). This stance is similarly echoed by the 'Forget Me Not' report (Audit Commission, 2000). This catchall approach is at the opposite extreme to never sharing diagnoses as it does not consider those people who actively do not want to know their diagnosis.

Within the literature advocating the sharing of diagnoses there is also a consensus of opinion regarding how diagnoses should be shared (Marzanski, 2000; Clafferty, 1999; Rice et al., 1997; Ahuja & Williams, 2000; Meyers, 1997; Pinner, 2000; Drickamer & Lachs, 1992). In summary, it is suggested that the sharing of diagnoses should be considered on an individual basis, with the person with dementia being consulted about their wish to know their diagnosis, prognosis and information about dementia. Marzanski (2000) goes further to suggest that this should happen irrespective of their level of impairment, whereas others (Rice et al., 1997) suggest that the sharing of diagnoses should be limited to those with 'mild dementia'. The imparting of information should not be a one-off event (Pinner, 2000), but more of an ongoing one with information being delivered and reconsidered as dictated by the needs of the person with dementia. With regards to what to tell, Clafferty (1999) suggests that people should be given 'the support and knowledge that allows them

the dignity to come to terms with their illness and be involved in plans about their current and future health care' (page 395).

Investigation of how diagnoses are shared and what people with dementia are told has been limited. The available evidence suggests that professionals sharing diagnoses often tend to minimise or normalise the experience of the person with dementia (Marzanski, 2000; Downs et al., 2002). This is often done through attributing difficulties to ageing and providing reassurance that there is little wrong with the individual. Downs et al. (2002) describe how it is often a way for professionals to manage their own concerns about the person with dementia experiencing distress by protecting the person from the facts. Marzanski (2000) found that in some instances, individuals are given unrelated explanations (including angina and bereavement) to explain cognitive symptoms. Others (Audit Commission, 2000; Downs et al., 2002; Gilliard & Gwilliam, 1996; Cody, Beck, Shue, & Pope, 2002) have found that even when professionals attempt to share diagnoses and information with people with dementia there is often a reliance upon euphemistic terms. Gilliard and Gwilliam (1996) found that professionals often perceive that they have given clear information about diagnosis and prognosis despite having used unclear euphemistic labels. Common labels include memory problems, confusion and the ageing process. Cody et al. (2002) reported that when information is given it includes disease progression, risks about driving, advanced directives, using memory aids and carer issues. This supports the findings of Downs et al. (2002) who report an emphasis on deficits and dysfunctions rather than a broader, more balanced picture with inclusion of the more positive side to living dementia including active coping and resilience (Kitwood, 1997; Sabat, 2001).

Overall, the opinion of those professionals advocating the sharing of diagnosis is that it should be patient-led. However, to date the emphasis of research has been on the perspective of practitioners and family carers and what they believe people with dementia need to know when diagnoses are being shared (Wilkinson & Milne, 2003), which is often unclear with an emphasis on the deficits and dysfunctions associated with dementia. However, there is a growing literature that aims to explore the experience of dementia and diagnosis from the perspective of the person with dementia. Marzanski (2000) canvassed the views of people with dementia about what information they would like to receive at diagnosis. His findings were that 70% of those people who responded to a questionnaire wanted to know what was wrong with them and wished to know more information than they had received at diagnosis. Some of the reports of questions to which people wanted answers were: is there any possibility of improvement; what causes dementia; and how long they would expect to suffer. Marzanski also found that the other 30% of the people who responded did not want to know about their diagnosis, with some reporting that this was an active choice in managing their illness.

There has also been some more recent work regarding the sharing of diagnoses from the perspectives of people with dementia. Pratt and Wilkinson (2001) interviewed 24 people with dementia about their experiences of being told their diagnosis of dementia. The aims of their study were to look at how people with dementia felt about being told of their diagnosis, to consider the opportunities and limitations offered by early diagnosis for the individual and to guide future best practice in the sharing of diagnoses. Overall, the participants felt that diagnoses should be shared and this should happen as early as possible. However, they also felt that for people who are at a later stage of dementia and may not understand their

diagnosis, sharing it with them might not be of benefit. Those participants who expressed this concern also felt that the decision to disclose should be done on an individual basis. The study found that people with dementia experience a range of emotional reactions to being told their diagnosis. These included shock, anger, fear and depression, and for some, validation in having an explanation for the changes that they had recognised. Importantly, feelings of fear were reported as being related to participants' prior experience and understanding of dementia. With regards to the desire to seek information, pertaining to diagnoses and prognoses, the study reports two approaches used by participants, one of actively seeking information and another of seeking it only as and when the person feels it is applicable to their situation. Participants felt that it was important for professionals to respect their choice of approach to information.

With respect to the second aim of looking at the opportunities and limitations of an early diagnosis being shared, Pratt and Wilkinson (2001) found that participants reported far more of the former. Opportunities included practical matters (making future plans and legal/financial issues), developing an understanding of the changes taking place within oneself, to make the most of their time (e.g. taking holidays and volunteer work), seeing dementia as a challenge to be managed, and increasing social support. Limitations included reduced self-confidence as a result of awareness of limitations and restrictions to daily activities such as driving. It is noticeable that the views of people with dementia about the opportunities linked to the sharing of dementia diagnoses are similar to those suggested by professionals (Pinner, 2000; Clafferty, 1999; Sullivan & O'Conor, 2001; Marzanski, 2000; Drickamer & Lachs, 1992). Conversely, the views of people with dementia do not support those reasons given offered by professionals for withholding dementia

diagnoses (Heal & Husband, 1998; Ahuja & Williams, 2000; Rao, 1997; Drickamer & Lachs, 1992; Clafferty, 1999; Goldsmith, 1996; Milne et al., 2000; Olafsdottir et al., 2000). Noticeably, emotional distress was not seen as a limitation of being given a diagnosis, which has been the main reason for not sharing dementia diagnoses and "protecting" people with dementia.

The third area explored by the "Tell Me the Truth" study involved best practice in diagnosis sharing. Unfortunately, participants gave few examples of good practice relating to diagnosis sharing. Areas of poor practice identified by people with dementia from their own experience included diagnoses not being shared early enough, and not being given enough information about prognosis. There were some suggestions offered such as: respecting the individual's choice and right to a diagnosis with choice over when and how to be involved; giving people enough time to ask questions on an ongoing basis; recognising that people's needs and interests around their diagnosis may change over time; and recognising the need for individualised support which takes account of existing networks.

From their findings, Pratt & Wilkinson (2003) developed a psychosocial model of the experience of receiving a diagnosis of dementia. The model consists of two axes that intersect at right angles to form four quadrants. The horizontal axis is 'the desire and ability to know diagnosis' representing the psychosocial factors which impact upon the experience of diagnosis including existing coping styles and the attitudes of professionals and families. The vertical axis, 'social context', represents the impact of factors including social stigma, family, carers, support and medical input. This model is represented in figure 3, below.

Figure 3:   *A psychosocial model of understanding the experience of receiving a diagnosis of dementia (Pratt & Wilkinson, 2003)*

Ability and desire to know diagnosis (high)

Distress   *Maximising coping strategies*

Social context ◄————————————————————————► Social context
(negative)   (positive)

Detachment   *Decline and denial*

Ability and desire to know diagnosis (low)
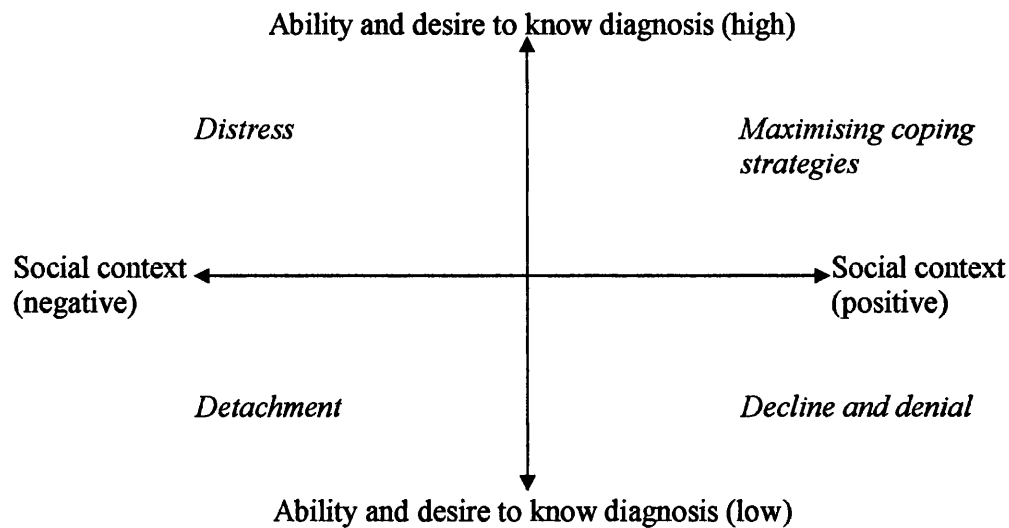
The model describes how in the process of receiving a diagnosis there is interplay between individual needs and ability and social contexts. Significantly, the experience of having information withheld when individuals want to know leads to distress, which withholding diagnoses has been argued to prevent. The sharing of information and diagnoses has been suggested to help the person with dementia to be able to maximise coping and support mechanisms.

One key limitation of this study, however, is that it sampled only people with early-stage dementia who have had their diagnoses shared with them and were willing to discuss this experience. However, there is another group people who have, for various reasons, not been told. The findings of this study can not be generalised to provide an explanation of the experiences of people who have not been told as they develop their understanding of what is happening to them.

This section has reviewed the current situation with regards to the disclosure of dementia diagnoses to people with dementia, where there has been a conflict between sharing and not sharing information. A recent systematic review (Bamford

et al., 2004) suggests that this conflict continues, leading to inconsistencies in clinical practice. The review reiterates many of the conflicts in the advantages and disadvantages of disclosure reported in this section and the difficulties that this presents clinicians when considering whether or not to share a diagnosis of dementia with the person. Bamford et al also reflect the paucity of work from the perspective of the person with dementia and the methodological limitations of work that has explored the perspectives of professionals. They also discuss some of the limitations of the studies included in the review, including that, as discussed above, there is a tendency to over generalise from non-representational samples.

From our understanding of how chronic illnesses such as dementia are viewed as a threat-to-self, and how the person with dementia plays an active role in managing the threat, the provision of information through diagnosis can be seen as an essential part of threat management through the construction illness representations. This has become more evident in more recent work in which the sharing of diagnoses has come to be seen as important by both professionals and people with dementia. The SRM requires information to be given to the person with dementia so that she or he has the opportunity to a develop representation of early-stage dementia. However, many people with dementia don't even receive a diagnosis, still less information that is useful to them. This is likely to impact on their coping as they are less likely to have a coherent representation of dementia to inform the development of strategies.

Having developed an understanding of illness threat through the development of illness representations, the SRM suggests that individuals then go on to develop coping strategies for managing both the objective features of the illness and their emotional reactions to it. The following section of this chapter explores the current

ideas of how people with dementia understand and manage the threat-to-self dementia represents through a review of the literature related to the experience of the person with early-stage dementia.

The Experience of the Person with Early-Stage Dementia

Dementia is a generic term used in reference to acquired cognitive impairment usually resulting from the pathological degeneration of cortical and/or sub-cortical structures. Some of the mechanisms behind the dementias include vascular, metabolic, and infectious disorders, with diagnostic labels having been developed according to neuropathology and presentation. These include Alzheimer's disease, Lewy Body disease, fronto-temporal dementia (with frontal and temporal variants), and vascular dementia and those of a more rare nature including Creutzfeldt-Jakob disease. Traditionally, the dominant models of dementia have emphasised a medical perspective. However, more recently there has been an emphasis on a psychosocial component. This was strongly influenced by the work of Tom Kitwood (Kitwood, 1997) who made the suggestion that the way in which people with dementia are treated within society and specific care-giving interactions may have an impact on their rate of decline. Kitwood called this the 'malignant social psychology' where the person with dementia is devalued by the society in which she or he lives. This is seen to lead to 'excess disability' as people are marginalised. The interplay between malignant social psychology and neurological changes can lead to increased rates of decline and disability that outstrip the rate of increasing neuropathology.

The exploration of the experience of people with dementia is an area of research that has been neglected until recent times. Clare (2003) considered the

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perspective of people with early-stage Alzheimer's disease (AD) in terms of managing threats-to-self and apparent awareness. One of the psychological consequences of the onset of disability or illness is a threat-to-self as changes occur in ability, roles and social interactions. Clare considers the psychological strategies, such as denial, that people with dementia may use to counter threats to self, and the way in which these may influence how they communicate and interact with others and how this may influence other people's perceptions of the awareness that the person with dementia has about her or his difficulties. This is presented in terms of a social constructionist understanding of self, with threats being greatest in relation to the aspects of self presented to others in social interactions.

From interviews with twelve people with early-stage dementia Clare (2003) proposes that people with early-stage dementia engage in a cyclical process of registering, reacting, explaining, experiencing and adjusting as they develop awareness of changes. These are influenced by several individual and social factors. Reacting is influenced by the individual factors of age and understanding of dementia and the social factors of responses of close others. Explaining is influenced by beliefs about memory and ageing and the responses of others and interactions with health professionals. Experiencing is influenced by preferred styles of emotional coping, need to maintain self-esteem and control and attitudes to death and dying, and the social responses of others. As changes are acknowledged and experienced people make adjustments to them. These are focused on the maintaining of self and range from 'holding on' (e.g. trying harder to overcome difficulties and hoping for a future break through such as a cure), through to compensating (e.g. consciously making changes to maintain the appearance of carrying on).

Clare (2003) proposed that the attempts of people with early-stage AD to manage the threat-to-self that the condition presents fall on a continuum of self-maintaining to self-adjusting styles. The self-maintaining pole describes attempts to maintain pre-illness self by, for example, normalising the situation and minimising difficulties, whereas a self-adjusting position describes making attempts to recognise difficulties and modify one's sense-of-self to incorporate the changes associated with dementia. There is no differentiation between self-maintaining and self-adjusting in terms of their relative value as strategies for managing threats to self resulting from illness.

In another study that has considered the experience of people with early dementia (Pearce et al., 2002), 20 men diagnosed with early dementia were interviewed. The authors discuss how this group were found to be engaging in an ongoing, circular process of balancing their prior sense-of-self against a need to reappraise and construct one that incorporates the experience of dementia. As with the Clare (2003) study, this process is represented as the dialectic between positions that are somewhat akin to self-adjusting and self-maintaining.

Another aspect of the understanding of illness as a threat is the importance of the role of the individual facing the threat. In the past this has been seen as a passive 'sick role' (Parsons, 1964), but has also been developed to take account of the experience of chronic illness (Roth, 1963) where the individual is seen as more active in facing threat. This includes interactions between health professionals and individuals. As has already been discussed, there has been much debate in the dementia literature around interactions between the person with dementia and health professionals, with an emphasis on diagnosis disclosure.

The findings of these studies that have explored the experience of early-stage dementia can also be related to the sharing of dementia diagnoses in terms of what information people want and need when diagnoses are shared. Considering the findings of Clare (2003), those people who are in the position of taking a self-adjusting stance would probably need clear, relevant information to help them to confront dementia-related changes and incorporate these into their sense-of-self. Conversely, those in a self-maintaining position may not want such a high level of information, as their response to the threat is to minimise change and difficulties, thus preserving their existing sense-of-self. This emphasises the need for individual contexts to be considered when sharing diagnoses of dementia. As described by Pratt and Wilkinson (2003), difficulties may arise when the strategy an individual is employing and the support and help in understanding the changes they are experiencing are incongruent. The participants interviewed by Clare (2003) also indicated that contact with professionals may actually influence approaches to threat management. When there was a lack of information, or information was presented in a blunt manner, self-maintaining strategies were promoted.

Pearce et al (2003) discuss how services can help people with dementia in this process through the provision of the opportunity to discuss and share diagnoses, receive information about dementia and discuss prognosis. Their model suggests that this needs to be done in a way that is reflexive to peoples' needs at different times as they move through the process of adjustment.

Whilst this work recognises the potential threat to self-concept and acknowledges that managing these threats involves adjustments in the practical, social and emotional domains, it does not provide a coherent model of how the individual interacts with the threat in order to manage the potential changes to self.

One such model of the maintenance of self in the face of threats to health is the self-regulation model of (Leventhal et al., 1984) which was discussed earlier in this chapter.

Self-Regulation Model and Early-Stage Dementia: A Summary

From an overall perspective, the findings of Clare (2003) support the SRM, suggesting that the experience of managing the threat of AD is a cyclical process, with people moving through stages of registering, reacting, explaining, experiencing and adjusting as they developing awareness of changes in early AD. These can be seen to correspond with the Leventhal et al. (1984) stages of perception, integration, awareness, coping, and evaluation. However, one added issue in early-stage dementia is that some people may not be very aware or even unaware of their difficulties.

With regards to the individual components of the model, the pre-attentive stages relate to the perception by an individual the he or she is experiencing some difficulty that is not within 'normal' experience. This fits with the early-stage dementia literature in terms of people recognising changes in themselves that are perceived as a threat. For example, using the model of awareness proposed by Clare (2004), challenges to an individual's cognitive models and beliefs of self through, for example, the recognition of changes in memory performance may bring about increased awareness of there being a difficulty that is more than benign forgetfulness through the comparison of changes with existing cognitive structures of self. This perceived threat-to-self leads to a desire to re-instate the prior state of homeostasis in terms of objective and emotional experience (Leventhal et al., 1984), which in the

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dementia experience literature may be represented by the continuum of self-maintaining to self-adjusting styles of responding (Clare, 2003; Pearce et al., 2002).

Leventhal et al. (1984) suggest that the next stage in the regulation of self in the face of illness threat is the development of awareness about the threat. As has already been discussed awareness is not as simple a concept as knowing about illness, but is, at the current time, best described as the interplay of biopsychosocial processes with an individual's cognitive and social concepts of self (Clare, 2004). Levels of awareness are liable to fluctuate between individuals, over time and between contexts. In early-stage dementia, neurological change may influence whether the SRM can be used to explain how representations are formed.

The SRM emphasises the need for information in awareness through the development of illness representations. This relates to the Clare model of awareness, which also acknowledges the contribution of information as one component of the framework needed to consider awareness in early dementia. Here, social components of interactions with family, friends, professionals; dimensions of social experience, including for example possible malignant social psychology and social representations; and biological changes contribute to knowledge and understanding of dementia. This information plays a key role in people's development of their psychological understanding of their difficulties, as also proposed by the SRM. The dementia literature relating to diagnosis disclosure and the response of health professional is also of relevance here. Firstly, much of the information needed for the formation of illness representations about dementia may come from being given a diagnosis and explanations about the threat of dementia from health professionals. Secondly, the attitude of health professionals is important in the development of awareness and understanding. Where the person with dementia is excluded from the

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diagnosis process, which often happens as carers, family members and professional attempt to 'protect' him or her (Wilkinson et al., 2003); this may have a further impact as the person with dementia may experience de-valuation, exclusion, secrecy and disempowerment. These are all aspects of the experience of social interactions that may influence an individual's level of awareness and understanding of dementia (Clare, 2004). The SRM also places some emphasis on the individual playing an active role in the development of his or her understanding and management of the illness threat, which is an idea that has also been suggested by Roth (1963).

Leventhal et al. (1984) propose that the representations people form about health threats provide them with their goals for action. With reference to the dementia literature, this may be reflected in the idea of people with early-stage dementia falling on the continuum between self-maintaining and self-adjusting, in that how they plan to manage the threat of dementia on this continuum may be related to the representations they form about it. Also of importance here are the personal characteristics described in the concept of self[2] (Sabat & Harré, 1992) including personality, past experiences and individual coping styles. This may influence coping with both the objective threat of dementia and the emotional impact.

Finally, the SRM includes a feedback loop that feeds the outcome of coping back into representation formation. Therefore, if an individual finds that her or his ways of managing the threat are helping to achieve his or her goals and are maintaining homeostasis, then little is changed; however, if the goals of managing the threat are not achieved, then representations and coping strategies are modified. Using the dementia literature, this may involve people assessing whether they are able to continue functioning day-to-day as they would before they received their

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diagnosis (self-maintaining), or adapting to manage dementia-related changes (self-adjusting). This feedback may be gained through both the individual's awareness of changes and how they are managing them, and also through feedback from social interactions.

Having reviewed the literature relating to the concept of illness as a threat-to-self, the SRM and the dementia literature relevant to the components of the model, the following section will consider the aims of the current study. Whilst there has been some work investigating the representations of relatives of people with dementia (Roberts & Connell, 2000), to date, as far as can be ascertained, there has been no exploration of illness representations in relation to the experience of people with dementia in the context of the SRM. The intention of this study is to act as a starting point to resolve this gap in the literature and consider how understanding the representations people with early-stage dementia hold about their condition and how they relate to their day-to-day experience can inform clinical practice.

The Current Study

Studies that have explored the experience of people with early dementia (Clare, 2003; Pearce et al., 2002) and the experience of receiving a diagnosis (Pratt & Wilkinson, 2001; Pratt & Wilkinson, 2003) have taken a phenomenological approach from which themes and suggestions of some models of experience have developed. The former studies have supported the ideas of Charmaz (2000) where chronic illness is regarded as a threat-to-self. There has been an emergent theme of people with early dementia engaging in a coping process with varying response styles along the continuum of self-maintaining to self-adjusting as they manage the threat of illness. With the studies of the experience of receiving a diagnosis of dementia, a

psychosocial model of the experience has been developed which emphasises the interaction of desire and ability to know about the diagnosis and the social context that the individual is in. Others (e.g. Cody et al., 2002; Downs et al., 2002; Gilliard and Gwilliam, 1996) have looked at what information is shared with people with dementia by those sharing diagnoses and what people with dementia would be like to told (Marzanski, 2000). There has also been a review of the concept of awareness in terms of dementia with the formulation of a biopsychosocial model (Clare, 2004). This incorporates the concept of self as the context for experience over time, interacting with biological processes and social interactions that determine expressed levels of awareness. Information is described as playing a part in the development of knowledge and understanding of experience, with the ability to apply this also impacting upon expressed awareness.

The work to date has provided some description of the experience of people with early-stage dementia, how diagnosis sharing is currently managed and what information is given, and what information people with dementia would like to receive at diagnosis. However, this literature, excepting that related to expressed awareness, is not really theoretically grounded and has some limitations. Primarily, whilst there have been suggestions of how people experience early-stage dementia, and the sharing of diagnoses, and of what information people would like to receive at diagnosis, these areas of research have not been placed in a framework that can give some understanding of how information can be used by the person with early-stage dementia to manage the threat it presents. The Self-Regulation model may be able to provide this framework. It has already been discussed above how the different areas of research into the experience of early dementia and diagnosis sharing provide some information about the constructs that make up the SRM. However, to date the

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literature does not provide any indication of: what representations people with early-stage dementia form about their difficulties; how these representations are formed; the impact of diagnosis disclosure on representation formation; and the impact of representations on managing the threat. Another important area that needs to be considered is that of awareness. Some people with early-stage dementia have difficulties with neurologically based unawareness, as described in the Clare (2004) model of awareness, and others have not had their diagnosis shared with them and therefore may not have received information about dementia. These areas may have a significant impact upon the ability to form coherent representations of dementia, which in turn may have an impact upon how well individuals manage the threat-to-self dementia represents.

This study will investigate how people describe the perceptions that they hold of dementia after diagnosis, and will explore the apparent impact of the information they receive on their understanding of their difficulties and how they cope with them. The study will use the self-regulation model as a framework for exploring representation formation and the impact that information received at diagnosis has on this process. The aim is to further our understanding of what information is given and is useful to individuals with dementia, during the sharing of a diagnosis, in terms of developing representations which help in the adaptation to having the label of dementia, and subsequently impact upon coping.

This project will investigate the following questions:

1.   What representations do people with early-stage dementia have following diagnosis?

2.   How do people's representations relate to the experience of early-stage dementia and how they manage it?

3.   What are the implications for theory from what people tell us about their experience?

Some studies of illness representations and coping which have employed the self regulation model as a framework (Whitmarsh et al., 2003; Helder et al., 2002; Moss-Morris, 1997) have used the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996). This is a 36-item questionnaire with items that correspond to the five key attributes of illness representations (identity, timeline, consequences, cause and control) suggested by the self-regulation model. Initially developed and validated to investigate the illness representations of people who had experienced a heart attack, others have adapted the questionnaire for use with Huntington's disease (Helder et al., 2002) and chronic fatigue syndrome (Moss-Morris, 1997). However, to date, the self-regulation model and illness representations have not been applied to how we might understand the experience of dementia; hence the IPQ has not been adapted or validated for use in exploring dementia. As we do not yet know very much about the illness representations people with early-stage dementia hold, this might make it difficult to modify the IPQ for use in research. Additionally, the IPQ is a measure of representations and does not take in to account coping and how the two may interact in the experience of people with dementia. Also, the reliance on self-report measures in exploring what people think or say they do in health contexts has been criticised in other contexts (Lobban et al., 2003) where the findings of Ajzen & Fishbein (1980), that there is generally little correlation between what people say and actually do, are cited. This could be

considered a difficulty in any study where one is asking people to report their experience, however, it is hoped that this will be reduced in this study through the developing of rapport with the participants over two meetings. Given the exploratory nature of the study in developing an understanding of the experience of how people with dementia develop an understanding of their difficulties and manage the threats to self that it presents a qualitative approach will be used in this study.

The intention in using a qualitative approach in this study will enable participants to describe their experience without overtly guiding their responses by imposing rigid pre-determined categories, such as those that may be found in, for example self-report measures and questionnaires. Instead, the interview schedule will use much broader categories based around the components of the SRM and the past and present experience of people with early-stage dementia. These categories will allow for the exploration of individual experience allowing the collection of data to be guided by what is important to the participant in the narrative of their experience whilst exploring the appropriateness of the SRM in understanding early-stage dementia. This approach has an advantage over the use of self-report or questionnaire measures as it is more flexible, allowing for differences in individual experience. Such an approach suits the aim of developing an understanding of the cognitive representations of illness and how they develop through subjective experience.

The qualitative approach which will be used in this study is Interpretative Phenomenological Analysis (Smith, Jarman, & Osborn, 1999). This approach attempts to understand people's beliefs about given topic through the assumption that there is an indirect link between what people report and underlying cognitions. Other qualitative approaches, such as discourse analysis (DA) (Potter & Wetherell, 1987), do not concur with this view, and regard verbal reports as behaviours which are the

focus of analyses. IPA takes the stance that whilst thoughts are not transparently available, conclusions about that thinking may be drawn through the analytic process. IPA is a phenomenological approach in that it in concerned with individual, subjective accounts and beliefs about an object or events and is interpretive in that it these accounts are elicited though a dynamic process in which the researcher's own beliefs play a part as they interpret data to develop an understanding of the participant's world. This study differs from much of the research that employs a qualitative approach, in that it is applying IPA to investigate the elements of a structural model in contrast to being purely exploratory. However, it is not the first to do so. For example, Carradice, Shankland, & Beail (2002) used IPA to investigate the practice of nurses in carer assessments in comparison to the components of the stress process model. A discussion of how qualitative methodology has been applied and developed to answer the questions on which this study focuses will follow in the method chapter.

Method

Participants

The participants for this study were invited to take part through an advertisement in the Alzheimer's Society national newsletter (see appendix 1 for a copy of the recruitment advertisement) that targeted people who had received a diagnosis of dementia. This advertisement was included in the national newsletter on two occasions, six months apart. Recruitment was also conducted through a supported coffee group for people with memory problems run by a branch of the Alzheimer's Society local to the researcher's base. This branch of the Alzheimer's society also ran a copy of the recruitment advert in their monthly newsletter.

This method of recruitment was chosen over other alternatives, such as recruiting through memory clinic services, for several reasons. The aim of the study was to sample a range of experiences of people with early-stage dementia. Recruiting from a single memory clinic would have most likely led to interviewing people who had had very similar experiences in the sharing of diagnoses. Advertising thorough an organisation not connected to memory clinic services may also enable participants to talk more freely about their experience as it removes any perceived connection between the researcher and the clinics that individuals have been involved with. A perceived connection may lead participants to feel that they can not talk openly and frankly about services, as in doing so they may feel that they are compromising their relationship with the help that they are seeking or receiving. Finally, recruiting participants in this way assumes that they have been in contact with services and received a diagnosis and have made contact with the Alzheimer's society as a source of support or information. This means that they are more likely to have had time to consider their experience and form representations of their diagnoses.

Inclusion criteria were derived from those employed by other studies that have involved interviewing people with dementia, such as Pratt & Wilkinson (2001). For this study the criteria for inclusion were that participants should:

1. have received a diagnosis of dementia,

2. have had this diagnosis shared with them and been able to retain this information,

3. be in a sufficiently early-stage of dementia to be able to talk with some degree of awareness about their experience,

4. be able to freely provide informed consent over the duration of the project.

Additionally, participants needed to be able to speak English fluently to take part in the interviews. Other studies (for example, Clare, 2003 and Pearce et al, 2002) have employed specific diagnostic criteria and assessment tools as a part of their inclusion criteria. These include the NINCDS-ADRDA criteria (McKhann et al., 1984) and the mini-mental state examination (MMSE; (Folstein, Folstein, & McHugh, 1975). Such an approach is often appropriate when recruiting through clinical services, where such measures are used as a component of the clinical assessment process, but wouldn't be as appropriate when recruiting in the way employed in this study, outside of a clinical setting. This study has avoided using such scales which place an emphasis on the cognitive deficits experienced by people with dementia and are often the focus of the diagnostic process. The focus of this study is not so much the cognitive deficits, which are one aspect of dementia, but the experience of people with early dementia in their understanding of it and how they manage the threat it presents. Therefore, the decision was made to use a less

cognitively oriented measure as a means of 'characterising' the sample. The measure chosen is the clinical dementia rating scale be (CDR; Hughes, Berg, Danziger, Coben, & Martin, 1982; Morris, 1986). This is a broad rating that includes an assessment of functional as well as cognitive capacities. It is presented as an interview and may be less likely to be perceived by participants in a negative, patronising or demeaning way as some cognitive and mental state examinations can (van Hout, Vernooij-Dassen, Bakker, Blom, & Girol, 2000). The CDR measures six areas of functioning (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care) on a five point scale (0 = none, 0.5 = questionable, 1 = mild, 2 = moderate, and 3 = severe). An aggregate score is calculated from the scores of the six areas of functioning. The most recent scheme for calculating the aggregate score can be found in Morris (1986). With regard to reliability and validity, Hughes et al. (1982) report inter-rater reliability as being good, with a correlation of 0.89 between independent rater's scores. They also report a good level of convergent validity with correlations with other clinical measures of dementia being significant at the $p<0.0001$ level.

The sample for this study consisted of nine persons with early-stage dementia, all of who had received a diagnosis. Of the nine, four were male and five female. The mean participant age was 65 years and 5 months, ranging from 58 to 76 years. Of the nine participants, one had received a diagnosis of vascular dementia; two had received a diagnosis of fronto-temporal dementia; one a diagnosis of dementia, but was unsure of what type; and five had received a diagnosis of Alzheimer's disease. Seven participants scored in the mild range (score = 1) on the CDR and two in the questionable range (score = 0.5). The questionable category relates to individuals who are experiencing memory impairment, but with little

significant impact on their day-to-day functioning. Hughes et al. (1982) describe this as a heterogeneous group including those with 'benign forgetfulness', functional difficulties including depression, and those that are in the very early-stages of dementia. In the current study, the two participants who were in the questionable range were considered to be in the latter group, given their contact with memory clinic services and their diagnoses.

The Researcher

One assumption of IPA is that the beliefs, values and experience of the researcher play a part significant role as they engage in interpretative activity. For this reason it is important for these to be acknowledged and then reflected upon with regards to the impact they may have on the interpretative process in the analysis of data. In the current study, the researcher is a Trainee Clinical Psychologist with experience of working with people across all stages of dementia from pre-training employment and clinical placements. One assumption was that participants with early-stage dementia would be able to provide a clear narrative of their understanding of dementia informed by past and current experiences. It was also assumed that they would describe a process of trying to understand their situation and manage the changes taking place.

Ethical Issues

Prior to commencing recruitment into the study ethical approval was obtained through application to the University of College London Committee on the Ethics of Non-NHS Human Research. A copy of the letter of approval can be found in appendix 2.

Several ethical issues were considered prior to commencing the study. Firstly, other studies that have looked at the experience of people with dementia (e.g. Clare, 2003; Pearce et al., 2002) have ensured, as a part of the procedure, that terms such as dementia and Alzheimer's disease are not used in discussion with the participant until they themselves have introduced them. However, in this study, the recruitment of participants is through the Alzheimer's Society, an agency that provides advice and support for people with dementia and their carers, using an advertisement aimed at people who have received a diagnosis of dementia. Therefore, it was felt that in this study it was not necessary initially avoid the use of the term dementia. However, labels relating to specific diagnoses, such as Alzheimer's disease or fronto-temporal dementia, were not used until participants had introduced them in reference to their own situations. This was to avoid imposing labels that may not have resonated with participants' understanding of their difficulties.

Throughout the interviews, the researcher remained sensitive to the potentially emotionally sensitive nature of the interviews. The emotional state of the participants was monitored, and if any signs of distress were observed, interviews were stopped, and participants asked if they wanted to continue or not. At no time was undue pressure exerted on participants to continue with interviews.

The issue of consent was raised with participants at several stages throughout their participation in the study. This is described in detail below. Consent was considered an ongoing process rather than a one off event in the context of the potential difficulties with memory people with early-stage dementia may experience. This issue was dealt with by periodically reminding participants about the aims of the project. This is based on the work of Crossan and McCoglan (1999), as cited in

Hubbard, Downs, & Tester (2002), who suggest this can be one way of maintaining the validity of consent when working with people with dementia.

Procedure

Upon expressing interest in participating in the study each potential participant was sent a 'Participant Information Sheet' (see appendix 3). This was designed with the person with early dementia in mind in that it gave details of the aim of the study, the procedure and covered consent and confidentiality without being 'over-informative' and creating a potential source of confusion for the person receiving it.

When the information sheet was sent out, arrangements were also made for the researcher to contact each potential participant to discuss whether or not they wanted to proceed with taking part. This was done by telephone, typically a week after the sheet had been sent out. If individuals wanted to participate after having reviewed the information sheet, a date was agreed for the first meeting to take place. Whilst nobody declined to take part at this stage, if any individual had declined the invitation to participate they would have been thanked for their interest and all personal information obtained would have been destroyed.

The initial meeting with all potential participants had several purposes. It was seen as an opportunity for researcher and participant to develop a rapport prior to meeting to complete the interview. It was also an opportunity to review the information sheet with each person and for them to have the opportunity to ask any questions they might have. This meeting was also used to discuss the issues of confidentiality and consent. Regarding the former, it was explained that all personal information and data recorded during the interviews would be kept confidential and

not shared, in an identifiable form, with people outside of the study. It would only be seen by the researcher and supervisor. It was also explained that all recordings would be made into typed transcripts which would be anonymous, with only the researcher being able to identify which transcript came from which interview. Following the completion of the transcribing, the recordings were erased. Finally, it was explained to potential participants that the study would initially be written-up as a component of the researcher's thesis and that they aimed to disseminate the results of the study through an appropriate peer-reviewed journal. Again they were assured that any data used in such a publication would be anonymous. Finally, each potential participant's attention was drawn to who they could contact if the situation arose whereby they had any concerns or queries about the study and their participation that they felt that they could not raise with the interviewer. These contacts were the principal researcher and the ethics committee.

Once the study had been discussed, confidentiality explained and any questions responded to, the issue of consent was considered. It was explained to each participant that once they had given consent, it was not binding for the duration of the study and that they were at liberty to withdraw their consent to participate at any time, without penalty to themselves. At this point it was also explained that if the participant had any concerns during the study they could contact the principal researcher or the ethics committee. Once all of this had been explained and discussed with each participant, they were invited to sign the consent form (see appendix 4 for an example of the form).

Following the initial meeting with each participant, a second meeting was arranged to conduct interviews. Qualitative data were collected using a semi-structured interview approach. Prior to commencing each interview, its purpose and

the aims of the study were reviewed, and the continuing validity of consent assured. Interviews were based around a schedule which, rather than containing specific questions, comprised of a series of topics. The topics were pre-diagnosis representations, diagnosis, post-diagnosis representations and managing/coping. Whilst guiding questions were generated prior to commencing the interviews, the process of exploring these areas was very much led by the participants' narratives. A schedule of guiding questions can be found in appendix 5. The interviewer used open-ended questions and a process of reflection to aid the participants in telling the story of their experience. Another area of consideration in the interviewing process was that of discussing participants' past experiences with them and the impact that possible memory difficulties may have on this. The participants in this study had early-stage dementia, so whilst it was recognised that they may have had some difficulties with recent episodic memory, they were less likely to have difficulty in accessing stored past memories and semantic information. The latter tends to be relatively well preserved in the early-stages of dementia when compared with recent episodic memory (Fox, Warrington, Seiffer, Agnew, & Rossor, 1998; Greene, Baddeley, & Hodges, 1996; Small, Molby, Laukka, Jones, & Bäckman, 2003). To aid recall during the interviews, questions were structured to promote recall, for example by attempting to keep information to one theme or idea per question and not putting individuals 'on the spot' during questioning. Alternatively, information was offered as a part of the question to act a cue to recall. This approach has been found to reduce anxiety and frustration in the interviewee and to reduce demands on memory recall, and thus promote recall in the person with dementia (Killick & Allan, 2001).

Throughout each interview, attention was paid to the continuing validity of consent, and if participants showed any sign of emotional distress as a result of the nature of the conversation, the interviewer checked whether they were willing to continue. The interviews often touched on areas of individual experience which were highly emotive. At these times, it was made clear that participants were not under any obligation to answer all of the questions put to them, and that if there were area of experience that they did not want to discuss they could freely decline to respond to related questions.

At the point of completion of the interview, the participant was engaged in a de-briefing conversation, the key aim of which was to ensure that the participant was not being left contemplating distressing or highly emotive issues without access to adequate support. All participants were offered the opportunity for further discussion once all of the data had been collected and analysed.

Data Analysis

Once the interviews were completed, audio recordings were transcribed by the author. Along with providing a workable document, the process of transcribing enabled the author to become increasingly familiar with the content of each interview. An example of an excerpt from a transcript can be found in appendix 6. Analysis of the data was performed using Interpretative Phenomenological Analysis (Smith et al., 1999). Before engaging in the coding and interpretive processes, each transcript was read and re-read a number of times to become familiar with the content. Then, working with each transcript, the key points were noted on the transcript itself. These key points remained as close as possible to the words of the interviewee. Next, a summary list of the key points was compiled (see appendix 7 for

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an example). From this list groups of themes were developed. In this stage of analysis related themes were put together under appropriate headings. This stage was conducted independently by the author and the research supervisor. Similarities and differences in the two theme lists were examined, and differences dealt with through discussion to reach a consensus of opinion. Selected transcripts were also reviewed by another, independent researcher with knowledge of qualitative methodology to ensure the validity of the emerging themes. An example of the themes from one transcript can be found in appendix 8.

Once themes had been developed for all of the individual transcripts, a composite list was compiled. This list was reviewed with the aim of looking for patterns of similarity and difference across the interviews, leading to representative themes from individual transcripts being grouped under main theme headings. As with the development of themes for the individual interviews, the process was completed by both the author and the supervisor, with the outcome being discussed and differences being managed through a consensus of opinion. Following this discussion, the process was repeated until it was felt that a coherent set of themes representing the psychological experiences described by participants in the interviews had been developed. Examples of the final list themes can be found in appendix 9. Once an agreed final set of themes had been developed, the interpretative process of understanding how these integrated with, or challenged, current theory was undertaken.

Through out the analysis process, the work of Elliott, Fischer, and Rennie (1999) was used as a guide to maintaining quality in the analysis process. They provide suggestions for quality control in the analytical process in qualitative research through the use of validity checks. These validity checks were developed

with the aims of: contributing to the legitimising of qualitative research; encouraging appropriate and valid review of qualitative work; encouraging better quality control through self and other monitoring of research processes; and furthering developments in qualitative approaches. The guidelines suggested by Elliott et al. (1999) include: the researcher owning her or his perspective through the recognition of her/his own values, interests and assumptions and the role these play in research; situating the sample; grounding the analytic procedure in examples from the data; providing credibility checks through checking how themes or accounts resonate with participants, using additional researchers as 'analytic auditors', and where possible triangulating with external factors, such as outcome measures; having a coherent narrative through results; defining the limits of the generalisability of results; and the narrative resonating with the reader or reviewer.

In this study, the appropriate aspects of these guidelines have been addressed. Earlier in this chapter the author's perspective was described in terms of its relevance to the research and the sample situated. Other researchers both involved in the study and independent to it audited the process of theme development in order to check the validity of the interpretation of the participants' accounts in the development of themes both within and across transcripts. Any differences of opinion in this process were discussed in order to reach a consensus. Issues relating to grounding themes in examples and discussing the generalisability of the results will be dealt with in subsequent chapters. Other intended validity checks included returning to those participants who were willing to engage in further discussion and checking with them the coherence of the narrative developed through the study.

Having considered the methodological approach used in this study, reviewed the areas that may give rise to ethical problems, and considered how to maintain the

validity of the results using the guidelines of Elliott at al. (1999), the following

chapter will discuss the results of the interpretative analysis in terms of the themes

that emerged and how they relate to each other.

Results

The analysis of the interview transcripts started with grouping the key ideas related to the participants' stories of understanding and experiencing early-stage dementia from the individual narratives. From this individual level themes were grouped to form a narrative of the experience of the sample as a whole. From this process two main overarching themes emerged around which this narrative is based. These themes are 'Understanding Dementia: It Will Get Worse', which represents the individual's knowledge and representations of dementia, and 'I Want To Be Me', which represents the lived experience of adapting to dementia. The first of these themes is constructed from a number of sub-themes. 'I Want To Be Me' has two components of 'Personal Dilemmas: Where Do I Stand' and 'Interpersonal Dilemmas: The Line Is Crossed', each of which is also constructed of further sub-themes. These themes are considered not to simply stand alone, but to interact to from a process of the experience of the person with early dementia in developing understanding of the threat it presents and how people my manage this threat. A graphic representation of the themes and how they may interact can be found in figure 4, below.

As described above, the main themes are constructed from sub-themes that emerged from the data. A summary of how each theme is constructed in terms of the sub-themes can be found in table 1, below. Additionally, a table of how each participant's data contributed to each theme can be found in appendix 10.This chapter will describe each of the themes in turn using excerpts from the transcripts to illustrate each idea.

Figure 4:   Organisation of the main themes of the current study

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                    ┌──────────────────────┐
              ┌────▶│ Understanding Dementia │────┐
              │     │                        │    │
              │     │   It will get worse    │    │
              │     └──────────────────────┘    │
              │                                   │
              │                                   ▼
              │         ┌──────────────────┐
              └─────────│  I want to be me  │◀───┘
                        └──────────────────┘
                        │                  │
              ┌─────────┘                  └─────────┐
              ▼                                      ▼
      ┌──────────────┐                      ┌──────────────┐
      │   Personal   │                      │ Interpersonal │
      │  Dilemmas:   │                      │   Dilemmas:   │
      │  Where do I  │                      │  The line is  │
      │    stand?    │                      │    crossed    │
      └──────────────┘                      └──────────────┘
```
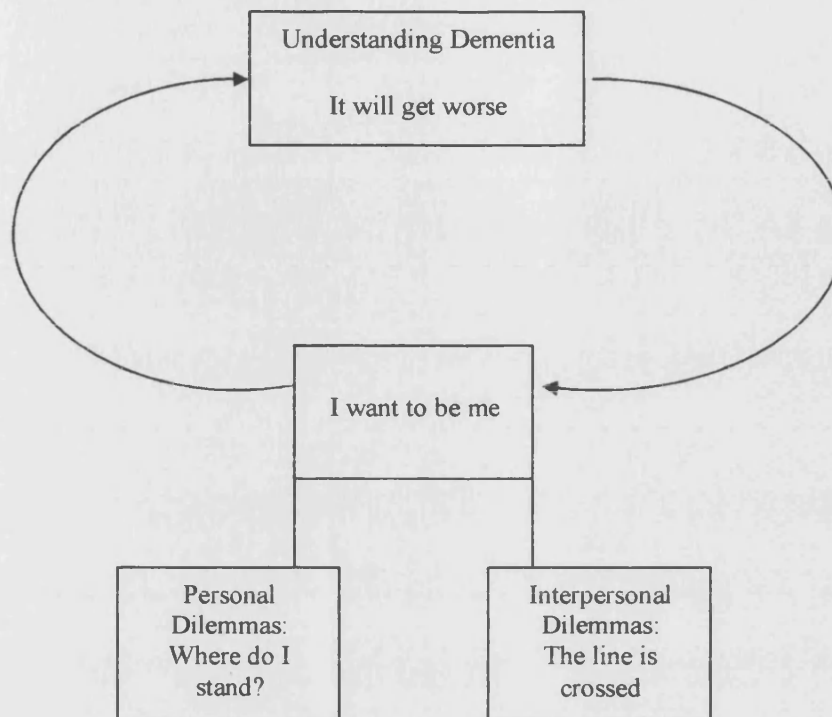
Understanding Dementia: 'It Will Get Worse'

This theme is composed of several sub-themes. These cover both how participants have developed their understanding of dementia and how they understand what dementia is and what it means to them.

Making Comparisons

From discussions related to how the participants had developed their understanding of dementia, it seemed that a key factor was their experiences with other people and from their own lives. In terms of other people, some had known relatives, friends or neighbours who had experienced difficulties similar to their own

Table 1:   *Summary of themes and sub-themes*

Overarching Theme	Themes	Sub-themes
Understanding Dementia: It will get worse		- Making comparisons - Certainties and uncertainties - How I understand dementia - It's possible to cope
I want to be me	Personal Dilemmas: Where do I stand?	- I want to be me but there are losses - I can carry on *versus* I can put an end to it - I will actively fight it *versus* I will passively accept it - Wanting to understand *versus* I want to avoid thinking about it
	Interpersonal Dilemmas: The line is crossed	- Problems are recognised by different people - Betrayal - Dementia has changed how people treat me - Some Professionals don't treat you how you expect - Some people tell me things, some don't - People should have a choice about being told

and through their observations and interactions with these people, ideas about dementia had been developed:

"apparently he could speak fluent Greek and French, now he can just go 'erohargh'" (participant 1)

"he seemed not too bad, but gradually it became evident that he actually did have Alzheimer's" (participant 2)

"gradually she became lower off, very slowly, you don't notice it" (participant 6)

For some this understanding developed from multiple roles, such as from being a professional, a relative, or carer:

"I've known loads of people [with dementia].......I've been nursing, district nursing a lot" (participant 3)

"it was my mother who went very weird" (participant 3).

"she became dirty, she became doubly incontinent, she became rude, she became outspoken" (participant 3)

Understanding also seemed to be coloured by the experience of interactions with different generations, particularly within families. For example, one participant,

in talking about her understanding of dementia, described her experience with his/her own father and child:

"There he is, he can't remember things or forgets things" (participant 4)

"_____ is, you know, training to be a doctor, and I sort of realised the other day that you know, it sounds as if, you know, that medication won't really help in the long run" (participant 4)

Some participants described how they made comparisons between themselves and others, with a particular emphasis on memory functions:

"I've yet to find anyone who in all honesty can not say that they have put something down.................come back to where you were and you think, 'oh what have I done with that'" (participant 1)

"talking of my sister and people of my age group, I kind of recognise they are much better than I am memory wise" (participant 6)

Along with the experience of others, participants talked about how they had drawn upon their own experiences to develop their understanding of dementia. Some of these areas overlap with those described above, in that people used their understanding of their experiences as carers, professionals and relatives to build their narratives. In addition, people described using their experience of past illnesses as a

model for understanding what was happening to them during the onset of their difficulties.

"when I was told the diagnosis of cancer, I didn't think that's it then, and I'm going to go through it and come out the other side" (participant 1)

"that was the similar sort of symptoms" (participants 3)

"perhaps one's experience in life erm colours your judgement" (participant 9)

Certainties and Uncertainties

The majority of the people who participated in the study spoke of recognition that dementia brings change, particularly in the form of facing decline and deterioration in their well-being:

"I have dementia and I'm going to reach a stage whereby I can no longer think as a logical person or do things in a logical way" (participant 1)

"there is no cure, you will not get better, you can only get worse" (participant 2)

"it just happens it's just deterioration" (participant 3)

"I know that it's going to get worse for me" (participant 4)

"what we call the last scenario, were not really there yet" (participant 7)

Whilst most described facing the truth of dementia in terms of decline, there was often uncertainty and a lack of clarity about what decline involves and what the future holds:

"I wonder if this is moving the thing forward a stage or whether it is one of those one off things" (participant 9)

"it does worry me that I might get worse" (participant 4)

"when is it going to kick in?" (participant 3)

"not given an idea of what to expect" (participant 1)

How I Understand Dementia

This sub-theme relates to how participants understood the concept of dementia. Whilst there were very divergent explanations of what dementia meant for individual participants, a clear pattern of themes emerged from the data. There are seven topics that make up this sub-theme, each of which will be described in turn. Some of the ideas expressed by participants were based on their own experiences, whilst others were based on their observations of other people they have known who have had similar difficulties to their own. However, no pattern of difference in the content of 'own' and 'other's' experience emerged from the data.

The first topic is *'understanding changes'*. This appears to describe how people view dementia and gives a sense of the changes that people experience as they, or others, begin to recognise these. Some participants described how dementia left people trapped, isolated and withdrawn:

"I end up in the 'cubicle' of being inside and looking out" (participant 1)

"Locked into your own little world" (participant 1)

"nobody even rang me up to see if I was dead or anything" (participant 2)

"she sort of cut off" (participant 6)

"I hope I never get like _____ where she's there in a little world of her own" (participant 9)

One particularly strong idea was that of memory. Some participants talked about memory as a difficulty and a change they had experienced:

"It was the business of these blank spaces" (participant 2)

"not being able to remember how to drive into town" (participant 2)

"I can't remember the words" (participant 4)

I hesitate over something due to the lapse of memory" (participant 5)

Some described dementia as not just being about memory. This recognition is described as being a change from previous ideas of dementia being a difficulty of memory:

"dementia also includes, as I say, organisational skills, erm, co-ordination skills, and memory skills, and I never used to use, consider these" (participant 3)

There was also a distinction between different types of memory, where changes were described in some types and not in others:

"my memory will go back centuries really" (participant 1)

"short-term memory is bad" (participant 5)

"people have no real trouble finding they can remember things that happened a long, long time ago" (participant 5)

A further distinction made between 'normal memory lapses' and memory lapses that were attributed to dementia:

"just normal memory lapses" (participant 5)

"even fit people can sometimes leave the tap on and flood the kitchen" (participant 8)

"doubtless I forgot things long before I ever heard of the word Alzheimer's" (participant 9)

Dementia was also described in terms of difficulties with thinking and how this slows down:

"clearly er, a potential mental problem" (participant 9)

"AD is not physically disabling, it is mentally disabling" (participant 9)

"the words that people were talking to me bouncing against a brick wall" (participant 3)

"I'm slow on the up take, on learning" (participant 6)

"I say can you go more slowly" (participant 2)

Related to this idea was that of not knowing or being muddled:

"He obviously hadn't a clue what was going on" (participant 2)

"the sort of confusion I was getting in" (participant 2)

"it's all er tangling up" (participant 3)

Others described experiences of confusion in terms of getting lost as a dementia-related change:

"I'm scared to go places because I get lost" (participant 4)

"I get lost" (participant 5)

"my wife will hand me a list and unless it's written down I'm completely lost" (participant 5)

Another of the topics related to how people represent dementia is that of 'labels'. This seems to relate to a differentiation between specific types of dementia (such as AD and VaD), dementia as a term in itself, and memory loss. Some made clear distinctions between the three:

"I always think about Alzheimer's as a disease with brains, not dementia" (participant 6)

"it would finish up going from Alzheimer's, in my definition, to dementia" (participant 9)

Alternatively, dementia was also considered to refer to a collection of different experiences:

"A collective term that is being used for various things" (participant 1)

For others it was not clear what label their difficulties could be given:

"some people might have the impression that Alzheimer's was a part of my problem" (participant 5)

One participant felt that the name for his difficulties was not important; it was what was happening and how to manage it that was more salient:

"the name is only a name" (participant 8)

"[I want to] be told what part of the brain it is" (participant 8)

Participants also described their understanding of the process of dementia in terms of ideas related to the topic 'Dementia is a pattern of change'. Some spoke of how dementia is a gradual process:

"gradually developing Alzheimer's" (participant 5)

"change came gradually" (participant 6)

There was also an idea that there are stages or a pattern of dementia:

"it would finish up from going from Alzheimer's, in my definition, to dementia" (participant 9)

"stages of Alzheimer's" (participant 9)

"if things fit into a pattern, the pattern would be Alzheimer's" (participant 9)

However it was also acknowledged that there is a degree of variability between people:

"[from one day being ok] to being absolutely, totally hopeless" (participant 2)

Regarding how people perceived the severity of dementia, on the whole it was discussed in terms of 'it's serious' and in a negative light:

"really rather cruel" (participant 4)

"a nasty sort of word" (participant 5)

"one of the nasty things that happen" (participant 5)

However, some participants reported that they saw a difference in severity between, for example, Alzheimer's, dementia and memory problems:

"it wasn't Alzheimer's well I thought "anything would be fine" (participant 6)

"dementia is alright" (participant 6)

"I was so elated that I didn't have Alzheimer's" (participant 5)

"[I] imagine that Alzheimer's could be sort of a worse situation than dementia, they forget different things" (participant 5)

Various ideas relating to the 'causes' of dementia emerged from the data. Some saw it as a part of an ageing process:

"At that stage in life you're stepping aside and letting other people getting on with it" (participant 1)

"always felt that dementia attacked old people" (participant 3)

"I wondered if we all go the same way" (participant 5)

"I've got this thing quite early really" (participant 7)

Another perceived cause of some types of dementia, in this case AD, is that it is an inheritable condition, with a genetic basis, that is passed from generation to

generation. This was talked about in terms of dementia running in the family and it being a difficulty for some and not for others:

"I didn't realise that it would be something that I would inherit" (participant 4)

"I felt that the girls would have the right sort of genes" (participant 4)

Some talked of a genetic basis having also considered that dementia is a part of the ageing process. This may suggest that there is a belief that there can be multiple causes in the same person, that individuals are prepared to hold and try different perspectives in their attempt to understand dementia, or they see it as complex and multi-faceted:

"if somebody's got this then there's a chance that others in the family have" (participant 6)

A participant with VaD saw the cause of his difficulties as being related to him/her having damaged his/her brain. Again this was in the context of already having suggested that dementia is a part of the ageing process. As with the situation above, this suggests that individuals may consider the general cause of dementia is ageing, a process that may have many ways of presenting itself:

"I know I have damaged my brain" (participant 1)

"I've got this problem on there that it's ruined cells" (participant 1)

There was also an idea that if people become socially isolated then this too can be a cause of dementia due to the lack of opportunity to interact with others:

"That was it, he was the only, she lost her husband, and he [other relative] wasn't there much" (participant 6)

"I spent too long doing things by myself" (participant 6)

"due to living alone of course" (participant 9)

Another perceived cause of dementia was people 'not trying'. This referred to people not 'exercising' their minds and 'giving up':

"she just gave up" (participant 3)

"if you had a brain you needed to keep it exercised" (participant 3)

With regard to 'how dementia is controlled and treated', it was seen to be irreversible or unpreventable. However, there were ideas about how dementia could be managed in terms of the progression stopped or slowed:

"I can't get over it" (participant 4)

"nothing much they can do about it" (participant 4)

"it can be stopped from progressing further" (participant 9)

"I don't think she went as far as to say it sort it out, cure it" (participant 9)

"I don't think there is anything one could have done to delay its onset" (participant 9)

Treatment ideas mainly focused on medication such as cholinesterase inhibitors:

"Once I was diagnosed and taking this Aricept, this [confusion] went" (participant 2)

"There is at the moment drugs out for people that if they have a stroke and if they can treat it quickly enough they can prevent the clots happening and settling on the brain" (participant 1)

However, there is some idea that even medication can not prevent decline:

"it sounds as if, you know, that medication won't really help in the long run, you know that it's going to get worse for me" (participant 4)

Finally, participants described the 'negative emotions' of early-stage dementia. On the whole these related to feelings of fear and anger. Some feelings of anger are

directed towards the way people with dementia find themselves being treated by others:

"some of them drive me bonkers "(participant 2)

"sometimes I'm absolutely furious" (participant 2)

Others felt anger towards the dementia itself:

"I hated the word" (participant 4)

"I hated my brain for doing this" (participant 4)

Some of the feelings of worry that were described related to the unknown future:

"new worries, what's going to happen?" (participant 2)

Others reported being concerned about the impact of symptoms, such as memory problems:

"despite that [checking] I still wonder [if I've remembered] and worry" (participant 9)

Finally, some participants spoke about being frightened, scared and upset about what was happening to them:

"the fear is not having control over my destiny" (participant 2)

"[dementia is] pretty depressing" (participant 4)

"I was very upset" (participant 7)

"although I was frightened I wanted to know" (participant 7)

It's Possible to Cope

The final sub-theme under the main theme of 'Understanding Dementia: It Will Get Worse' is related to how people reacted in terms of managing the threat and coping with changes. Participants described coping as being an individual process developed through the experience of managing the onset of dementia:

"coming to terms with it in my way" (participant 3)

"you learn more from doing that if you have to cope" (participant 4)

"some sort of strategies to get around these problems" (participant 5)

"It [coping] doesn't always work" (participant 8)

"you come up with all sorts of wrinkles [based on past experience] to make sure things get done efficiently and on time" (participant 9)

The participants in this study described how there are different spheres of coping, which individuals seem to use to different degrees, depending on their style of coping and past experience. Some reported that expressing the emotions related to the onset of dementia can be helpful:

"I have a little cry some times" (participant 4)

"much better to cry" (participant 4)

Others did not find emotional expression to be a helpful way of coping:

"having a good cry didn't help" (participant 3)

Many of the participants reported that they had found practical ways of coping with the threat and changes associated with the onset of dementia:

"I have to write things down" (participant 2)

"more practical ways of coping with memory" (participant 6)

"I try to be methodical" (participant 8)

"Having practical routines" (participant 8)

"I often check things several times until I'm happy" (participant 9)

Some found that medications such as cholinesterase inhibitors and anti-depressants helped them cope:

"Once I was diagnosed and taking this Aricept, this [confusion] went" (participant 2)

"this is a really good drug (participant 2)

However, others have found that medications have not helped them cope and have even prevented them from coping in ways that they would like to:

"I had to get off that medication and get on you know, be a real person....it's normal to have a cry" (participant 4)

"it [Aricept] made me very wild.....I was pleased to stop it" (participant 8)

Friends were also regarded as a coping resource by some. This was in terms of both practical help and emotional support:

"friends have been very supportive" (participant 2)

"having someone to talk to" (participant 2)

"an excellent gang of friends" (participant 3)

Finally, having information was seen by participants as both a helpful adjunct to coping and as being not so helpful:

"if I had more information then I can better deal with it" (participant 2)

"it helped me [to have information] very much because I became aware of it" (participant 6)

"it was the truth; I had to work with that" (participant 7)

"it helps to have it [information]" (participant 8)

"there might be some advantage in hearing it [information]" (participant 9)

Some participants, including those who felt that information is important in coping and adjusting to dementia, also considered that at times it is possible to have too much information, a situation that is unhelpful in coping. They also recognised that information may not be helpful to everybody with early-stage dementia, and may only help those who want to know:

"to start with I might have been given too much [information]" (participant 6)

"in case you get the wrong answers" (participant 9)

"information should be there if the person concerned wants to know" (participant 9)

I Want to be Me

This overarching theme relates to the participants' reports of how they reacted to the changes and threat associated with being faced with a diagnosis of early-stage dementia. The overarching theme is constructed from two further themes, *'Personal Dilemmas: Where do I stand?'* and *'Interpersonal Dilemmas: The line is crossed'*.

Personal Dilemmas: Where Do I Stand?

The first of these themes relates to a series of personal dilemmas that they appeared to be engaged in a process of exploring as they experienced dementia in their day-to-day lives. The first sub-theme in this group is *'I want to be me but there are losses'* which seems to represent the desire to remain the same person whilst facing the threat of dementia-related changes. Other sub-themes represent how reactions are varied, with some actively engaging with understanding the threat, *'Wanting to understand'*, and others actively avoiding thinking about it, *'I want to avoid thinking about dementia'*. Others represent tensions for the person with early-stage dementia, such as *'I will fight it versus I will passively accept it'*. These sub-themes will now be discussed individually using examples from the transcripts of the interviews to illustrate them.

I Want To Be Me But There Are Losses

The onset and diagnosis of dementia represents a threat to the person in the changes it precipitates. These may be concrete, symptom related changes or changes in how the person perceives self and is perceived by others. This sub-theme represents participants' desires to resist change and maintain their pre-dementia view of themselves in the face of the changes and threats to self that dementia represents. Some participants described how they did not want dementia to change them:

"forever trying to hide the fact that I might not be as I was 10 years ago" (participant 3)

"I don't want people to say oh, you know, 'you've got to make allowances for her'" (participant 3)

"I don't want to be just sitting round being looked after" (participant 4)

"I want to be me" (participant 8)

"I want to be capable still" (participant 8)

This desire to want to remain the same is also reflected in how participants talked about maintaining independence:

"I don't want to lose my independence" (participant 3)

"that's what's important, to know what I'm like, I like to be independent"

(participant 2)

Others participants talked about how they perceived little, if any, change in some aspects of themselves as a result of the onset of dementia, comparing their post-diagnosis self to their pre-diagnosis abilities:

"I'm as active as I always was" (participant 9)

"no I don't think I've changed" (participant 9)

"I can still make sense of things" (participant 8)

"it doesn't mean to say that you have to stop doing things" (participant 8)

"why shouldn't I have my own ideas" (participant 2)

Whilst participants described this strong desire to maintain their perceived pre-diagnosis sense-of-self, they also described how dementia-related changes are a source of current and potential loss. The losses described by participants covered a range of aspects of their lives, from loss of roles to loss of confidence. People also described losses that they had already experienced along with those that they feared in the future:

"I'd hate to be in the situation whereby if I diminish so far that I'm not able to look after her" (participant 1)

"losing my autonomy, that really, really bothers me" (participant 2)

"a complete loss of confidence" (participant 3)

"I'm giving up various activities because I have the onset of Alzheimer's disease" (participant 9)

"I've been divorced from my well-being, my livelihood and my pleasure as well" (participant 8)

"it took away the future, our future" (participants 3)

Some participants saw it as a loss or a waste of their lives:

"a waste of a lot of time in life" (participant 4)

"a termination of a long life really" (participant 3)

I Can Carry On *versus* I Can Put an End To It

This sub-theme depicts reacting to the threat of dementia as being a tension between carrying on with life in the face of change and ending it all and seemingly both about controlling change. Participants seemingly did not hold one view in this

dichotomy, but tended to switch between the poles, sometimes in some situations talking about wanting to continue with their lives in the face of the threat and changes related to dementia. At other times, in other situations, the same participants talked about ending their lives in the context of this offering them the ultimate control over the changes to self that dementia may bring. Carrying on was described in such ways as:

"My determination I shall still carry on looking after my wife and doing my cooking" (participant 1)

"I'd rather go on making a bit more of this life" (participant 4)

"You've got to keep things going" (participant 6)

Carrying on was also represented through the idea of optimism with participants talking about ideas of how the situation with regards to the medical treatment of dementia may change and improve in the future:

"Looked forward to hearing the day the blips on the brain are healing..." (participant 1)

"I'm looking forward to doing new things" (participant 1)

Others talked about optimism in terms of how in some ways good things had come out of their experience of early dementia, which were also seen as reasons to carry on. These ideas included:

"a lot of good has come out of it" (participant 3)

"the support of friends has come out of it" (participant 3)

"I think there might be a positive side" (participant 2)

Whilst on one hand participants talked about carrying on with life in the face of change, they also discussed their thoughts about ending life through suicide. This was mainly talked about as a way in which there was some control over the changes they faced in that people described suicide as the ultimate way of controlling dementia-related changes at the time they become too great a threat:

"either sort of commit suicide or carry on" (participant 4)

"If it should be the case that I'm going to sit in the corner dribbling out of the side of my mouth and soiling my clothes then I shall put an end to it" (participant 1)

"I will not, ever, suffer dementia seriously" (participant 3)

"if I felt that it was getting to that stage I will cope with it then, but not until then" (participant 3)

I Will Actively Fight it *versus* I will Passively Accept it

Another sub-theme that emerged related to how people react to the threat of early-stage dementia was that of fighting it versus accepting it. On one hand, some participants described taking an active stance in fighting the changes that accompany the onset of dementia:

"I'll stand me ground and fight it at the moment, in my own way on my own" (participant 1)

"I won't go down without fighting" (participant 1)

"I can confound these people [by fighting it]" (participant 9)

"realising that you've got to go on trying" (participant 4)

"I'll have to get through somehow" (participant 4)

Other participants described how they tended to take a more passive approach, accepting dementia and the changes that it brings. However, as with the carrying on/ending it all theme, some of those participants who described fighting the changes also described how at other times they were more accepting of the changes:

"just something that's full of funny things that I have to put into my body everyday" (participant 4)

"you can't do anything about it" (participant 7)

"I was a bit of a pin cushion" (participant 7)

"I don't go out very much now" (participant 4)

"but you know, that's how life is" (participant 2)

As with the previous sub-theme, this theme appeared to be dichotomous in nature, either actively fighting change or passively accepting. However, it may be that it is more of a continuum, where people are more or less active in resisting change.

I Want to Understand but Sometimes I Can't Think About Dementia

This sub-theme represents another personal dilemma that emerged from the data. The majority of the participants talked about how they wanted to understand what is happening to them:

"knowing and understanding is a lot better than playing around the edges" (participant 1)

"I would like more information" (participant 2)

"it's just natural, I've always had an enquiring mind" (participant 3)

This is despite the fact that for some, it was a frightening experience finding out that one has dementia:

"although I was frightened I also wanted to know" (participant 7)

Some described not just simply wanting to understand what dementia is, but why they happened to develop it and what may have caused it:

"you go through your life with a toothcomb thinking what can have caused this" (participant 3)

"I just wonder why, whether I've gone wrong" (participant 4)

"I think that the _____ thing could be a causal one" (participant 8)

"what has happened to make this happen?" (participant 9)

Some participants talked about wanting to understand what will happen in the future:

"new worries, what's going to happen?" (participant 2)

Others described how they wanted to understand their new experiences in context with existing experiences:

"that's fitting a situation into a framework......." (participant 9)

Whilst most described wanting to understand what was happening to the, some of the same people described wanting to avoid thinking about dementia and the implications it has for them. Rather than this being a situation where people take one stance or another, they tend to switch between both. This is not a passive approach whereby people simply ignore what is happening to them; the participants described actively avoiding thinking about their experiences, with some giving examples of strategies they used to achieve this:

"I'm facetious with it ..." (participant 1)

"Perhaps dementia I didn't like the sound of so I pushed it out of the way" (participant 3)

"I suppose the barriers had gone up at that stage" (participant 3)

"I don't want to know anymore than that" (participant 6)

"[thinking about] it made me scary of what is going to happen to me" (participant 6)

Interpersonal Dilemmas: 'The Line Is Crossed'

This final theme, the second theme under the '*I want to be me*' overarching theme, is constructed of three sub-themes that relate to how people with early-stage dementia find others respond to them. This includes the reactions of professionals and how they treat sharing diagnoses and information. It considers how relationships may have changed as people become aware that an individual has early-stage dementia. Here some participants talked about the experience of the stigma attached to being a person with early-stage dementia.

Dementia Has Changed How People Treat Me

Some participants found that people placed too much emphasis on dementia as a significant part of the participant's identity, leading to day-to-day events being blamed on dementia when the person with dementia saw no connection:

"To those near to me it is too easy for them to turn around and say that I'm doing such and such a thing because I have dementia" (participant 1)

"they wouldn't have done that had they not known that I had dementia" (participant 2)

There was a sense of people being overly protected by other people to the point that some participants felt restricted:

"Wife is over-cautious" (participant 1)

"told her mother, who was my ex-colleague that I shouldn't be driving because I had dementia" (participant 2)

"when people are over protective" (participant 2)

Other people found that people around them could be overly pessimistic, especially when the person with dementia is trying to be positive about their situation:

"All I want is those near to me, instead of looking on the black side, put a hand out" (participant 1)

There was also a sense of some people not having their difficulties acknowledged, and that this can be just as problematic as when people attribute too much to dementia-related changes and are too supportive:

"they probably don't realise that I need help" (participant 4)

"_____ gets cross with things that I can't, that are difficult" (participant 4)

"my [partner], I think, said, "oh, you should remember" (participant 4)

The ways in which people found themselves being treated by others led to perceived losses. One participant talked about being treated like a child in the sense of the loss of adult status and independence:

Tended to treat them like a child" (participant 3)

Other losses, which have already been discussed, that are related to how people treat people with early-stage dementia include independence:

"Doesn't let me out of her sight" (participant 1)

"it's what other people think is appropriate for me" (participant 2)

Although many participants reported instances when people had treated them in ways that were unhelpful, some talked about how other people had been helpful:

"they're trying to help people like me" (participant 4)

People also spoke of the stigma they felt was attached to dementia. This included a sense of being excluded by others, who do not have dementia:

"they were 'over there' in a room" (participant 2)

"it was like you must not get near these people" (participant 2)

There were also ideas related to a loss of dignity and embarrassment in the changes:

"lose your dignity perhaps I'm trying to say" (participant 3)

"I wish the room would open and the floor would open and swallow me up" (participant 9)

Some described how they felt that the label of dementia is one that comes with a lot of emphasis once it has been applied to somebody:

"you're the other side of the fence now" (participant 8)

"once you've got big D you're in a big heap" (participant 8)

"just the other side of the line" (participant 8)

For some, the stigma of dementia is significant enough that they are concerned about others finding out about their difficulties:

"he's going to find out that I've lost my memory" (participant 5)

Problems Are Recognised by Different People

The way in which other people reacted to the participants was also evident in relation to who initially recognised the changes in the person with dementia. Some reported having noticed the changes themselves, whilst others talked about others noticing the changes first. Sometimes the person with dementia noticed changes that others did not acknowledge:

"I knew something was wrong" (participant 2)

"I kept saying it's not stress, it's something else" (participant 002)

"I began to find I couldn't remember things which I could" (participant 004)

"I'm aware that I've been forgetful for some time" (participant 9)

"I'm misconstrued and misunderstood until I...blow" (participant 1)

Conversely, some people noticed changes that the person with dementia did not:

"I hadn't really appreciated that it could be a problem until [my wife] decided that this was getting a bit much" (participant 9)

"I think one or two of them realised that there was something there I think" (participant 7)

"I didn't think you were aware" (participant 006)

Betrayal

Participants described how they often felt betrayed to some degree as people talked about them and discussed dementia behind their backs:

"I felt there was treachery afoot" (participant 1)

"Discuss it with me, I'll do anything" (participant 1)

"I had a car accident, and that was the pre-text that got me there" (participant 3)

"'are you saying you can't remember because you don't want to tell me or can you genuinely not remember'" (participant 3)

"people tend to talk about them behind your back rather than to your face" (participant 8)

Some people gave possible reasons as to why people might have kept things from them:

"people do this because they are shielding the person with dementia" (participant 8)

"they're talking about me behind my back, there's something [serious] going on" (participant 9)

Some People Tell Me Things, Some Don't

This sense of betrayal also extended to the relationship participants had with the professionals they came into contact with, particularly in relation to the sharing of diagnoses and giving of information. This sub-theme describes the experience of receiving information and highlights the variability people experienced. Individuals described how often, one person would be helpful and another not so helpful. Experiences of not being told included:

"they never tell me anything" (participant 2)

"nobody has ever said anything about symptoms, ever" (participant 2)

"I think that they were a bit secretive about things" (participant 4)

"I don't think they offered much as to what's happening" (participant 7)

"what we don't know is what the long-term prognosis is" (participant 8)

There also seemed to be a reluctance to share information about the assessment process and give understandable feedback from any tests:

"the memory test, ... no feedback what so ever, even when I asked" (participant 4)

"I thought what on earth is all this [testing] leading to" (participant 8)

"I honestly don't know exactly what they were doing or what they were trying to get for, to" (participant 7)

Some participants described how in some cases, professionals did share information, but it was presented in such an unclear way that it didn't help:

"what does it mean?" (participant 2)

"went into a lot of terms that I couldn't take on board fully" (participant 1)

"very medical and dense" (participant 8)

As a result of the apparent reluctance of some professionals to share information and that when it was shared it was often unclear, some participants talked about how difficult is was for them to know where to turn to find out the things they wanted to know, and some described relying on 'picking things up' as they went along:

"I don't know how to get that sort of information" (participant 2)

"the average man in the street who doesn't know about this" (participant 8)

"it's only through hearsay or picking things up" (participant 2)

"The general feeling that we've picked up so far..." (participant 8)

Although some people had a difficulty in getting the information they wanted from some professionals, there are those who had a positive experience of professionals sharing diagnoses and information with them in a manner that was understandable:

"they were showing me some overgraphs [scans]" (participant 7)

"GP's straight forward explanation...was very helpful to me" (participant 2)

"it helped because he was the only person who seemed to tell me the truth, that was what I wanted" (participant 2)

"you can follow it, you know what he's talking about" (participant 3)

"she could tell me things about it" (participant 4)

People Should Have a Choice about Being Told

Participants also expressed some ideas about how they thought information and diagnoses should be shared. Most of these ideas were based on people having a choice as to whether or not they are told of their diagnosis and receive information:

"It comes down to this business whether people with terminal illnesses should be told..." (participant 3)

"I think most people should know" (participant 3)

"we have a right to know" (participant 3)

"if people want to know then they should be able to know" (participant 8)

"information should be there if there person concerned wants to know" (participant 8)

"It was the truth; I had to work with that" (participant 7)

There was also an idea that there were some people who would and others, who would not, be able to cope with their diagnosis being shared with them or being given information about their difficulties:

"they couldn't have called it Alzheimer's to her" (participant 6)

"they could say, 'your memory is going'" (participant 6)

"a strong willed girl…I think she could take it" (participant 6)

"she could take the truth" (participant 6)

Some Professionals Don't Treat You How You Expect.

Relationships with professionals were also important to some. This was separate from the practicalities of diagnosis sharing and being given information, and related more to rapport with professionals. People seemed to prefer professionals whose personal style suited their needs, such as taking a direct approach. This was seen by some as being as important as any action that professionals took:

"the hospital needs the, needs the patient, so, the patients have to be on tack [tap], there" (participant 7)

"they just put us in our beds and that was it" (participant 7)

"If I'm a patient, nobody seems to care" (participant 8)

"you would like to know that you have the time to explain if you have difficulties explaining" (participant 8)

"the bedside manner wasn't what it should have been" (participant 1)

Some found that when the professional's approach matched their expectations, this was very helpful.

"we had this sort of rapport between myself and the neurologist" (participant 8)

"his manner was more important than what he did" (participant 7)

"I can talk to him [GP], so as long as he hangs on in there we'll be alright" (participant 3)

Summary

The themes that have emerged from the data represent the experience of people with early-stage dementia as they develop an understanding of dementia and develop ways of managing the threat to sense-of-self that it represents. At one level people are developing their knowledge and representations of dementia. This is represented by the theme 'Understanding Dementia: It will get worse'. At another level there is the lived experience that is represented by the overarching theme 'I Want to be Me'. This reflects the two themes of 'Personal Dilemmas: Where do I stand' and 'Interpersonal Dilemmas: The line is crossed'. These themes represent the

decisions and challenges that people with early-stage dementia face in day-to-day

life. Knowledge and representations interact with the lived experience as they inform

the decisions that people with dementia have to make in relation to the dilemmas that

they face.

The next chapter will consider how the results fit with the SRM in more

depth and will further consider the issue of the threat to sense-of-self and how this

may or may not be accommodated within the existing model.

Discussion

The analysis of the participants' narratives of their understanding of early-stage dementia yielded two overarching themes of 'understanding dementia: it will get worse' and 'I want to be me'. This chapter will briefly summarise the findings described at length in the results chapter and then consider each of the research questions in turn in relation to the results. Following this there will be a discussion of the results in relation to what they add to the understanding of the experience of early dementia and consideration of further areas of research. There will also be some consideration of any methodological limitations that the study may have, and the implications these have for the validity of the results. Finally, there will be a discussion of the implications of the study for clinical practice.

How People with Early-Stage Dementia Appear to Understand Their Condition: A Summary of the Results

The findings of this study have confirmed that people with early-stage dementia are able to hold cognitive representations about their condition as represented by the theme 'understanding dementia: it will get worse'. The data gathered from the interviews suggests that the representations held by people with early-stage dementia are constructed using a range of ideas that incorporate biological, psychological and social dimensions within an explanatory framework. Participants seemed to make comparisons with the experience of others and their own past experience in order to develop these ideas. They also use their own experience from different roles in life, including having been a carer in the past, professional roles, and their current role as a person with dementia. Most of the

sample also expressed a mixture of certainty and uncertainty in their understanding of what dementia is and what the future may hold. The participants used a range of strategies that they use in order to cope with the threat that early-stage dementia represents, based on their understanding of dementia.

In addition to the theme relating to how participants understand, or represent, dementia, a second theme emerged from the data which illustrates the day-to-day experience of living with dementia. This theme, termed 'I want to be me', is constructed of two sub-themes, both dealing with the dilemmas that people with early-stage dementia seem to face as they manage the threat the condition presents. The first of these sub-themes relates to individual, personal dilemmas in which people with early-stage dementia describe how they are faced with a struggle to maintain their prior sense-of-self whilst facing and acknowledging the fact that dementia leads to changes and losses. The dilemmas that were expressed included wanting to fight dementia-related changes versus accepting them, carrying on versus ending it all, and wanting to understand dementia versus not wanting to think about it. The second sub-theme relates to interpersonal dilemmas. This portrayed the interpersonal difficulties that the participants encountered. These included the observations that other people responded differently to them; feeling betrayed by family, friends and professionals; and experiencing conflict with other people in relation to what they and others considered, or not, to be dementia-related changes.

These two main themes of 'understanding dementia' and 'I want to be me' reflect a cyclical interaction, in that people's understanding of the condition is seen to inform their day-to-day lived experience as they engage in managing the threat dementia presents and attempt to resolve the dilemmas they face. In turn, as they engage with these dilemmas and attempt to reconcile them, they are adding to their

understanding of dementia through their personal and interpersonal experiences. Through this interaction the individual engages in a process of adjusting or maintaining his or her sense-of-self as understanding develops and dilemmas are faced.

The Research Questions

What representations do people with early-stage dementia have following diagnosis?

The first question posed by this study was to enquire what representations people with early-stage dementia have of their difficulties following diagnosis. The SRM of Leventhal et al. (1984) attempts to explain how people make sense of and manage the threats to sense-of-self posed by illness and disability. This model developed out of the Parallel Response Model of Leventhal (1970) which proposed that, in understanding illness, people form cognitive and emotional representations of threat which are acknowledged and managed in parallel processes. It is proposed that symptom and illness information is symmetrical, in that people use information from physical symptoms to define illness labels and conversely search for symptoms to confirm labels. Information is available from bodily experiences, social interactions (with friends, family, carers, professional and the media) and past experience of illness (Leventhal et al., 1980). Illness representations are considered to have five elements (Leventhal et al., 1997). These are identity (label and symptoms), time line (time to develop and duration, i.e. chronic, acute, or cyclical), consequences of the health threat, causes and controllability. These representations are believed to lend themselves to the development of strategies to manage the threat that illness presents, which sit alongside more formal interventions.

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From the data gathered in this study, the sub-themes that combine to make up the overarching theme 'understanding dementia' seem to reflect many of the components of illness representations. Each of the sub-themes will now be considered in relation to the content of illness representation as described by Leventhal et al. (1997) and how they developed.

Identity

This component of illness representations is reflected by 'Understanding changes' and 'Labels', which are sub-themes of 'How I understand dementia'. The data in the first of these describes the symptoms that people experience, of which there is quite a wide range. Most commonly, and not unsurprisingly, the majority of people reported memory difficulties as being a key symptom of dementia. However, others talked about a slowing down in general thinking processes, confusion in terms of being muddled and getting lost, and becoming cut off and unable to communicate with others. Various labels were discussed including dementia, Alzheimer's, fronto-temporal dementia, and memory loss. On the whole these were considered to be discrete difficulties with each having a different level of severity along a continuum. It was considered that Alzheimer's was the most serious, with dementia and memory problems being considered as decreasing in severity. Not unsurprisingly, those who used a label of dementia to describe their difficulties described relief at having dementia in relation to the possible alternative of, for example, Alzheimer's. At an extreme, in one case the participant recalled being told not to worry because he only had dementia, and not AD. However, at the same time, there was some idea that dementia is a collective term for a range of difficulties.

It was not completely clear from the data where this apparent confusion related to labels had emerged from; however, there was some suggestion that these labels may be used interchangeably at the time of diagnosis-sharing, with terms such as memory problems being used as euphemisms for describing specific dementias. This use of euphemism in the sharing of diagnosis has been described in the literature (Audit Commission, 2000; Downs et al., 2002; Gilliard & Gwilliam, 1996; Cody, Beck, Shue, & Pope, 2002) and appears to continue to be an issue. The question of the perceived difference in the severity of dementia and Alzheimer's may also be related to the sharing of diagnoses. It has been found in the past that some health professionals tend to minimize the difficulties of people with dementia when sharing diagnoses as a means of managing their own anxieties in sharing such information (Marzanski, 2000; Downs et al., 2002). This apparent confusion, with dementia being considered as less severe than conditions given specific labels, may have arisen from such minimization of difficulties at diagnosis. Alternatively, this confusion may stem from the so-called "alzheimerization" of dementia (see Kitwood, 1997), where over the last 30 years there has been an increase in the use of Alzheimer's as a label for what was previously known as 'senility' or 'senile dementia'. Its use has grown from a small numbers of professional in the dementia field to the point of it becoming a household word. Kitwood describes the changes in the use of Alzheimer's having come about through the use of the label to attract funding into research. Today, the term 'Alzheimer's' has two meanings, the first in reference to a broad category of neurological pathology and the second, more general term used to replace 'senility'. This may lead to confusion in interactions between health professionals and people with dementia when the term Alzheimer's is used as each group may have its own, different understanding of what the term means.

Time Line

The time line component of the illness representations of the participants in this study was represented by the sub-theme 'Alzheimer's is a pattern of decline'. The general consensus is that dementia has a gradual, slow course of decline involving successive stages, and that ultimately it is a life-long condition. There is some suggestion of variability in the time line, both between individuals and between different types of dementia.

Consequences

The consequences of dementia, as described by this sample, are not included in the 'Understanding Dementia' theme, but are a part of 'I Want To Be Me', as they are seen as a part of the 'I want to be me but there are losses' sub-theme. The main consequence of dementia described by the participants was that of loss. This covered many different areas of loss, including the loss of roles, loss of independence and the loss of future possibilities. Some considered receiving the diagnosis of dementia as indicating the end of their life, suggesting a belief that it brings an end to people's pre-diagnosis sense-of-self. This may reflect the self-adjusting style of coping described by Clare (2003). The perceived threat to sense-of-self for some may be so great that, for those who adopt a self-adjusting stance, managing it requires a level of adjustment that brings an end to the pre-diagnosis sense-of-self as the person with early-stage dementia sense-of-self develops.

Causes

A wide variety of possible causes were described by participants. A predominant theme was how dementia was seen to be related to the ageing process.

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This was not just in terms of physical decline in the ageing process, but as a social process where people may be at a point in their life-cycle where they are taking a less active role in life. This reduced activity was described as being a contributing factor to dementia. Other physical causes included a genetic component to dementia, with difficulties 'running in the family', and brain damage. Other psychosocial causes of dementia included being lonely and people giving up and not trying. It seemed that people recognised that their might be more that one causal factor contributing to their difficulties. For example, some recognised a physical component in terms of their brain having been damaged, whilst at the same time describing that the ageing process contributed to this difficulty. This biopsychosocial understanding of dementia in lay representations of the condition reflects the ideas of Kitwood (1997) who argued against the dominant, purely neurological theories of dementia in favour of explanations that are more inclusive of the social context of dementia. With the participants in this study, whilst there was recognition that physical processes unpinned their difficulties, they included psychosocial factors as contributing to their condition. This supports that findings of a study by Coulson, Marino and Minichiello (2001) who found that, when asking older people about the prevention of VaD, people gave explanations that included biological and psychosocial factors.

Controllability

This element of illness representations seems to be reflected in the idea of 'how dementia is controlled and treated'. There was some idea that the progressive decline in dementia could be controlled, and in some cases stopped, but that the changes that people experience cannot be reversed and that the onset of difficulties cannot be prevented. The main mechanism of control described was the use of

medication, with some consideration for maintaining cognitive function through 'exercising one's mind' using puzzles and crosswords. This is interesting in respect of the way that the causes of dementia are described as being a combination of biological and psychosocial factors, yet the dominance of physical explanations returned with regard to intervention, with only some awareness of potential psychosocial interventions. This may be the result of the continuing emphasis on the dominant medical model in dementia care. Alternatively, this may reflect a gap in the knowledge of people with early-stage dementia in the psychosocial interventions and services that may be available to them. Whilst there has been some investigation of the knowledge and use of services in relation to people who are the carers of people with dementia (e.g. Toseland et al., 1999), there appears, to date, to have been little, if any, research from the perspective of the person with dementia.

It was expected that some ideas regarding the illness representations of people with early-stage dementia would emerge from the data in the form of the elements described by Leventhal et al. (1997) as the interview schedule was constructed in order to explore these elements. However, it has been surprising how broad these representations are and how they incorporate a spectrum of biological and psychosocial ideas. These ideas are often not held separate from each other, but it seems that people are integrating them to develop their individual models of dementia. An example of this integration of ideas in the literature is the personal account of Morris Friedell (Friedell, 2002) who describes the experience of facing the changes and threats that dementia presents. However, it is notable that when people consider how dementia is controlled that the dominance of the medical model seems to prevail.

Leventhal et al. (1980) describe how the information that is used to develop representations is drawn from three basic sources. These are bodily sensations, information and interactions with the social environment, and past personal experiences of illness. These are reflected in the results of the current study through the 'making comparisons', and 'some people tell me things, some don't' themes.

'Making comparisons' refers to how people use multiple sources of information based on comparisons to others and their own past experience in developing their illness representations of early-stage dementia. These comparisons come from experience in different roles, as a carer, a relative, a friend, as a professional, as a person with early-stage dementia, and as a person who has experienced other health threats. People also use the information they are able to gain from health professionals. However, the sample in this study described how information was not always forthcoming from this source and at times it was unclear leading to the sort of confusion described above under the heading of identity.

The SRM proposes that not only do people construct cognitive representations of illness threat, but that the emotional impact of illness threats is dealt with by individuals in a parallel process. In early-stage dementia, people report experiencing a range of negative emotions in response to the threat their condition represents. These include fear, shock and anxiety.

The formation of illness representations provides a guide to coping with the threat-to-self presented by illness. Having cognitive models of illness results in symptoms being available and tangible to the individual which allows for the ongoing formation and evaluation of coping strategies. The more concrete the representation, the more specific the goals for action (Leventhal et al., 1980). In this sample of people with early-stage dementia there was a lot of evidence that

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suggested that individual representations of the condition influence the formation of goals and coping strategies.

Firstly, it was considered by most that coping with the threat early-stage dementia presents is possible. There was suggestion that approaches to coping were individual processes, based on a person's past experience of coping and her or his representation of dementia based on the five elements of representations discussed above. The importance of information in the development of representations leading to coping was acknowledged by the participants. With regard to how people actually coped, there was an emphasis on practical coping strategies used to manage symptoms. There was also an acknowledgment of emotional coping being a component of managing the threat early-stage dementia presents. In addition to these areas, friends and social contacts and medication were also regarded as potential aids to coping. This suggests that the biopsychosocial theme that runs through the illness representations of people with early-stage dementia continues on through their approaches to managing the changes and threat that it represents. The idea that these personal approaches to coping reflect a more biopsychosocial understanding also suggests a difference in how people with early stage-dementia consider how it can be managed compared to the apparent dominance of biological approaches in more formal interventions used in dementia care, as was discussed above under the heading 'controllability'.

Whilst the data collected in this study suggested that people with early-stage dementia develop illness representations, which they use to develop ways of managing their condition, most of the participants described a degree of uncertainty about what to expect in the future. They reported not having had the opportunity to discuss future symptoms at the time of their diagnosis. For some this was an

agreeable situation, as a part of their coping style involved a preference for not considering the future. This relates to the findings of others, (e.g. Clare, 2003 and Marzanski, 2000) who have found that some people with dementia actively avoid thinking about it as a part of their coping style. However, for some who did want to know what the future had in store, it seems that a lack of information left them unable to form representations about what to expect. This in turn might lead to difficulty in forming ways of coping with regard to thinking about the future and making future plans. It has been demonstrated in other studies (e.g. Pinner, 2000; Clafferty, 1999; Sullivan & O'Conor, 2001) that this is an important area for some people with early-stage dementia in terms of making decisions about their future that may become more difficult, or eventually impossible, to make as changes in functioning and capacity unfold.

Overall, the findings of this study reflect how people with early-stage dementia develop illness representations that are similar in their content to the representations that people have been suggested to develop for other illnesses. The representations the participants in this study have of their condition reflect the attributes described by Leventhal et al. (1997) of identity, time line, consequences, causes and controllability. The process of representation formation and illness threat management described by the participants in this study appears to follow the pattern described by Leventhal et al., (1984) in their self-regulation model. There is evidence of cognitive representations of the condition and the parallel representations of the emotional impact of early-stage dementia, both of which contribute to the formation of strategies for coping with symptoms and emotional responses. This indicates that that an illness involving cognitive changes and impairments does not preclude the SRM's applicability. The importance of information gathered from personal

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experience and social interactions, as described by Leventhal et al. (1980), in the formation of coherent representations is highlighted by the difficulties people expressed when faced with not receiving, or receiving unclear information from health professionals. A notable point of interest is how the people interviewed for this study reported having broad representations of dementia which recognised biopsychosocial factors. This will be discussed later in this chapter when the implications for theory are considered.

How do people's representations relate to the experience of early-stage dementia and how they manage it?

The second overarching theme described in the results chapter is that of 'I want to be me'. This is constructed of two further themes, 'personal dilemmas: Where do I stand' and 'interpersonal dilemmas: The line is crossed'. This theme seems to describe the daily experience of the person with early-stage dementia as being a process of adjustment in which a series of dilemmas are faced. These dilemmas are both individual, relating to managing the threat to sense-of-self that early-stage dementia represents, and interpersonal as the individual with dementia negotiates his or her way through social interactions with friends and family in the context of having a diagnosis of dementia, and with professionals as they move through the process of assessment, diagnosis and beyond.

The participants in this study wanted to maintain the sense-of-self that they recognised as a pre-diagnosis, pre-dementia self. However, at the same time they recognised that dementia and the difficulties associated with it present a significant threat to this pre-diagnosis sense-of-self. These difficulties are predominantly construed as losses including loss of status, roles, confidence, and abilities. As

people attempt to resolve this tension between maintaining sense-of-self and adjusting to dementia-related changes, they are faced with a series of dilemmas. These include carrying on versus ending it all, actively fighting it versus passively accepting it, and wanting to understand versus avoiding thinking about it. The first of these relates to carrying on with life and adjusting to the changes, or alternatively, avoiding the threat of changes through suicide. The second dilemma represents maintaining and adapting respectively through actively fighting the changes or, alternatively, passively accepting them. The third, again, seems to represent a processes of maintaining a pre-dementia sense-of-self and adapting to change through either actively avoiding information or actively seeking to find out about the condition. With the majority of individuals these processes are not something where, in early-stage dementia, one position is adopted over another. The results of this study suggest that for each process people move between the two positions as they negotiate the threat-to-self and work towards what seems to be the goal of maintaining self to a degree within the context of an acceptance that changes are unavoidable.

These findings fit with the findings of other studies of the experience of early-stage dementia (Clare, 2003; Pearce et al., 2002). Clare (2003) proposed that in managing the threat to sense-of-self presented by early-stage dementia, people fall along a continuum of responding styles, from self-maintaining styles of coping to self-adjusting styles. The dilemmas that are described in this study seem to reflect these coping styles. It would appear that as people move through the experience of early-stage dementia, they are not responding in one defined way, either maintaining or adjusting, but are moving along the continuum between these coping styles depending on the context in which they are in. This is suggested by the way in which

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participants described managing early-stage dementia by both adjusting and maintaining. This is a similar idea to that presented by Pearce et al. (2002), who suggested that people with early-stage dementia are engaged in an ongoing, circular process of balancing their prior sense-of-self against a need to reappraise and construct one that incorporates the experience of dementia. It should be considered that the participants who volunteered for the current study may be more likely to adopt this approach to managing the threat of early-stage dementia. In contrast those who may take a predominantly self-maintaining style, using avoidance, minimising and denial as strategies, would not have volunteered to participate.

Along with the personal dilemmas faced by the person with early-stage dementia, a second theme relating to interpersonal dilemmas emerged from the analysis of the data. These can be summarised by the idea that once a diagnosis has been shared 'a line has been crossed', and the individual is now regarded by others in the context of being a person with dementia, at the cost of their prior self identity.

Most participants described how, following their diagnosis, their family and friends had changed the way in which they treated them. They talked about how things that previously would have been regarded as not having any significance, such as misplacing something, had suddenly become significant, and were blamed on the dementia, even when the person with dementia did not regard this as appropriate. Some described similar events occurring in terms of emotions and personality, for example, a loss of temper being considered by others as reflecting dementia-related changes in personality, whereas the person with dementia sees no change. This led to difficulty for participants as it seemed to enforce a position of adjusting to dementia-related changes as they were being emphasised by others to such a degree that it made it very difficult to take a self-maintaining coping style.

This difficulty of the perceptions of others versus the perceptions of the person with early-stage dementia was also pertinent in the process of the initial recognition of difficulties. There was variability in who recognised the difficulties, where in some cases it was the person with dementia, and others a relative, colleague or friend. There seemed to be some differences in opinion at the initial stages, where there would be disagreement between the person identifying the difficulties and others. In some cases, the person with the difficulties did not recognise the changes seen by others and, conversely, in some instances, other people did not see that the concerns of the individual with the difficulties were of significant concern.

These interpersonal challenges may have several explanations. Firstly, this could reflect differences in people's illness representations. The representations of relatives and friends may, in some way, be fundamentally different from those of the person with early-stage dementia. This could be related to the idea that, as described by Leventhal et al. (1980), a part of the process of representation formation is based on the experiencing of symptoms and comparing these with past illness experiences within the social context. Therefore, the representations of others may differ as they are not directly experiencing the threat of early-stage dementia and presumably have varying degrees of knowledge and experience of it.

At this point the issue of awareness in early-stage dementia must also be considered as a mechanism that is contributing to the experience. As was discussed in the introduction, awareness is a complex issue that, to date, appears to be best explained though a biopsychosocial model using the concept of self as the unifying context across time (Clare, 2004). Another potential explanation for some of these difficulties may be found in the model of Clare (2004). For some, there may be an element of neurologically based unawareness, which could explain some of the

discrepancy between the recognition of difficulties by others compared to that of the person with dementia. At a psychological level, the response style, beliefs and personality of the person with the difficulties may also play a significant role in their response to the onset of dementia, which may be at odds with the responses of other people. Finally, the expression of awareness is seen to be influenced by the way in which the social environment responds to the person with dementia. It may be that when the responses of others do not match the response style of the person with dementia the latter may respond with a more exaggerated expression of their coping style. For example, if an individual is using a maintaining style and is faced with a social situation where others are placing an emphasis on dementia-related changes, he or she may respond to this with an even stronger maintaining style by, for example, minimising or denying difficulties.

Another theme described by participants that related to social interactions, in this case with a particular emphasis on relatives and carers, was that of betrayal. This predominantly described how through the diagnosis process people found that they were often excluded from discussions and decision-making where they, and their difficulties, were the centre of attention. This seemed to be particularly difficult for those where a partner was involved in this situation. As with the experience of people with dementia finding that others may change the way they interact with them, this may be explained by differences in understanding and representations of early stage dementia. This finding reflects the diagnosis disclosure literature which continues to report a tendency for professionals and carers to exclude people with dementia from the sharing of diagnoses. However, this study suggests that this approach has seemingly been unhelpful for the person with dementia. Firstly it seems to place relationships with professionals and carers under strain as people perceive being left

out of the process as being betrayed. Secondly, as has been discussed already, both the illness representation literature and the experience of the participants in this study place an emphasis on the need for information in developing an understanding of early-stage dementia and ways of managing the changes. The need for information is also emphasised in the awareness literature, with people needing a certain amount of information about their difficulties in order to begin to develop and express awareness of their difficulties.

The need for information was discussed by participants. They described how there is variability in how much information professionals are willing to share, and when information is provided, in the quality and clarity. This again is a source of a sense of betrayal, in that people with dementia are trying to find out about their condition in order to understand and manage the threat, but are unable to obtain clear information from those they see as being there to help. Participants seem to recognise this reluctance as an attempt to protect them, echoing the findings of Wilkinson and Milne (2003), who found that myths around the need to protect people with dementia from the pain of receiving a diagnosis continue to be pervasive in clinical practice. The general feeling among participants was that people should have a choice about when and how diagnoses and information are shared. This links with the ideas of people with early dementia wanting to understand what is happening to them as a component of the adjusting style of coping. The negative consequences of withholding information from people with dementia who want to know their diagnosis has been highlighted in a previous study by Pratt and Wilkinson (2003) whose findings suggested that when this situation arises, it is more likely that distress is increased rather than decreased as is often mistakenly believed by some health professionals.

The difficulties with relationships with professionals described by people with dementia extend beyond the sharing of diagnoses and information. Some people report finding a disparity between what they need and expect from the professionals they are involved with and how those professionals behave. This can include people feeling that professionals are not as empathic or supportive as they expect, or do not give them enough time. As with the way that people with dementia find that the way people interact with them changes in other social relationships, this difference between expectation and experience in dealing with professionals may relate to differences in representations of early-stage dementia. Many of the professionals that participants described having contact with have a medical background. It may be that professional representations have a more medical emphasis, placing less emphasis on the psychosocial components of dementia that hold a strong position in the illness representations described by the participants in this study. Supporting this, those participants who described having found particular professionals helpful described how their manner suited what they expected and there was a similarity in understanding that helped with rapport building. Weitzman and Weitzman (2003) report how interpersonal conflict between people and health professionals, such as the discrepancies discussed above, can be particularly difficult for older people, especially those who may be experiencing cognitive impairments, to mange. They suggest that it can often lead to avoidance of contact with health professionals. In the context of people developing an understanding of their condition, this may lead to people not receiving the information and help they need to develop representations of their condition.

What are the implications for theory from what people tell us about their experience?

In general, illness representations and the SRM appear to be a useful framework for understanding how people with early-stage dementia understand their difficulties. Whilst it was an assumption of the researcher that people with early-stage dementia would be able to provide a coherent narrative of their understanding of their condition, the results have demonstrated that the understanding that people have is much broader than was expected. Whilst the narratives told by the participants in this study have corresponded with the elements of illness representations described by Leventhal et al. (1997), they have also demonstrated how people with early-stage dementia draw upon both biological and psychosocial ideas in constructing narratives of their experience. A possible explanation for this comes from Leventhal et al. (1980), in that people draw on information from a wide range of sources, including family, friends, health professionals, the media and past experiences, in the process of developing illness representations This finding reflects and supports the ideas of Kitwood (1997) who proposed the need for a more biopsychosocial approach to understanding dementia, based on the limitations of purely biological models in explaining dementia-related changes.

The need for expanding frameworks for understanding dementia from being purely biological to incorporate psychosocial theory has recently been supported by Clare and Downs (submitted) in a critical review of the literature related to both the neuropsychiatric and psychosocial models of dementia that has been published in the last 15 years. They suggest that whilst neuropsychiatric perspectives have value in understanding dementia, they need to be considered in the context of psychosocial models in providing a coherent framework as if taken alone they do not fully explain the experience of people with dementia.

This is supported by the findings of this study which has suggested that the representations of dementia used by people with early-stage dementia to understand and mange the threat it represents have a biopsychosocial scope. This does not correspond with the dominant biological perspective, leading to a potential dissonance between how people with dementia understand their difficulties and how professionals and others understand them. This is important in the context of how people with dementia are enabled, or not as the case may be, to make use of their personal models of dementia in managing their difficulties. For example, a dominant theme in neuropsychiatric theory is the notion that a key symptom of the condition is that people with dementia are lacking in agency (Pollitt, 1996; Kitwood 1997). Whilst this work relates to people with more advanced dementia, this idea seems to be reflected in the findings of this study through the descriptions participants gave of people discussing them and acting without their involvement. This created conflict with their representations of themselves as people with dementia who are able to make decisions and act as they did prior to them being diagnosed, leading to a sense of being betrayed by others. It is hypothesised that this conflict between the representations of people with dementia and dominant medical representations may inhibit the formation of clear representations on the part of people with dementia. Leventhal et al. (1980) highlight the difficulties that incoherent representations may present for people as they develop strategies for managing health threats based on their representations. This further challenges the dominance of purely neuropsychiatric theories of dementia.

Another aspect of the experience of people with early-stage dementia that may differ from the experience of people with other, more physically oriented illnesses such as cancer is that of the threat to sense-of-self. Whilst in illnesses such

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as cancer there are potential threats to self, such as women who have a breast removed feeling that their identity is threatened (Moyer, 1997), we accord a special place to cognitive functioning and the brain, which is damaged in dementia, in relation to people's sense-of-self. Sense-of-self played a large role in the experience of the people interviewed in this study as they explained the tension between maintaining their pre-diagnosis sense-of-self in the face of significant changes and losses. In dementia these changes include cognitive losses such as memory, which can be seen as a central component in the construction of self, and the responses of others to the onset of their difficulties, which, as described by the participants here, may lead to loss of roles and status. In other illnesses, for example cancer, there may be a differing trajectory to the threat-to-self. In dementia, the very nature of the condition in it being a progressive decline of cognitive and social functioning brings the threat to sense-of-self to the fore from the outset. However, with more physical illnesses it may be that this trajectory of threat-to-self is somewhat different. Whilst it is recognised that illnesses that present a threat to life are likely to present an eventual threat to sense-of-self, initially illness representations appear to be focused more on the physical nature of the illness, with threats to identity coming from disfigurement and physical disability (Grunfeld et al., 2003), rather than a perceived loss of self.

Considering these aspects of the need for a more biopsychosocial understanding of the experience of dementia and an emphasis on the concept of sense-of-self within the context of the findings of this study, Figure 5, below, displays a tentative model of how illness representations may interact with the biopsychosocial representations of experience reported by the people with early-stage dementia who took part in this study.

Figure 5:   *The role of illness representations in the experience of people with early stage dementia*

Knowledge/

Representation

Lived

Experience

```
                    ┌─────────────────────────┐
                    │  Understanding Dementia  │
                    │                          │
                    │    It will get worse     │
                    └─────────────────────────┘
                              ↕
                           ( Self )

                    ┌─────────────────────────┐
                    │     I want to be me      │
                    └─────────────────────────┘

      ┌──────────────┐          ┌──────────────┐
      │  Personal    │          │ Interpersonal│
      │  Dilemmas:   │          │ Dilemmas:    │
      │  Where do I  │          │ The line is  │
      │  stand?      │          │ crossed      │
      └──────────────┘          └──────────────┘
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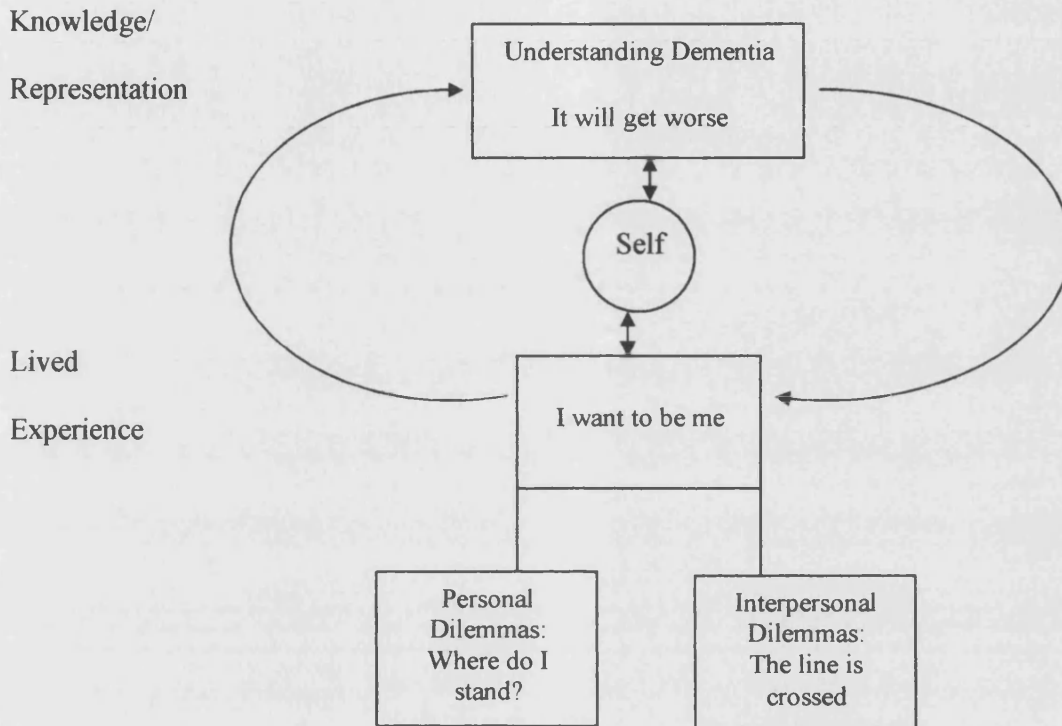
As is suggested by the SRM, it is proposed that illness representations provide people with dementia with a model of their condition which informs the development of strategies to manage the threat it represents in the context of existing coping styles. As I have already discussed above, in the construction of these representations people with dementia appear to draw on a broad range of biopsychosocial concepts. It is hypothesised that the representations are drawn upon by the person with early-stage dementia to understand day-to-day experience in terms of the biopsychosocial impact of dementia. The experience of living with and managing early-stage dementia is seen as having the reciprocal role of furthering the

person's understanding of her or his condition through informing the maintenance or adaptation of their representations. This process is seen to be influenced by sense-of-self, thorough the impact of the individual's past experience and styles of coping on the formation of representations and in living through and negotiating the day-to day experience of being a person with early-stage dementia. In turn, the person's sense-of-self is considered to be influenced by both representations and experience as they face the dilemmas of maintaining a sense-of-self and adapting to dementia-related changes. This process is one that involves intra- and interpersonal dilemmas and experiences.

It must be emphasised that the model of how people with early-stage dementia represent and experience their condition that has been presented here is tentative and that further work would be needed in order to develop it. One area of further research that has arisen from the study is to consider the representations other groups of people hold in relation to early stage-dementia. This may include the representations of the relatives and carers of people with early-stage dementia and the professionals who work with this group. As I have discussed above, the broad biopsychosocial representations that the participants of this study reported often seem to be in conflict with the way in which others understand the condition, as suggested by the difficulties in interpersonal relationships described in the interviews of this group. The role of the concept of self in people's representations and experience of early-stage dementia in comparison to other illnesses may also be an area for future work. This may further understanding of the possible importance of this concept in early-stage dementia in the context of the trajectory of decline in this condition compared to other illnesses. Whilst the complex issue of awareness as a biopsychosocial concept (see Clare, 2004) in early-stage dementia has been

acknowledged as a factor that may influence the formation of people's representations and how they live with the experience of early-stage dementia, it is not clear what the impact may be. This model of awareness, with its recognition of the importance of information, social interactions and self-concept in developing awareness, may be a starting point for further exploration of this area. Finally, the tentative model presented here does not account for how representations may develop and change over time in the context of decline. Suggestions for future work in this area include the use of a longitudinal methodology to follow people over time to evaluate possible changes in representations. Similarly, a prospective approach, following a cohort of participants as they enter and move through the diagnostic process may further understanding of the development of representations over time. The 'in the moment' nature of the understanding of the representations of people with early-stage dementia presented here could be considered a shortcoming of this study. However, the context in which it has been conducted would have made the use of either of the more complex methodologies suggested above problematic. Whilst using the methodologies outlined above may have provided more of a picture of how representations develop over time as people experience decline, the cross-sectional approach employed has been valuable in providing an initial picture of the representations people with early-stage dementia have about their condition and how they develop them.

Methodological Issues

Whilst it has been possible to use the results of this study to develop a tentative model of the representations and experience of people with early-stage

dementia using the SRM as a framework, there are some methodological issues that must be considered in interpreting the results.

Firstly, the sample for this study was taken from a population of people with early-stage dementia that have received a diagnosis and at least some information related to their condition, and in some sense taken this on board in considering their difficulties. However, there is also a population of people with possible early-stage dementia who do not, for personal reasons or for reasons related to practice on the part of some health professionals, have a diagnosis shared with them, let alone the opportunity to explore their difficulties. There is also a group of people who may have difficulties that never get recognised as they are not, for various reasons, able to access appropriate services. This raises issues for the wider applicability of the results of this study, as they can not be used to consider the experience of people who may have similar difficulties to this sample, but do not have a name for these difficulties or have the information needed to develop representations of them.

The age of the participants who took part in this study may also have implications for the wider applicability of the results. With a mean age of 65 years and 5 months, this could be considered to be a 'young' sample of people with early-stage dementia. This has implications in terms of cohort effects, in that for these people the experience of dementia and the need to develop an understanding of their experience may be more significant to them, given that the onset of dementia for them has been relatively early. This is reflected in the representations of some of the participants in considering dementia as a problem related with old age. This may make it difficult to apply the results and their interpretation to people with early-stage dementia across a wider age range.

A third and final sample related issue is that due to the nature of the method of recruitment the sample was one that self-selected. For this reason, it could be suggested that there could be a sampling bias, in that the sample may be representative of some smaller sample within the target sample. For example, it could be that the people who responded to the advert are those that, even though they had their diagnoses shared with them, they felt that they had not received good treatment though the clinical service in which they were seen. However, based on the author's contact with the participants, there were no indicators that, other than the issue with the mean age, the sample was representative of a particular group.

In summary, the results of this study are useful in providing a starting point for furthering our understanding of how people with early-stage dementia represent their condition and the influence representations have on the lived experience of early-stage dementia. However, the points discussed above have implications for how widely these results can be applied in considering the experience of other groups with similar difficulties.

With regard to the data, it could be considered that the interview schedule, which was constructed in order to explore the elements of illness representations described by Leventhal et al. (1997) and the SRM (Leventhal et al., 1984), overly influenced the nature of the data being collected. However, care was taken not to use 'technical' labels and use leading questions to avoid the data simply being a direct reflection of the interview questions. Additionally, the interviews did seem to allow participants to talk broadly about the lived experience of early-stage dementia and the dilemmas it brings. The data rich quality of the stories given by each of the participants were actually very powerful when considered on their own, making them

an interesting series of accounts of the experiences of people with early-stage dementia as they develop their understanding of their conditions.

Validity Checks

Throughout the analysis process effort was made to ensure that the quality of the data and results was maintained through the use of a series of validity checks (Elliott et al., 1999). The first of these was for the author to own his perspective in order that it may be taken into account when readers are evaluating the results. In this study the author's perspective has been acknowledged and described in the method section. It was recognised that the author held the view that the people with early-stage dementia who participated in this study would be able to provide a clear narrative of their understanding of dementia. This possibly influenced the study and its findings in that during the interview process, participants had the opportunity to explore and tell their stories in an environment that validated their experiences. This may have aided them in considering their experiences from the broad range of perspectives reflected in the results by the biopsychosocial understanding of early-stage dementia reported.

The method chapter also contains a description of the sample of participants interviewed in this study. This allows the reader to consider the results in respect of the sample and make judgements about the range of situations and people to which the results might be applicable.

Throughout the coding of the interview transcripts and the analysis of the data, the author's research supervisor audited each step of the process in order to review the reliability of the process. When discrepancies in the steps of analysis occurred, these were settled through discussion to reach a consensus of opinion. This

process was also replicated with selected transcripts using another qualitative researcher not connected with this study in order to further the reliability of this process.

It was initially proposed that a part of the procedure of this study would include giving each of the participants the opportunity to meet with the researcher following the analysis of the data in order that they could discuss the overall findings of the study. This was also planned as a check of how the results resonated with the participants. However, the constraints of the time available to complete this study have meant that this step in the validity checks has yet to be completed. It is planned to complete this step to add to the validity of the results prior to further work and preparation of journal articles. Care has been taken to ensure that the understanding of the experience of people with early-stage dementia based on the analysis of the data has been presented as a coherent narrative grounded in examples from the individual stories of the participants.

In the designing of this study, consideration was given to potential ethical issues that might have arisen from the research process. In general there were no ethical concerns that threatened the research process. However, there were two issues that needed some consideration. Firstly, the author, as described in the method chapter, is trainee clinical psychologist, who has experience of conducting interviews in clinical settings. In the research setting of this study he initially had to ensure that he was aware of the difference in context, in that the aim of interviews for this study was for participants to be able to tell their story in a safe setting (which has similarities with some clinical work) rather than gather clinically relevant information with the aim of intervention. Additionally, interviews were conducted in participants' homes, where people's partners and other family members were

present. On some occasions family members wanted to participate in interviews. In these situations a discussion took place between the participant, family members and the researcher in terms of the emphasis of the research being the experience of the person with dementia without excluding other family members. On each occasion this seemed to clarify the situation for family members. If the situation had arisen that family members still wished to participate, their presence at the interview would have been negotiated whilst allowing the participant to tell their story.

Clinical Implications

Finally, the results of the study have some implications for clinical practice, both in general terms and specifically for Clinical Psychology. Firstly, in relation to the process of diagnosis sharing and information provision, the results suggest that people with early-stage dementia would like to have a choice about how they hear about their diagnosis and what information they are told. This suggests a need for a more reflexive approach in the diagnosis sharing/information giving process with people with early-stage dementia being actively involved in what is told and how and when it is delivered.

When exploring dementia and diagnoses with people with early-stage dementia, the results suggest the need to consider how people's representations are very individual, and based on broad, biopsychosocial concepts. This suggests that there is a need to avoid imposing narrow models of dementia, such as a purely neuropsychiatric model, which may conflict with how the person with dementia understands their difficulties. The narratives of the people who participated in this study reflect how, when there is a conflict between their understanding and those imposed by others, this can easily lead to feelings of betrayal.

The idea that people with early-stage dementia, their families, friends and carers and professionals who work with people with dementia have differing understandings of what dementia is and what it means for the individual has implications for working with groups and systems. These multiple ideas and needs may not necessarily agree, so there is a need when working with people with dementia and their wider social systems to ensure that differing understandings are heard and that the opportunity for people feeling betrayed, as described in this study, is limited. When there is difficulty within social systems, systemic, family type clinical interventions may help in ensuring that differing needs and ideas are recognised and accommodated. A review of communication between older adults and health professionals by Weitzman and Weitzman (2003) also has implications for managing differences in people's understanding of early-stage dementia. They suggest that interpersonal conflict resolution and communication skills may help in bridging the gap between personal and professional understanding and expectations.

The results of this study have suggested that whilst illness representations and the SRM are an important aspect in understanding how people with dementia understand their condition and develop ways of managing difficulties, understanding day-to-day lived experience is also important in understanding how people with early-dementia understand and manage it. For example, people in this study expressed the view that day-to-day they believe that they can go on and fight the changes of dementia, in the context of also having thoughts about how dementia is a condition of decline, and that maybe for some, suicide is a way of preventing the deterioration and change. This suggests that in clinical work with people with early-stage dementia it is important to acknowledge these day-to-day experiences as ways

of managing the experience in the context of some of the more overarching representations.

Finally, the concept of sense-of-self and its maintenance is a strong theme for people with early-stage dementia. This may have implications for the use of specific interventions, for example 'Self-Maintenance Therapy' (SMT; see Romero & Wenz, 2001). This intervention is aimed at helping people maintain a sense of personal identity, continuity and coherence as they are faced with decline and incorporates ideas from validation and reminiscence therapy. SMT has four components, these being; psychotherapeutic support; self-related knowledge training, where accessible autobiographical memories are used to develop a life-story used for supported, systematic reminiscence; satisfying everyday activities; and validating communication in care giving. The maintenance of self as an important theme in the experience of people with early-stage also has implications for the adoption of a general stance in professional practice. Kitwood (1997) described the need to maintain personhood through 'positive-person work' in dementia care for people in later-stage dementia. This kind of approach would seem to be equally applicable to working with people with early-stage dementia.

Summary

In this qualitative study, nine participants with early-stage dementia were interviewed to develop individual narratives regarding their representations of their condition and their experiences of living with their difficulties. Using IPA, themes were developed from across the interviews which were used to develop a tentative model of how illness representations impact upon people's lived experience of early-stage dementia. The SRM was found to be a useful framework for understanding

how people with early-stage dementia understand their condition and manage their difficulties. Participant's stories also illustrated how this knowledge plays a role in the negotiation of the day-to-day experience of living with early-stage dementia as people negotiate personal and interpersonal dilemmas that dementia-related changes raise. Using the results, implications for clinical practice were discussed. People with early-stage dementia need to be directly involved in the process of sharing diagnosis, if they so choose, where there needs to be a recognition of the broad range of representations that people with early-dementia, families and professionals hold. The need to maintain sense-of-self whilst adjusting to the condition needs to be facilitated through both structured interventions, such as 'Self-Maintenance Therapy' and the adoption of a general approach to working with people with early-stage dementia, such as that described by Kitwood (1997) in relation to later-stage dementia.

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Appendix 1

Advertisement for Participants

Version: 1
Date: 21/03/2003

Advertisement for Recruiting Participants

Would you be willing to talk about your experiences of dementia and receiving a diagnosis? I am undertaking a research project looking at how the information given at the time of diagnosis can affect how people with early dementia understand their situation and how this may influence ways of coping. If you are a person with early dementia who has been given a diagnosis and would like to take part in this study, please contact Guy Harman, Trainee Clinical Psychologist, University College London, on 07905 943 654. This is an answer-phone service where you can leave your name and a contact telephone number so that I can call you back.

Appendix 2

Letter of Ethical Approval

The Graduate School
University College London
Gower Street London WC1E 6BT

Professor Leslie C Aiello
Head of the Graduate School

Tel:
Fax:
Email: gradschoolhead@ucl.ac.uk

8 May 2003

Mr Guy Harman
Trainee Clinical Psychologist
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

Dear Mr Harman

Re: Notification of Ethical Approval

Project ID: 0056/001: The Impact of Information on Illness Representations and Coping in People with Dementia from the Perspective of the Person with Dementia – A Phenomenological Approach

The above research has been given ethical approval following review by the UCL Committee for the Ethics of non-NHS Human Research for the duration of the project (1 July 2003 – 31 August 2004) subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: http://zzz.grad.ucl.ac.uk/ethics/ and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events.
For non-serious adverse events you will need to inform Ms Helen Dougal, Ethics Committee Administrator (**h.dougal@ucl.ac.uk**), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events
The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

3. On completion of the research you MUST submit a brief report (maximum of two sides of A4) of your findings to the Committee. Please comment in particular on any ethical issues you might wish to draw to the attention of the Committee. We are particularly interested in comments that may help to inform the ethics of future similar research.

Yours sincerely

(

Sir John Birch
Chair of the UCL Committee for the Ethics of Non-NHS Human Research

Cc: Dr Linda Clare

Appendix 3

Participant Information Sheet

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

General Enquiries:
Clinical Tutor Team:
Senior Secretary:
UCL Switchboard:
Code from overseas: +44 20
Fax:
www.ucl.ac.uk/clinical-health-psychology/

CONFIDENTIAL

A Study of How Information Influences Illness Understanding (Representations) and Coping in People with Dementia

Participant Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Your participation in the study is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not result in any adverse consequences for you. Any information that you may have given up to the point of withdrawal will be kept confidential.

The aim of this project is to explore how people with dementia understand dementia, what information may help them to understand dementia better, and how they believe they are coping with dementia.

The study whole is expected to take 18 months to complete. The researcher, Guy Harman, will meet with each person on three occasions. It is suggested that these meetings can take place in people's homes. However, if this is not suitable for anyone, alternative arrangements can be made. The first meeting is to for each person and Guy Harman to get to know each other. This will also involve a short questionnaire. (This will not be a memory test). The second meeting is to complete the interview which will take one to two hours.

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The third meeting will be for Guy Harman to feed back the results the interviews and to check that it is an accurate representation of the participants' responses.

Whilst there are no immediate benefits for those people participating in the study, it is hoped that this work will add to our understanding of how to improve the way in which diagnoses are given to people with dementia.

Any information that is shared during the interviews will be treated with strict confidence, and once the study is completed, it will not be possible to identify individual's interviews. Throughout the study only the researchers, Linda Clare and Guy Harman, will have access to information. It is planned to write an article for publication from the results of the study. Individuals will not be identifiable from any such publication.

If you require further information please do not hesitate to contact Guy Harman on   this number provides an answer service where a name, telephone number and message can be left enabling him to contact you.

Thank you for taking the time to read this information sheet.

The researchers are:

Guy Harman   Linda Clare

Sub-dept. of Clinical Health Psychology   School of Psychology

University College London   University of Wales Bangor

Gower Street   Bangor

London   Gwynedd

WC1E 6BT   LL57 2AS

Appendix 4

Participant Consent Form

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

General Enquiries: 0 7670 1897
Clinical Tutor Team
Senior Secretary: 020
UCL Switchboard: 0
Code from overseas:
Fax: 9
www.ucl.ac.uk/clinical-health-psychology/

CONFIDENTIAL

UCL Project ID number: 0056/001
Participant Identification Number for this study:

Form date: 21/03/03
Form version: 1

CONSENT FORM

Title of project: A Study of How Information Influences Illness Understanding (Representations) and Coping in People with Dementia

Name of Principal Investigator: Linda Clare
Name of Second Investigator: Guy Harman

Please initial Box

Have you read the Participant Information Sheet?	
Has the project been explained to you orally?	
Have you had the opportunity to ask questions and discuss the study?	
Have you received satisfactory answers to all your questions?	
Have you received enough information about the study? Who have you spoken to? Dr/Mr/Mrs/Ms/Professor	
Do you understand that you are free to withdraw from the study without penalty at any stage?	
Do you agree with the publication of the results of this study in an appropriate outlet/s?	

Continued on next page/

1 form for Participant;
1 to be kept as part of the study documentation,

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UCL Project ID number: 0056/001
Participant Identification Number for this study:

Form date: 21/03/03
Form version: 1

Name of Principal Investigator: Linda Clare
Name of Second Investigator: Guy Harman

Comment or Concerns During the Study

If you have any comments or concerns you should discuss these with the Principal Researcher. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should e-mail the Chair of the UCL Committee for the Ethics of Non-NHS Human Research (gradschoolhead@ucl.ac.uk) or send a letter to: The Graduate School, North Cloisters, Wilkins Building, UCL, Gower Street, London WC1E 6BT who will take the complaint forward as necessary.

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of Person taking consent   Date   Signature

_____   _____
Researcher (to be contacted   Email/phone number

if there are any problems)

1 form for Participant;
1 to be kept as part of the study documentation,

<p align="center">page 2 of 2</p>

Appendix 5

Interview Schedule

Interview Schedule/Guiding Questions

Pre-diagnosis representations

- Had you heard of dementia/Alzheimer's before you were given your diagnosis?

- Where had you heard about it? E.g. films, books newspapers, t.v., friends and acquaintances.

- What had you heard about it?

- What did you think dementia was before you were given your diagnosis?

- Have you ever known anyone who has dementia?

- How did you understand what was happening to them?

- Did you have any ideas about the causes dementia?

- Did you have any ideas about what having dementia means to a person?

- Did you have any ideas about the management or treatment of dementia?

Diagnosis?

- Who told you of your diagnosis?

- How did they tell you?

- In what circumstances did it happen?
    - How long did you have to wait for a diagnosis?
    - How long did the person who told you take over telling you?

- What were you told?
    - Were you told about the symptoms associated with dementia (*inc. labels*) and what they mean?
    - Were you given information about the duration of dementia?
    - Were you given any information about what causes people to develop dementia?
    - Were you given any information about what to expect in the future?
    - Were you given any information about how dementia may be controlled (*or cured?*)?

- Do you think that you were given too much information, or too little?
- Did you think that the information you were given was useful at the time?

- Was there anything you were not told but wanted to know?

- Was there anything you were told but didn't want to know?

Post-diagnosis representations

- What do you think dementia is now you have been given a diagnosis?

- What is your understanding of dementia after having been given your diagnosis?

- Did being given a diagnosis change your understanding of dementia?

- How?

- How do you expect the dementia to change over time?

- Do you have any thoughts about what caused your dementia?

- What symptoms do you expect to experience?

- How do you expect your difficulties to be managed?

Coping

- How are you coping with your difficulties?

- Do you have any particular ways of coping with particular difficulties?

- Did being told your diagnosis help you develop ways of coping?

- What information was most hopeful?

- What was unhelpful about what you were told at diagnosis?

- What, if anything, would help you develop ways of coping?

Appendix 6

Excerpt from Transcript

P: yeah, yeah, a couple of years back it was my wife's birthday, 60th, and as a present

the children decided to send us to Majorca, everyone went with us, children, grand

children, everything, a great secret and [daughter] went to see [consultant] and asked

if it was right that I could travel, to fly, and then when I went on my appointment

5   which was due, prior to going away, and by his mannerisms and facial expressions I

can see there's something going on inside, his mind you see, and he sat there, we had

this great, what I'd been through and I've come through it fantastically, and you've

done very, very well etc, etc and you ought to have a medal, and I said I don't know

about me I think you ought to have one because you're the one who bought me

10   through it and I said if you take me by the coals I'd do it, if your holding me by the

hand.

G: It sounds as though [consultant] is someone you have a lot of respect for the way

he's treated your physical......

15

P: I admire him and I respect him but added to that was that I could tell that he was

going to say something. Now when we went on this occasion, whereby I was

introduced to the psychologist I could see that he was welling up inside him, that he

wanted, he was going to say something and then er, my good lady wife said "he can

20   remember things from the past, but if he puts something down he can't find it", so

then we went on to another track then, I turned round to [consultant] and said, "you

can't tell me that you don't do the same thing" and he went umm,mm, er, and then he

said that I should go and see, or asked me if I minded to go and see the psychiatrist,

and I said, you can't do it, cause he's done everything else, I mean he's brought me

25   through everything. I felt after I had gone through this meeting with the psychiatrist

afterwards it hurt me, the way that the psychiatrist explained it, and I felt that there was treachery afoot, and I knew that someone had spoken to [consultant] beforehand and I did think that it was my younger sister, er daughter rather, beg your pardon, er but it my eldest daughter turned around and said "It was me", and I put my arms

5   around her and I said et tu Brute, which curled her up, and I said I can take it so long as you discuss it with me first. Discuss it with me, I'll do anything.

G: Ok, so...

10   P: I felt as though people had gone behind my back and put me in a situation that I really didn't want to be in and I didn't like it.

G: Right, so there's something about if people had sort of given you the information and told you what was going on, and maybe explained some of there concerns then

15   maybe it would have been a different situation for you

P: It still would have been there, but I did feel that, like I say et tu Brute

G: Ok.....

20

P: I felt I had been knifed in the back, a conspiracy,

G: So when you had been to see the psychiatrist and the psychologist and had a CT scan, was it then that you were told by the psychiatrist what was.....

25

P: Well the psychologist first who did the old, 21 backwards business, and he suggested then that he would prefer me to see a colleague of his who dealt with a different field as it was put

5 G: Did they explain what the different field was?

P: not til later, and then on each occasion I wrote these different event down and I looked up what their different occupations was and, like I was with you, I turned around and asked you what you do you do, and er I didn't like the way it was put to

10 me then, because as I have said, in the past with everything else [cancer] they've had the good grace to sit down and on a one to one basis explain things to me. On the second visit when I reprimanded him to such an ex, some extent, he said oh I was flate, straightforward the first time. Well he thought it, and so he went through it again.

Appendix 7

Example of Key Points from Transcript

001

1   You're wandering round saying where have I done with that screwdriver

2   My wife's aunt, she had er er er dementia

3   She couldn't recognise people

4   She didn't recognise her own sister

5   But she recognised my wife

6   That was something she always did when my wife was a little girl

7   Everyone then said they're happy in their own little world, they're quite happy

8   I have wondered since then, not personally for myself, whether people are

9   If they realise that it is going on around them

10   They find they can't express themselves, they're locked into this situation

11   Locked into your own little world

12   Didn't actually go in

13   Waited outside

14   I listen to the radio

15   A lot of times you hear so many programmes about people suffering with dementia and progressively later in life

16   To some people it takes it comes early and to others it comes later or more to the end of their life

17   I put it in the way of being an active life cycle

18   They've got the children grown up they haven't got responsibilities there

19   At that stage in life you're stepping aside and letting other people getting on with it

20   For it to come in early life to people I think it's a very tragic thing

21   Difficult to answer

22   From listening to accounts from other people

23   They could have, as I have had, strokes

24   Or been involved in some traumatic incident

25   He fell down some stairs and broken his hip, and since then had suffered with memory loss

26   Not from the accident, but on a normal situation daily basis

27   Can remember things from years ago but I cannot tell you what I had fro tea last night, which is in the short term phase

28   Early on it is it's possibly a traumatic experience with the brain

29   Later in life it's the gradual winding down of the brain cells

30   There'll be tablets out shortly you'll be able to take to replace the brain cells

31   In my case where there's a clot on the brain there'll be operations to remove the clots

32   Get in quick enough to administer medication they can prevent the stroke, the clots forming

33   That's what one hears

34   Having the first stroke I never had any high blood pressure at all

35   Each time I had been in hospital they've done my obs to start with and they've said, not every time, that it's remained static

36   Cholesterol was never entered in to

37   I often wondered why

38   It was checked with my consultant said............that's about average

39   He said I can't find anyone who can tell me what cholesterol level should be

40   Things have altered now

41   They've worked it out

42   I had a Doppler to which they found a slight amount of calcium

43   Not operable and such best left alone

44   We've always been very careful on our food intake

45   An average amount of what we fancy

Appendix 8

Example of Themes from One Transcript

Theme list 001

Fighting

Facing the truth/decline

Inside looking out/trapped

Developing representations from others/own experience

Optimism

A collective term

A part of a life cycle

Carry on with life

Defences

Taking a different perspective

A new brain/parts of brain

Treating it with drugs

Wanting to Understand

Not really knowing what will happen

Confused/unclear

Health professional's manner is important

Thinking of past experiences of illness

Things I do get blamed on dementia/people treat me in peculiar ways

Family restrict me

Betrayal

Causing arguments and distress

Others can be pessimistic

Damaged my brain

Loss of roles

Just like others

A good memory

Putting an end to it

Appendix 9

Themes From Across Transcripts

Themes Across Interviews/5

Understanding Dementia: It Will Get Worse

<u>Making Comparisons</u>
Others
Developing representations from others/own experience (001)
Developing representations from others/own experience (002)
Experience of dementia from different generations
(bridge between generations): *Previous, Next (004)*
Experience of dementia as a: *Carer, Professional,*
As a person with dementia (003)
Representations from other's experience/own experience:
As a relative and carer, As person with dementia (006)
Developing understanding from the experience of others (009)
Making memory comparisons with others (006)

Self
As a Person with Dementia
Developing representations from others/own experience (001)
Developing representations from others/own experience (002)
I knew something was wrong (002)
Experience of dementia as a person with dementia (003)
As a Person Who Has Been Ill in the Past
Thinking of past experiences of illness (001)
Comparing dementia to experiences of other illness (003)
As a Carer
Experience of dementia as a: *Carer (004)*
As a Professional
Experience of dementia as a: *Professional (004)*
Person with a past
Past experience helps to make sense of the present (009)

<u>There are certainties and uncertainties in change</u>
Certainties

Facing the truth/decline (001)	Facing the truth/decline (009)
Facing the truth/decline (002)	Facing the truth/decline (003)
a: it will get worse	*a: it will get worse*
Decline/facing the truth (006)	Slowing down (006)
Facing the truth/decline (004)	Facing the truth (007)
a: it will happen	*A gradual/slow change (006)*
I knew something was wrong (002)	I knew something was wrong (004)
Really it was confirmation (003)	At first you don't really know what it is (008)

Uncertainties

Not really knowing what will happen (001)	Confused/unclear (001)
Hope (002)	Facing the truth/decline (002)
b: I would like but don't know	*b: I'm not sure where I am on this continuum*
People were saying different things (003)	Some things are not clear (007)
Differing professional opinions (008)	Difficult to understand (008)
Is this dementia or not? (009)	Facing the truth/decline (003)
Facing the truth/decline (004)	*b: Where am I on this continuum*
b: what will happen?	Facing the truth/decline (008)
	Will I end up like this?

I had no idea what to expect or how the examination would progress (009)
At first you don't really know what it is (008)   At first you are aware of something but not everything (009)
You are not aware of why the changes happen at the time (006)
There's no clear name for my memory difficulties (005)

How I understand dementia
How dementia is controlled and treated
A new brain/parts of brain (001)   Treating it with drugs (001)
It may be controlled but not stopped (009)
                    Stopping progression
                    It can't be reversed/prevented

Negative Emotions
Makes me angry (002)   Shock (002)
Hatred (003)   dementia is upsetting (004)
Feeling depressed (004)   Scared (001)
Hospital leaves you in that one posture of frightened (007)   Forgetting makes me worry (009)

It's serious
Dementia is cruel (004)   Alzheimer's is nasty (005)
Brains are serious (007)   Alzheimer's is worse than dementia (006)
It's a relief not to have dementia (006)   Alzheimer's is more serious than memory lapses
                                                                                      or dementia (005)

Understanding changes
Trapped/isolated/withdrawn
Inside looking out/trapped (001)   isolation (002)
ignored (002)   being cut off (006)
withdrawn (009)

Memory
Not remembering (002)   It's not just memory (003)
Can't remember things (004)   Memory lapses are normal (005)
It's not all types of memory (005)   Some people without dementia can forget (008)
memory comes and goes (005)   not all forgetting is dementia (009)

Thinking
Unable to think (003)   dementia is mental disability, not physical (009)

Getting Lost
I get lost in different ways (005)   I get lost (004)

Slowing Down
Slowing down (006)   slowing down (002)

Not knowing
Not aware (002)   unable to recognise people (002)
muddled (003)

A range of experience
There is a range of experience in dementia (009)   dementia comes in different forms (008)

Dementia is a pattern of change
Alzheimer's and dementia are different stages (009) AD is a gradual process (005)
A gradual/slow change (006)   stages of Alzheimer's (009)
I can't get over it (004)   Up and down/variability (002)
A gradual/slow change (006)   stages of Alzheimer's (009)
Alzheimer's and dementia are different stages (009) AD is a gradual process (005)
Alzheimer's is a pattern (009)

Labels
Alzheimer's, memory loss and dementia are all different (006)
Alzheimer's and dementia are different stages (009) Alzheimer's is worse than dementia (006)
The name is not important (008)   A collective term (001)
There's no clear name for my memory difficulties (005)

The Causes of dementia

Brain Damage

damaged my brain (001)

Luck

Luck (004)

It runs in the family

it's a family thing/it's the way I'm made, my
genes (004)

AD runs in the family (006)

Loneliness

Loneliness can contribute to dementia (009)

loneliness can contribute to dementia (006)

Not trying

Not trying (003)

Stress

Stress plays a part
(002)

A part of the ageing process

A part of a life cycle (001)

Something that happens to old people (003)

Alzheimer's is a problem for some when they are older (005)

Memory loss is related to old age (006)

Dementia is typically a problem of the old (007)

I wonder if we all go the same way (005)

ageing and dementia are related (009)

Coping is individual

Coping is individual (003)

Cope for yourself (004

Dwelling on memory problems does not help (006)

Focus on positives (008)

Coping is individual (008)

A way of coping (004)

There are ways around memory lapses (005)

It is possible to cope (008)

coping does not always work (008)

past experience helps with coping (009)

Emotional

I don't find being emotional helps (003)

Checking up (009)

It's good to have a cry (004)

Practical

There are things you can do to cope with memory problems (006)

    Some ways of coping with memory are practical

    There's something around being active

There are practical ways of coping (008)

Practical coping (002)

Checking up (009)

It's good to keep your mind active (009)

Information

Awareness of your problems helps you cope longer(006)

It helps to know what is happening (008)

Being given information may help (009)

Some information you just pick up (008)

You can have too much information (006)

I'm glad I was told about my problems (006)

Information can help you cope(008)

Too much information is unhelpful (009)

Information can be helpful (009)

Being given information may help (009)

It helps to know what is happening (008)

There is never enough information for me (008)

Medication

Medication helps me (002)

medication can be unhelpful (008)

Some medicines stop me coping (004)

Friends

Friends are important (002)

Friends can be supportive (003)

I Want To Be Me

Personal Dilemmas: Where do I stand?

<u>I want to be me but there are losses</u>
<u>I want to be me</u>

I want to be me (008)
I can still do most things (009)
Recognising who you are (006)
People's past is important in self
Maintaining independence (002)

I don't want dementia to change me (003)
I can still do the same things (008)
I want to carry on as I was (004)
Having own ideas (002)
I don't think I've changed (009)

<u>Losses</u>
Loss of roles (001)
An ending of a life (003)
I want to be as I was (003)
A waste of a life (004)
Losing part of life (008)

Family restrict me (001)
I don't want to lose my independence (003)
Loss of confidence (003)
It's all about re-learning (004)
Delays have cost me

Alzheimer's means I have to give up some things (009)

<u>I can carry on *versus* I can put an end to it all</u>
Carry on with life (001)
I can go on (004)
You've got to keep going on (006)
Optimism (001)
Optimism (003)

Ending it all suicide (003)
Putting an end to it (001)
Suicide or not? (004)
A positive side (002)

<u>I will actively Fight it *versus* I will passively accept it</u>
Fighting (001)
Fighting it to the end (004)
Fighting it (009)

I'm a thing people do things to (004)
Resignation (002)
Dementia has changed me (004)

<u>Wanting to understand *versus* I want to avoid thinking about it</u>
<u>Wanting to Understand</u>
Wanting to understand (001)
Wanting to know more (002)
Trying to find a reason for it happening (003)
Trying to understand what is wrong (008)
Looking for causes (008)
Making frameworks of experience (009)

what is going to happen? (002)
Wanting to find out about dementia (003)
Where have I gone wrong? (004)
is it just a part of me (008)
Looking for reasons why (009)

<u>I want to avoid thinking about dementia</u>
Defences (001)
I don't want dementia to change me (003)
Denial (004)

Defending self from thinking about dementia (003)
I couldn't believe there was anything wrong with me
the future is too scary to ask or think about (006)

Interpersonal Dilemmas: The line is crossed

<u>Problems are recognised by different people</u>
<u>I recognised I was having difficulties at the beginning</u>
I knew something was wrong (002)
I knew something was wrong (004)
Awareness (changing representations of awareness) (006)
    People with dementia are aware of the changes
At first you are aware of something but not everything (009)
<u>Other people were first to notice my difficulties</u>
Awareness (changing representations of awareness)
    Your not aware of why the changes happen at the time (006)

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Others noticed my problems first (007)
Others see it as a problem (009)

Betrayal
Betrayal (001)   Deception/underhanded (003)
Some people try to deceive you (006)   Some people talked behind your back (008)
Some people talk behind my back (009)   *Trying to protect*
When things are kept from you it's serious (009)

Dementia has changed how people treat me
Things I do get blamed on dementia/people treat me in peculiar ways (001)
Family restrict me (001)   Others can be pessimistic (001)
Some people treat you in a peculiar way (002)   Some people treat you in a peculiar way (004)
Some people can treat you in a peculiar way (006) Causing arguments and distress (001)
There are people trying to help (004)   Some people treat me in a peculiar way (009)
Some other people don't think I have a problem (009)
dementia is like being a child (003)
Stigma
Us and them (002)   Suffering the indignities of dementia (003)
Worried that people will find out (005)   The label sticks (008)
Once you have a diagnosis of dementia the line is crossed (008)
The changes can be embarrassing (009)

Some professionals don't treat you how you expect
The most helpful professionals are those whose manner suits my needs (002)
Some people think the hospital is more important than the people (007)
Manner and rapport is important in the relationship with professionals (008)
Manner is as important as action (007)   Professionals need to give you time (008)

Some people tell me things, some don't
They never tell me anything (002)   Being told the truth (002)
Some people tell me nothing (004)   Some people tell me things (004)
Some people in hospital didn't tell me anything (007) Some people tell you things (006)
Some important things are not talked about (008)
Some people told me/showed me things about my difficulties (007)

I should have choice about hearing my diagnosis
People have a right to know (003)
Some people with dementia can cope with being told (006)
Some people shouldn't be told they have AD (006)
People should have a choice about being told (008)

Appendix 10

Contribution of Individual Participants
Transcripts to Themes

Overarching Theme	Themes	Sub-themes	1	2	3	4	5	6	7	8	9
Understanding Dementia: It will get worse		- Making comparisons	✓	✓	✓	✓		✓			✓
		- Certainties and uncertainties	✓	✓	✓	✓	✓	✓	✓	✓	✓
		- How I understand dementia	✓	✓	✓	✓	✓	✓	✓	✓	✓
		- It's possible to cope		✓	✓	✓	✓	✓		✓	✓
I want to be me	Personal Dilemmas: Where do I stand?	- I want to be me but there are losses	✓	✓	✓	✓		✓		✓	✓
		- I can carry on *versus* I can put an end to it	✓	✓	✓	✓		✓			
		- I will actively fight it *versus* I will passively accept it	✓	✓		✓					✓
		- Wanting to understand *versus* I want to avoid thinking about it	✓	✓	✓	✓				✓	✓
	Interpersonal Dilemmas: The line is crossed	- Problems are recognised by different people		✓		✓		✓	✓		✓
		- Betrayal	✓		✓			✓		✓	✓
		- Dementia has changed how people treat me	✓	✓	✓	✓	✓	✓		✓	✓
		- Some Professionals don't treat you how you expect		✓					✓	✓	
		- Some people tell me things, some don't		✓		✓		✓	✓	✓	
		- People should have a choice about being told			✓			✓		✓	

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