

**MAKING SENSE OF DEMENTIA AND
ADJUSTING TO LOSS:
PSYCHOLOGICAL REACTIONS TO A
DIAGNOSIS OF DEMENTIA IN COUPLES**

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ABSTRACT

The current emphasis on early detection and disclosure of a diagnosis of dementia means that it is possible to examine the shared understanding of the diagnosis of dementia in couples at an early stage of the disease. This study aimed to investigate psychological reactions to a diagnosis of dementia in couples where one partner had received a diagnosis of either Alzheimer's disease or vascular dementia. This was an exploratory study designed to build on research looking at the experience of dementia from the perspective of people with dementia and their partners. The study involved elaborating couples' shared construction and understanding of and responses to the diagnosis of dementia and the appraisals couples made about the illness. Several theoretical frameworks were used to inform and guide the research including systemic theory, and social constructionist and dialectical models of dementia.

Nine couples were interviewed using a semi-structured interview schedule. The data was transcribed and then analysed using qualitative methods. Firstly, interpretative phenomenological analysis was used to explore participants' experiences of receiving a diagnosis of dementia, which were compared and contrasted across couples. The ten themes extracted from the qualitative data fell into two higher-order categories, "Not quite the same person, tell me what actually is wrong" and "Everything's changed, we have to go from there". The first category related to couples' attempts to make sense of what was happening to the person with dementia and how this process had been influenced by their experiences of receiving a diagnosis of dementia. The second category related to the losses and difficulties described by couples as well as the coping strategies they used to adjust to their situation. An overarching theme also emerged, "Making sense and adjusting to loss", which is presented in a model that encapsulates the processes couples appeared to go through in making sense of the experience of early stage dementia and adjusting to the losses and difficulties evoked by the illness.

Secondly, this analysis was supplemented by a voice relational method that examined the 'voice' which was heard from each person and the types of conversation interactions between partners. The analysis revealed two categories of interaction style displayed by couples, which related to partners either "silencing" or "supporting and facilitating" their spouse with dementia to have a voice. The clinical and service implications of these results are discussed, and focus on how services can support couples who receive a diagnosis of dementia to create a joint construction to help them make sense of their situation, to find ways to adjust to the changes experienced in their roles and identity, and to manage the losses they face in the early stages of dementia.

CHAPTER ONE

INTRODUCTION

Overview

In recent years the disclosure of a diagnosis of dementia has attracted the interest of both medical and psychological researchers. This research has focused on the advantages and disadvantages of disclosing a diagnosis of dementia in the early stages and has begun to describe the psychological and social impact of receiving a diagnosis for people with dementia. However few studies have combined the perspective of people with dementia and their partner in the early stages of dementia or examined how couples begin to make sense and adjust to the initial changes in the person with dementia or explored how receiving a diagnosis of dementia impacts upon this process. Receiving a diagnosis of dementia undoubtedly has a major impact, not only on people with dementia, but also on their partners and both perspectives are important to consider in order to provide effective psychological support for couples in the early stages (Clarke & Keady, 2002).

This review begins with an overview of the medical model of dementia and presents an alternative model which incorporates social and psychological factors in the conceptualisation of dementia as well as cognitive decline. The following section provides a description of social constructionist theories of dementia, health psychology theories about the impact of illness, and theories of loss, and considers the use of these theories in providing a theoretical framework for this study which aims to examine psychological reactions to a diagnosis of dementia in couples. The next section provides a description and critical review of the existing research literature that has examined the experience of people with dementia in the early stages of the illness, the

disclosure of a diagnosis of dementia, and reactions to a diagnosis for people with dementia. It also contains a brief overview of caregiving research and reviews research that has examined the experiences of carers and couples in the early stages of dementia.

While this research provides a good theoretical basis for the current study, this review will demonstrate the need for further research to examine how couples communicate around the issue of a diagnosis of dementia and explore factors which help couples to manage the process of receiving a diagnosis, as a starting point for developing effective psychological support for couples at this time.

1.1 Conceptualisations of dementia

This section provides a brief introduction to the medical model of dementia. The influence of this model on dementia research and its limitations are described before an alternative model is presented that considers how social and psychological factors may influence the course and progression of dementia. In the following section, theoretical perspectives of the psychological and social impact of dementia are described in more detail.

Dementia as a disease process

In Western cultures during the twentieth century, dementia was traditionally defined as an organic mental disorder. Medical definitions of dementia, and hence diagnostic criteria, are heavily reliant on the presence of neuropathology and cognitive deficits. The term dementia is used by health professionals to cover a range of symptoms, with memory loss being the most common (Lezak, 1995). In this context the term dementia is used to refer to two related concepts, a syndrome that comprises a broad pattern of clinical symptoms, and a number of specific although potentially

related diseases, such as Alzheimer's disease or vascular dementia (Lishman, 1987).

The medical model assumes that neuropathology determines the cause and progression of dementia (Morris, 1996) and treatment approaches have therefore focused on arresting and preventing the pathological processes thought to underlie dementia. One implication of this is the assumption that people's social and psychological resources have limited influence on the experience or course of the illness. The medical model further predicts that the onslaught of neurological impairment leads to an inevitable decline in a person with dementia, resulting possibly in the loss of self (Cohen & Eisdorfer, 1986). Thus for many years psychological inquiry into dementia was limited to the study of caregivers with little attention paid to the impact on the people with dementia themselves.

However, one major criticism of the medical model of dementia is that it says little about how to care effectively for a person with dementia (Cheston & Bender, 2000). The model implies nothing will get any better until medical breakthroughs occur, which leaves people with dementia and their families with the negative and deterministic view that there is "no cure, no help, no hope" (Kitwood, 1997). The dominance of the medical model has arguably led to an imbalance in research, with a lack of focus on the impact of the inadequate social arrangements that typically exist for people with dementia. Yet some research has suggested that a person's physical and social environment may influence the presentation of dementia (Kitwood, 1997), although questions remain about the role of people's psychological resources within the course and presentation of dementia. Therefore critics of the medical model of dementia highlight the need for a more comprehensive framework to assess the presentation of dementia and to inform treatment.

Putting the person before the disease

Over the past twenty years there has been an increase in empirical research examining social and psychological factors that may influence the course and progression of dementia, with particular reference to Alzheimer's disease. Tom Kitwood was among the first to present a paradigm for the study of dementia, which put the person first rather than the disease (Kitwood, 1987). According to Kitwood's theory, the process of dementia is due to both cognitive decline and a person's social-psychological environment, with patterns of relationships and social interactions forming a central social context. Kitwood's research provided a rationale for an approach to dementia care that looked more to the person and their social environment than to medical solutions, and led to an increasing interest in the experiences of people who have been diagnosed with dementia. The implication of including the social context in relation to dementia has guided more recent research in attempts to incorporate not only the biological and neurological aspects of the illness but also acknowledge the effect of a person's history, personality and social environment on the presentation and course of the disease.

Recent research has also viewed those with dementia as people who are able to describe their experiences (e.g. Husband, 1999, 2000; Marzanski, 2000), and these studies have provided a great deal of insight into the psychology of people with dementia. Such research has indicated the potential value of seeking the views of people with dementia, who have been found to have plenty to say (Goldsmith, 1996; Wilkinson, 2002). In particular, people in the earlier stages of the disease are able to talk about their experiences and sustain their attention so that detailed interviews are possible (Cotrell & Schultz, 1993). The inherent message in more recent research is that individuals with dementia are important actors responding to and adapting to the disease, rather than passive individuals who are succumbing to deficits (Cotrell &

Schulz, 1993, Long, 1997).

The subjective experience of people with dementia remains a relatively new area of research. Yet such research is becoming increasingly important in the UK since the publication of the National Service Framework in 2001, which sets new national standards of care for all older people and aims to reconfigure NHS services in a way that addresses the needs of older people, including those with dementia. There is also a current emphasis on the early detection and diagnosis of dementia, so as to enable older people and those caring for them to access appropriate help and treatment, allow planning for future care, and help individuals and their families to come to terms with the diagnosis and prognosis (National Service Framework, 2001). Thus there is a need to continue to develop our understanding of the experiences of people with dementia, particularly in relation to issues such as diagnosis disclosure (Pratt and Wilkinson, 2001).

1.2 Theoretical perspectives of the psychological and social impact of dementia

Little is known about the experience of individuals with dementia or their families when a diagnosis of dementia is received or the initial impact of this diagnosis on their lives. In particular, few studies have focused on how couples are affected when one partner receives a diagnosis of dementia. Yet the study of the social context of diagnosis disclosure for people with dementia is crucial, as a person's response to the disclosure is likely to be influenced by both psychological and social factors. Adjusting to a diagnosis is unlikely to be a purely individual process for people with dementia who live as part of a couple; instead there is an issue for couples of developing a shared construction of the situation and working out ways of adapting that are effective for both. This section provides an overview of the theoretical

perspectives that were used to guide this research, which aims to explore the experiences of couples both before and after they receive a diagnosis of dementia for one partner.

The social construction of dementia

Social constructionism may be a useful paradigm within which to develop an understanding of how people with dementia and their partners experience the illness. Social constructionism examines “how we *make* our worlds and are in turn made by our worlds” (Harding & Palfrey, 1997, p.9). This approach makes it possible to acknowledge the influence of social or psychological processes on a person with dementia and can encompass the view that receiving a diagnosis of dementia will have different meanings for different people. A social constructionist perspective of dementia does not deny the importance of the biological aspects of dementia; rather the biological processes themselves “... become social constructions when our understanding of how they will affect us determines how we act in response to them” (Harding & Palfrey, 1997, p.12).

Social constructionism also emphasises the view that perceived reality is constructed in interaction with other people, expectations and the social environment. People with dementia are social actors who live with impairment and interact with others in caregiving relationships within a variety of socially structured environments (Lyman, 1989). This raises the possibility of multiple and different understandings of dementia (Clark & Keady, 2002), which need to be considered in research into dementia and in particular how people make sense of receiving a diagnosis of dementia.

Tom Kitwood (1997) provided a comprehensive framework to consider the social context of people with dementia. Kitwood and his colleagues (e.g. Kitwood,

1988, 1993, 1997; Kitwood & Bredin, 1992) have argued for the importance of ‘personhood’ with regard to people with dementia, and for the need to see the person first and the dementia second. Kitwood defines personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, 1997, p.8). Personhood, as defined by Kitwood, arises through interactions with others (Kitwood & Bredin, 1992) within the context of a dyad’s relationships and social being. Kitwood (1997) presented a dialectical model of dementia, which described a person with dementia in terms of their personality, biography, physical health, neurological impairment and social psychology, and argued that maintaining the personhood of those with dementia is both a psychological and neurological task. He further described the ‘malignant social psychology’ that surrounds people with dementia, which included seventeen elements of social interaction that can undermine the personhood of those with dementia, for example ignoring, labelling and disempowerment. Thus the malignant social psychology surrounding the individual attacks his or her personhood through a dialectical process whereby gradual neurological impairment interacts with a process of disempowerment, a loss of self-esteem and the stereotyping assumptions of others.

Kitwood’s work raised awareness and stimulated an agenda of change particularly aimed at challenging the malignant social psychology to which people with dementia are often subjected (Kitwood, 1993, 1997). This perspective is crucial for research examining how people with dementia and their partners respond to receiving a diagnosis, and highlights the implication of including the social context in relation to dementia and the need to understand the individual’s experience of dementia in combination with his or her social context (Pratt & Wilkinson, 2001). An individual’s sense of worth may be altered when a diagnosis of dementia is received, and it is likely

that the reactions of others around him/her will impact upon his/her sense of identity as a person who has received a diagnosis of dementia.

Narratives, as personal, interpersonal and social creations through which health and illness are given meaning (Radley, 1996), are an important means for the investigation of people's experience rooted in their social and cultural context (Murray, 1999). When a person receives a diagnosis of dementia, a narrative reconstruction may be necessary to link up and interpret the events surrounding the onset of the illness so that these make sense to a person's life story, and this process may also help them cope in a difficult time (Radley, 1996; Williams, 1984). Storytelling helps humans make sense of their experiences (Ellis, 1998) and find meaning within the complexity of their lives, which is bound up with their sense of identity. Killick and Allan (2001) described how 'telling our story' is inherently a social act, as situations provide a framework for people to relate to each other, test out reactions, affirm and enjoy one another's qualities and reinforce their self image. Thus the emotional content of the stories people with dementia who have received a diagnosis choose to tell, and the way they tell them, can provide information about their understanding and experience of the world, their condition and how the reactions and opinions of other people affect them (Killick & Allan, 2001).

A systemic approach invites multiple perspectives and could be a useful framework to consider the importance of the diagnosis for each member of a couple, as well as for the couple as an evolving system (Roper-Hall, 1998). As cognitive abilities decline and the need for assistance with basic activities of daily living increases, the individual with dementia becomes less able to contribute reciprocally to the couple's relationship (Orona, 1990). The inter-relationship between a caregiver and a person with dementia is likely to be dynamic and multidimensional, and may also be

instrumental to the identity and sense of self of a person with dementia (Whitlatch, 2001). The central systemic concept of ‘circular causality’ implies that in a system every individual influences and is influenced by its members (MacKinnon & James, 1987). Exploring the many influences between relationships, ideas and beliefs in couples rather than individuals may offer a new way forward in dementia research.

The social construction of chronic illness

A body of literature has explored attitudes and coping abilities of those diagnosed with chronic illness. Research has suggested that reactions such as concern or fright are culturally based and ‘expected’, as are decisions on how to show illness and ask for treatment (e.g. Radley, 1996). An individual’s reaction to the early signs of dementia, like reactions to bodily signs in chronic illness, is likely to produce an evaluation of the meaning of a symptom. Some research has suggested there is an uncertainty and bargaining in illness recognition, and whether one is ill or not is a matter of social negotiation rather than something individuals contemplate in isolation (e.g. Radley, 1998). It often involves other people, as being given a diagnosis of a disease affects our ‘symbolic status’ of how we are treated by peers and medical professionals (Radley, 1996).

Further, health psychology literature has indicated that chronic disorders can have a devastating impact on couples, who need to meet the challenge of maintaining a balanced mutual relationship while assuming roles of patient and caregiver in the face of threatened loss (Rolland, 1994a, 1999). This research may be useful to consider in attempts to understand how people with dementia make sense of the early signs of their illness and how they involve others around them as their status as an essentially ‘healthy’ individual begins to change.

Conrad (1987) has identified concepts based on the chronic illness literature

that can be usefully applied to research with people with dementia; these are ‘stigma’, ‘self’ and ‘identity’ (Husband, 1999; 2000). This perspective provides an organised way of looking at the source and impact of various losses sustained by individuals with dementia, which some authors argue ultimately leads to a ‘loss of self’ (e.g. Harvey, 1998). People with dementia have to adjust to a wide variety of psychological losses (Lipowski, 1969), for example, loss of bodily and cognitive functions, as well as deprivation in personally significant needs and values. Depression is common in the earlier stages of dementia (e.g. Reisberg, 1983, see 1.3.1), which may be attributable to an individual’s awareness of intellectual loss and other losses. Dementia in a spouse also involves a range of losses potentially including, the loss of one’s confidant(e), the loss of support from family and friends, and the loss of previous lifestyle (Dempsey & Baago, 1998). There may also be joint losses of family interaction and socialising with friends (Chwalisz, 1998).

Theories of loss

Existing theories of loss may provide a useful framework to consider how people with dementia and their partners adjust to the losses inherent in receiving a diagnosis of dementia and how they learn to adjust to these losses. Traditional loss research focused on stages of grieving (e.g. Kubler-Ross, 1969; Tatelbaum, 1984) and coping with loss. According to stage theories of loss, ‘normal’ grief follows a sequence, in which the main stages are denial, anger, depression, acceptance and reconstruction (Harvey, 1998) and there are some parallels to this in adjusting to the progression of dementia. Pratt and Wilkinson (2001) suggested that receiving a diagnosis of dementia should be considered as a process of adjustment and acceptance, from noticing initial symptoms and receiving a diagnosis, through crisis, prognosis, distress, denial, and maximising coping strategies to acceptance.

However, critics of the stage models of grief have highlighted that although grief is a social construct, it is treated as a social fact and has become a commonly accepted construct (e.g. Wambach, 1985), although not all individuals will travel through these proposed stages in a similar manner. In contrast to other chronic illnesses, many people with dementia are often not told their diagnosis and even if they are, the diagnosis may encompass very differing meanings and different kinds of information for different individuals. Therefore people with dementia may grieve for a variety of losses, and the stages contain a range of possible challenges.

More recent perspectives on loss have indicated that people may never return to their pre-loss state (Harvey, 1998). These theories describe a need to survive the loss, come to terms with it and then integrate oneself into a new social context or identity (Miller & Omarzu, 1998). This perspective highlights the need to acknowledge the social context of loss and grieving and how this influences identity and attributions. Dual process models of coping and adjusting to loss (e.g. Stroebe & Schut, 1995, Stroebe, Schut & Stroebe, 1998) have described loss-oriented and restoration-oriented grieving. These models take into account not just the loss of relationships, but coping with changes in the surrounding world consequent to the loss. Dual process models of loss may provide a useful framework for considering how people with dementia and their partners grieve for aspects of themselves and their relationship that have been lost, and also how they begin to reconstruct their identities as a person with dementia and a carer, and their life together as a couple.

1.3 The experience of early stage dementia

This section provides an overview of research which has examined the psychological and social experience of early stage dementia. The first section reviews

personal accounts and empirical research which has examined the psychological experience of the onset of dementia. The next section reviews medical literature that has examined the diagnosis of dementia and discusses the possible benefits of receiving a diagnosis of dementia. The final section reviews research which has examined psychological reactions to receiving a diagnosis of dementia in people with dementia, caregivers of people with dementia and couples.

1.3.1 Research which has examined psychological experiences of the onset dementia

This section begins with a brief review of research evidence which suggests that feelings of depression and a sense of loss are common experiences for people in the early stages of dementia. The following section outlines research that has explored the psychological experiences of people with dementia in the early stages of the illness, including how they make sense of the early changes, their awareness about what is happening and the ways people with dementia find to adjust and manage the changes experienced.

Depression and loss

Epidemiological studies have estimated that depression has a prevalence of between 15 - 57% (e.g. Kral, 1983; Lazarus, Newton & Cohler et al., 1987; Liston, 1983) in early dementia. Several authors have considered how the social context that surrounds people with dementia might influence the experience of depression in the early stages of dementia, for example, Reifler and Larson (1990) suggested depression may create an 'excess disability' in early stage dementia, the most prominent symptom of which is a loss of energy and interest in life, which they argued, should not be confused with the effects of cognitive impairment. In a case study of a woman with Alzheimer's disease, Sabat (1994) proposed that part of her depression may be a

reaction to the same malignant social psychology (Kitwood, 1990) that coincides with the appearance of excess disability. Sabat suggested that testing such a hypothesis would require a greater appreciation of the Alzheimer's disease sufferer as a person and of the psychological environment in which her or she lives than is generally given (Sabat, 1994).

Cognitively impaired individuals may also become depressed as they experience continuing failure in life and a sense of loss. Loss has been closely linked to depression throughout the psychotherapeutic literature, and of all stressful life events, loss has been shown to be a key precipitant of depression (Beck, 1995; Seligman, 1992). Within cognitive theory, loss is considered to act as a trigger for provoking latent maladaptive cognitive schemata which then act to process information in such a way as to maintain low mood and functional disability (Beck, 1995). Depressed mood attributable to an individual's awareness of intellectual loss has been observed in clinical settings (e.g. Reisberg 1983; Cohen & Eisdorfer, 1986; Verwoerd, 1981). However, empirical verification of these clinical observations is an important area of inquiry (Clare, in press, b). Yet recent exploratory work with people with dementia has demonstrated the potential benefits of both cognitive therapy to enhance mood and psychosocial adjustment (Husband, 1999) as well as cognitive rehabilitation to aid adaptation and adjustment to cognitive decline (Clare, Wilson, Carter, et al., 2000; Robinson, 2003).

Little research has explicitly examined the sense of loss experienced by those with dementia in the early stages of the illness, although it has long been recognised that those with dementia experience a number of losses (e.g. Lipowski, 1969). Contracting illness can be construed as a loss event, involving for example loss of health, loss of physical strength, and perhaps loss of life expectations (Miller &

Omarzu, 1998). Literature examining the difficulties of living with chronic illness has indicated that people are often highly aware of previously taken for granted aspects of the self that are now lost (Charmaz, 1983, 1991). Charmaz (1983) suggested that the sense of loss is exacerbated by social and psychological conditions surrounding the person, which has a profound effect on a person's identity, for example living a restricted life, experiencing a discredited definition of self, existing in social isolation, and becoming a burden. From this perspective, individuals must reconfigure their previous self. While the previous self remains to an extent, physical suffering is mediated through a sense of its loss (Charmaz, 1983).

The cognitive deficits experienced by those with dementia could potentially lead to the loss of bodily and cognitive functions, deprivation in personally significant needs and values, a loss of capacity to function autonomously, and a decrease in self-esteem, mastery and control. In early dementia, the person experiencing cognitive changes may also experience anticipatory loss of his or her abilities and plans for the future (Roper-Hall, 1998). Thus loss may be an important concept to consider when working with people with dementia who are in the early stages of adjusting to a diagnosis. An experience of loss shatters the meaningful world people have assembled for themselves and often individuals have a strong desire to understand, manage and recover by creating an account that makes sense of loss and puts the pieces back together (Ellis, 1995).

More research is needed to examine loss from the perspective of people with dementia and their partners and the probable relationship between the losses faced and depression. Such research would provide more information about how the losses inherent in dementia are understood and interpreted by couples in which one partner receives a diagnosis. This information could also guide the development of appropriate

therapeutic interventions for depression for people with dementia or their partners in the early stages of the illness.

Psychological reactions to the onset of dementia

Personal accounts of the experience of living with dementia have been published by people with dementia and by their partners (e.g. Bayley, 1998; Simpson & Simpson, 1999). These accounts have provided information about the experience of living with dementia as the disease progresses, but often have not combined the perspective of people with dementia and their partners. In addition, these accounts describe subjective experiences and empirical research is needed to consider the usefulness of these accounts as a basis for developing psychological support for couples in the early stages of dementia.

Keady, Nolan and Gilliard (1995) interviewed six people with dementia about their experiences, to expand knowledge of the perspective of people with dementia and to guide service provision. The participants described dementia as a process which “happened to people”, insidious in nature with debilitating qualities. In the early stages a variety of experiences were expressed, including fear of the unknown, being out of control, anger towards the dementia, an unfolding sense of loss, and motivation to be secretive. In particular, the interviews highlighted the tension between preserving skills and independence and hiding cumulative losses even when the diagnosis was known, in order to protect caregivers and family. A positive state of mind was revealed as crucial for adapting to and accepting a diagnosis of dementia, which centred on making the best of the remaining time and preserving functions, tasks and roles within the family to promote self worth. Keady and colleagues (1995) argued that eliciting these positive coping statements, behaviours and routines were just as important as identifying feelings of anger and inner turmoil that may accompany the onset of dementia.

Research by Clare (2000, 2002a, 2002b, in press, a; Pearce, Clare and Pistrang, 2002) has also indicated that the onset of dementia places major demands on coping resources and that the development of adaptive coping strategies is crucial in order to optimise well-being and to minimise excess disability for people in the early stages of dementia. Clare (2000) presented a model of psychological responses to the onset of Alzheimer's disease, which described how the impact of cognitive change was experienced in the context of a person's self-concept and social relationships. This model also focused on the variability in reacting to the onset of Alzheimer's disease and how people with dementia selected cognitive coping strategies that gave them greater strength when their self-concept was under threat, for example focusing on information that confirmed their self perceptions and their biases that their memory problems were "not that bad".

Clare (2002a) explored the self-protective and integrative responses (see Clare, in press, a, below) that people with dementia described as they attempted to hold on and compensate for the cognitive decline they were experiencing. Clare (2002a, b) described these responses along a continuum which people with dementia used to both engage with the reality of a progressive disorder and maintain sufficient optimism to carry on from day to day. In another study, Pearce and colleagues (2002) explored the appraisals and coping processes of twenty men in the early stages of dementia. The thematic analysis that emerged, suggested that the men attempted to manage their sense of self by balancing their wish to maintain a prior sense of self against their need to reappraise and construct a new sense of self, which appeared to be an ongoing, circular process. This study also highlighted the importance of understanding people's own constructions of their illness and the effect that this had on how they managed their sense of self.

In a recent study, Clare (in press, a) examined the views of both people with dementia and their partners and provided information about the interaction between people's appraisals of dementia and their coping strategies. Twelve patients in the early stages of Alzheimer's disease were interviewed to provide a phenomenological perspective on the nature of awareness of changes/difficulties in early stage dementia. The thematic analysis that emerged, described individual's responses to the early changes of dementia as a spectrum of responses which formed a continuum of coping styles running from 'self maintaining' to 'self-adjusting'.

Self-maintaining responses referred to people with dementia attempting to normalise their situation and minimise their memory difficulties which Clare suggested, may serve to maintain continuity with previous sense of self. Self-adjusting responses referred to people with dementia attempting to confront the difficulties and adapt their sense of self accordingly, which Clare suggested may serve to allow the impact of dementia to be integrated into the self-concept. This research indicated that people with dementia bring to the situation a range of resources and preferred ways of responding that in turn influence the expression of awareness in different contexts (Clare, in press, a).

On the whole, these studies indicate that people with dementia in the early stages often make selective comparisons or seek positive evidence to counterbalance their memory failure, in order to minimise or normalise their problems as a protective way of maintaining and restoring self-esteem as their impairment worsens, as well as gradually begin to accept the limitations and losses involved in the early stages of dementia. This research has provided information about the experience of people with dementia at an early stage of the illness, and considered how their experiences change as the illness progresses, the cognitive coping strategies that people with dementia may

use to help them adjust to the onset of dementia, and the social context of living with dementia. However these studies did not examine specifically, the impact of receiving a diagnosis of dementia on the process of making sense and adjusting to the illness or how receiving the diagnosis impacts upon the process of accepting the limitations and losses experienced in the early stages. Nor do they provide clear implications for service provision around the time of the disclosure of a diagnosis of dementia.

1.3.2 Disclosure of a diagnosis of dementia

There is a growing interest in the disclosure of a diagnosis of dementia in medical literature (Pinner, 2000). A number of explanations have been proposed for the increased interest in diagnostic disclosure and also for the related interest in psychosocial interventions after a diagnosis is received (Husband, 1999). These have included increased public awareness, earlier presentation and at a stage of milder cognitive impairment, health professionals being more open, and ethical considerations of the rights of people with dementia. It has been debated widely whether people with dementia should be told their diagnosis. Traditionally arguments against telling an individual their diagnosis have included uncertainty in the diagnostic process, causing distress for people with dementia, and there being little point as no treatment is available (Drickamer & Lachs, 1992). However these assumptions are challenged by more recent research (e.g. Heal & Husband, 1998; Pratt & Wilkinson, 2001; see below), the development of new treatments for dementia and a consideration of the ethical implications of withholding a diagnosis.

Johnston, Bourman and Pinner (2000) examined the practice and attitudes among geriatricians and old age psychiatrists to telling people with dementia their diagnosis. The results suggested that only 40% of health care specialists of the elderly regularly told patients their dementia diagnosis and 20% saw no benefit in telling

patients. However, 72.5% of the respondents said they would wish to know themselves if they were suffering from the illness (Johnston et al., 2000). Other studies examining the practice of general practitioners, geriatricians and psychiatrists have shown similar findings (e.g. Gilliard & Gwilliam, 1996; Rice, Warner, Tye & Bayer, 1997; Clafferty, Brown & McCabe, 1998; Vassilas & Donaldson, 1998). A study by Milne, Woolford, Mason and Hatzidimitriadou (2000) reported that 20% of GPs had negative attitudes towards early diagnosis of dementia, largely due to concerns about distressing people with dementia. In addition, even when medical professionals are in favour of disclosing a diagnosis of dementia, it may in practice be hidden behind the term ‘memory problems’ (Crossman & McColgan, 1999), which raises major ethical and methodological dilemmas for research in this area (Clarke & Keady, 2002).

Whether to disclose a diagnosis of dementia has also been examined in research with caregivers of people with dementia. Marzanski (2000) summarised research which suggested most (57% - 83%) relatives of people with dementia do not want the patient to be told the diagnosis, but more than 70% of the relatives would want to be told the truth if they had the disorder themselves (e.g. Maguire, Kirby, Coen et al., 1996; Barnes, 1997). Furthermore, in cases where the diagnosis had been given, most of the caregivers found it helpful both for themselves (98%) and for their partners (84%), (Smith, King, Hindley et al., 1998). Yet, in general caregivers report that when they receive a formal medical diagnosis of dementia, little explanation is available of the meaning or consequences of the disorder (e.g. Aneshensel, Pearlin, Mullan et al., 1995). They also receive virtually no information about caregiving, the potential formal resources they might utilise or the legal and financial implications (Zarit & Edwards, 1996). These studies imply more research is needed into how a diagnosis of a dementia can be disclosed in a way that is helpful and supportive for caregivers (West, 2003).

One of the commonest reasons given by medical professionals and caregivers for withholding a diagnosis of dementia rests on preventing harm (Gillon, 1985) due to the distressing nature of the condition (Maguire et al., 1996). A diagnosis of dementia also carries a stigma and relatives may be concerned to hide the diagnosis from those with dementia, as well as acquaintances and other family members (Heal & Husband, 1998). However, arguments that awareness of the diagnosis of dementia does damage by causing stigmatisation and depression (Drickamer & Lachs, 1992) are not based on empirical evidence (Meyers, 1997; Heal & Husband, 1998; Holroyd, Snustad & Chalifoux, 1996). For example, in a study by Cattell & Jolley (1995) of 100 cases of suicide in older adults, only one case had received a diagnosis of dementia. Such findings may indicate pessimism about how a person given a diagnosis of dementia will react (Heal & Husband, 1998). Furthermore, just like anyone coping with a devastating diagnosis, people with dementia can employ psychological coping mechanisms and psychological defences including denial (Bahro, Silber & Sunderland, 1995) and some people may be unaware of changes due to neurological impairments. Both these factors could be reflected in their responses to a diagnosis of dementia in various ways (Clare, in press, a) and this mitigates against arguments that awareness of a diagnosis of dementia will necessarily lead to lasting psychological damage.

Further, although there are fears about the possible harmful effects of giving people with dementia information about their diagnosis, the harmful effects may be balanced by the potential benefits. Chronic illness literature has suggested that being given a diagnosis validates a person's experience and can be a relief and a 'load lifted' (Murray, 1999). For example, in a study by Reid, Ewan and Lowy (1991), women given a diagnosis of chronic pain reported the positive benefits of having a name for their illness, described increased support from others, and felt their experience was

made more real. Murray (1999) suggested that receiving a diagnosis of cancer gives the opportunity to re-order one's life history and self-definition, to develop a more coherent narrative and sense of self, and to bring order to the crisis of illness. Other literature has described how those who are not given a clear diagnosis are put in an ambiguous position as they feel ill but are not medically defined as such (e.g. Radley, 1996).

The probable benefits of receiving a diagnosis of dementia include providing an opportunity for patients to participate in important decisions about health care and financial planning before cognitive decline worsens (Meyers, 1997), having the right to know, reduction of uncertainty, and giving the opportunity to access services for people with dementia (Fearnley, McLennan & Weeks, 1997). Some research has suggested that receiving a diagnosis of dementia helps make sense of early experiences of memory loss, and helps individuals interpret and ascribe some meaning to the changes in themselves (e.g. Robinson, Ekman, & Wahlund, 1988). Further, the availability of acetylcholinesterase inhibitors (e.g. donepezil) offers a treatment option for people in the early stages of dementia for the first time. Although these drugs do not help everyone and do not represent a cure, offering as they do a way of delaying but not preventing cognitive decline (Rogers & Friedhoff, 1998).

On the whole, this research suggests that the opportunities provided by receiving a diagnosis of dementia outweigh the limitations. Such research offers a contrasting perspective to studies which have highlighted negative attitudes towards disclosing a diagnosis of dementia due to concerns about the distress caused (e.g. Maguire et al., 1996). To date there have only been small studies which have examined psychological reactions to a diagnosis of dementia in either people with dementia or caregivers. Although there is increased awareness that older people must retain and

maintain choice and control in their lives (Nusberg, 1995), people with dementia have generally had a silent and excluded voice (Wilkinson, 2002). The shift to including the perspective of those with dementia in research reflects the emphasis of community care legislation (Department of Health, 1990) and the duty placed on care managers to actively seek the views of those being assessed (Keady et al., 1995). Research into the personal perspectives of people in the early stages of dementia has used fairly small numbers of participants, which perhaps reflects the depth of understanding necessary to examine their experiences (Clarke & Keady, 2002).

The National Service Framework (2001) promotes the general benefits of an early diagnosis of dementia and the subsequent sharing of the diagnosis with the person with dementia (Clarke & Keady, 2002). An inclusion of the views of people with dementia in research into the impact of a diagnosis of dementia is crucial to provide information to guide improvements in the provision of services for these individuals. Currently, what people with dementia actually want to be told remains largely unknown (see 1.3.3.1). Little published research has investigated what people with dementia would like to know about their diagnosis and prognosis. Yet it is crucial that research continues to examine the views of people with dementia themselves in order to increase understanding of how the process of disclosure can be improved and be made beneficial to people with dementia and their families.

Overall, the understanding that health professionals have of the experience of people with dementia remains poorly developed and we need an increased understanding of the early stages of dementia when people are able to give their views. Research that has begun to explore possible psychological reactions to a diagnosis of dementia in people with dementia, caregivers of people with dementia and couples is outlined below.

1.3.3 An outline of research which has examined psychological reactions to receiving a diagnosis of dementia

This section begins with an overview of personal accounts, case reports and empirical research that has examined the psychological impact of a diagnosis of dementia and the views of people with dementia about their experiences of receiving a diagnosis. The following section briefly reviews research evidence which has explored the experience of caregivers of people with dementia and highlights how little is known about both their experiences in the earlier stages of illness or about their psychological responses when their partner receives a diagnosis of dementia. The final section presents two case examples of reactions to a diagnosis of dementia in couples, and considers how couples may begin to adjust together after the diagnosis is received.

1.3.3.1 The perspective of people with dementia

Personal accounts and case reports

Wilkinson (2002) included two chapters written by people with dementia about their experiences of receiving a diagnosis of dementia and also how they felt about taking part in a research project (Pratt & Wilkinson, 2001). Robinson (2002) gave a positive description of her experience of participating in research: “a chance to say exactly as it is, good and bad”, and commented it was good “to help others”. She also talked about the difficulties of having differing medical opinions about her diagnosis and the right of people with dementia to have competent medical professionals involved in their care who liaise with others. McKillop (2002) described his shock when he received a diagnosis of dementia, “the world stopped”. He further described how receiving a diagnosis allowed him to “start to confront” the dementia and learn to adapt to new limitations. He emphasised how essential it was to be told the diagnosis clearly at the right time and place, by a person who thoughtfully allowed plenty of time

for explanations and any questions.

Bahro and colleagues (1995) used a psychodynamic framework to make interpretations about the responses of people who received a diagnosis of Alzheimer's disease. Case reports based on clinical observations illustrated the range of defence mechanisms utilised by each person regarding the cause, symptoms and prognosis of Alzheimer's disease. The defence mechanisms they observed included partial or complete denial, avoidance of naming the illness or seeking out information about it, dissociation of affect, vagueness and circumstantiality in discussing their condition, minimization of the severity of their functional impairment, externalisation, displacement, somatization, and self-blame. These authors suggested that denial could have an adaptive function of bolstering self-esteem rather than facing the reality of decline (Bahro et al., 1995). Husband (1999) also used a case study approach to examine the effects of learning a diagnosis of dementia. Husband discussed how the effect of the diagnosis on self-esteem and personhood was of paramount importance for the three patients described. These studies provide a useful framework for understanding the psychological processes involved in beginning to make sense of a diagnosis of dementia, and how the diagnosis impacts upon a person's sense of self. However the later two studies interviewed people who attended services in hospital and day care settings, who arguably may have more cognitive decline than people with dementia who remain at home in the early stages of their illness.

Research studies

Husband (2000) interviewed people who had presented for neuropsychological assessment of memory problems. In this study a person's ability to engage and talk was measured formally using the MMSE (Folstein, Folstein & McHugh, 1975) and MEAMS (Golding, 1989). Ten people who agreed to participate and who were judged

to be able to engage with the research at assessment were asked two opened-ended questions six months after their appointment: 'what are you most worried about in relation to the diagnosis?' and 'what effects has the diagnosis had on you?'. Content analysis and frequency counts were carried out on the qualitative data from written notes made at interview. Common worries included the fear of others finding out, the fear of social embarrassment, long-term dependency needs, and not being listened to. Common effects included social withdrawal, and hyper-vigilance for evidence of cognitive failures.

Overall, social stigma was revealed as a major issue for these people. Participants talked about the experience being humiliating, the need to maintain secrecy, the fear of others finding out, and the fear they would become incompetent or stupid. In addition, Husband (2000) found that these negative beliefs about self led to unhelpful coping strategies that decreased access to a valued social identity and increased anxiety. Husband concluded that those with dementia who know their diagnosis have worries which effect their behaviour in a way likely to result in low self-esteem, self-stigmatisation and impaired quality of life. This research provided useful information about the experience of people with dementia in the early stages after they received a diagnosis and highlighted the importance of considering the social context of receiving a diagnosis of dementia and how it influenced social interactions. However the analysis did not provide a detailed thematic account of the experience of people with dementia leading up to receiving a diagnosis of dementia. Nor does this study specifically address how people with dementia make sense of their diagnosis as part of a couple or how their experiences are influenced by their partner's responses to a diagnosis of dementia.

Marzanski (2000) aimed to explore what patients with dementia thought was

wrong with them, whether and what they had been told by their physicians about their condition and what they would like to know about their illness. Thirty consecutive patients (with various types dementia) were interviewed. Their responses indicated that overall the quality of the information received had been poor and that many patients had not been given an opportunity to discuss their illness with anybody, with the majority declaring they would like to know more about their illness. Most participants complained accurately of problems with memory. A few gave alternative explanations for their difficulties (e.g. loneliness, old age), although these could reflect things they had been told by medical professionals, who may have chosen to talk about the memory difficulties in terms of “accelerated ageing” rather than dementia. The study also found that some patients did not want to know what was wrong with them or receive information about their illness.

This study illustrated a wide spectrum of responses in people with dementia, from acceptance and openness about the diagnosis, through a more or less conscious decision not to know the truth or to talk about the illness. This study also supported previous research which indicated that telling a person their diagnosis in a single session may not adequately meet their psychological needs (Husband, 1999; Pinner, 2000). However while this study provided a useful exploration of the ways people with dementia talked about their illness, it did not examine how people with dementia were feeling psychologically around the time of receiving their diagnosis or how their negative experiences of services influenced how they made sense of the illness and the appraisals they made about it. Nor did this study explore the social context of receiving a diagnosis of dementia and how the explanations people gave about their difficulties were influenced by their interactions with others around them.

Pratt and Wilkinson (2001) interviewed twenty-four people with dementia to

assess the effect of being told a diagnosis of dementia. A key finding was the range of negative emotions experienced after receiving a diagnosis, for example shock, anger, depression and fear. However the authors also found that withholding a diagnosis led to distress and depression. Pratt & Wilkinson (2001) further revealed a range of positive opportunities identified by people with dementia after receiving a diagnosis. These included being able to make plans, accessing appropriate support, making the most of one's time, developing memory aids, understanding what was going on, and providing an explanation and understanding of behaviour and memory loss, which gave a sense of relief. In general, the people with dementia interviewed identified few limitations to receiving a diagnosis. Some participants mentioned loss of self-confidence and driving restrictions, although Pratt and Wilkinson (2001) argued these limitations were due to the impact of the disease, rather than the diagnosis *per se*.

Pratt and Wilkinson (2001) further found that social support was important to enable people receiving a diagnosis of dementia to develop coping skills. The interviews revealed that the experience of receiving a diagnosis was affected by many social factors, including, medical practice, caregiver attitudes, availability of information, social stigma, and the opportunity to talk to others. Pratt and Wilkinson (2001) argued that services for people with dementia need to break down the stigma and lack of understanding of living with dementia as well as providing supportive environments (e.g. day centres) to make social support available. Finally, this research revealed that all the participants who knew their diagnosis felt in principle that people with dementia should be told as soon as possible, with information given about prognosis and follow up support from medical staff made available. This implied that people with dementia need appropriate support and information to help through the time of 'crisis' which can occur after the disclosure. In particular, the participants

emphasised the right/need to choose how much information is received at any given time, whether all at once or gradually over several meetings.

Overall, Pratt & Wilkinson (2001) found many positive outcomes of receiving a diagnosis and revealed that withholding a diagnosis also had negative implications and could cause distress. Pratt and Wilkinson (2001) developed a framework to help guide their analysis and build on the knowledge they acquired about the experience of people with dementia, which highlighted some of the processes that people went through prior to and following diagnosis disclosure along two axis. The first axis ‘desire and ability to know diagnosis’ referred to the combined influence of an individual’s desire and ability to know or understand their diagnosis and reflected the combined influence of these quite different factors. The second axis ‘social context’ referred to the combined influence of positive and negative social factors (e.g. impact on carers, social stigma). This research provided a wealth of useful preliminary information about the experiences of people with dementia who receive a diagnosis of dementia and how their experiences are influenced by their social context. However, it did not combine the perspectives of people with dementia and their partners who live as a couple or explore how couples come to a shared understanding of the diagnosis or examine the joint appraisals couples make about the illness in the early stages.

In summary, the research presented here clearly demonstrates that people with dementia have many views concerning the impact of dementia on their lives. They are able to discuss the pros and cons of receiving a diagnosis and reflect upon how useful the information given to them about their diagnosis has been. A critical time is in the early stages of the disorder when impairment is mild. The research described above demonstrates that it is indeed possible to examine psychological processes in people with mild dementia. Case studies (e.g. Cohen & Eisdorfer, 1986) have also suggested

that useful data can be collected directly from people with mild to moderate dementia. Individuals at this stage are fully capable of articulating their feelings and concerns, maintain an effective attention span and answer a variety of questions with a high degree of accuracy and reliability (Feinberg & Whitlatch, 2001). Furthermore, long before the diagnosis is sought, individuals know that something is wrong. Factors that lead to identification and definition of dementia and factors that contribute to a request for diagnosis need to be studied at this stage (Cotrell & Schulz, 1993).

The perspective of people with dementia must be included in future research. On the whole, these studies illustrate that the effects on personhood and self-esteem are paramount for those told a diagnosis of dementia. Thus far the emphasis has been upon whether people with dementia should be told their diagnosis or not and the negative impact of receiving a diagnosis of dementia. Some of the studies reviewed have highlighted that people with dementia feel strongly that they have the right to receive a diagnosis on their own terms and that although the diagnosis potentially has a negative impact, it also provides positive experiences for people with dementia. However the research reviewed also suggests that many people do not adopt the medical terminology for their memory problems and may not incorporate the information received from the diagnosis to help them make sense of the changes in their lives. It is also possible that studies which talk explicitly about the diagnosis may skew the responses they receive from people with dementia in comparison to studies which do not.

In addition, the research presented emphasises the need for studies to consider the social context surrounding people who receive a diagnosis of dementia. The existing research suggests there is a clinical need to develop interventions to increase self-esteem, maintain identity, enhance well being and facilitate continued engagement

in social communities for people given a diagnosis of dementia (Husband, 2000). However little of this research has considered the impact of the diagnosis on the relationship between a person with dementia and their partner (if they have one) or how they make sense of the information as part of a couple, facing the later years of life.

1.3.3.2 The perspective of caregivers of people with dementia

The primary caregivers for people with dementia are family members who have been the focus of a great deal of research in the past decades. Yet little of this literature has focused on a family's reaction to a diagnosis of dementia in the early stages (Montgomery & Williams, 2001). Instead the research has been guided by 'stress-process' models of caregiving (e.g. Pearlin, Mullan, Semple & Skaff, 1990) and has focused on identifying determinants of caregiver strain and the psychiatric and physical morbidity effects of dementia caregiving (Harahan, 2001; Schulz, O'Brien, Bookwala & Fleissner, 1995). This general model of the caregiving stress process has led to interventions that moderate/buffer the stresses of caring for a person with dementia (Toseland & Rossister, 1989; Gottlieb & Johnson, 2000) and help caregivers to continue caring through the later stages of the illness (e.g. Mittelman, Ferris, Steinberg et al., 1993). Traditional caregiver research has turned away from issues relating to the person with dementia and instead has used subjective reports from the caregiver or objective observer ratings to ascertain the person with dementia's preferences. Therefore the research has rarely asked care receivers questions about conditions of care and or their experience (Whitlatch, 2001).

Overall, the caregiving literature has revealed the formidable financial, social and emotion burden in caring for a relative with dementia (e.g. Zarit & Edwards, 1996). Some research has focused on the detrimental effects of caregiving on

emotional health. Although many caregivers adapt well (e.g. Williamson & Schulz, 1993) they have a higher risk of poor mental health outcomes than non-caregivers (Schulz et al., 1995), for example caregivers have higher levels of depressive symptomatology, especially if caring is appraised as a burden (Wright, Clipp & George, 1993). However less is known about affective reactions to caregiving such as anger or hostility (Anthony-Bergstone, Zarit & Gatz, 1988) and anxiety (e.g. Bodnar & Kiecolt-Glaser, 1994; Vitaliano, Becker & Russo, 1989; Vitaliano, Russo & Young, 1991).

The research thus far has arguably neglected the fact that as caregiving continues, the progression of dementia inevitably impacts upon the relationship between the caregiver and care recipient. This is critical since it is typically this relational connection or history that prompts relatives or friends to assume the caregiving role in the first place (Montgomery & Williams, 2001). Eventually the person with dementia is unable to recognise or communicate verbally with the caregiver. Some research has suggested that the costs of caring for a family member with dementia are not equal for all families (Zarit & Edwards, 1996), for example husbands caring for a wife report less emotional distress than wives even after controlling for severity of the disease (Zarit, Pearlin & Schaie, 1993). It is possible that different family members experience different care responsibilities and there are many different responses to these care responsibilities. The caregiving process seriously damages some individuals and families, while others are better able to cope and remain intact (Montgomery & Williams, 2001). A hypothesis has emerged that caregivers with rewarding, close and affectionate relationships with the person they care for would be vulnerable to emotional distress as this relationship is lost (e.g. Biegel, Sales & Schulz, 1991, Williamson & Schulz, 1990). Yet empirical research, though scarce, has suggested the

reverse (e.g. Williamson & Schulz, 1990, Uchino, Kiecolt-Glaser & Cacioppo, 1994).

In addition, little is known about the impact of a partner receiving a diagnosis of dementia. Few studies have examined how a husband or wife reacts to the information that their partner has dementia, how they begin to make sense of the information, the impact the diagnosis has on their lives in the early stages of dementia and how they begin to make the transition from a husband or wife to a caregiver. Spouses may also be a valuable source of information regarding the phenomenological perspective of their partner who has received a diagnosis of dementia. Their responses on behalf of the person they care for are unlikely to be entirely independent from their own views. Nevertheless issues that are raised for the person with dementia at this stage may remain relevant to postverbal functioning (Cheston & Bender, 2000; Cotrell & Schulz, 1993).

It is likely that receiving a diagnosis of dementia affects each potential caregiver in different ways, depending upon many factors in their relationship with the person with dementia and their culture. Montgomery and Williams (2001) have suggested that ‘role relationships’ are the critical variable in defining caregiving context and that this largely determines a caregivers’ experience. The authors described two levels of role relationships. First is the *structural level*, the norms that regulate the relationship between the care recipient and caregiver (e.g. role as a spouse), and that usually predate the current relationship. Second is the *individual history level*, the specific dynamics that have emerged over time for a dyad, which can influence the norms that regulate their relationship. Montgomery and Williams (2001) described how each member of a couple adapts general societal norms to the specific realities of his or her own family and thereby creates an individualised set of expectations for their roles as caregiver and care recipient. Dilworth-Anderson (2001)

expanded this concept to include cultural norms, at both the broader societal and sub-cultural levels, which help determine relationships that reflect dimensions within a socio-cultural context. What happens to the relationship between individuals in a couple when one receives a diagnosis of dementia is a new area of research and should be considered in future studies.

Dementia in a spouse also involves a range of losses, for example no longer being able to share experiences that the person with dementia finds hard to recall. With the onset of dementia symptoms, caregivers may experience a perceived loss of the pre-morbid version of their partner and a loss of the relationship's potential and therefore the loss of hopes and aspirations in the future. Montgomery and Williams (2001) have suggested that spouses are more likely to experience relational loss than children caring for a parent, due to the difference in norms and expectations that vary by generation. Spouses not only experience the devastating effects of dementia on their loved one, they also have to face the emotional trauma of losing the relationship with their partner while assuming the major responsibility for their care (Montgomery & Williams, 2001). It has been suggested that caregivers are thus faced with additional demands of grieving for the loss of their relationship while continuing to meet objective demands for care (Dempsey & Baago, 1998).

Conceptualising the experience of caregivers of people with dementia as a loss, termed by Miller (1996) as 'psychic loss', may not be straightforward however, due to the insidious nature of the illness and the periodic reappearance of the 'former self' of the person with dementia, as well as the continued physical presence of the person. In some health psychology research, partners of people with brain injuries have described an experience of "mobile mourning" (Murray & Chamberlain, 1999), because the tentative nature of prognosis leaves family members uncertain with regard to the extent

to which they have permission to grieve the loss of their partner's former self. Others have conceptualised caregiver grief as 'disenfranchised grief' (Chwalisz, 1998), the grief associated with a loss that cannot be openly acknowledged, publicly mourned or given much social support (Doka, 1989). Detailed accounts of the responses of caregivers to their partner's diagnosis are therefore required to explore the validity of these conceptualisations. If caregivers' responses can be conceptualised in terms of grief, there may be some overlap between caregivers' experiences and the experience of grief following a bereavement, although the continued physical presence of the husband or wife means that one experiential domain does not map exactly onto the other (Solomon & Draine, 1996).

Psychological interventions with caregivers of people diagnosed with dementia may usefully be directed toward assisting caregivers and families in work required to grieve the losses and find meaning in their situation (Chwalisz, 1998, West, 2003). Grieving in response to the relationship lost with spouse, psychological support and acknowledgement of loss may be an appropriate intervention (Dempsey & Baago, 1998). However, this strategy may have negative consequences for the person with dementia who is struggling to retain a sense of identity and integrity (Killick & Allan, 2001). In addition, some personal accounts have taken a different view, arguing that despite the changes and losses wrought by dementia, the essence of their loved one persists (e.g. Brough, 1998). Thus more research is needed into the experience of caregivers of people with dementia in the early stages and attention given to whether their experiences can usefully be conceptualised in terms of existing theories of loss.

1.3.3.3 The couple's perspective

It has generally been thought that where one partner has dementia, this has a destructive effect on relationships. Therefore the role of psychological and social

factors (e.g. actions and opinions of those around a person with dementia) in the preservation and growth of relationships has been neglected. However, case study presentations of clinical observations are beginning to reveal that couples may experience the early stages of dementia in many different ways.

Roper-Hall (1998) described two case studies of couples referred to a family therapy service after the husbands had received a diagnosis of probable Alzheimer's disease. The first couple had accepted the diagnosis both fearfully and as some sort of relief, as it provided them with an explanation of some recent "disastrous mishaps" and had drawn the couple closer. For this couple the label of Alzheimer's disease received was of less importance than the experience of "doors opening" to services, for which they were grateful (Roper-Hall, 1998). The second couple had also accepted the diagnosis, but the husband had plunged into a deep depression, alienating his wife. For him the diagnosis was constructed at the time as his "worst fear" in the context of his previous employment as an inspector of services for people diagnosed with dementia. For this couple the influence of the diagnosis was devastating and resulted in the husband living his "worst nightmare", despite him showing none of the difficulties he described as fitting with the diagnosis (Roper-Hall, 1998).

These two case studies highlight two very different experiences of receiving a diagnosis of dementia for couples. The descriptions also highlight how the different belief structures contextualising the situations for each couple resulted in two very different outcomes, which led to different interventions (Roper-Hall, 1998). In addition, Killick and Allan (2001) described case examples of a growing number of accounts from relatives and friends of people with dementia suggesting that new and positive developments in relationships occur through the experience of dementia (e.g. Brough, 1998). These authors have argued the need to embrace a position of openness

and to find new ways of learning from the perspective of people with dementia about their relationships and the support they may need to maintain them.

Rolland's (1994a) Family Systems Illness model, which is based on a concept of the systemic interaction between an illness and a family that evolves over time, provides a framework for the structural and emotional changes that are likely to take place in a couple's relationship when illness occurs and may be a useful framework to consider how couples are affected when a diagnosis of dementia is received. Rolland (1994b) detailed skews that may occur within a couple's relationship, which included issues of whose problem it is, boundary issues, patient care-giver roles, togetherness and separateness, psychosocial recovery, and cognitive impairment. He further suggested that dealing with these skews could promote couples resilience (Rolland, 1994b).

Long (1997) provided a summary of some of the many challenges faced by people with dementia and their partners in the early stages of the illness:

- Communication problems, e.g. the challenge of lack of understanding, repetition, slowed speech, fabrications and withdrawal.
- Financial and legal concerns, e.g. power of attorney.
- Questions about institutionisation, e.g. change in environment, confusion, and strains in loyalty.
- Power and renegotiation of roles, e.g. powerless over dementia.
- Dealing with grief, e.g. emotional turmoil, disintegration of self, uncertainty, and stuckness.
- Unresolved family-of-origin issues, e.g. relationships, lack of understanding in family.
- Adjustments in sexual relationships.

This research could usefully inform this study about some of the challenges faced by couples when one member of the dyad receives a diagnosis of dementia.

Conditions like dementia that involve irreversible cognitive impairments are generally considered the most difficult for couples because of the real loss of aspects of intimacy and some spousal/co-parenting roles (Borden, 1991; Lezak, 1978). Research has suggested that for families to adjust to loss the process must involve shared grieving and recognition of what has happened (Carter & Goldrick, 1987). This implies that if a person with dementia or their carer hides the knowledge of the illness (or perhaps diagnosis) in an attempt to protect themselves or each other, barriers to communication are created which may lead to misunderstanding and distancing between members of a couple (West, 2003). Further, in older people grief and mourning are unlikely to be simple processes for individuals or inter-related social systems. Couples potentially have a long history of significant events experienced together, which provides important contextual information about their reactions to loss (Roper-Hall, 1998).

Further, some authors have suggested that a balance in cognitive abilities is a critical facet of growth in healthy relationships and that the loss of this vital part of intimacy can be devastating (e.g. Rolland, 1994a, b). Serious disorders are also likely to confront both partners with a powerful reminder of existential dilemmas about their own mortality and the realisation that intimacy occurs in the face of an eventual loss (Rolland, 1994b). Research is needed to provide a deeper understating of what each person brings to their daily interactions with each other to inform policies and programs of intervention (Harahan, 2001) for people with dementia and their partners.

Receiving a diagnosis of dementia may also reveal stark differences in each partner's capacity to work towards life goals. Rolland (1987) suggested that this is

experienced most acutely at transition points of the couple and individual lifecycle, when the normative developmental tasks of the next phase of life must be considered in the context of illness or disability. After retirement, transition involves each partner re-evaluating personal and relationship goals as fantasies and plans for the use of leisure time often come to the fore (Falicov, 1988). Compromise necessitated by a chronic condition may heighten feelings of “being robbed” (Rolland, 1994b). Future plans such as travel that have been deferred to later life may need to be confronted as unrealistic. Little research has examined how couples who have received a diagnosis of dementia manage these transitions and come to terms with the loss of possible future plans or dreams expected to be fulfilled in later life.

1.4 The need for further research

In line with Kitwood’s holistic person-centred view of dementia, it is important to widen the scope of investigation to include topics not ordinarily studied within a medical model of dementia (Whitlatch, 2001). Research needs to avoid reinforcing negative stereotypes about the incapacity of people with dementia to share their views and experiences (Wilkinson, 2002) and to see people with dementia as people who have valid experiences and whose behaviours are driven by meaning (Sabat, 1994). Pratt and Wilkinson (2001) have argued that there are few opportunities for people with dementia to express their views about diagnosis disclosure, but it is essential to hear their voices in order to develop good practice. There is a need for greater understanding of people with dementia in the early stages rather focusing only on interventions helping caregivers in the advanced stages (Keady et al., 1995). This will enable us to develop more individualised and distinct services, which allow people with dementia to have an enduring voice in the assessment process (Keady et al., 1995).

The need for additional information is crucial, as relatively little is known about the attitudes of people with dementia have towards receiving a diagnosis or the emotional consequences of receiving diagnostic information (Marzanski, 2000). Empirical information is necessary to inform protocols for disclosing a diagnosis and service provision. In addition, little is known about the effect that learning the diagnosis of dementia has on the ways people try to cope and this limits the development of early psychological interventions (Husband, 2000). It would be helpful to have more knowledge about how the information is received by people, the extent of their understanding and their methods of understanding it and coming to terms with it (Goldsmith, 1996).

In addition, caregiving research has rarely explored the relationship between caregivers and the people with dementia who they care for, and how this influences the behaviour and outcomes for carers (Fortinsky, 2001). Neither are questions typically asked to assess carer's perceptions about the illness and the appraisals they make about the changes in their partner in the earlier stages of the illness. A better understanding is needed of the changes in roles and the relationship that may occur for carers in the early stages, to aid the development of effective caregiver support programs and policies, and increase positive outcomes for people with dementia and their carers (Harahan, 2001).

Finally, there is currently little published research, which has combined the perspectives of the person with dementia and their partner when a diagnosis of dementia is received. Yet a more realistic sense of the couple's situation may lead to more useful and effective interventions (Whitlatch, 2001). Following diagnosis mild to moderately impaired individuals and their partners must begin reorganizing and adapting to the disease and role loss (Montgomery & Williams, 2001), develop a

shared construction of their situation, and make adjustments in their lives that help them cope effectively. Little is known about how this process occurs. Further research is needed to examine how couples communicate about the issue of dementia, in order to increase our understanding of the impact of a diagnosis of dementia for couples. Such research will be a starting point for developing effective support for couples who have received a diagnosis of dementia (Pratt & Wilkinson, 2001). Research has suggested that families or couples withdraw from services if their beliefs and experience of a health problem feel unacknowledged or misunderstood (Rolland, 1998). Thus it is vital to explore the experience of people with dementia and their partners, who receive a diagnosis.

1.4.1 An overview of qualitative research methods

This study will aim to explore psychological reactions to a diagnosis of dementia in couples. The study will be informed by the psychological theories and literature described above, and will use a qualitative methodology. In this section the use of qualitative research methods with people with dementia and their partners will be discussed, and the rationale for choosing an interpretative phenomenological analysis over other qualitative approaches presented.

Qualitative research methods seek detailed and complex interpretations of specific socially and historically located phenomenon. Within psychological research, qualitative methodology corresponds to a move away from measurement to understanding, from causation to meaning, and from statistical analysis to interpretation (Smith, Harré & Van Langenhove, 1995). The strength of qualitative methods is their emphasis on revealing meanings within human transactions and behaviour, which is particularly advantageous when studying psychological phenomena not previously extensively researched (Murray & Chamberlain, 1999). Qualitative

research emphasises the pursuit of uncovering the meaning of a person's experience, rather than some 'objective truth', and of helping individuals to make sense of what is happening in their lives (Murray & Chamberlain, 1999).

Kitwood (1997) argued for the use of qualitative methods in research with people with dementia because these methods recognise that each person is unique and avoid making generalisations about people, which can sometimes be taken too literally and detract from attempts to understand any particular person. For the present study I wanted to adopt a method of analysis that could characterise individual experiences and meaning, whilst also wanting to contextualise the processes arises during the interviews with couples, for example in terms of power relations, protection and social positioning. There are also ethical reasons why qualitative research may be a more appropriate approach for research in this area. Qualitative research is intended to be a collaborative exercise which avoids the abuse or exploitation of people with dementia, who are already in a relatively powerless position (Owens & Payne, 1999). Questionnaires and measures which are commonly used in quantitative research may also confuse people who have declining cognitive abilities. People with dementia may be better able to discuss their experience in a supportive environment using interview techniques (Bahro et al., 1995; Goldsmith, 1996). In addition many individuals, especially in the earlier stages, may welcome an opportunity to discuss their experiences of the disease and express needs that can be met by supportive, open discussion about their illness (Marzanski, 2000).

Three methods of qualitative analysis were considered, interpretative phenomenological analysis (IPA: Smith, Jarman & Osborn, 1999), grounded theory (Charmaz, 1995) and discourse analysis (Potter and Wetherell, 1994). The aim of IPA is to gain participants' personal perceptions or accounts of the topic under

investigation, as opposed to an objective reality. IPA recognises the research process as a dynamic one, with the researcher interpreting this personal account, and considers the ways in which these interpretations may have influenced the analysis. During IPA themes are extracted from the interview data and compared and contrasted across participants, which allows the researcher to slowly build up a more general categorisation or theory (Smith et al., 1999).

Grounded theory aims to develop a theoretical analysis of the data that fits the data, has relevance to the area of study and provides the tools for taking conceptual qualitative analyses into theory development. Grounded theory builds the research as it ensues rather than having it planned before the data collection, and allows the researcher to shape and alter the data collection to pursue the most interesting and relevant material (Charmaz, 1995). Levels of abstraction are built directly upon the data and are checked and refined by gathering further data (cf. Glaser & Strauss, 1967; Henwood & Pigeon, 1992). Discourse analysis focuses on the social impact of speech acts and texts, moving away from phenomenology. It makes the assumption that every piece of speech or writing is a social action, for example a persuasion, justification, or establishment of social position. Discourse are studied to discover the impact and purpose of discourse on the social world (Potter and Wetherell, 1994).

IPA was chosen as the most suitable methodology as it offered sufficient flexibility for the researcher to explore contextual issues arising within the interviews and most closely offered a means of answering the aims of the study, to explore a couple's understanding of and response to a diagnosis of dementia, as well as their appraisals about the illness. Smith, Flowers and Osborn (1997) note that IPA can help reveal the gap between an illness and an individual's perception of it, which may help explore how two people diagnosed with the same illness may offer very different

personal accounts. Grounded theory was rejected because the research does not aim to develop theory in this area, but rather to gather preliminary information about the phenomenological perspective of a small sample of individuals. Further the research aims to focus on comparing the experiences of couples who have received a diagnosis of dementia, rather than pursuing other topics for these couples. In addition, whilst discourse analysis offered a method that provided greater insight into the historical, social and cultural conditions within which couples exist, it was felt to be less appropriate in answering the research aims of exploring their experiences and joint construction of the diagnosis of dementia. However, the IPA analysis will be supplemented using Brown and Gilligan's (1992, 1993) voice relational method'. This method's focus on the voice of those disempowered in society is likely to be relevant to the voice which is heard from the person with dementia in each couple. The method also allows some exploration of the messages that are given by society to older people with dementia (Harding & Palfrey, 1997), which are likely to influence a person's understanding of and response to a diagnosis of dementia. This method has been successfully utilised by Proctor (2001) who interviewed four women with dementia about their experiences of services and focused on issues of power in relationships with medical staff for these women.

1.4.2 Research questions, implications and explicit aims

The present study aims to explore psychological reactions to a diagnosis of dementia in couples in which one partner had received a diagnosis of dementia during the previous two years. The study will attempt to elaborate couples' shared constructions and understandings of, and responses to, a diagnosis of dementia, and to explore the extent to which their responses can reasonably be interpreted and understood in terms of theories of loss. The assumption is made that people who have

received a diagnosis of dementia within the past two years will be able to remember their experiences of receiving the diagnosis if their cognitive impairment is mild (Cotrell & Schultz, 1993; Goldsmith, 1996), as previous studies have demonstrated the strong emotional impact of receiving a diagnosis dementia (see 1.3.3.1). Thus both members of a couple will be asked about how they reacted to the diagnosis and the impact it had on their lives. Specific attention will be paid to the appraisals couples make about the illness, including how the couple have chosen to talk about the illness, as some couples may deny or minimise the memory problems (Bahro et al., 1995; Clare, in press, a), their interpretations of the illness, and the perceived effect of the illness on their marital relationship. It was considered that interviewing participants as a couple would increase the validity of the findings and provide additional insight into the couple's relationship. Although interviewing the couple together may inhibit people's responses to talking honestly about their relationship, it provides an opportunity to see the couple interacting together and a chance for carers to provide a view of the couple's experience which is not affected by cognitive decline.

The results could potentially inform service provision for people with early stage dementia and their caregivers. This is particularly relevant now as there is more of an emphasis on early diagnosis of dementia in the NHS. The research findings will also be useful for the development of systemic and couple interventions, which could help people with dementia and their partners resolve problematic feelings and issues about being diagnosed with dementia, as well as enhancing communication and mutual support within the couple. In the longer term this would be expected to reduce excess disability for the person with dementia and caregiver strain for the partner. In addition, information collected from people with dementia and their spouses at an early stage of dementia may remain relevant in the later phases of dementia when verbal

communication may no longer be possible for the couple.

The aim of the study is to provide an exploratory analysis of psychological reactions to a diagnosis of dementia in couples at an early stage in the process of dementia. The study aims to explore similarities and commonalties between couples in how they have made sense of what is happening to the person with dementia and their understanding of the illness. For example, it will consider how couples differ in their experiences of services and how this experience may impact upon their acceptance and understanding of a diagnosis of dementia. The study also aims to examine any differences between people with dementia and their partners in the experience of receiving a diagnosis of dementia and the impact of the information on a person's life. For example, it will consider how each partner's life has been changed by the diagnosis of dementia, and what kinds of coping strategies each has adopted. Overall the study aims to compare and contrast the themes that these couples discuss and offer a framework for understanding how couples in the early stages of dementia experience the process of receiving a diagnosis of dementia and the adjustments they begin to make after the diagnosis has been given, both as individuals and as a couple. These themes will be related to existing literature about the psychological reactions of people with dementia and theories of loss, and implications for a model of making sense of a diagnosis of dementia for couples will be discussed.

CHAPTER TWO

METHODS

2.1 Design

A qualitative interview study offered the potential for exploring the meaning, experiences and content at an individual and joint level for each couple. Data were gathered using in-depth interviews based upon a semi-structured interview schedule, designed to facilitate exploration of issues relevant to the research questions. Individual transcripts were analysed using interpretative phenomenological analysis, which allowed for exploration of individual and couple accounts, leading to the identification of themes emerging across the sample as a whole. This analysis was supplemented by a voice relational method that examined the ‘voice’ which was heard from each person and the types of conversation interactions between partners.

2.2 Participants

2.2.1 Inclusion criteria

The study included heterosexual married couples aged 65 - 85 years. One member of each couple had received a diagnosis of probable Alzheimer’s disease or vascular dementia within two years prior to taking part in the research. Potential participants with dementia needed to have been diagnosed at their local memory clinics and categorised as having mild or early stage dementia. In keeping with the aims of the study and its person centred philosophy, participants were not re-assessed using cognitive tests or other standardised measures, in order to minimise their discomfort while taking part in the research. Instead information about the diagnosis, and whether it had been disclosed, was obtained from hospital notes and from a

conversation with a health professional who knew the couple well. Participants did not have to be aware of their diagnosis to be included in the study but I noted whether the clinic had shared the diagnosis with the person with dementia and/or his or her partner. In addition, scores of 18 or above on the Mini Mental State Examination (MMSE) (Folstein et al., 1975) were used as an approximate index of mild impairments (Lezak, 1995).

To be included in the study, couples had to be living together in the community and both members of the couple needed to agree to participate. It is likely that a person's culture and social environment would affect their reaction to a diagnosis of dementia, thus the study aimed to collect a reasonably homogeneous sample to increase the validity of themes that emerged from the data. It was anticipated that including participants from multiple ethnic backgrounds might cause difficulties in examining variations between couples, as it would be unclear which were attributable to differences in ethnicity. Further, people from minority ethnic groups are under-represented proportionately in referrals to mental health services for older adults (Woods, 1996). Therefore in the present study ethnicity was limited to people of white ethnic origin, born in the United Kingdom (UK).

No participants had any other current major physical or mental illnesses, as additional illnesses might also affect their response to a diagnosis of dementia and the appraisals couples made about the illness. Finally, it was anticipated that a large proportion of potential participants diagnosed with probable Alzheimer's disease would be taking anti-cholinesterase inhibiting medication such as Aricept. Thus it was impractical to exclude people who were currently taking medication for Alzheimer's disease. Instead the effect of medication was considered by asking people about the tablets they had been prescribed and their responses to it.

2.2.2 Recruitment process

Participants were recruited from four memory clinics across North London, to take part in a wider study examining communication, mutual support and psychological reactions to a diagnosis of dementia, of which the present study formed a part. In each clinic, permission to access hospital notes was obtained from the consultant psychiatrist. After potential participants were identified from their hospital notes, permission to contact each couple was sought from the consultant psychiatrist or key worker for each couple. These health professionals were also able to confirm that the couple met the inclusion criteria for the study, and provide information about the disclosure of the dementia diagnosis. Next an invitation letter to take part in the research and an information sheet detailing the aims and process of the study was sent to potential participants (see Appendix I). The wider study's short title, and the title used on all communication with participants, was "The experience of couples when one partner has memory difficulties". The terms 'dementia', 'Alzheimer's disease' or 'vascular dementia' were not used in the information sheets. This decision was made because not all people with dementia or their partners are aware of or agree with their diagnosis, and research suggests that even when a health professional says a person knows his/her diagnosis, it may be hidden behind the term "memory problems" (Crossman & McColgan, 1999). Further this study focused on eliciting couple's shared constructions and understanding of and response to a diagnosis of dementia, rather than imposing a clinical diagnosis and medical definition upon their experiences. In practice all the consultant psychiatrists reported that they had disclosed the diagnosis of dementia to either the person with dementia or their partner (see 2.2.3).

Potential participants were contacted by telephone a week after the letter was

sent, so that both the person with dementia and their partner could ask any questions about the research project. Informed consent to participate in the research was gained at this stage with both members of the couple and also discussed at the initial visit with each couple. Written consent was obtained at the beginning of the first visit to a couple, and continuing consent discussed at each further visit (see Appendix II). Couples who declined to take part were told they would not be contacted further.

2.2.3 Characteristics of the sample

Twenty-three couples were approached to participate in this study. Of these twenty-three couples, twelve declined to take part in the research, and two withdrew after initially agreeing by telephone. Although couples did not have to offer a reason, some mentioned ill health or low mood or indicated that one partner did not want to talk about memory difficulties. Five women and four men with a diagnosis of dementia and their nine partners were interviewed for the study. All the couples were heterosexual and married. The length of time the nine couples had been married ranged from 8 to over 60 years; mean length 47 years ($SD^1 = 15.54$). A brief description of each couple is presented below, names and identifying details have been changed to preserve confidentiality.

Couple one: Ruth and Donald

Ruth is a seventy-three year old woman with probable Alzheimer's disease, diagnosed two years before she was interviewed (MMSE 19/30). Donald is her seventy-one year old husband; they have been married for over forty-five years and have two children. Ruth and Donald both left school at fourteen years old and worked in semi-skilled jobs until they retired. Ruth and Donald have both been told Ruth's

¹ Standard Deviation

diagnosis. Donald said they had never discussed it but that he knew Ruth had “Alzheimer’s disease”.

Couple two: Ewan and Catherine

Ewan is a seventy-five year old man with probable vascular dementia, diagnosed six months before he was interviewed (MMSE 23/30). Catherine is his seventy-five year old wife; they have been married for over fifty-five years and have one child. Both left school at fourteen years old and worked in semi-skilled jobs until they retired. Catherine has reportedly been told about Ewan’s diagnosis but both are confused about why Ewan has memory problems.

Couple three: Carol and Phillip

Carol is a seventy-four year old woman with probable Alzheimer’s disease, diagnosed eight months before she was interviewed (MMSE 23/30). Phillip is her seventy-six year old husband; they have been married for over forty-five years and have two children. Carol and Phillip are university educated and both worked in professional jobs until they retired. Both have been told about Carol’s diagnosis. Phillip talks openly about Carol having “Alzheimer’s disease” and Carol talks about her “memory difficulties”.

Couple four: Abigail and Michael

Abigail is a seventy-nine year old woman with probable Alzheimer’s disease, diagnosed one year before she was interviewed (MMSE 25/30). Michael is her eighty-one year old husband; they have been married for over fifty-five years and have two children. Both left school at fourteen years old and worked in semi-skilled jobs until they retired. Abigail and Michael have both reportedly been told Abigail’s diagnosis but Michael said he did not understand what was causing Abigail’s memory problems. Abigail said there is nothing wrong with her.

Couple five: Emma and Jerry

Emma is an eight-five year old woman with probable vascular dementia, diagnosed nine months before she was interviewed (MMSE 19/30). Jerry is her eighty-year-old husband; they have been married for over sixty years and have one child. Both left school at fourteen years old and worked in semi-skilled jobs until they retired. Emma and Jerry have reportedly been told Emma's diagnosis but both said that her memory problems were due to old age.

Couple six: Justin and Constance

Justin is an eighty year old man with probable Alzheimer's disease, diagnosed a year before he was interviewed (MMSE 28/30). Constance is his sixty-eight year old wife; they have been married for eight years and have no children. Justin and Constance are both University educated and pursued careers in the health profession. Both have been told Justin's diagnosis and talk openly about Justin having "Alzheimer's disease".

Couple seven: Harold and Georgia

Harold is an eighty-four year old man with probable Alzheimer's disease, diagnosed two years before he was interviewed (MMSE 19/30). Georgia is his seventy-year-old wife; they have been married over fifty years and have no children. Both are university educated and pursued careers in academia. Harold and Georgia have reportedly been told about Harold's diagnosis. Georgia said they do not discuss his memory difficulties and Harold said he has no memory problems.

Couple eight: Ruby and Jake

Ruby is a seventy-five year old woman with probable Alzheimer's disease, diagnosed six months before she was interviewed (MMSE 25/30). Jake is her seventy-eight year old husband; they have been married for over forty-five years and have two

children. Both are university educated and worked as skilled professionals until they retired. Ruby and Jake have both been told Ruby's diagnosis and they talk openly about Ruby having "Alzheimer's disease".

Couple nine: Keith and Veronica

Keith is a seventy-three year old man with probable Alzheimer's disease, diagnosed two months before he was interviewed (MMSE 28/30). Veronica is his seventy-four year old wife; they have been married for over fifty years and have one child. Keith is university educated and worked as a skilled professional until he retired. Veronica did twenty years of voluntary work after raising her daughter. Keith and Veronica have both been told Keith's diagnosis and they talk openly about Keith's "memory difficulties", but said they do not like to use the words "Alzheimer's disease".

Overview of participants with dementia

The nine people with dementia ranged in age between seventy-three and eighty-five years, with a mean age of seventy-seven years and three months ($SD = 4.48$). Seven had received a diagnosis of probable Alzheimer's disease and two a diagnosis of probable vascular dementia. Six of the people with a diagnosis of probable Alzheimer's disease were taking acetyl-cholinesterase inhibiting medication. The nine people with dementia had a mean MMSE score of 23/30 ($SD = 3.26$) and their scores ranged between 19 and 28. The length of time since the diagnosis had been disclosed ranged from two to twenty-four months, with a mean time of eleven months ($SD 7.76$). Eight of the people with dementia had reportedly been told their diagnosis. Of these eight, two talked about having "Alzheimer's Disease", four talked openly about their "memory difficulties", and two said they did not have any memory

problems. Eight of the people with dementia were born in the UK and one was born in a neighbouring European country but had lived in the UK for forty-six years. All nine were of white ethnic origin. Five of the people with dementia had received a university education and the others had left school at normal school leaving age (approximately fourteen years old).

Summary of the partners

The nine partners ranged in age between sixty-eight and eighty-one years, with a mean age of seventy-four years and nine months ($SD = 4.49$). All of the partners had reportedly been told about their spouse's diagnosis. Four partners talked about "Alzheimer's disease" in front of their spouse, two talked about "memory difficulties", and three said they were not certain what was causing their partner's memory difficulties. Eight of the partners were born in the UK and one was born in the Middle East but had lived in the UK for fifty-six years. All nine were of white ethnic origin. Four of the partners had received a university education and the others had left school at normal school leaving age (approximately fourteen years old).

2.3 Procedure

All the interviews were conducted at the participants' homes at a time convenient for them. Before the interview commenced, couples were reminded of the main aims of the study and invited to ask questions about the research. Each couple were also asked a number of demographic questions, requesting information about their age, the length of their relationship, and occupational history. This informal conversation was not taped and represented a first attempt to build trust and allay suspicion with the couples so that they could feel able to provide an open and honest account of their experiences (Keady et al., 1995). If participants still wanted to take

part, both partners signed a consent form. Participants who agreed to take part in the research were interviewed as a couple for approximately 45 minutes. Each interview was recorded on a tape recorder. The interviewer reassured people that they could stop at any time to take a break or terminate the interview. In practice, seven of the interviews lasted 45 minutes without a break. One interview lasted an hour and a half with one break, and one was terminated after 20 minutes. All interviews followed a semi-structured format (see 2.5). At the end of each interview participants were invited to talk about anything that had not been covered in the interview which they felt it was important to discuss. Participants were also asked to comment on their experience of taking part in the study. In practice the majority of participants reported finding the process a positive one, were pleased to help with research in this area and found it helpful to talk. On completion of the interview a full debriefing was given and any questions that participants had were answered. In addition, each couple was offered an individual or joint (depending on their preference) follow-up counselling session with the interviewer, to talk through any feelings of distress. No participants felt the need for another meeting but all were encouraged to telephone the interviewer if they subsequently changed their mind.

2.4 Ethical considerations

The North Central London Community Research Consortium granted ethical approval for this project. Ethical approval was also requested from and granted by one local ethics committee (see Appendix III).

In this sample of people with early-stage dementia, it was anticipated that it should be possible to obtain informed consent in all cases. However, it was probable that people with dementia might have more difficulties than their partners in

understanding the aims and the purpose of the study. Therefore, before the interview commenced, both partners were asked about their understanding of the study and separately asked whether they wanted to take part. To minimise social pressure on people with dementia and their partners to take part in the study, and to continually monitor consent to take part, couples were told on several occasions that either of them could withdraw from the study or postpone interviews if they did not feel able to take part on a specific day. In practice, two couples rearranged their interviews when given this option. Further, both members of the couples were told that they could switch the tape off if they were unhappy about the information that was being recorded, or retain the tape after the interview if they wanted to limit the information available as research data (Knox, Mok & Parmenter, 2000). In practice no participant switched off the tape recorder or asked to retain the tape.

The interviews were carried out at participants' homes, because talking in a familiar environment may be beneficial for people with dementia (Clark & Keady, 2002). The research aimed to elicit psychological reactions to a diagnosis of dementia in couples, and both partners were interviewed together in order to explore their shared understanding about the diagnosis and to give couples the chance to respond to what each other were saying. Interviewing people with dementia and their partners together can allow the partner to support the person with dementia during the interview (Pratt, 2002). It was hoped that partners might monitor each other's level of comfort and/or ask important questions not thought of by the interviewer. It was also hoped that partners without dementia might perhaps help the interviewer to ask the person with dementia questions in the best possible way.

The interview was conducted using a basic counselling style format, following the recommendations of Coyle (1998), to facilitate a supportive and open discussion

about the couples' experiences, views, feelings and perceptions, and to minimise discomfort. The interview format was used flexibly to allow couples to talk more about the aspects of their experience which they wanted to focus on, reinforcing the view that they were the experts on which areas were important to cover. A flexible interview process also allowed participants to tell their story in their own words, and meant the interviewer could tailor the interview to the level of comprehension and articulation of the person with dementia (Fielding, 1993) and follow the pace set by the person with dementia (Cotrell & Schulz, 1993). Further, couples were not pushed to talk in detail about topics which either person appeared uncomfortable about discussing or indicated they did not wish to talk about. In practice four couples did not want to talk about how their relationship had been affected by receiving a diagnosis of dementia, beyond acknowledging that there had been some minor changes. Also, one couple appeared uncomfortable when asked about the memory difficulties of the person with dementia, and their request to terminate the interview without moving on to other topics was respected.

Due to the sensitive nature of the research topic it was anticipated that the interview had the potential to cause some distress for participants. In practice only one participant (a person with dementia) showed signs of distress about being interviewed and left the room before the interview was concluded. In this instance, following the guidelines recommended by Pratt (2002), the interviewer remained in the couples' home until the person became less distressed, and the interviewer made positive reflections about coping strategies that had been discussed. In addition, care was taken to remind the couple several times that they could contact the interviewer for a follow up counselling session about their experience of taking part. This offer was declined. Further, if the occasion arose, information was available on the local Alzheimer's

Society support groups. In practice this information was only passed on to one couple, and professional help from the memory clinic that had assessed the person with dementia was requested on the couple's behalf.

2.5 Interviews

As mentioned above, the interview followed a semi-structured format (see appendix IV) and participants were interviewed as a couple. A short introduction orientated the couple to the purpose of the interview. The interview went on to cover the following topics:

- When the couple first realised one of them had memory difficulties.
- What thoughts and feelings each person had at this time, and how these have changed over time.
- Whether the couple had sought a diagnosis and how they received the diagnosis, including their experiences of services.
- How each person reacted to the diagnosis and how it had affected the couple's relationship and involvement in activities.
- What reactions other people have had to the diagnosis/the couple.

The interview followed couples' response to the interview questions in a person-centred way, to discover which parts of their experience were important to them and to obtain sufficient depth of information (Polit & Hungler, 1987). In particular, empathic listening without actively confirming any possible distortion of reality was used to encourage people to share their feelings and frustrations in a non-judgmental way (Bahro et al., 1995). If a couple did not acknowledge the diagnosis of 'dementia', the interview followed their interpretation of the situation, used their words and asked how "the problem" (in their own words) had affected them.

All the interviews were later transcribed verbatim. Details which might identify participants, such as names, where the couples lived and places of employment, were excluded from the transcripts to ensure confidentiality.

2.6 Choice of Methodology

The study aimed to explore and understand the experience of dementia from the perspective of people with dementia and their partners by elaborating couples' shared constructions, understanding of and response to a diagnosis of dementia and the appraisals couples made about the illness. A qualitative rather than quantitative methodology was therefore considered most appropriate. The subjective experience and views of people with dementia have largely been neglected as a focus for research, and qualitative research enables people with dementia to participate in research that does not place an emphasis on cognitive skills that may have declined (Feinberg & Whitlatch, 2001) and instead aims to uncover the meaning of a person's experience rather than an objective truth (Murray & Chamberlain, 1999). Thus the transcripts were analysed using interpretative phenomenological analysis (IPA; Smith et al., 1997, 1999), which was supplemented by a voice relational method (Brown & Gilligan, 1992, 1993). Further it was anticipated that limited numbers of couples might be found who met the inclusion criteria and agreed to participate, and that a more in-depth research process with a small sample of couples with one partner who had dementia would be most feasible.

2.6.1 Interpretative phenomenological analysis (IPA)

IPA was used to develop an 'insider's perspective' (Conrad, 1987) of participants' experiences and focus on the meanings that they attached to their

experiences. IPA was chosen over grounded theory methods (Charmaz, 1995) as it allows the detailed analysis of the accounts of experiences offered by small samples, with the aim being to say something meaningful about the cognitions and emotions which are reflected in these accounts. IPA recognises that the research product necessarily represents the outcome of a dynamic interaction between participants' accounts and the researcher's interpretative frameworks (Smith et al., 1999). It is therefore necessary to reflect upon the researcher's interpretative framework during the analysis and consider the ways in which these frameworks may have influenced the analysis. In the planning stages of this research, the researcher's interpretative frameworks were developed from literature about dementia, loss, systemic theory and personal experience working with couples who had received a diagnosis of dementia. These frameworks influenced the design of this research (interviewing couples rather than individuals) and the initial interview schedule.

An idiographic case study IPA approach (Smith et al., 1999) was used to analysis the data collected from the nine couples. This approach works well with small samples, as it allows the researcher to retain an overall mental picture of individual cases and the location of themes by examining each individual transcript in detail, before comparing across participants. Each transcript was read and re-read and the emerging themes from the data noted. Following the process outlined by Smith and colleagues (1999), preliminary thoughts and connections were noted about the participants' experience in the form of memos. When examining each transcript, notes were made in the right margin, usually using the participant's own words, that appeared to say something meaningful about the person's cognitions and emotions regarding their experiences. These right margin notes were then typed out in a full list, and the transcript re-examined to make sure everything had been covered and nothing

had been missed. The right hand margin notes were then grouped into thematic areas with two levels of hierarchy, themes and sub-themes, using participants' own words as theme headings. Each instance of each theme was then coded in the left margin of the transcript, which provided the opportunity to check the fit of the themes, make sure every instance of each theme was noted and adjust themes where necessary.

Next the individual analyses were compared across the nine couples, looking for similarities and differences. A summary list of theme labels from all nine analyses was made and grouped into super-ordinate themes, themes and sub-themes. All the transcripts were fully recoded using this list of themes, which was also further adapted as necessary. This process was cyclical and continued until a final list of themes emerged that reflected all the participant's transcripts. This cyclical process also provided a check that the themes were represented in the verbatim transcript so as not to let the researcher's own bias affect the selection of themes. In addition the research memos were retrospectively examined to check the validity of the emerging interpretative framework. Two other researchers also examined the transcripts, initially for potential themes and in the latter stages to check the fit of the evolving themes to the original data. Feedback and comments from these researchers were used to modify the themes. Finally the themes were subjected to a further interpretation stage to develop a model of the processes described in the ten themes that emerged from the couples' accounts. These procedures aimed to ensure the themes were a good reflection of the verbatim accounts and increase the validity of the final thematic account (see also 2.6.3).

2.6.2 Voice relational method of analysis

The transcripts were also analysed using an adapted form of Brown and

Gilligan's (1992, 1993) voice relational method. This method focuses on the voice of those disempowered in society, which provided a useful theoretical framework to examine the 'voice' that was heard from the person with dementia in each couple. Similar to IPA, this method characterises individual experiences and meaning, whilst also contextualising the processes within the interviews, for example in terms of power relations, protection and social positioning within the couple's relationship. This method was used to analyse the transcripts to examine which partner had the dominant voice in the interview and whether the person with dementia was enabled to have a voice by their partner, by considering the different types of conversational interactions between partners.

This supplementary analysis paid particular attention to examples of what Brown and Gilligan (1992, 1993) termed "psychological" and "political" resistance. Firstly, psychological resistance refers to situations where the dominant cultural voice about dementia leads either the person with dementia or their partner to bury thoughts and feelings and instead show confusion, uncertainty and dissociation about what has happened. The transcripts were examined for examples of psychological resistance when the person with dementia said they were unable to say anything about a topic, perhaps due to complete silencing by others (Proctor, 2001) and how their partner responded to these statements. Case examples, including direct quotes from couples, are presented to highlight the main themes found in this analysis across the nine couples.

Secondly, political resistance refers to examples when the person with dementia or their partner struggles against abuse and fights for a relationship in which it is possible to disagree openly with their partner, and articulate a full range of emotions. The conversational interactions between partners were examined to

establish whether the person with dementia disagreed with their partner, whether they were able to speak openly from their own perspective, and how their partner supported/hindered their contribution to the interview. Again, case examples and direct quotes are presented to highlight the main themes found in this analysis across couples.

2.6.3 Validity and credibility in qualitative research

Several authors have published guidelines for qualitative research which have been used in this study to maximise the rigour of the qualitative research process and analysis. In section 2.2.3, the research participants and their life circumstances are briefly described to enable the reader to judge the range of persons and situations to which the findings might be relevant (Elliot, Fischer & Rennie, 1999). In presenting evidence for the analyses (Smith, 1996, Yardley, 2000), extracts and the associated analyses are presented in the Appendices to allow the reader to take part in the interpretation that was made by the researcher. Further, the main themes emerging from the transcripts are supplemented with verbatim quotes and line references from the transcripts. Appendix V displays four pages of individual level analysis from a transcript and the memos made after the interview and during the analysis. Appendix VI displays the complete list of themes developed from two interviews. Appendix VII displays the final list of themes and highlights where themes from each interview have been condensed. Appendix VIII displays the final versions of theme two with all relevant extracts.

Further, the research process was made open to audit (Stiles, 1993), allowing others to follow the steps the researcher had taken, through independent audit and researcher reflexivity (Smith, 1996). Two separate transcripts, together with the

coding, analysis, notes and results were submitted to the internal and external research supervisors for audit. They had the task of checking that the process of analysis was a credible one in terms of the data collected and that a logical progression ran through the chain of evidence. On the whole this was found to be the case, and only minor comments were noted, which were then discussed resulting in some amendments to the thematic account. As mentioned, the researcher's reflexivity was addressed by the researcher keeping detailed memos to note down thoughts and ideas that came to mind during the analysis and to reflect on the researcher's own views, position and interests in relation to the research (Yardley, 2000). These memos were reflected upon during the development of a model, which described the processes encapsulated by the thematic account and were also discussed in supervision.

Internal coherence (Smith, 1996, Yardley, 2000), a consideration of whether the study presents a consistent argument and makes sense, was addressed in three ways. Firstly, participants who took part in the research were consulted about the analyses and their comments about its coherence used to refine the thematic account. Secondly, the research supervisors were consulted to gain their views about the coherence of the analyses with regard to the relevant research literature. Thirdly, the analysis was presented to health professionals who worked with older adults with dementia and their comments about coherence were also used to refine the thematic account. Member validation (Smith, 1996), checking the researcher's interpretation of the research interview, was addressed by the researcher returning to couples and asking for their comments on the analysis and the understanding developed from it (see Appendix IX). Finally, to assess the accuracy of the researcher's categorisation and to gain a consensus about the validity of the themes (Coyle, 1998), another researcher read one of the transcripts and the emerging themes, and for a few

highlighted extracts was asked to assign codes and themes to the text accordingly.

CHAPTER THREE

RESULTS

Overview

This chapter describes the themes extracted from the couples' interviews. It then proposes a model, based on these themes, that summarises the processes that these couples engaged in to make sense of what was happening before and after one partner received a diagnosis of dementia. The model illustrates an overarching theme that developed from the data, "Making sense and adjusting to loss", as well as exploring some of the variations between people with dementia and their partners in the processes they engaged in and how they responded to the information received about the diagnosis.

Ten themes emerged from the qualitative data collected from the couples' interviews. These themes relate to the couples' shared construction, understanding of and response to a diagnosis of dementia, to the couples' appraisals about the illness and the changes in their lives, and to the strategies couples used to adjust to these changes. The themes are not mutually exclusive and if a participant's comment could be categorised in more than one theme, it was included in each one. The ten themes are subsumed within two higher-order themes, "Not quite the same person, tell me what actually is wrong" and "Everything's changed, we have to go from there". It would seem that the first higher-order theme describes a cyclical process of gradually noticing changes in the person with dementia and making sense of these changes as a couple. This process also includes how couples begin to accept what is happening and how this connects to receiving a formal diagnosis of dementia and couples' expectations and experiences of services (positive and negative).

The second higher-order theme seems to describe an oscillating process in which couples move between acknowledging their current difficulties and losses and recognising their resilience and developing coping strategies. The couples experienced a process of adjustment that includes both these aspects, which appeared to serve to allow them to maintain and reconstruct their sense of self and their sense of self in relation to their spouse. This process describes the impact of the illness on individuals in terms of themselves and their relationships with others; the movement between themes in this process expresses a dynamic of switching focus between what is lost and what remains for each member of a couple which allows them to cope with and adjust to their current situation.

In this section each individual theme is described within the context of the higher-order themes and then a model summarising the processes observed in the couples' accounts is proposed. Each theme is illustrated with quotations from participants and each quote notes the identity number of the participant cited. Alongside the number of the couple, a letter 'm' denotes that it was a quote from the husband during the interview and a letter 'f', a quote from the wife. In addition the letter 'D' denotes that the quote was from a person with dementia during the interview and a letter 'P', a quote from a partner.

Each theme is described from the perspective of both partners. Although most of the couples made comments related to the majority of the emerging themes, there were some variations in the couples' accounts of their understanding of and response to the diagnosis of dementia and how their lives had been influenced by the diagnosis. The description of each theme details variations between couples and between people with dementia and their partners. These variations are summarised in section 3.2 and also explored in the context of the proposed model in section 3.3 below.

3.1 Not quite the same person, tell me what actually is wrong

All the couples discussed and provided examples about how they had gradually noticed changes in the person with dementia and their understanding about what had happened to bring about these changes. The interviews indicated that couples were aware of small changes in the person with dementia, which were initially passed off until a point where the decision was made to contact services as the cognitive difficulties worsened. Some couples had accepted the difficulties and said they “knew” it was dementia before they were seen by a health professional. Other couples said they had little idea what was happening before they received the diagnosis. For some couples this uncertainty continued after the diagnosis had been given, which appeared to lead some couples to continue to dismiss the memory difficulties because they lacked a clear explanation for what was happening.

Five themes from the couples’ interviews addressed their initial appraisals about what was happening to the people with dementia, their acceptance of the situation and experiences of receiving a diagnosis. Table 1 presents each of these themes and their prevalence across the sample. This table shows that the majority of the themes were present within all of the couples’ interviews and so most couples shared aspects of the experience of receiving a diagnosis of dementia. Each theme will be discussed, taking note of any differences between couples and differences between the people with dementia and their partners.

Table 1: Themes relating to ‘not quite the same person, tell me what actually is wrong’

| Themes | Prevalence ¹ | |
|---------------------------------------|-------------------------|----------|
| | Person with dementia | Partner |
| You don’t notice straight away | Medium | Frequent |
| Coming to the conclusion | Frequent | Frequent |
| I quite accepted it | Frequent | Frequent |
| It did nothing for me | Frequent | Frequent |
| Coming here helped | Frequent | Frequent |

¹ Prevalence of themes is categorised as: Frequent when more than two thirds of participants mentioned the theme, medium when between one and two thirds of participants mentioned the theme and infrequent when less than one third of participants mentioned the theme.

Theme One: You don’t notice straight away

On the whole, the couples described a process of gradually realising that one partner had memory difficulties in the period leading up to making a decision to seek professional help. The couples’ comments about this process can be divided into two categories. The first category, “Anyone can forget”, refers to couples’ descriptions of dismissing, passing off, ignoring and disbelieving the early signs of memory difficulties in the partner with dementia and finding it difficult to decide whether the memory difficulties were an exacerbation of previous traits or a more serious problem. The second category, “Gradually creeps up”, refers to couples’ descriptions of how slow the process was of realising there was a significant problem and gradually noticing a repeating pattern of memory difficulties.

Anyone can forget

Most of the people with dementia found it difficult to remember the specific details of what had been happening in the period leading up to receiving a diagnosis of dementia. When asked about what was happening before he received a diagnosis of Alzheimer's disease, one husband replied:

"It's difficult to think when it's normal and when it's abnormal really, when you have reached that point... where it crosses over yes... one begins to notice things but it takes time." [mD6]

This description was similar to partners' comments about finding it *"difficult to put a finger on"* [fP6] when they first started to notice memory difficulties in their partner.

One wife commented how it had taken her and her husband:

"Quite a while to see whether it was more serious in one case than in the general cases." [fP7]

During this time period, partners talked about *"passing it off"* [mP1] and *"disbelieving"* [mP3] that their spouse had memory problems. One wife gave this description of first noticing her husband's memory difficulties:

"You wait until he starts to pick up, just thought well I'll ignore it... I thought he would perhaps start coming back to being a bit more like his old self."
[fP2]

Partners also talked about *"laughing at first"* [fP2] over the changes in their spouse.

One husband recalled:

"When she was mislaying things at the start, we used to laugh and joke about it. I mean it was a giggle oh you haven't lost it again you know and all that lot." [mP1]

Other partners talked about how the initial changes they noticed led to anger and an

increase in arguments for the couple. When asked about early changes in the marital relationship one husband replied:

"I used to get very annoyed with her and scream at her because I simply did not accept the fact that she should make such mistakes. At the beginning I did not believe and I was getting furious." [mP3]

In addition, people with dementia talked about feeling *"depressed"* [fD3] in the early days of their memory difficulties. When asked how he was feeling when he first began to notice his memory difficulties one husband replied: *"I totally descended into a total abyss"* [mD9]. Another husband said: *"I was terrible depressed, I couldn't see the funny side of anything"* [mD2]. Partners also described noticing their spouse feeling *"depressed"* [mP3], *"feeling angry"* [fP9] or *"withdrawing"* [fP6] at this time.

Gradually creeps up

Couples described how slow the process was of realising there was a significant problem. One husband with dementia commented: *"it was so slow, so slow"* [mD6]. Partners also described *"a slow process of change not a sudden one"* [fP6] of noticing memory difficulties in their spouse. Partners described *"quite a long period"* [fP7] where *"you don't notice it"* [mP1] and said in retrospect: *"It must have started a long time before that"* [mP1]. Partners further described noticing a repeating pattern of memory difficulties which *"happened so many times"* [mP1], and seemed to prompt them to begin to wonder what was happening to their spouse. When asked who first noticed his wife's memory difficulties one husband replied:

"I was aware, I was the first to notice but it took some time. C doing things which were not in her character and it was repeating itself." [mP3]

Overall the couples' comments appeared to highlight that although the

majority of partners were first to notice early memory changes in the people with dementia, over time both began to notice changes and together couples experienced a process of passing off these changes at first. People with dementia made more comments about how they were feeling at the time, rather than recalling specific details about what they first noticed was different about their memory. Several couples recalled the person with dementia feeling depressed at this time. The couples responded to the early changes in memory and perhaps depressed mood experienced by the person with dementia in several ways, ranging between humour and anger. Several partners also found it difficult to remember exactly when they first noticed the memory difficulties in their spouse, highlighting how gradual the changes were for both members of the couple.

Theme two: Coming to the conclusion

Couples described a process of beginning to realise that the person with dementia had a memory problem, wondering about what might be happening to cause the memory difficulties and deciding to seek professional help. The couples' comments about this process can be divided into three categories. The first category, "Noticed there had been some changes", refers to couples' descriptions of knowing there were definite changes in the person with dementia and what their explanations were for these changes before they sought a diagnosis. The second category, "Anyone would wonder", refers to couples' descriptions of wondering why the person with dementia was having memory problems, including explanations based on genetic inheritance and old age. The third category, "Deciding to go", describes how couples made the decision to go and see a professional about the memory difficulties. Couples appeared to share a sense that it might be useful to see someone. Some people with

dementia also described feeling reluctant to face what might be happening.

Noticed there had been some changes

Some partners described a shared process of noticing the changes: *"I'd noticed changes in my wife and she'd noticed"* [mP8]. Other partners talked about the spouse with dementia: *"not realising there were changes taking place"* [mP3]. Only one partner talked about his son *"noticing more than me"* [mP4] and commented:

"I see her everyday know what I mean? I... there was no change for me then, it wasn't then but to him it was a change." [mP4]

Couples also talked about their knowledge of what was happening to the person with dementia before they sought a diagnosis. When asked what he thought was going on at that time one husband with dementia said: *"I just couldn't make out what it was all about"* [mD2]. Other people with dementia talked about knowing they had Alzheimer's disease: *"I knew by then what was going on"* [mD6]. When asked about what she had thought was happening, one wife with dementia replied:

"I knew there was something wrong at the time... I would see the word Alzheimer's so I realised that was something to do with me." [fD8]

Couples appeared to have a shared knowledge about dementia and what was likely to be happening before the formal diagnosis was given. When one husband with dementia described how: *"I knew myself before that..."* [mD9], his wife commented they were: *"reluctant to use the word"* [fP9]. Other couples described how they had *"no idea what was happening"* [mP4] before they received a diagnosis.

Anyone would wonder

Couples talked about *"the process of why me"* [mP8], seeking explanations for why the person with dementia was experiencing memory difficulties or referred to: *"... the condition of unknowing why I came to encounter the condition"* [mD9]

when asked about their understanding of the memory problems before the diagnosis was given. On the whole, the explanations couples had for why one partner was experiencing memory difficulties varied between old age and genetic inheritance.

Firstly, couples referred to their age as an explanation for their memory difficulties: *"We're not young now"* [fD5]. One husband with dementia said: *"I suppose everybody says it as they get older, oh I forget"* [mD6]. Partners also said: *"... it's only changed because of our age"* [mP5] as an explanation for the memory difficulties experienced by their spouse.

Secondly, couples in which family members had experienced dementia commented: *"her mother had the same thing"* [mP4] and gave this as an explanation why the person with dementia was experiencing memory problems. When asked what her initial explanation was for her memory problems, one wife with dementia replied:

"I suspect I got my problem with my mum... I realise that she probably had the problem that I now have." [fD3]

Deciding to go

Couples described how they made a decision to go and see a professional about the memory difficulties experienced by the person with dementia. Partners talked about: *"A point when you think that something perhaps should be done about this"* [fP7]. Many partners presented this as a joint decision: *"We'd decided... we got in touch, we came along"* [mP8]. When asked what was happening around this time, one wife recalled:

"... having a conversation together really about whether it would be a good idea to get a referral... to get a diagnosis to get you on some medication."
[fP6]

Couples talked about their shared expectations that they could receive help from

services. Many mentioned hearing about *“some sort of medication that just might help”* [fP9]. When asked about his expectations before he attended a memory clinic one husband with dementia replied:

“I had a feeling there was help for memory problems. We were hopeful in a sense that there could be something in me that wouldn’t be lost.” [mD9]

One wife described how her husband with dementia (a former medic) had:

“... been reading about medication in the BMJ and thinking that it could be beneficial if it was Alzheimer’s.” [fP6]

In addition, partners talked about being *“keen for the assessment”* [mP8] and *“pleased to come”* [fP9]. In contrast people with dementia said they: *“... didn’t really know what they would gain from it”* [fD8]. When asked about his feelings around the time of making a decision to attend the memory clinic, one husband with dementia replied:

“I don’t know, this is a dilemma that arises in many other aspects of my existence what to know and what not to know. I thought this is probably wise I don’t know... having it confirmed that you are slowly going round the bend is not a very helpful situation to be in.” [mD9]

Another partner replied:

“There is a question how do you agree that it’s necessary to have something done.” [fP7]

A comment which seemed to reflect that this couple needed to find a way to agree that it was time to seek help from services.

Overall the couples shared a process of beginning to acknowledge that the memory difficulties experienced by the people with dementia were worsening and in different ways decided to seek help or try and find out more about what was

happening. During this process couples varied as to how much they knew what was or might be happening and why they thought the person with dementia was experiencing memory difficulties. Some couples made the decision to seek services with accurate knowledge about what was likely to be happening, while for other couples there was a clear lack of knowledge and a great deal of uncertainty about what was happening to the person with dementia and why. Finally, all the couples shared an early expectation that they could gain help from services.

Theme three: I quite accepted it

All the couples described a process of gradually accepting that one partner had dementia and that the memory problems were likely to be a permanent change in the person. The couples' comments about this process can be divided into three categories. The first category, "Of course I realise", refers to couples' acceptance about what was happening, with both partners talking openly about memory difficulties, including whether to tell others about the diagnosis. The second category, "No-one can do anything", refers to couples' feelings of hopelessness that nothing can be done to help people in their position. The third category, "I'm not any worse", refers to couples minimising the impact of the memory experienced by people with dementia and/or finding it difficult to accept that the memory difficulties are permanent.

Of course I realise

Many people with dementia talked about having: "*...no memory now, this is my problem*" [fD3]. When asked about his memory difficulties one husband with dementia replied: "*I am losing my memory... I recall very little*" [mD9]. When asked whether he agreed with his wife's descriptions of his memory loss, another husband

commented:

"I would say I have changed and there is a problem, and that I have what plenty of other people have." [mD6]

This husband went on to talk about how he *"had accepted it"* [mD6] and had made a decision to stop driving: *"I noticed I could no longer follow familiar routes"* [mD6].

Partners talked further about accepting the memory difficulties experienced by the person with dementia, with three openly talking about *"Alzheimer's disease"* [mP8] in front of their partner. When asked about his wife's memory problems one husband replied: *"She forgets, it's as simple as that, it's the basis of the illness"* [mP8]. Some partners reflected that they had come to accept that: *"However many times I repeat things... he[or she] doesn't remember and that's it"* [fP9].

Couples also talked about the reactions of other people around them to the memory loss experienced by the person with dementia and whether or not to tell people about the diagnosis. Some people with dementia commented that they did not want others to know about their memory problems. When asked about the reactions of other people, one wife with dementia commented: *"I prefer others not to know... not need to know, unnecessary"* [fD8]. In contrast one husband with dementia turned to his wife and asked:

"Are there people who don't know about it?... I just assume everybody knows... well tell me who doesn't know and I'll tell them." [mD6]

Several partners talked about *"a question of whether to tell others"* [mP8] and how to handle this situation. When asked about telling friends and family about the people with dementia's difficulties one wife replied:

"One issue actually has been whether um whether to leave it to J to tell people or whether for me to tell them and I think that's often difficult for me to

judge." [fP6]

Other partners talked about the people with dementia withdrawing from others since the illness began or how they no longer saw people as often as they used to. One husband commented:

"she don't see so many people out now like she used to" [mP1] and that
"other people don't come round like they used to" [mP1].

No-one can do anything

When asked how they felt about having memory problems many people with dementia commented: *"there's nothing I can do"* [fD5]. One wife with dementia replied:

"Well there's no cure, they haven't found any solutions have they to my problem... it's just a curse but what can you do?" [fD3]

Partners made similar comments. When asked how he felt, one husband replied:

"Well you can't do nothing about it you know these things can you? She's had it and that's it finished... can't do nothing." [mP4]

Other partners replied: *"the rest is up to us"* [mP8], reflecting a feeling that no-one else could really help: *"what can they do?"* [fP2].

I'm not any worse

All the people with dementia made comments during the interviews to the effect that their memory problems were *"not that bad"* [fD8]. People with dementia appeared to accept but minimise their memory difficulties: *"I don't think that's a big problem really"* [fD3]. One wife with dementia commented: *"You don't think about it"* [fD5]. Other people with dementia found it difficult to talk about how they had changed. When asked for her views about what her partner had been saying about her memory problems one wife with dementia replied: *"I don't like to speak like that"*

[fD1].

Some partners talked about their spouse with dementia *“passing off”* [mP1] their memory problems, with one wife commenting that: *“He doesn’t like being reminded that he doesn’t remember things”* [fP9]. Partners also minimised their spouse’s memory problems: *“It’s gonna take time for him to get over it”* [fP2]. When asked about her husband’s memory problems one wife replied: *“... two people with memory problems”* [fP7], presenting memory problems as a joint issue for the couple.

Overall the majority of couples both accepted and minimised the memory problems experienced by the person with dementia, regardless of their knowledge about what might be causing the memory problems. Couples’ acceptance of the memory problems further seemed to influence their view of whether other people should be told about the difficulties one partner was experiencing. Couples also appeared to feel hopeless about their situation and shared a view that no-one could do anything to help them.

Theme four: It did nothing for me

All the couples described their dissatisfaction with the services they had received and some expressed confusion about what was happening to the person with dementia, despite reportedly having been told about the diagnosis. The couples’ comments can be divided into two categories. The first category, *“Hoped for something more”*, refers to couples’ descriptions of feeling disappointed with the services offered and negative experiences of the services they received. The second category, *“Tell me what actually is wrong”*, refers to couples’ descriptions of confusion about what is actually wrong with the person with dementia and a feeling that they should have been told more by health professionals.

Hoped for something more

People with dementia made comments about services being *“a sheer waste of time”* [mD2] and being *“disappointed”* [fD8] with how little was done. When asked about her experiences of attending out-patient appointments one wife with dementia said: *“I don’t know why we go there”* [fD4]. Another husband with dementia replied:

“Can I be helped more substantially except having my own self-knowledge professionally reinforced? This is my question, can I?” [mD9]

Several people with dementia made comments about being: *“only in there for a couple of minutes”* [fD5] and appointments being a *“mere chat”* [mD9]. One wife with dementia described her experiences as:

“... repetitive, little is done... questions had before, off you go and not a lot else really.” [fD8]

Partners made similar comments about their experiences: *“no benefit, no point, little is done”* [mP8]. When asked what she thought of the feedback given by the memory clinic, one wife replied:

“Both of us are very articulate, we can understand words but we had hoped for something more than comforting words. As far as K’s condition is concerned it’s been absolutely negative.” [fP9]

Other couples described the memory assessment as: *“More for the benefit of psychology... nothing followed, no advice”* [mP8]. Couples also said they had *“not been told what to anticipate”* [fD8].

All the couples described feeling dissatisfied with their experiences of services. Some partners had tried to cancel follow up out-patients appointments and one commented:

“I wrote and said I didn’t see the point... I resent being pressed to go to the

next appointment.” [mP8]

Several partners mentioned the *“long wait”* [mP8]. Others made comments about the *“factory aspect”* [fP9] of appointments or about the waiting room being *“the most depressing place on earth”* [fP6]. In addition one partner felt they *“had to work hard”* [fP6] to get a referral to psychology and another commented: *“they forgot about us”* [fP9].

Explained to me but didn’t explain

People with dementia found it difficult to recall talking to a health professional about their memory difficulties: *“I don’t remember what she told me”* [fD3]. When asked about what her consultant had said, one wife with dementia replied:

“Sometimes they don’t remember properly to tell you at the doctors... they don’t tell you anything do they?... That’s the answer they give you today, it’s one of those things, it’s your age.” [fD5]

Her partner shared this view and commented: *“They haven’t said anything to me either”* [mP5]. Other partners described how: *“Lots of things went on that we don’t know about”* [fP2]. When asked what he had been told about his wife’s memory problems one husband replied:

“I’d like him to tell me what actually was wrong... he should explain a bit more to us than what he has done... I asked that nurse, she said the same as him, exactly the same as him so you get nowhere.” [mP4]

Overall couples shared a feeling of dissatisfaction with the services they had experienced and also the information they had received about dementia. Both partners and people with dementia made many comments which described a process of being disappointed about both what was on offer to help couples in their position and what followed on from receiving the diagnosis of dementia. Some couples also commented

on the lack of information given about the diagnosis/illness, which left them feeling confused about what was wrong with the person with dementia.

Theme five: Coming here helped

Couples did describe feeling helped and supported by some aspects of receiving the diagnosis, despite their general dissatisfaction with the overall service they had received. Most couples also expressed their views about how the person with dementia was being helped (or not) by receiving medication for memory problems. The couples' comments can be divided into three categories. The first category, "Supportive and caring", refers to couples' descriptions of feeling supported, cared for and helped by health professionals. The second category, "A problem clearly defined", refers to couples' positive descriptions of what happened at the memory clinic and the information they received about the diagnosis. The third category, "Medicine from the doctors", refers to couples' descriptions about the usefulness of medication for memory problems.

Supportive and caring

People with dementia talked positively about their experiences of attending memory clinics: *"I quite enjoyed being examined"* [fD3] or described how they: *"came away with pleasant feelings"* [mD9]. When asked about her experience of services one wife with dementia replied: *"I got the feeling that she might be able to do something"* [fD8]. Another said: *"I was grateful they were looking after me"* [fD3].

Partners also talked positively: *"... very understanding, the support was there"* [mP8]. When asked about her experience of services one wife replied:

"I really am grateful for what was done... I thought it was supportive and

optimistic." [fP9]

Couples also commented: *"they've all been nice the people"* [fP7], when talking about individual health professionals they had met.

A problem clearly defined

Some couples talked in detail about the assessment which the person with dementia had completed at the memory clinic: *"They tested you, asked you questions didn't they?"* [fP7]. One wife with dementia recalled: *"... lying on a bed with a thing over my head"* [fD3], whereas a husband with dementia said the assessment: *"Confirmed I couldn't do certain tests"* [mD6]. One partner also described the *"shock to see the damage"* [mP8] and said he found watching his wife's assessment *"horrifying"* [mP8].

When asked about the how they felt about the information they had received from the memory clinic after the assessment, a few people with dementia commented how it *"confirmed I had a problem"* [mD9] and *"suggested certain areas of difficulty"* [mD6]. One husband with dementia described his experience as:

"Now the falsity has gone... I've had to stand up without my clothes on... pulled skeletons out of the cupboard... I thought oh dear, it seems to be coming from all directions." [mD9]

Partners described some positive benefits to receiving the diagnosis, *"it helped us understand what was happening"* [mP8]. When asked about her reactions to the diagnosis, one wife replied:

"It clarified that it is a condition, it's been resolved... I can accept it because it's been officially sanctioned." [fP9]

Another wife talking with her husband with dementia during the interview described:

"A marked improvement really in your condition in that you became much less

withdrawn really and seemed quite relieved that the whole thing had been diagnosed.” [fP6]

Her husband agreed and commented: *“Well it just confirmed and I accepted” [mD6].*

This wife also talked about the assessment being helpful in terms of *“advice, ideas and practical suggestions about things which we might do” [fP6].* Other couples were left asking: *“Well what could be done about it?” [mP1]* and one partner commented: *“They don’t say nothing to you, just give you tablets” [mP5].*

Medicine from the doctors

Most couples talked about the impact of medication on the memory problems experienced by the person with dementia: *“I’m getting some medicine from the doctors” [fD3].* One partner said: *“I think Aricept might be doing some good” [fP7]* whereas the other couples had found it more *“difficult to decide if they’re handy” [fD3].* When talking about his wife’s medication, one husband remarked:

“It’s only slowing the deterioration but certainly the deterioration is continuing.” [mP3]

Another couple had *“heard there was some sort of medication that just might help” [fP9],* and were disappointed that none had been offered, with the husband with dementia commenting:

“I’m not taking any medication so you know essentially none of these conversations are self-revelatory.” [mD9]

Overall couples made positive comments about the individual health professionals they had seen. However it appeared that partners described the process of receiving a diagnosis more positively than people with dementia, who were unable to recall many details about the information they received. Couples who had received clear information about the diagnosis commented on how the diagnosis made it easier

for them to accept what was happening, but most were left wondering if there was any practical help available. There were also mixed views about the benefits of medication for memory problems, although the majority of couples shared an expectation that medication was available and would be useful. Some couples shared a feeling that prescribing medication was done in the absence of explaining what was actually happening to the person with dementia and one couple felt disappointed that they had not been offered medication.

3.2 Everything's changed, we have to go from there

All the couples discussed and provided examples of how living with memory problems had changed their lives as individuals and as a couple, and described a process of trying to adjust to these changes. The interviews indicated that each participant shared a construction of not being the same person as they were previously. Both people with dementia and partners commented on the loss of aspects of their previous self as well as the loss of roles within their relationship. All the couples also described their resilience as individuals and as a couple, and provided examples of successful coping strategies. The couples appeared to describe a process of oscillating between acknowledging difficulties and problems and carrying on despite the feelings of loss evoked by the illness. This process appeared to help couples make sense of what has changed and over time allowed them to adjust to what had been lost for each partner as well as find ways to cope together in spite of their difficulties. For many couples, this adjustment process also involved making comparisons between their current abilities and relationship and how things were in the past.

Five themes from the couples' interviews addressed their appraisals about

changes in their lives as individuals and as a couple and ways they had begun to adjust to these changes since they received a diagnosis of dementia. Table 2 presents each of these themes and their prevalence across the sample. This table shows that the majority of the themes were present within all of the couples' interviews, and so most couples had shared aspects of the experience of living with memory problems since they received their diagnosis of dementia. Each theme is discussed below, taking note of any differences between couples and between people with dementia and their partners.

Table 2: Themes relating to 'everything's changed, we have to go from there'

| Themes | Prevalence ² | |
|---|-------------------------|----------|
| | Person with dementia | Partner |
| I would say I have changed | Frequent | Frequent |
| Taking over the reins | Medium | Frequent |
| Take it as it comes | Frequent | Frequent |
| Coping very well | Medium | Frequent |
| Wouldn't mind doing it all again | Frequent | Frequent |

² Prevalence of themes is categorised as: Frequent when more than two thirds of participants mentioned the theme, medium when between one and two thirds of participants mentioned the theme and infrequent when less than one third of participants mentioned the theme.

Theme six: I would say I have changed

All the couples described progressive changes in the person with dementia in the period of time since they had received a diagnosis. The couples' comments can be divided into two categories. The first category, "I don't remember", refers to couples'

descriptions about the memory difficulties experienced by the person with dementia and making comparisons between past and present memory abilities. The second category, "I'm fed up with it", refers to couples' descriptions of the people with dementia feeling depressed, anxious and frustrated about having memory difficulties.

I don't remember

When asked about their memory problems, people with dementia talked about their loss of memory: "*I am losing my memory*" [mD9] and difficulties with their memory: "*I couldn't remember my way around familiar routes*" [mD6]. One wife with dementia commented:

"I just can't remember... you can't remember your Dad, who... what was his name... when we were kids, I can't remember it." [fD1]

Other people with dementia talked about difficulties with "*recent things*" [fD5] and talked about how their memory loss "*varies like*" [fD5]. When asked about his memory one husband with dementia replied:

"I can remember the big liners... I worked on them, they're past... you get memories of that type of thing." [mD2]

Partners talked further about the memory loss experienced by their spouse with dementia: "*she forgets whether she's cooked dinner*" [mP5] or remarked to their partner "*you just keep repeating yourself*" [mP5]. Some partners talked about their partner's memory loss negatively in front of them: "*R is much worse now her memory's gone*" [mP1]. Other partners made negative assumptions about what their partner could remember: "*I don't suppose E remembers much about it*" [fP2]. A few partners referred to differences in what their spouse with dementia could remember about the past and present: "*Oh yeah years back but not recent though*" [mP5]. One wife commented:

“He’s thinking about things from years ago. He can tell you lots of things and you think oh well yes that’s it, he’s alright, he’s not so bad... it’s the present day time you can tell him something, ten minutes, and then he forgets.” [fP2]

I’m fed up with it

People with dementia talked about feeling depressed about their memory loss:

“I was so depressed I think” [mD2]. When asked how she felt about her memory problems one wife replied:

“I am depressed... I’ve been really upset because I knew I was doing the wrong thing.” [fD3]

Partners also talked about the people with dementia *“suffering from depression”* [mP3]. When asked about her husband’s depression one wife replied:

“One time he wouldn’t even bother to look at a paper and he wouldn’t bother to have the television on. He completely lost I’d say the plot he just didn’t want to do anything.” [fP2]

People with dementia also talked about their annoyance at not being able to remember things: *“it’s frustrating for me”* [mD2]. One wife with dementia described:

“It’s a bit annoying when you’re trying, ‘cause some things you can remember and some things like, you just can’t.” [fD5]

Partners talked further about their spouse feeling annoyed: *“You must get frustrated not being able to remember”* [mP1]. When asked to comment on what his wife with dementia had described feeling about her memory loss, one husband replied:

“She gets very annoyed... I noticed that C is getting upset very quickly... she gets upset and she cries.” [mP3]

Another partner described her husband with dementia as: *“a terrible worrier... gets himself in a right state”* [fP2]. Her husband with dementia agreed and commented:

"I get worked up, panicked... I'm worried about this worried about that... I wake up and I'm worried about the time." [mD2]

Overall couples' comments about changes in the people with dementia, focused on memory loss and a process of feeling increasingly fed up and frustrated by the memory problems as the cognitive deficits worsened. In addition some partners made negative comments and assumptions about their spouse's remaining abilities, reflecting a form of personal detraction. This could contribute to feelings of depression and anxiety about the loss of aspects of self for people with dementia or decrease their confidence or their self-esteem (see 3.5 below).

Theme seven: Taking over the reins

The couples described a process of change in the partner's role in the relationship as he or she became a carer, and the difficult feelings this sometimes evoked for both partners. The couples' comments can be divided into three categories. The first category, "Trying to do everything", refers to couples' descriptions of having to take on the role of a carer, doing more things around the home and remembering for both of them. The second category, "Lose your patience, my temper comes right out", refers to couples' descriptions of finding it difficult to be patient and feeling or being angry towards the person with dementia. The third category, "It gets me down", refers to couples' descriptions of partners feeling depressed and restricted by their current situation and also sadness about their spouse's illness.

Trying to do everything

Partners described many changes in the role they had in their marital relationship: *"All I am is cook cleaner now"* [mP1]. Some partners commented: *"I need to be there to remember"* [mP8], with one wife reflecting: *"I have to remember*

more things than are probably good for me" [fP9]. When asked about changes in their relationship since the diagnosis one wife replied:

"You've got to think ahead all the time...I try and think of everything, details of running a home, remembering what he has to take... continuous you get no breaks." [fP2]

Partners further described how their role as a carer took up a lot of time: *"She wants me all the time"* [mP4].

People with dementia also commented on the changes in their partner's role: *"Oh he does it now"* [fD4]. When talking about his memory problems one husband commented:

"From V's perspective obviously you know it's been quite an inconvenience."
[mD9]

Lose your patience, my temper comes right out

When asked how they felt about the changes in their role, four partners described times when: *"it can drive you a bit up the wall"* [fP2], and feelings of *"stress"* [mP3]. One husband explained:

"I do have to be more patient, much more understanding, more caring, and I am." [mP8]

Another husband talked about how the change in his wife's behaviour:

"Gets me, I don't know why it just gets me, makes my temper comes right out. (clenches his fist) As if I could go over there and hit her head in, I'm sorry to say... yeah that's what I hate about it." [mP4]

When asked for examples of things which they found difficult, several partners replied: *"she(he) repeats herself"* [mP4]. One wife commented:

"To keep repeating and to keep asking you the same questions is very tiring..."

I get to the stage sometimes, if I don't go out and have that cigarette because I can feel myself getting a bit uptight with him asking me these endless questions... perhaps after the tenth time you are beginning to lose your patience." [fP2]

It gets me down

When asked if she'd noticed changes in her husband, one wife with dementia replied: *"I don't know why he's so wrong... he's worse down than before"* [fD1]. Partners talked about feeling restricted by their role as a carer: *"I can't go and do the things I want to do, things I enjoyed"* [mP1]. When asked about the difficulties experienced in recent months, one husband commented:

"I would like her to go into a home for one a couple of days weeks, know what I mean? so I could have a break... just a few days then send her home and it will be alright. That's all." [mP4]

Other partners talked more about feeling *"upset"* [fP9] and feeling *"so sorry that I can't help"* [fP9]. When asked about changes in her relationship one wife replied:

"Obviously there are losses and you know things that it's much more difficult to share now in terms of memories." [fP6]

Overall couples' comments described a difficult process of adjustment for the partner in taking on the role of a carer. In particular, partners appeared to find the loss of their independence alongside an increased dependence of the person with dementia difficult to manage, leaving them feeling stressed, frustrated and depressed. The comments made by people with dementia make it clear that they too had noticed the difficult feelings their partner was experiencing and changes in their partner's attitude and behaviour towards them.

Theme eight: Take it as it comes

All the couples described a process of continuing their lives together as they always had and gradually adjusting to their current difficulties. They also talked about things that hadn't changed in their lives. The couples' comments can be divided into two categories. The first category, "We carry on", refers to couples' descriptions of how they are carrying on together as a couple and their commitment to each other. The second category, "Living my ordinary life", refers to couples' descriptions of how they are carrying on as individuals, and things about themselves that have not changed.

We carry on

When asked about her daily life one wife with dementia replied: *"things happen, we just take each day as it comes"* [fD5]. Partners also emphasised that: *"the main thing is we're managing"* [mP3], and how *"we're comfortable"* [fP2]. When asked how things were at the moment, one husband replied:

"We just take the whole thing, we are living a normal life and whatever has changed has also become part of the normal life... she is my wife and I love her." [mP3]

After which his wife with dementia commented:

"You adjust to it, I mean the abnormal has become normal (laughing) as you might say." [fD3]

Another husband said: *"we've been together so long now it doesn't really matter"* [mP1] and his wife explained: *"we're happy together"* [fD1].

When asked about changes in their relationship some partners commented: *"well it hasn't really"* [mP5]. One wife replied:

"You still enjoy art as much as you ever did and we can go to an exhibition"

together and enjoy it... you still enjoy being out and about walking and appreciating the countryside which was what a lot of our early relationship was based on." [fP6]

Another wife talked about improvements in her relationship:

"We used to laugh a lot and we didn't laugh for the last two years... we're laughing again which is nice, we have got to go from there." [fP9]

Couples also shared a perception how it would be *"worse if alone"* [mP8] and compared their situation to older people *"entirely on their own and God help them"* [fP2]. Several people with dementia further expressed their appreciation of their partner: *"I'm glad he's there"* [fD8].

Living my ordinary life

Many people with dementia gave descriptions of a *"thing that hasn't gone"* [mD9] and talked about how: *"I get on with my own interests"* [fD3]. One husband with dementia commented:

"I can do just about everything really but sometimes you just forget, out of 360 degrees I might have lost about 60%, still plenty left to go round working very well." [mD9]

Many partners also emphasised aspects of that spouse that hadn't changed: *"but other than that [repeating yourself] you don't really act any different"* [mP5]. One wife commented to her husband with dementia during the interview: *"Well you wouldn't be you if that wasn't your attitude"* [fP9]. Partners further talked about themselves *"doing alright as well actually"* [mP3].

Overall the couples' comments highlighted their resilience to living with memory difficulties and their capacity to adjust to a difficult situation. Both partners and people with dementia described a process of incorporating changes into their

daily routine together and enjoying aspects of the previous relationship that remained in the early stages of the illness. The couples' responses also gave a sense that each individual retained aspects of themselves that had not been lost, and were able to carry on with parts of their lives that were less affected by dementia.

Theme nine: Coping very well

All the couples described a process of finding strategies to help them cope with their current difficulties. The couples' comments can be divided into two categories. The first category, "My way of relaxing", refers to couples' descriptions of strategies they use as individuals to help them cope. The second category, "Try not to tell him", refers to partners' descriptions of strategies they use to cope with difficult times in their relationship. The third category "Someone else to talk and worry with", refers to couples' descriptions of the benefits of social support from other people.

My way of relaxing

When asked about ways they had found to manage their current situation, several partners talked about their "*time out*" [fP2] or their "*day off*" [mP3]. When asked what he found useful about going out on his own, one husband replied:

"That's how we cope with it... it's definitely helpful otherwise it's difficult."

[mP3]

One couple talked about how they both found relaxation strategies useful: "*it makes me feel very relaxed afterwards*" [mD2], with his wife commenting: "*the relaxation would help a lot of people*" [fP2]. The wife in this couple also described how for her own sake:

"I can't keep looking on the black side of everything because you'll have two of us winding up like it. I've got perhaps, I've got a weird sense of humour

but I've got to laugh at things... if you don't laugh you're gonna cry. " [fP2]

Try not to tell him

Some partners talked about coping strategies they used to manage difficult moments in their relationship: *"I try to change the subject"* [mP3]. One wife described a strategy she found useful to lessen her husband's anxiety about his memory loss:

"I've got now if anybody's coming I try not to tell him 'cause fore they come he's, he's working himself up." [fP2]

When asked about how he coped with difficult times in his relationship, one husband replied:

"I remind myself that this is part of the symptoms and I have to control my emotions... it's not all that easy but I do try to control myself." [mP3]

Someone else to talk and worry with

Many partners described a *"very supportive family"* [mP8] or how *"friends and visitors are a main source of entertainment"* [mP3]. When asked about the reactions of other people to his wife's memory problems, one husband replied:

"They've always asked me if they see me how A's doing and all this and that how is she today, what you been doing?" [mP4]

One wife commented:

"It's become more and more helpful to have someone else around... to think up ways that will help and things like going on holiday um it becomes much more possible... things that otherwise we might find difficult." [fP6]

Overall the coping strategies described revealed a difference in perspective between people with dementia and their partners. The couples' comments suggested that on the whole, as partners adjusted to their role as a carer, they began to find

practical ways to cope with their current situation, whereas people with dementia reported fewer coping strategies. It appeared that helping people with dementia cope with their memory problems was given less of a priority within couples, than the carer finding ways to manage the stressful feelings that caring for their spouse sometimes evoked.

Theme ten: Wouldn't mind doing it all again

Many of the couples described themselves, their relationship and their lives in the past, and compared this to their current lives. The couples' comments can be divided into three categories. The first category, "We used to be happy", refers to couples reminiscing about their lives, generally talking about happier times. The second category, "The story of my life", refers to couples reminiscing about their lives as individuals and/or partners talking about the person with dementia in the past. The third category, "This age", refers to couples talking about their current age and stage of life.

We used to be happy

Some people with dementia described their relationship in the past during the interview: *"He used to play football and I used to watch him play"* [fD5]. Partners further described happier times in their relationship in the past: *"We used to be very happy"* [mP1]. One wife described how:

"We had freedom... before we both done what we wanted... we had a very easy, quite a comfortable life, we never had a big row... we had that understanding." [fP2]

Only one wife with dementia talked about difficult times in her relationship:

"I used to get furious, having married me he dumped me, although I had given

him two children." [fD3]

In contrast with the other couples interviewed, this couple appeared to have a difficult marriage and displayed many disagreements and arguments during the interview (see 3.5.1 below).

The story of my life

Many people with dementia gave descriptions of themselves before their memory problems began: "*I was a great dancer*" [fD1]. When talking about her memory one wife with dementia recalled: "*I used to run a petrol station I could remember everything then*" [fD5]. One husband with dementia described himself before his memory problems began as:

"To put it crudely aging, egocentric, male, pampered, very well looked after, superbly fed, doing very nicely thank you." [mD9]

When asked about his life, another husband with dementia replied: "*I've seen some sights in my working life*" [mD2], and talked at length about his younger days in the army and the jobs he did when he left. Partners also gave descriptions of the people with dementia in the past: "*The type of person he was*" [fP2] and contrasted past strengths with the person's current difficulties: "*she was an excellent linguist*" [mP3].

This age

A few people with dementia talked about being older and how this linked to coping with their memory problems: "*At our age it's just right*" [fD8]. When talking about her memory problems, one wife with dementia commented:

"You've got to when you get older innit, yer got to take things as they come as you get older, can't complain too much can you?" [fD5]

Partners also talked about ageing: "*Things we used to do you know, you don't do now 'cause you're not fit enough*" [mP5]. Referring to her age one wife commented:

“When you get to this age there’s not a terrible lot you can do... you don’t go out so much when you’re old.” [fP2]

Overall, talking at length about the impact of memory problems in their lives led the majority of couples to reminisce during the interview about happier times before the memory problems started, making comparisons between then and now. In addition, for some couples the adjustment to living with one partner having memory problems appeared to have been facilitated by their age and perhaps a belief that memory loss is to be expected as you get older.

3.3 Summary of the variations between couples and people with dementia and their partners

Although the majority of the couples made comments related to the themes described above, not all couples shared the same early experiences or appraised their current situation in the same way. Firstly, some couples shared an accurate understanding of what was happening to the person with dementia before they sought a formal diagnosis. All the couples who commented that they had a clear idea about the likely diagnosis of dementia were university educated. Other couples shared a lack of understanding about what was happening before they sought a diagnosis and some of these couples described how the diagnosis helped them begin to understand and accept what was happening. Further, a minority of couples lacked a clear understanding of what was happening to the person with dementia or an acceptance of the illness even after seeking a diagnosis.

People with dementia and their partners also differed in their construction and acceptance of memory problems and in how receiving a diagnosis impacted on their understanding of the difficulties. The majority of people with dementia found it

difficult to recall receiving the diagnosis of dementia and few people with dementia talked positively about their experiences of services in terms of making sense of what was happening for them. In contrast, the majority of partners found some benefit in receiving the diagnosis, especially some of the partners who lacked a clear understanding of the changes they had noticed in their spouse.

Secondly, couples varied in the way they appraised their current situation and how they were adjusting to the changes. Some of the couples spoke in detail about how difficult they were finding their current situation. Other couples focused less on the difficulties in their current relationship and instead appeared to have adjusted to or be coping with their current situation at the time of being interviewed. Indeed some couples talked very little about things being difficult and instead focused during the interview on things which had not changed, or presented the memory problems as a joint difficulty due to old age. Couples further varied in the way they interacted with each other during the interview. It appeared that couples who were experiencing some difficulties with the changes in their lives as individuals and as part of couple, had a more negative style of communicating with each other during the interview. This difference between couples is explored further in section 3.5 below.

People with dementia and their partners also differed in their appraisals of things that had changed in their current lives. The majority of people with dementia talked about their memory problems during the interview, but emphasised their past abilities and achievements and tended to minimise the impact of memory problems on their daily lives. In contrast, the majority of partners focused more on the difficulties in daily life that their spouses' memory loss created, commented on how they were left trying to cope with difficulties, and compared their current life to the life they had led previously.

3.4 Making sense and adjusting to loss

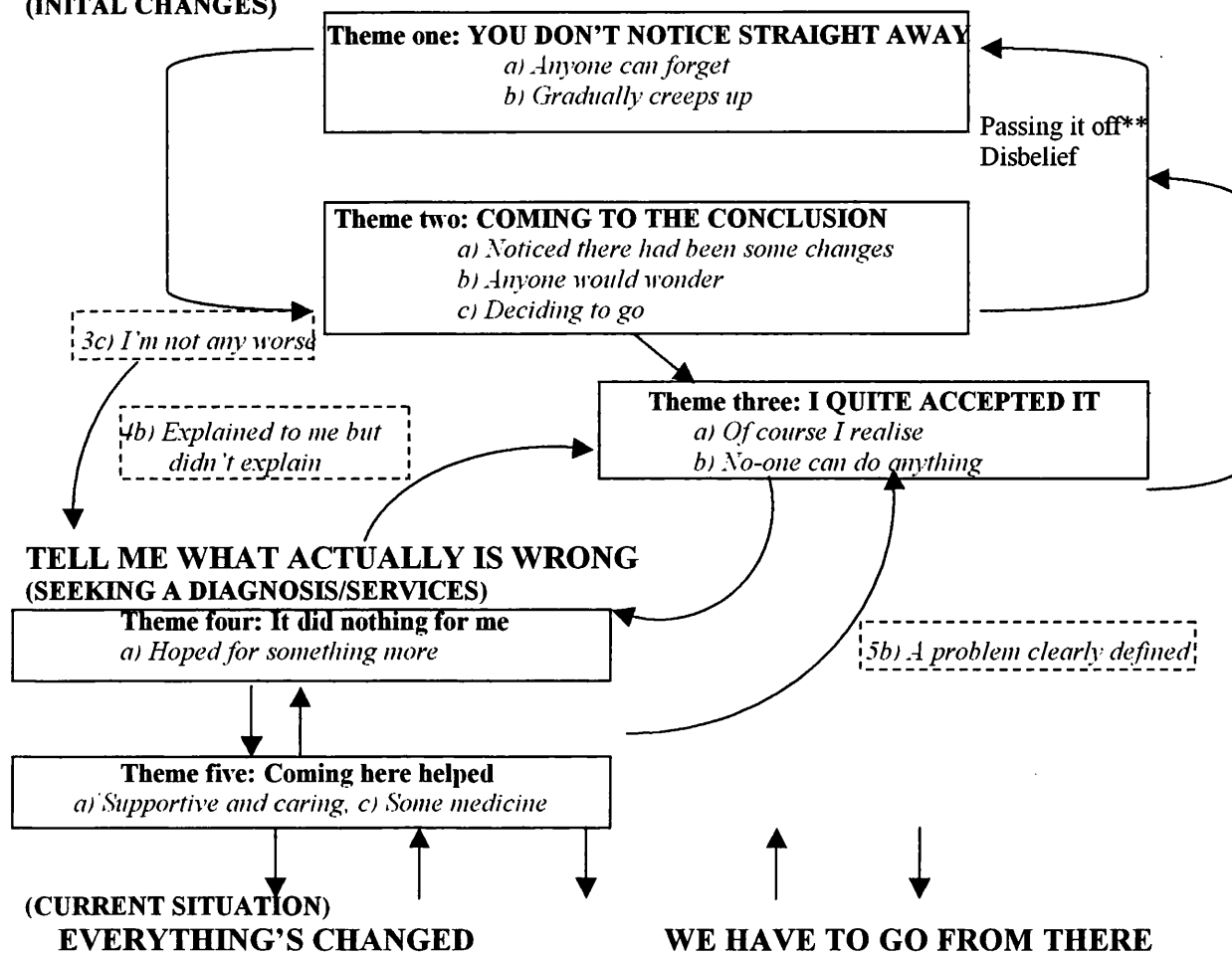
An overarching theme emerged from the analysis, “Making sense and adjusting to loss”. This theme developed as the researcher made connections between the ten themes, considering how the process described by couples developed and changed over time, examining differences between couples and between partners in how they made sense of their experiences, and discussing the analysis in supervision and with colleagues. “Making sense and adjusting to loss” encapsulates the process couples appeared to go through in order to understand and make sense of the initial changes in the person with dementia and adjust to the loss and difficulties in their current lives, as individuals and as a couple. This process is summarised in Figure 1 below.

Firstly, the model shows a cyclical process of how couples made sense of the person with dementia being “not quite the same person,” and how seeking a diagnosis “explained to me but didn’t explain”. Themes such as “Coming to the conclusion” and “I quite accepted it” describe a process of gradually understanding what is happening to the person with dementia and beginning to accept that the memory problems are permanent. As described above, for some couples this process is helped or hindered by receiving a formal diagnosis of dementia. Secondly, the model shows an oscillating process of couples acknowledging the losses in early stage dementia and adjusting to “everything that has changed”. The process occurs over time and couples appear to oscillate between difficult feelings of loss, frustration and depression and feelings of resilience, coping and adjusting to their difficulties. All the couples described aspects of both these experiences, but varied in how well they were coping with their current situation as more changes were experienced by the person with dementia and his or her spouse. Themes such as “I would say I have changed” and

“Take it as it comes”, describe a process of acknowledging both the things that have been lost and the things that remain for each member of a couple and gradually integrating these changes into their lives as a couple and their sense of self and identity as an individual. The theme “I wouldn’t mind doing it all again” incorporates the way in which making comparisons with the past is an important part of the process of adjustment for most of the couples.

Finally, although the two processes are presented as separate events in time, it is likely that the processes overlap. Before and after couples receive a diagnosis of dementia both processes are likely to be experienced as couples begin to gradually make sense of and adjust to the losses in early stage dementia.

**NOT QUITE THE SAME PERSON
(INITIAL CHANGES)**



(CURRENT SITUATION)

EVERYTHING'S CHANGED

WE HAVE TO GO FROM THERE

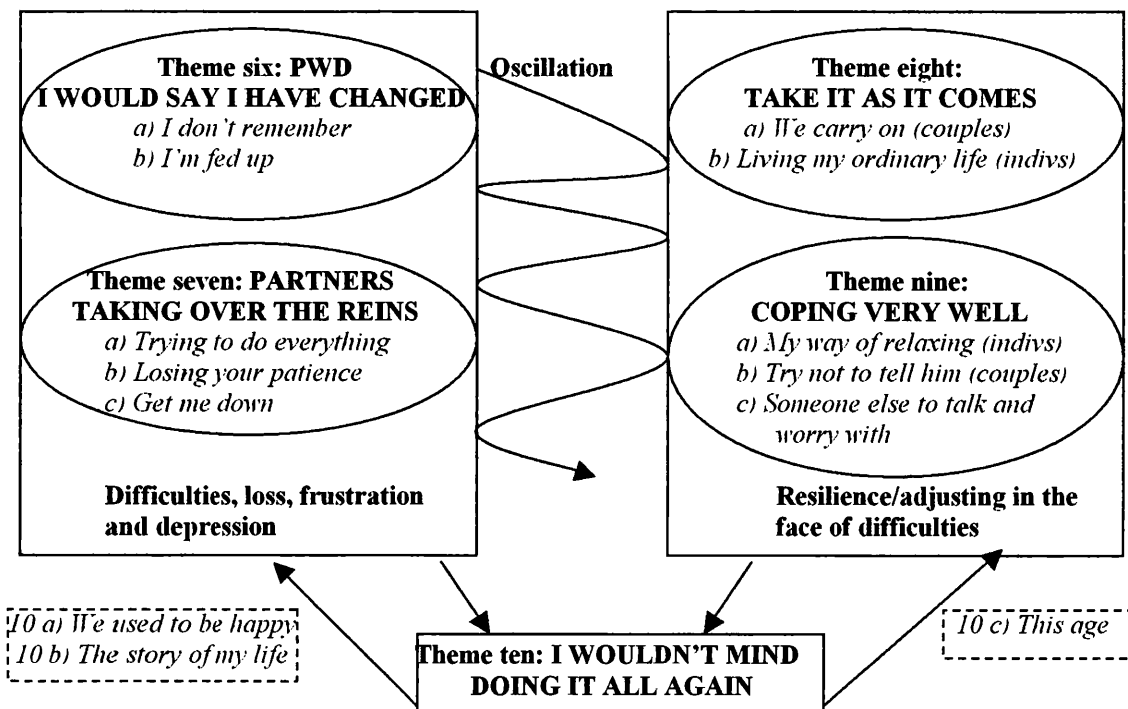


Figure 1: Making sense and adjusting to loss

** cyclical process

3.5 A preliminary relational voice analysis of people with dementia and their partners during the interviews

As the couples were interviewed together in this study, it is possible that partners' responses could make it harder or easier for the person with dementia to express their views and describe their experience (and vice versa). In this analysis, the transcripts were examined for examples of psychological resistance when the person with dementia said they were unable to say anything about a topic (perhaps due to complete silencing by others, Proctor, 2001) and how their partner responded to these statements. The conversational interactions between partners were also examined for examples of political resistance, to establish whether the person with dementia disagreed with their partner, whether they were able to speak openly from their own perspective, and how their partner supported/hindered their contribution to the interview.

The analysis revealed that couples seemed to adopt a fairly stable pattern of interaction and tended to be consistent in their way of responding to each other throughout their interview. In particular, partners appeared to adopt one of two styles of responding to the person with dementia, with about half of the partners interviewed adopting each. These two styles of interaction will be briefly described below based on examples from all the interviews (see Appendix XI, for details of these examples).

The first style, "partners silencing the voice of their spouse with dementia", refers to a more negative interaction style that some partners used when responding to their spouse during the interview. This negative style of communication appeared at times to "silence" the spouse with dementia and prevent him or her expressing a point of view and included examples of both psychological and political resistance. The key features of this style included partners taking the lead in answering all the interview

questions, ignoring the comments made by the person with dementia during the interview, interrupting the person with dementia and taking over answering from them, correcting what the person with dementia was saying, personal detraction, talking about their spouse's difficulties in front of them, and disagreeing with what their spouse with dementia was saying. The people with dementia in these couples appeared to respond to and or contribute to this negative interaction style in various ways, which included challenging, disagreeing and arguing with their partner during the interview, minimising their memory difficulties or saying they couldn't say.

The second style, "partners supporting and facilitating their spouse with dementia to have a voice", refers to a more positive interaction style that some partners used when responding to their spouse during the interview. This positive style of communication appeared at times to encourage the spouse with dementia to express his or her point of view. The key features of this style included partners allowing the person with dementia to take a lead in answering the interview questions, not interrupting the person with dementia when they were talking, including the person with dementia in what they were saying, cueing and prompting the person with dementia to recall information, having conversations with the person with dementia during the interview, providing the person with dementia with information when asked, pointing out the strengths of the person with dementia, agreeing with what the person with dementia was saying, and validating their point of view. The people with dementia in these couples appeared to respond to and or contribute to this positive interaction style in several ways including agreeing with what their partner was saying, calmly discussing differing points of view, laughing with their partner, and contributing to the interview.

On the whole couples appeared to use one of these styles of interaction

predominantly for the duration of the interview. Further, it appeared that the interaction style that had developed between couples was influenced by the difficulties partners were experiencing at the time of being interviewed. Partners who talked about how difficult they were finding their current situation tended to interact with their spouse with dementia in a more negative way than partners who reported fewer difficulties. In particular, partners who were experiencing restrictions as their role within the marital relationship changed, and who were unable to continue their lives as they had done previously, appeared to interact with their spouse with dementia using a more negative style. In addition, the interaction styles did not appear to be influenced by the gender of the partner or person with dementia. Both male and female partners adopted the more negative interaction style and appeared to have difficulties adjusting to some aspects of being a carer. In the following sections, two interviews are used as illustrative case examples of each interaction style.

3.5.1 Partners silencing the voice of their spouse with dementia

The interview with Phillip (partner) and Carol (spouse with dementia) contained many examples of Phillip taking the lead role in the interview and talking in ways that made it difficult for Carol to have a voice. Phillip reported many difficulties that he was experiencing as his wife's carer at the time of being interviewed, for example Carol no longer being able to do the housework as she used to, Carol shouting and screaming at him, Carol accusing him of hitting her, and Carol arguing with him about difficult times in their past relationship as if they had just occurred. Phillip said he was finding it increasingly difficult to manage these changes in Carol's behaviour. They both reported that their marriage had always been "stormy" and Carol said that in the past she had just "put up" with the things Phillip did that upset her. The interview with Phillip and Carol will be used as an illustrative case example

to describe how partners made it difficult for the person with dementia to talk, give their point of view and/or disagree with their partner during the interview.

Throughout the interview, Phillip took a lead in answering the majority of the interview questions. He appeared to put himself in a position of being an authority about what had happened to Carol: *"I'm always.. I have to give information for her"*. When Carol talked, Phillip often ignored what she said and instead took the lead back from Carol, dismissing what she had said and taking over answering the interview questions.

Interviewer (to Carol): "What changes have you noticed in your life since you received the diagnosis?"

Carol: "... I just struggle on doing my usual chores from the past and..."

Phillip (interrupting Carol): "She has become slow..." (Phillip talks on about the changes he's noticed in Carol)

In taking the lead position, Phillip does not allow Carol to contribute to the interview and instead talks about her in her presence, an example of personal detraction. Phillip does not allow Carol to tell her side of what has happened. Instead he ignores the comments she makes, corrects and contradicts her, and thus his voice remains dominant and Carol is silenced in the interview.

During the interview, Carol made many attempts to talk and include herself, and seemed to get annoyed and upset by what Phillip was saying. Carol interrupted Phillip to question him about what he was talking about, for example, *"who are you talking about?"* or *"recently, when was that?"* or *"well, what was happening for you?"*. Carol rarely let Phillip talk without interrupting him which he appeared to find more and more exasperating as the interview continued. Carol also tried to make herself heard by challenging what Phillip was saying, for example, *"absolute*

rubbish” or “I don’t even know what you’re talking about”. However, Phillip carried on talking, making his point and ignoring Carol, even when Carol voiced strong disagreement about what he was saying and shouted at him.

Phillip: “... she goes furious with us.”

Carol (shouting): “No I don’t go furious, I just have to put up with it don’t I?”

Phillip(ignoring Carol): “So that’s why she for instance...” (Phillip talks on about Carol as if she hasn’t spoken)

At points in the interview, Carol threatened Phillip: *“if you go on like that I will say a few things you don’t like”*, and later *“Phillip if you say one more word about that...”*, which he ignored. Carol appeared to have to work very hard during the interview to have her voice heard, as Phillip completely ignored a lot of what she said, as if she was not even there. Phillip also had to work hard to give his point of view as Carol constantly tried to interrupt and challenge what he was saying.

When Phillip did respond to Carol’s objections to what he was saying, he appeared to use several strategies to silence her. Phillip corrected or amended what Carol said: *“yeah we know them but we don’t see them”*. Phillip also contradicted and Carol when she tried to correct him.

Phillip: “So she learned Arabic.”

Carol: “I didn’t learn Arabic.”

Phillip: “Well she did, she still understands it.”

Phillip defended what he said by referring to the purpose of the interview, for example: *“I’m only trying to explain”* or *“I have to give information for (...) the tape”*, perhaps due to his beliefs about the research and the purpose of it. Phillip laughed at Carol’s objections: *“(laughing) it happens every day”*. Phillip also listed several examples of what he was talking about, as this extract shows:

Carol: “*Like what?*”

Phillip: “*Like putting the cutlery in the wrong place, whatever, all the plates, or like filling the dishwashing machine in the order she used to do it, or like putting the pans in the right place and so on.*”

Using these various strategies Phillip appeared to effectively silence Carol's objections and retained his lead in the interview. This enabled him to continue to make his points and talk about Carol's difficulties without consulting her, asking her opinion or showing any consideration to how she might be feeling.

Finally, the differences in opinion between Phillip and Carol led to several heated arguments during the interview, with both raising their voices:

Carol (shouting): “*Oh for Christ sake!*”

Phillip (shouting): “*Nurofen plus has codeine.*”

Carol (shouting): “*Don't give me that shit.*”

At times Phillip even started shouting at the interviewer about Carol during an argument. He ignored what she was trying to say and excluded her from the conversation he had with the interviewer at this point:

Phillip (shouting): “*Absolutely untrue because I'm looking after her I think; she's my wife.*”

Carol (shouting): “*Well you do the shopping...*”

Phillip (shouting): “*I tell her...*”

Carol (shouting): “*... and the cooking that's all you do.*”

Phillip (shouting): “*... that I love her, I tell her that I disagree with you, or this, this is the best...*”

Carol: “*You love me?*”

Phillip (shouting): “*... time for me to run away and liberate myself.*”

These arguments appeared to be the result of Carol's voice being ignored or dismissed by Phillip, and Carol having to shout at Phillip to make him respond to her and what she was saying. These arguments also appeared to be a result of Phillip's increasing annoyance that Carol was interrupting and disagreeing with the things he was saying.

Overall, the interview with Phillip and Carol was very difficult to be part of. Phillip saw the interview primarily as a chance to give his views about Carol for the purpose of research and he took a position of being an observer of Carol, rather than her husband. His belief that this justified talking negatively about Carol, with little regard for her feelings, was difficult to witness. Carol battled against Phillip's attempts to talk about her as if she was not there throughout the interview, challenging and disagreeing with what he was saying. Carol did not really talk much about herself or Phillip during the interview and instead responded to what Phillip was saying about her, seeming locked in a battle with him not to let him say things about her which she disagreed with and to have a voice in the interview. It seemed that the more Carol argued with what Phillip had to say, the more negatively he talked about Carol, and the more angry she became so that she was increasingly determined to get him to listen to what she had to say.

3.5.2 Partners supporting and facilitating their spouse with dementia to have a voice

The interview with Constance (partner) and Justin (spouse with dementia), contained many examples of Constance taking a role in the interview and talking in ways that facilitated Justin in having a voice. Constance and Justin did not report any difficulties they were experiencing at the time of being interviewed. They also said they rarely argued and that their marriage had always been a happy one. This interview will be used as an illustrative case example to describe how partners

supported the person with dementia to talk, give their point of view and/or disagree with their partner during the interview.

Throughout the interview Constance appeared to do everything she could to give Justin a voice. Constance allowed Justin to respond to all the interview questions first, at times leaving long pauses to give Justin time to think about his response. Constance did not interrupt Justin when he was speaking. On the whole Constance only talked during the interview when invited to, by either Justin or the interviewer. Even when Justin asked Constance to respond to an interview question, Constance did not immediately start talking.

Justin: "No I can't think, perhaps Constance can."

Constance: "Mmm I can remember yeah yeah."

Justin: "Can you?"

Constance: "Yeah mmm."

This appeared to give Justin a message that what he had to say in the interview was equally as important and gave Justin another chance to respond. Constance also commented that she was finding some things hard to recall during the interview, for example: *"it's coming back now"* or *"I'd forgotten that"*. In making these comments, Constance may have been attempting to redress the balance between her ability to contribute to the interview and Justin's, when he was struggling to recall events or she may have genuinely found it hard to remember.

Constance encouraged Justin to speak during the interview in several other ways. Constance validated what Justin was saying by agreeing with his account of what had happened: *"I think I agree"*. Constance also used minimal encouragers while Justin was talking, such as *"Mmm mm"*, and took an interest in what he was saying. At some points in the interview Constance cued Justin; for example she

reminded him about what had happened and then gave him a chance to talk further about the topic if he wished. Justin was able to use these cues to say more about topics during the interview.

Constance: "You actually made the decision before the next review came up, didn't you"

Justin: "Did I?"

Constance: "Yes, and you went to the retest..."

Justin: "Yes"

Constance: "... and said that you thought you should stop."

Justin: "Yes, and when the diagnosis came..." (Justin talks on giving his account)

When cueing Justin, Constance also stressed his role in what had happened: *"you were making a lot of the comments"*, and was tentative when talking from his perspective, for example, *"I think you would say"* or *"I don't know, that might not be the way you remember it"*. In this way, Constance included Justin in what she was saying and invited him to comment on whether he agreed with what she was saying about him. Constance again allowed long pauses to give Justin plenty of time to speak.

Constance: "My memory was that you were getting um you were quite depressed..."

Justin: "Depressed, I see."

Constance (pausing): "... At least I think that's what you said was happening..."

Finally, Constance was concerned about how what she was saying during the interview was impacting on Justin: *"this all feels very one-sided... don't give him a*

chance to say things about me". At these points in the interview, Justin reassured Constance.

Constance: "I'm quite a little anxious about what I've said on the tape and what Justin thought about it."

Justin: "I thought it was alright."

Constance: "Whether I've said thing that you um hadn't expected me to say."

Justin: "No I think you said the things I expected."

Overall the interview with Constance and Justin provided many examples of a couple validating each other's personhood and providing a shared construction of what they had been through. Both partners respected each other's point of view and invited the other's opinion on the things that they had said. As a partner, Constance was very careful about what she said in front of Justin and maintained his personhood during the interview. Constance encouraged Justin to take the lead in the interview and assisted him to have a voice when he found it difficult to remember things. Constance also appeared to lessen the contrast between her memory and Justin's, by slowing down her pace of recalling what had happened and asking Justin if he agreed with the way she remembered things.

CHAPTER FOUR

DISCUSSION

This exploratory study aimed to examine psychological reactions to a diagnosis of dementia in couples at an early stage of dementia. In addition, it attempted to explore the extent of variations between couples and between people with dementia and their partners, in their understanding of and response to a diagnosis of dementia and the appraisals made about the illness. This chapter begins with a brief overview of the study. It then reviews the main themes that were developed in the analysis of interview data collected from nine couples in which one partner had recently received a diagnosis of dementia. The themes are discussed with respect to the two main research questions and in the context of previous theory and research. This chapter also reviews the processes by which couples created a joint construction of their situation, made appraisals about the illness, and found ways to manage in a difficult situation. It then considers the methodological issues raised by the study, and outlines the study's main limitations. Finally, recommendations are made for future research that may build on the results of this study, and the implications of the study's findings for clinical practice and service provision are considered.

4.1 Overview of the study

Nine people with dementia and their partners were interviewed together and each interview followed a semi-structured format. The interviews attempted to elicit couples' views about their experience of receiving a diagnosis, and their experiences in the period of time both before and after the diagnosis had been given. This included their early explanations about what was happening to the person with dementia, their experiences of services and each couple's current situation. On the basis of the

interviews, a thematic analysis described how these couples had made sense of what was happening to the person with dementia, their understanding of the diagnosis, and how they were adjusting to living together with one partner having memory problems.

Ten themes emerged from the data and were developed into two higher-order categories, “Not quite the same person, tell me what actually is wrong”, and “Everything’s changed, we have to go from there”. The first category reflected the couples’ attempts to make sense of what was happening to the person with dementia and how this process had been influenced by their experiences of receiving a diagnosis of dementia. The second category reflected the losses and difficulties couples experienced as well as the coping strategies couples used to adjust to their situation. Finally, an overarching theme emerged, “making sense and adjusting to loss”, and a model was proposed that encapsulated the processes these couples appeared to go through in understanding and making sense of the changes in the person with dementia and adjusting to the losses and difficulties in their current lives.

4.2 Making sense and adjusting to early memory loss

This section reviews the themes and processes emerging from the couples’ interviews that encapsulate their experiences of making sense and adjusting to the losses involved in early stage dementia and their reactions to a diagnosis of dementia. The themes and processes described in the analysis are compared and contrasted to previous research that has examined the experiences of people with dementia in the early stages of the illness and theoretical literature concerning illness and loss.

4.2.1 A gradual process of accepting the changes

A cyclical process of denial, minimisation, gradual realisation and acceptance

In the period of time leading up to seeking a diagnosis, the couples described a

very slow process of gradually noticing changes in the person with dementia creeping up on them. As suggested by previous authors, it seemed that long before the diagnosis was received couples noticed, denied and worried about what might be happening to the person with dementia (West, 2003). The model proposed in this study illustrates a cyclical process of denial, minimisation and acceptance that appeared to be a common experience for both members of a couple as they made sense and adjusted to initial changes in one partner's cognitive abilities. The couples described how debilitating abilities were noticed first, for example forgetting familiar routes (cf. Keady et al., 1995) or feelings of depression or withdrawing from others (cf. Cheston & Bender, 2000; Lazarus, 1987). In general, couples described initially passing off these problems, perceiving them as an exacerbation of previous traits or due to ageing, and by ignoring or laughing them off.

Cheston and Bender (2000) suggested that partly as a consequence of ageist stereotypes, deficits in memory, social withdrawal and low mood are often misinterpreted as the unavoidable consequences of ageing. In the period of time before the diagnosis was given, denial and minimisation may also have helped couples cope in a positive way that maintained continuity with each person's perceptions of the previous sense of self of the person with dementia, whilst gradually adapting these perceptions (Clare, in press, a) in order to make sense together of what was happening.

Some couples commented that the early signs were only noticed in retrospect as neither really talked about or acknowledged what was happening at first. Bahro and colleagues (1995) suggested that some people with dementia in the early stages use denial adaptively as a defence mechanism, to avoid talking about what is happening, minimise the severity of the memory impairments and bolster self-esteem. For some

couples, denial or avoidance of talking together about the initial changes in memory appeared to be part of a process of gradually turning to face the situation, rather than accepting it immediately. Couples described a process of gradually beginning to accept that the changes in memory experienced by the person with dementia were likely to be permanent and deciding to find out more about what might be happening. Nevertheless, most of the couples found it difficult to think retrospectively about what led to the decision to contact services or how they negotiated this process as a couple.

Overall, it appeared that over time couples gradually began to realise and accept that one partner had memory problems and began to wonder what might be occurring, before they decided to contact services to find out more about what might be happening. Couples described this as a joint process of both partners noticing and passing off changes, although in most cases partners said they were the first to notice early changes. These descriptions are consistent with previous research in which people in the early stages of dementia refer to the “insidious nature” of dementia (Keady et al., 1995). This analysis also revealed that couples experienced a gradual cyclical process of making sense and accepting the early changes in the person with dementia.

Variations between couples in their understanding of and explanations for the early changes in the person with dementia

On the whole, the couples described a shared level of understanding about what was happening before they sought a diagnosis, with people with dementia and their partners either both ‘knowing’ or ‘not knowing’. Yet it appeared that couples who had received a university education had more understanding about dementia, what it was and how it affected people in the early stages, before they contacted services. These couples also described using other sources of information to find out

more about dementia, for example the Alzheimer's Society. Couples who had not been university educated shared an explanation that the early memory difficulties were a normal part of ageing and did attempt to find out more about the memory problems to help them make sense of what was happening.

A social constructionist view of dementia (Harding & Palfrey, 1997) emphasises the need to consider how social context affects appraisals and coping strategies. The analysis revealed that couples who had been university educated had a more accurate understanding of what was happening to the partner with dementia and used external sources of information to find out more about dementia before they contacted services. This result supports previous studies which have suggested factors such as education and socio-economic status influence the coping strategies used by men in the early stages of dementia (cf. Pearce, 2000; Pearce, Clare & Pistrang, 2002). However, further research is needed to examine the theoretical and practical implications of this finding, as it is unclear whether the couples' use of different strategies to help make sense of the early changes in the person with dementia was due to differences in education or social class. The results suggest that receiving a university education and having a higher socio-economic status influenced the knowledge that couples had before they received a diagnosis of dementia and the strategies they used to find out more about dementia.

Overall, it appeared that couples gradually began to notice changes and search for explanations for the early memory loss and low mood experienced by the person with dementia before they approached services. Although within couples this was described as a joint process, couples varied in how much knowledge they had about the likely diagnosis of dementia. Yet all the couples interviewed shared an early expectation that they could receive help from services regardless of their

understanding and prior knowledge about what might be happening to the person with dementia.

4.2.2 The experience of receiving a diagnosis of dementia

Ambiguity, uncertainty and hopelessness

The proposed model illustrates that receiving a diagnosis of dementia had multiple effects on couples, both positive and negative. The model also illustrates that receiving a diagnosis of dementia did not necessarily increase couples' understanding and acceptance of what was happening to the person with dementia.

The analysis revealed that for some couples, receiving a diagnosis was a relief and many couples felt gratitude towards health professionals for their support in helping things become clearer for them both (cf. Reid et al., 1991). This result supports previous research which has suggested receiving a diagnosis of dementia has the potential to help couples make sense of what is happening and interpret and ascribe meaning to changes in order to provide an explanation and understanding of memory problems (Pratt & Wilkinson, 2001; Robinson et al., 1988). This result also supports the argument that one positive benefit of receiving a diagnosis is that it can decrease uncertainty and ambiguity about what is happening (Fearnley et al., 1997; Radely, 1996). The model illustrates that for some couples, receiving the diagnosis confirmed that there was "a problem" which increased their acceptance of the memory loss and made it more difficult to minimise or deny what was happening. Some couples also described how the knowledge gained from the diagnosis led to positive developments in their relationship, for example less anger towards the person with dementia for forgetting or greater validation of their experiences.

However, the analysis also revealed that for other couples the diagnosis did nothing to alleviate their uncertainty about what was causing the memory difficulties

and did little to help them understand and make sense of what was happening. Further, all the couples shared a view that they should have been told more by health professionals about the diagnosis and also about the prognosis. People with dementia found it difficult to recall details of what they had been told about their condition and partners had many questions about their spouse's illness that had not been addressed.

This result supports previous research which has suggested that often the quality of information received about a diagnosis of dementia is poor, leaving most people wanting to know more (cf. Marzanski, 2000; Pinner, 2000). The analysis also suggested that a degree of uncertainty remained for all the couples after they received the diagnosis, with many couples finding it hard to accept what was happening to the person with dementia or being concerned about what to expect in the future. It is possible that couples may have been choosing not to know rather than being unable to recall the details about what they had been told (cf. Clare, in press, a). Thus the results may suggest that both members of a couple employ self-maintaining cognitive strategies to protect their previous sense of self, which could influence the awareness couples have about what is happening to the person with dementia.

Further, the couples described feelings of hopelessness and shared a perception that nothing could be done to help them after they received the diagnosis. At a psychological level, couples' dissatisfaction with services is likely to be influenced by the nature of dementia itself, and the psychological impact of living with an incurable progressive illness (Miller & Morris, 1993). However, this finding may suggest that not knowing what to expect and for how long can compound a sense of panic when facing an uncertain future for some people with dementia and their partners (West, 2003). The analysis may also suggest that contrary to the guidelines provided by the National Service Framework, receiving a diagnosis of dementia did

not give couples access to services and treatment options that they found beneficial (cf. Fearnley et al., 1997) or which met the needs they had in the early stages of dementia.

On the whole, couples expressed their dissatisfaction about the services they had experienced, with one couple feeling they were forgotten about during a very difficult time and another struggling to get a referral. Further, couples did not see much benefit in attending regular out-patient appointments after the diagnosis had been received. In practice, only one couple described receiving any practical support or suggestions after the diagnosis. The lack of practical or emotional support offered to the couples, may have increased their feelings of isolation and further reinforced a belief that no-one could do anything (Cheston & Bender, 2000). Even couples who had received medication saw little point in the person with dementia taking it as it did not offer a “cure” and could only slow the progression of cognitive decline. These perceptions also reveal the dominance of medical models of dementia in society, which may reinforce beliefs that, without a cure, nothing can be done to help couples (cf. Kitwood, 1997).

Overall, receiving a diagnosis of dementia did not necessarily have a large impact on how couples made sense of what was happening to the person with dementia or the appraisals couples made about the illness. Many couples were left with little more information than they had obtained themselves before they sought the diagnosis. Further the analysis revealed that the couples were dissatisfied by the services they received and suggested the experience of receiving a diagnosis of dementia confirmed couples’ view that nothing could be done to help them and their feelings of hopelessness about their situation.

Variations between couples and between people with dementia and their partners

This study revealed two key dimensions along which participants differed in their experience of receiving a diagnosis of dementia. The first dimension along which couples varied was in their shared understanding and acceptance of the diagnosis of dementia. Some couples appeared to share a construction of the diagnosis, acknowledge the diagnosis and possibly grieve together for the loss involved (Carter & Goldrick, 1987). In other couples, people with dementia and their partners took different views and instead argued during the interview about what had happened and whether one partner had a serious memory problem.

West (2003) suggested that if one partner chooses not to acknowledge a diagnosis of dementia, a barrier in communication can be created, which might lead to misunderstandings and distancing between partners. The analysis also considered the social interactions between couples during the interview and the contribution made by each partner to the interview. Couples appeared to fall into one of two categories, either talking together in a supportive and co-operative way presenting a joint view of what had happened to the person with dementia or taking opposing positions when talking about their experiences, disagreeing and interrupting each other to present their individual points of view.

There are likely to be many factors which influence how couples interact during a research interview. Yet, in this study, partners who were observed to communicate with their spouse with dementia using a more negative style of interaction tended to report more difficulties and changes in their lives together since the memory problems had started. In particular, the partners in these couples commented on the restrictions they had experienced since their role in the relationship had changed from a spouse to a carer, for example no longer being able to leave their

spouse with dementia alone or having to take on more responsibility for household chores.

However it is probable that the interaction styles adopted by couples were also influenced by long standing patterns of communication, their relationship history (Montgomery & Williams, 2001) and each person's understanding and acceptance of the diagnosis of dementia (Pratt & Wilkinson, 2001). The interaction styles adopted may also have been influenced by each couple's view of the purpose of the research, and how comfortable partners felt talking about difficulties in their relationship (past and present) with the interviewer (see 4.3.3). Therefore on the basis of this analysis it is difficult to distinguish whether different perspectives about the difficulties experienced by couples lead to a more negative style of interaction or whether the style of interaction reflected a long standing pattern that was being continued or whether the interaction style that had developed was influenced by a mixture of these two factors.

Nevertheless, the interaction styles adopted by couples when talking together about their experiences of receiving a diagnosis of dementia may be a reflection of how they are coping as a couple with the early-stages of dementia. It may also reveal whether partners help their spouse to be seen as a valid person (Kitwood, 1997) in the presence of others. Partners who respond in more negative ways, ignoring the person with dementia and talking negatively about them in their presence, could undermine and silence a person with dementia, whereas partners who encourage the person with dementia to give their views and facilitate their recall create a more positive social environment that may help maintain personhood. This social context is also likely to influence how couples make sense and adjust to the loss involved in the early stages of dementia (Sabat, 2001).

The second dimension along which people with dementia and their partners varied was in their attitude towards receiving a diagnosis of dementia. Partners in particular were keen to find out more about what might be happening, whereas some people with dementia expressed reluctance to face what might be happening or did not think the assessment was much help. Other authors have indicated that people with dementia often have differing views towards wanting to know what is wrong or receiving information about their illness (cf. Marzanski, 2000; Pratt & Wilkinson, 2001). The present study supported this finding, but also revealed that partners may be more keen to find out what is wrong, which is likely to influence how much choice a person with dementia has over how much to be told and when.

There may be many explanations for this difference between partners and people with dementia in terms of willingness to contact services and perceived benefits of receiving a diagnosis. Many of the people with dementia interviewed found it difficult to recall details of receiving the diagnosis and may have found it difficult to consider any positive impact it had in helping them make sense of what was happening. Alternatively, some authors have suggested that the self-concept of people with dementia is likely to be threatened by the onset of dementia, which can result in a range of cognitive coping strategies (e.g. Clare, in press, a). The people with dementia interviewed in this study may have been reluctant to face what was happening in order to protect themselves, and maintain and restore self-esteem, as their memory impairment progressed (Clare, 2002a).

Overall, this study revealed that couples may also have a range of responses to the changes they experience in the early stages of dementia, their willingness to receive a diagnosis of dementia and their acceptance and understanding of the diagnosis. The analysis suggests that for some couples their responses may become

polarised, for example in their attitude towards receiving a diagnosis of dementia. This result supports previous research which suggests that the desire and ability of people with dementia to understand their diagnosis was influenced by their social context, for example the impact of finding out on their carers (Pratt & Wilkinson, 1999). The analysis further suggests that couples can vary in their desire to know the diagnosis and their ability to make sense of the information and that couples who experience more difficulties as their roles change within the relationship or who differ in their acceptance of the diagnosis, may communicate using a more negative style of social interaction.

4.2.3 Everything's changed, we have to go from there

All the couples interviewed described how living with memory problems had changed aspects of their lives as individuals and as a couple, and described a process of trying to adjust and cope with these changes.

Loss orientated and restoration oriented responses to loss

The model proposed in this study illustrates the experience couples described of over time, acknowledging losses and difficulties and also adapting and coping with the changes in their lives. The model presents this experience as a process of oscillation, as the process couples described of making sense and adjusting to loss, appeared to be similar to the process of adjustment outlined in dual-process models of grief. These theoretical models describe how people come to terms with and adjust to what has been lost by oscillating between loss-oriented responses, such as anger or depression, and restoration-oriented responses, such as seeing friends or denying what has happened (Strobe et al., 1998). The results suggest that couples experience a similar process of adjustment as they begin to grieve for the losses involved in early stage dementia and begin to make sense of their new lives together, adapting their

roles within the relationship and finding ways to cope with the changes and carry on together as a couple.

In this study, the couples described a process of acknowledging what had been lost, for example memory loss or loss of independence and feelings of depression and frustration that accompanied these losses, as well as carrying on as a couple by focusing on what remained for each person and for the couple, for example minimising the impact of memory problems on daily life and developing coping strategies to deal with difficult feelings. This process of adjustment appeared to occur both before and after a couple received a diagnosis of dementia as couples made sense of and adapted to the changes in their lives. This process may also help both partners to begin to integrate themselves into their new identity as a person with dementia or a carer (cf. Miller & Omarzu, 1998).

This research builds on previous work which has examined cognitive coping strategies and awareness about memory loss in people with dementia at an early stage of the illness (e.g. Clare, in press, a). The model proposed in this study illustrates the perspective of both partners and provides an overview of how couples share the experience of making sense of and adjusting to loss in early stage dementia. The model describes restoration-oriented and loss-oriented processes that occur for both members of a couple as well as for the couple as an evolving system (Roper-Hall, 1998).

The themes that emerged relating to the losses and difficulties experienced by couples in the early stages of dementia are discussed in relation to previous research with people with dementia and their carers and theoretical literature about loss and illness below. In the following section, the emerging themes that relate to the resilience and coping strategies described by couples are also discussed.

Losses, difficulties and changes in role for couples

All the couples described aspects of themselves and their lives that had been lost (as individuals and as partners), difficulties caused by the memory problems and changes in their roles within the marital relationship. Firstly, couples described the difficulties in memory and the loss experienced by the person with dementia. Couples referred to the person with dementia feeling depressed about their memory loss as well as annoyed, anxious and frustrated by their memory problems. Depression is considered a common experience for people in the early stages of dementia (see 1.3.1) who may have to come to terms with multiple losses including taken-for-granted aspects of self that are lost (Charmaz, 1991), as well as the loss of life expectations (Miller & Omarzu, 1998). The analysis supported these observations and also revealed that anxiety about memory loss and frustration were experienced by people with early stage dementia, especially when comparisons were made between current and past abilities and when the limitations placed on their current lives by their memory loss were considered.

In addition, the analysis suggested that although people with dementia talked about their memory loss, they also emphasised past abilities and minimised the impact of memory problems on their current lives. Some authors have suggested that people with dementia may minimise their memory problems in order to retain a valued sense of self as well as gradually adjust to the psychological losses they experience (Clare, 2002; Clare in press, a). This analysis further revealed that people with dementia may minimise their memory problems when their partners talk about the difficulties created in their daily life by their spouse's memory problems and talk negatively about the person with dementia in his or her presence. Partners who respond more negatively to the changes in the person with dementia may make it difficult for the

person with dementia to create positive new roles within the relationship and adapt old ones to adjust to the onset of dementia. As discussed this may silence the voice of people with dementia and may also make it difficult for them to discuss their memory difficulties and retain status within their relationship (Kitwood, 1997).

On the whole, the memory loss and low mood experienced by people with dementia appeared to affect their identity and sense of self. Some people with dementia commented that they were “not the same person” (cf. Charmaz, 1983) and others talked about how they had changed since the memory problems began. This supports previous research which has suggested that people with dementia in the early stages have to cope with a restricted life and discredited definition of self and may experience a sense of loss as they begin to reconfigure their previous sense of self (Roper-Hall, 1998).

Secondly, couples described changes in the partner’s role as s/he became a carer and experienced aspects of carer stress (cf. Schulz et al., 1995). Some partners further described feelings of anger and frustration and in particular losing patience with their spouse for repeating themselves (cf. Long, 1997). Some people with dementia also commented on being a burden or worrying about “inconveniencing” their spouse. These results support previous research that has suggested that cognitive decline is likely to lead to inequalities of power within a martial relationship (Rolland, 1998). People with dementia appeared to lose status within the martial relationship and they were no longer viewed as an equal partner. Instead some couples perceived the person with dementia as somebody who needed looking after, and experienced difficult feelings and stress as they adjusted to their new roles and developed new identities as a “carer” and a “patient”.

In addition, the analysis revealed that the impact of the skews that can occur as

couples take on new roles (cf. Rolland, 1994a). Some partners found the extra responsibility that they had to take on particularly stressful and others found the increased dependence of their spouse with dementia difficult to cope with. Partners further described aspects of their previous life they had lost, for example they spoke about loss of independence and feeling restricted. As suggested by previous research, some partners found it difficult to acknowledge and adjust to the loss of their previous relationship (cf. Dempsey & Baago, 1998), and at the same time struggled with assuming the responsibility for the care of the person with dementia (Montgomery and Williams, 2001).

Finally, some partners also appeared to have some difficulties negotiating the changes in their partner who still looked the same, but in some ways was very different (cf. Chwalisz, 1998), for example some partners described their frustration in trying to communicate with their partner as they had always done. Yet, the analysis also suggested that this may have been influenced by the lack of information some couples had received about the diagnosis and prognosis of dementia. Couples who had understood and accepted the diagnosis of dementia appeared to find it easier to make sense and adjust to differences in their spouse. However, as discussed, other factors may also influence how couples make sense and adjust to the changes in the person with dementia, for example educational background or past relationship history.

Overall, loss was a key theme for both partners, which included descriptions of memory loss and loss of previous roles and lifestyle. After receiving a diagnosis of dementia, couples continued to try and make sense of the changes in past and present cognitive abilities and mood, changes in individual roles and changes in their marital relationship. From a systemic perspective of circular causality (MacKinnon & James, 1987), both partners experienced the changes in their relationship, for example the

depression, anger and frustration that may be prominent in the early stages of dementia, and both eventually looked for solutions to the changes and skews that were occurring (Rolland, 1998).

Adjustment and coping

Little previous research has examined the changes that occur for couples in the early stages of dementia, how they adapt to these changes, and the aspects of their relationship that do not change. The analysis does not fit with the assumption that one partner having dementia has a destructive effect on relationships or that for everyone receiving a diagnosis is a couple's worst nightmare (cf. Killick & Allan, 2001; Roper-Hall, 1998). The couples described a process of gradual adjustment, which included finding ways to carry on together in spite of their difficulties as well as focusing on aspects of their lives that had not changed, as individuals and as a couple.

On reflection most couples commented that despite the difficulties they faced in living together with one partner having memory problems, they had adjusted to these difficulties over time and incorporated changes into their daily routine so that the "abnormal" had become "normal". Both partners also described aspects of their previous selves they had retained as well as aspects of their relationship that had not been lost. These descriptions again illustrate how couples presented a dual picture of how they had responded to the changes in their lives, which included feelings of loss and depression as well as resilience and finding ways to cope or focusing on parts of their lives that had not been affected by dementia. A positive state of mind was emphasised by several couples as a crucial part of adapting to and accepting a diagnosis of dementia (cf. Keady et al., 1995).

Further, many couples commented that living with memory problems was worse for people who lived alone. This result again emphasises the need to consider

how social context affects appraisals and coping strategies in early stage dementia. Many partners described the importance of having time out away from their spouse, often achieved through the support of other people. This appeared to have joint benefits for a couple as it provided valued social interaction for the person with dementia and gave the partner some “time out”. The results suggested that maintaining social roles was a useful coping strategy for couples and may have acted as a buffer against the more difficult aspects of early stages of dementia (Cheston & Bender, 2000; Husband, 2000).

However, the results also suggested that some couples became more socially withdrawn or had less contact with other people in the early stages of dementia. Previous authors have provided several explanations about the function and impact of withdrawing from others for people with dementia in the early stages of dementia. Keady and colleagues (1995) suggested that some people with dementia try to hide their cumulative losses to protect friends and family. There is also fear and stigma within society associated with dementia (Husband, 2000) and negative stereotypes about the meaning a diagnosis may lead people with dementia to withdraw from others to maintain secrecy (Clare, 2002a), as well as contributing to friends and family members withdrawing social support. This analysis supports this research and further revealed that couples may isolate themselves from others in the early stages of dementia. Further the results imply that couples who lose contact with their wider social network may have decreased access to a valued social identity, which could contribute to the lower mood experienced by both partners (Husband, 2000).

Overall, the results suggested that couples experienced the period of time before and after they received a diagnosis of dementia as a time of adaptation to gradual change for both partners. Couples described a process of creating new roles

within their relationship and adapting their old ones to adjust to the onset of dementia. The analysis also revealed the importance of social support for couples as they adjust to the difficulties experienced in the early stages of dementia. The results suggest that after acknowledging the difficulties, couples survive or maximise their abilities using a variety of coping strategies (cf Keady and colleagues, 1995) and find ways to adjust to the changes and carry on together.

4.3 Methodological Considerations

One strength of this study was that the qualitative analysis allowed the similarities and commonalities between couples to emerge, as well as revealing dimensions of difference that can be explored in future studies. The steps taken to maximise the validity and credibility of the study are outlined in section 2.6.3. These were based on guidelines published by Elliot and colleagues (1999), Yardley (2000) and Smith (1996). This section considers the study's limitations and the appropriateness of the study's conclusions. The validity of the findings and some areas for future research are also discussed.

4.3.1 Research design and procedure

Several factors in the research design and procedure could affect the validity and credibility of the study's findings. First, the study aimed to focus on participants with dementia who had a mild cognitive impairment and relied on individual clinicians to refer only people who had completed medical and neuropsychological tests that had suggested mild dementia. However, the participants were recruited from several memory clinics and out-patient psychiatry departments that were likely to use differing psychometric batteries and differ in their approach to the assessment and management of people with dementia, including policies for disclosing a diagnosis of

dementia. It is likely that these differences led participants with dementia to differ in the severity of their cognitive deficits at the time of receiving a diagnosis and the service they had experienced both before and after they received their diagnosis. This could well have affected the impact of memory problems on the lives of couples and the appraisals they made about the illness. However early stage dementia is heterogeneous, and clinical practice also varies within services depending on which health professional is seen. Therefore including a range of clinics may have led to a better understanding of couples' experiences of early stage dementia, as it sampled a wider range of clinical practice.

There were also variations in three other participant variables that are likely to have affected the couples' psychological responses to a diagnosis of dementia. First, the people with dementia differed in their MMSE scores as well as their functional abilities as reported by couples, although all the participants were categorised as being in the early stages of dementia with mild cognitive impairment. The degree of difference between participants in terms of memory loss may have influenced the how much people with dementia were able to recall about their experiences of receiving a diagnosis. The differences in adaptive functioning could also have impacted upon the coping strategies available to couples, which helped them adjust to their memory loss, for example being able to independently access social support.

Second, the couples differed in whether the person with dementia had received a diagnosis of Alzheimer's disease or vascular dementia. It is likely that some aspects of couples' experiences of early stage dementia differ depending upon the type of illness that is progressing. Alzheimer's disease typically involves a gradual and progressive decline, whereas vascular dementia typically involves a series of small strokes or infarcts with an abrupt onset (Lezak, 1995). Third the couples also varied as

to whether the person with dementia was male or female. There are many biological and sociological differences between men and women that are likely to influence their psychological reactions of a diagnosis of dementia as an individual and as a spouse, for example differential role loss (Zarit & Edwards, 1996).

Differences on all three of these participant variables are likely to have affected psychological reactions to a diagnosis of dementia in couples and perhaps explain some of the variations seen between couples' experiences. This difficulty with the design could have been partially resolved if the inclusion criteria had been tighter. However it would have been difficult to recruit same-sex participants with fewer variations between their cognitive and functional skills and the same diagnosis within the time frame for the current study, and still fulfil the other research criteria. Further, Kitwood (1997) and others have indicated that the assumption that there is a linear relationship between people's level of disability and cognitive deficits is a false one; thus such an attempt may have been misguided.

In addition, the diagnosis of dementia can be unreliable as, although the symptoms described in textbooks for each type of dementia are apparently clear-cut, in clinical settings people can show symptoms of both Alzheimer's disease and vascular dementia (Lezak, 1995). Finally, this exploratory study aimed to examine psychological reactions to a diagnosis of dementia in couples and explore similarities and differences between people with dementia and their partners, rather than focusing on gender differences. Exploring differences in early stage dementia that are influenced by gender is undoubtedly an important area for future research. Previous research has suggested that women with dementia are more likely to be disempowered by society and those around them in the early stages of dementia (Proctor, 2001) and that women and men differ in the emotional distress they experience as a carer (Zarit

et al., 1993).

A second factor that may have affected the validity and credibility of the findings was how comfortable and at ease couples felt during the interview. This is likely to have influenced each person's ability to talk openly about his or her experiences of receiving a diagnosis of dementia. It is probable that even with the informal nature of the interviews and the attempts to make sure that people with dementia and their partners were well informed and engaged with the interviewer, not all of the couples felt able to talk in an uncensored way about their experiences. In practice one person with dementia commented that he felt uncomfortable being tape-recorded during the interview despite giving consent to be tape-recorded. Further, although this study aimed to explore the perspective of couples, for some couples the presence of their partner may have influenced their ability to talk openly and frankly about their experiences. In practice most couples had fairly frank exchanges with the interviewer and discussed painful issues despite being interviewed together. However two wives appeared reluctant to talk in detail about the changes in their husband with dementia during the joint interview and spoke more candidly about the diagnosis to the interviewer during informal conversations when their partner was not present.

In addition, for couples in which partners used a more negative style of interacting with their spouse with dementia, for example taking the lead from the person with dementia or ignoring their comments, it may have been difficult for the person with dementia to have a 'voice' during the interview. It is also possible that the cognitive decline experienced by the people with dementia affected their ability to recall information during the interview, which may have affected the interactions between couples during an interview when there was a need to recall factual information about their experiences. Couples may have differed in their interaction

style in a study that did not guide the interview to cover a chronological period of time and instead encouraged couples to talk about their experiences of living together without imposing a structure that ordered events.

However, interviewing couples together provided an opportunity for each to comment on what the other was saying, and the interviewer actively invited each to do so. Some partners were also able to fill in some gaps for the people with dementia, and prompt their memory using effective cues. This meant that through comparing and contrasting the information from both partners during the interview process, detailed information about both individual perspectives and their joint construction of the situation was obtained. Further, the interaction style observed between couples may have been a reflection of everyday life to some degree for situations where the cognitive decline experienced by the person with dementia made it difficult for him or her to recall factual information.

A third factor that may also have affected the validity and credibility of the findings, were the differences in social and environmental variables between couples. Although all the couples were married and living together at the time of receiving the diagnosis, the couples' relationship in the past, their social support network or families' reactions to the illness may have impacted upon couples' responses to living with one partner with memory problems. It is therefore difficult to ascertain clearly whether the difficulties experienced by couples were the direct result of living with one partner having memory problems or whether these experiences were due to other factors, such as a couple's past relationship. In addition, some couples also attributed changes in their marital relationship to factors other than dementia such as old age (memory loss is to be expected as you get older), rather than directly due to one partner having memory loss.

This study has however, generated some interesting suggestions about how people with dementia and their partners differ in their appraisals about receiving a diagnosis of dementia, for example the differences in partners' willingness to receive a diagnosis of dementia. Such differences could have many service implications and merit further investigation. It is also possible that the attributions and explanations couples had for the memory problems reflected in part what couples had or had not been told by health professionals about the memory problems. Alternatively, these attributions may have facilitated a couple's adjustment to living with memory problems by minimising the illness.

A final difficulty in the study's design is related to the study's title, which focused purely on memory problems, and may have influenced some of the couples' answers or expectations about topics which were relevant to mention. The short title, "The experience of couples when one partner has memory difficulties", was chosen to emphasise the perspective of both partners and to avoid biasing the appraisals couples made about the illness by mentioning the diagnosis of dementia. However, only mentioning memory difficulties rather than including other possible areas of difficulty within the relationship might have prompted couples to focus on the memory difficulties experienced by the person with dementia during the interview process, rather than talking about other areas of difficulty.

However, the title related to one of the main areas where change is expected in early stage dementia and which couples were likely to have in common. Therefore it was hoped that the title prompted couples to focus initially on how their lives had been affected by memory loss, share their concerns and views about aspects of the process of receiving a diagnosis that had been difficult, as well as giving couples permission to talk about areas of their relationship that had not changed or been

affected, by the diagnosis. Further, during the semi-structured interviews, couples were sensitively guided to explore other areas of their relationship that had been affected and this led to an in-depth account of the process of receiving a diagnosis of dementia. In practice, nearly all the couples mentioned other cognitive, functional or social abilities that had been affected by the dementia, and losses and difficulties in their relationship, as well as areas of their lives that had not been affected by the disease.

4.3.2 Representativeness of participants

The participants were recruited from four memory clinics. Before a couple was contacted, the hospital notes for the person with dementia were examined and the researcher spoke to a health professional who knew the couple well, to ensure that the criteria for the study were met. However, twelve couples did not accept the invitation to participate and it is possible that there might be different reactions to a diagnosis of dementia between couples who participated in the study and those who did not. For example, at least two couples chose not to take part in the study because the person with dementia did not like to talk about his or her memory problems. In addition, during the recruitment stage other couples who appeared to fit the criteria were not invited to take part in the study, because their clinician advised the researcher not to approach the couples due to current marital difficulties, the person with dementia feeling severely depressed or high levels of carer stress.

Therefore it is possible that the majority, although not all, of the couples interviewed had found ways to talk about the memory difficulties as a couple and were managing their difficulties to a greater extent than couples who declined to take part in the study. Thus the couples who decided not to participate, or who were excluded by their clinician, might have expressed a different understanding of and

response to the diagnosis of dementia, have showed different appraisals about the illness and have held differing views about how they were managing as a couple. However, the study's findings still have important implications because gaining an understanding about how some couples respond to the process of receiving a diagnosis of dementia should help to enable clinicians to identify ways of assisting people who have difficulties adjusting to the diagnosis.

Recruiting couples through memory clinics will also have biased the sample. Past studies have suggested that many people with dementia, especially those in the early stages with mild cognitive decline, do not contact health services (Cooper & Fearn, 1998). Thus many couples in which one partner is experiencing the early stages of dementia are likely to be living in the community with no contact with or help from statutory services. Again it is possible that there would be differences between these couples and those who seek services and receive a diagnosis of dementia, in how they make sense of the earlier part of the illness and their understanding of what is happening to the person with dementia.

However due to the nature of the research aims, participants had to be recruited via health services to ensure that they had received a formal diagnosis of dementia. Therefore while the couples' accounts may not be representative of all couples in which one partner fits the criteria for a diagnosis of mild dementia, they are likely to be reasonably representative of couples who attend memory clinics and receive a diagnosis. Thus these accounts can be used to further knowledge about couples' reactions to receiving a formal diagnosis of dementia and can aid the development of interventions to meet their needs and increase the effectiveness of interventions for this group of people. This analysis can also be used to consider whether or not receiving a diagnosis at an early stage is helpful and for whom it is

most helpful, to guide the development of protocols for disclosing a diagnosis of dementia.

Finally, another limitation to the validity and credibility of this study is that it only aimed to include married heterosexual couples, of white UK origin, who lived together in the community and in which one partner had received a diagnosis of dementia. Therefore the themes and model suggested are specific to this group, rather than to other ethnic groups, couples who live apart or people with dementia who live with same-sex partners or with other friends or family relations. It is likely that these people may differ in how they make sense of the diagnosis of dementia. Therefore although this study provided many insights into how a subsection of people with dementia and their partners responded to a diagnosis of dementia, similar studies would need to explore the perspectives of other groups of people with dementia and their partners.

4.3.3 Data analysis

Interpretative phenomenological analysis (IPA) was used to analyse the interview data as it helps to describe participants' experiences and the meanings that they attach to these as well as permitting an exploration of differences between couples. In line with suggested guidelines for good practice in qualitative research (Elliot et al., 1999; Yardley, 2000), IPA also recognises that the thematic outcome of the analysis represents both the researcher's interpretative framework and the participants' accounts. Therefore the analysis and findings from this study may have been influenced by my pre-existing beliefs as well as the psychological literature that informed the study. My previous work with couples in which one partner had dementia guided my interest in psychological reactions to the diagnosis of dementia. The couples I had worked with seemed to respond in a variety of ways to the

information, and the existing literature provided little theoretical guidance about how the process of receiving a diagnosis of dementia impacted upon couples or how psychological interventions could best help couples at this time. Working in a psychology service which emphasised the interaction between a person with dementia and his or her social environment and cognitive deficits in clinical hypothesising about dementia, and which provided systemic interventions to couples, also influenced my research interest in this area.

My work as a health professional providing assessments for people in the early stages of dementia is likely to have influenced both couples' perceptions of me and my interpretations of their responses. First, couples may have made assumptions about my position as a colleague of the health professionals they had seen. This may have influenced their responses to the interview questions, for example taking care to praise the individual clinicians they had seen or altering the information they gave in order maintain a positive relationship with services. Alternatively, couples may have perceived the interview as a chance to complain and their willingness to take part, may have been influenced by how unhelpful they had found aspects of the service provided by my team. In practice, I found that couples talked about how friendly and supportive they had found individual health professionals, but also talked about the lack of practical help available or expressed their dissatisfaction with brief out-patient appointments they had experienced or talked about other difficulties they had had in their contact with services.

Second, I may have developed assumptions about the service provided to couples in the early stages of dementia due to my own emotional response to couples in this situation and through empathising with their feelings of hopelessness about being helped in any useful way. As a younger woman, I also feel I hold some negative

stereotypes about what it means to be older and about the impact of memory problems in older couples as a result of living in an ageist society. This negativity may have biased my view that there is a need for improved psychological interventions for couples, whereas many couples may adjust and cope with these difficulties as they have coped with previous difficulties in their lives, without the help of services. Further, my emotional responses to the distressing nature of the interactions witnessed in some of the interviews may have influenced my interpretations of the difficulties experienced by couples that have received a diagnosis of dementia. However, many of the couples may have been using styles of interacting that had developed long before the memory problems began or have been the result of other difficulties experienced by the couples.

In order to monitor how my own subjectivity may have influenced the interpretations I made during the analysis, I carried out several credibility checks. First, I kept detailed memos about each interview in which I recorded my clinical observations as well as my emotional responses to each couple. These were used to record the initial thoughts I had about a couple and were later examined for negative assumptions about a couple, ageist stereotypes or strong emotional reactions that could have influenced the analysis of each couple's interview.

Second, as suggested by Elliot and colleagues (1999) the themes extracted from the interview data were ordered into a coherent structure in order to resonate with the reader. To achieve this, participants' own words were used in this study to label and describe the themes, rather than using psychological terminology to label each category. Third, the themes were also combined into an overall framework in an attempt to illustrate the connections between the thematic processes that couples described. Fourth, once the analysis was completed, credibility checks of the themes

and the overall framework were carried out. This included two supervisors auditing the data, participants being asked to comment on the results and presenting the results to health professionals who had referred participants and worked with older people with dementia and their families. The comments made by supervisors, participants and health professionals about the coherence of the analysis were used to refine the thematic account and the overall framework that described couples' experiences. These checks aimed to ensure the themes were a good reflection of the couples' accounts and helped to increase the validity of the findings. Finally, descriptive data about each participant has been presented to allow the reader to make judgements about the trustworthiness of the findings for their own clinical work.

4.4 Future research and implications for clinical practice

In the analysis of this study a model was developed which described the psychological process couples may experience as they begin to make sense of one partner's memory loss, receive a diagnosis of dementia, and adjust to their situation. This study revealed some of the complexities in how this process occurs. It suggested that receiving a diagnosis of dementia was just one event within a time period in which couples slowly acknowledged and adjusted to changes in the person with dementia, experienced changes in their roles as individuals and as a spouse, and in some cases struggled to understand what was happening even after the diagnosis had been sought. Further research is needed to explore the variations in the process outlined, refine the proposed model of psychological reactions to a diagnosis of dementia in couples, and consider how wider social factors affect couples' responses. Some suggestions for future research are presented in the next section. The main clinical implications of this study are then discussed before some conclusions are

drawn.

4.4.1 Suggested areas for future research

This study revealed two areas of difference between couples that appeared to influence their response to a diagnosis of dementia: how they made sense of what was happening to the person with dementia, and how they adjusted to and coped with living together with one partner having memory problems. These two differences may be important areas to examine in future studies. Firstly, this study revealed a difference between couples who had received a university education and those who had not, which suggested that a couple's educational background influenced their explanations and knowledge about dementia in the early stages. This difference needs to be explored in future research as it was unclear whether the variation between couples who had attended university was due to their education or their socio-economic status. Further research could explore this issue and examine the implications at a social level for couples and others in the early stages of dementia. Studies could examine whether a university education influences a couple's motivation to access services and other resources to find out more about what is happening in the early stages of dementia as well as exploring differences between couples from differing socio-economic backgrounds in the strategies they use to make sense of and adjust to the losses in early stage dementia.

Secondly, this study revealed that couples could be categorised on the basis of the partner's interaction style with the person with dementia. It is interesting to consider what it is that makes couples fall into one or other category. Couples were fairly consistently described on the basis of one category, which has implications for couples who live in the community with a partner with dementia who interact using a more negative style. It is possible that which interaction style dominates is

predetermined to an extent due to pre-existing styles within a couple's relationship. Alternatively, couples' interaction styles may change in response to the onset of dementia and receiving a diagnosis.

The interaction styles exhibited by couples in the early stages of dementia, and how a diagnosis of dementia influences social interactions between people with early-stage dementia and their partner, are important areas for further research. Future studies which include a more fine-grained analysis of the social interactions within couples, may reveal variations on a continuum between the two categories of negative and positive styles of interaction presented here. Future research could also draw on marital literature studies to explore the interaction styles exhibited by couples in the early stages of dementia and examine the extent to which the interaction styles are situation specific or a long-standing pattern of interaction.

This study further revealed a difference between people with dementia and their partner in their willingness to receive a diagnosis or dementia and how useful they found the information given about the diagnosis. These variations between people with dementia and their partners may also need to be explored in future studies. As described above, there may be many explanations for this difference between partners and people with dementia, perhaps due to differences in the retention of information or due to the increased threat to self for people with dementia. Exploring these two explanations in more detail may help clinicians, firstly to consider how people with dementia can be assisted to retain the information given about their diagnosis and secondly to consider the rights of people with dementia to be told about their diagnosis in a way that maintains a more positive view of self.

Finally, as mentioned, this study examined a subgroup of people who had received a diagnosis of dementia and more research is needed to examine

psychological reactions to a diagnosis of dementia in a wider range of people. Future research could explore the usefulness of the proposed model, which is based on the experience of couples, for understanding how people with dementia living with same sex partners and/or other friends and family members respond to the diagnosis. Future research could further examine differences between men and women with dementia who receive a diagnosis or differences between people who receive a diagnosis of Alzheimer's disease or vascular dementia or people from a variety of ethnic backgrounds.

Alternatively, a longitudinal research design could be utilised to examine psychological reactions to a diagnosis of dementia in couples over time, both before and after the formal diagnosis is received, as many participants found it difficult to recall events retrospectively. Such research could examine whether the cyclical and oscillating processes of making sense and adjusting to the early changes in the person with dementia continue over time and could track how other life events impact on making sense of a diagnosis of dementia for couples. Future studies could also attempt to focus on people who have not yet received a diagnosis, or are waiting to hear the results from their medical and psychological assessment of dementia to find out more about couples' experiences at this point in the process of receiving a diagnosis of dementia.

4.4.2 Clinical implications and recommendations for services

The current study has several clinical implications which will be useful for health professionals to consider in their work with couples in which one partner has received a diagnosis of dementia. First, the analysis revealed that for many couples receiving a diagnosis of dementia did little more than confirm a couple's own knowledge. Few couples gained further information about dementia from receiving a

diagnosis and all the couples were left with unanswered questions about either the diagnosis or prognosis of dementia. In particular, people with dementia were unable to recall details about the feedback they had had from services about their memory loss, even when they had only received a diagnosis a month prior to their interview.

Although it is possible that some couples choose not to know about the diagnosis of dementia (Clare, in press, a), on the whole, this result implies that couples are not told enough about the diagnosis of dementia and that memory clinics need to develop guidelines and protocols surrounding what people are told about their diagnosis which meet the needs of people with dementia and their spouses. These guidelines could recommend that clear and understandable information about the diagnosis is given, that is accessible to people from a variety of backgrounds and is presented in a way that maximises the retention of information for couples, for example providing written information that can be read and re-read after the event.

Consistent with previous research, the analysis further implied that health professionals need to allow plenty of time for questions and explanations (cf. McKillop, 2002), and also acknowledge that the diagnosis may need to be discussed over time, perhaps over several meetings (Pratt & Wilkinson, 2001), to address concerns as they come to mind. Therefore the protocol could also recommend that disclosing the diagnosis should not be viewed as a one-off event as couples may need time to consider the information they have received and have the information repeated at regular intervals. In addition, the protocol could include encouraging couples to obtain information about their diagnosis from other sources, for example through voluntary organisations such as the Alzheimer's Society. This would provide couples with another resource which they could access to gain information about the diagnosis and prognosis of dementia. Alternatively, clinicians could attempt to offer

more information about the diagnosis themselves, as well as give out leaflets from organisations such as the Alzheimer's Society.

Second, the analysis revealed that after the diagnosis had been received, couples were left feeling helpless and expressed a belief that very little could be done to help them. This belief may be due in part to the psychological impact of living with dementia or negative stereotypes about memory loss and old age that are dominant in society. It could also be due to the dominance of the medical model of dementia which implies that the absence of a medical "cure" for dementia leaves few options for couples in which one partner has dementia. However, many of the couples interviewed were dissatisfied by what services had offered and expressed a view that they were left to get on with things, coping as best they could. Such perceptions may further reinforce the view that dementia is simply part of the ageing process for which there is no cure rather than leading couples to seek help that is available from services. Further, it is vital that strategies are put in place to ensure that couples experience services more positively as support offered at this time is likely to affect their expectations of how they can be helped in the future (Rolland, 1998).

As outlined by the National Service Framework, services need to assist couples to access available help and treatment that may be beneficial in coming to terms with the prognosis of early stage dementia. In particular, the results imply that the options available from services for people with dementia and their partners should be made clear after the diagnosis of dementia has been received. The analysis further supports prior research that has revealed a need for services to provide psychological and psychosocial interventions around the time of receiving the diagnosis (cf. Moniz-Cook & Woods, 1997; Clare, 2000). Services may be improved by offering couples more emotional support and practical help after they receive a diagnosis of dementia.

This may help to change feelings of hopelessness by challenging the belief that little can be done to sustain or enhance the quality of life for people with dementia and their partners.

Useful psychological and psychosocial interventions for couples could include education about dementia as well as emotional support to help them make more sense of the diagnosis, make adjustments as a couple and manage feelings of stress, depression and anxiety. Interventions could be aimed at supporting couples through this transition in more positive ways to counteract the malignant social psychology that typically surrounds people who receive a diagnosis of dementia. The process of adjustment described in the proposed model suggests that couples could benefit from interventions which explore loss-oriented and restoration-oriented responses to early stage dementia to enable them to grieve together for the losses experienced and find ways to carry on together as a couple. Such interventions could be guided by the existing literature about loss (e.g. Harvey, 1998) and theoretical models of grief (e.g. Strobe et al., 1998). Systemic interventions could also explore the differences between people with dementia and their partner in their understanding of and response to the diagnosis of dementia and help them create a shared story about what has happened and find ways to talk together about their experiences (White & Epston, 1990). The results further imply that people with dementia may benefit from interventions that include cognitive rehabilitation strategies as well as emotional support to help them adjust to living with memory problems and that partners may benefit from carer support and practical help to help them manage the changes in their role from a partner to a carer.

Thirdly, the analysis also revealed that although emotional distress undoubtedly occurs when a diagnosis of dementia is received, couples gradually

adjust to the changes and are able to continue their lives together despite the losses involved in early dementia. This finding supports the current National Service Framework recommendations for the early detection of dementia to give couples enough time to make positive changes and maintain a purposeful life, friendships and relationships after a period of adjustment and making sense of the illness. However the analysis also revealed that some couples experienced more difficulties in adjusting to their current situation than others. For some couples receiving the diagnosis of dementia led to improvements in their relationship, whereas other couples continued to struggle to make sense and cope with the changes that had occurred in the person with dementia.

The results suggest that some couples may be assisted in coping and adjusting to the loss if they are given information about dementia that helps them regain control and understanding about what is happening. Other couples appear to understand little about dementia in the early stages and therefore have problems trying to live with what they do not understand. This may be due to variations between couples in terms of their educational background or it could be due to differences in a couple's ability to accept and adjust to the changes in their lives or due to the lack of clear and understandable information given to couples about the diagnosis. Alternatively this variation may be due to the cognitive decline experienced by the person with dementia, and may imply that the diagnosis is not usefully retained by people with dementia even in the early stages, although the emotional impact of the information may be experienced, for example depression. Such results imply that a challenge exists for services to provide interventions that can meet the range of needs that couples have in the early stages of dementia. One way services could meet this demand is by providing a range of interventions such as those described above, as

well as assisting couples to access resources that can help them help themselves.

Finally, the analysis revealed that social support was an important factor in helping couples cope with the early stages of dementia. Social support appeared to benefit people with dementia who perhaps gained an opportunity to develop social roles which could act as a buffer against the losses they face (Cheston & Bender, 2000). Social support also appeared to provide partners with a break from daily interactions with their spouse that they found difficult to manage. This result implies that couples may benefit from attending support groups for people with dementia and their carers, provided either by statutory services or voluntary organisations such as the Alzheimer's Society. As mentioned, these organisations can also provide people with accessible information about dementia, as well as the opportunity to meet others in a similar situation and develop informal support networks. Couples may also gain an opportunity to share experiences with others and perhaps learn different coping strategies.

4.5 Conclusions

This study has proposed a model of how couples make sense and adjust to the losses they experience living together with one partner having memory difficulties. This model illustrates how couples experience a gradual cyclical process of realisation, denial, minimisation and acceptance as they make sense and adjust to the initial changes in the person with dementia. The model further illustrates that although receiving a diagnosis of dementia assists some couples in understanding and accepting what is happening to the person with dementia, for others the diagnosis does little to change the appraisals they make about the illness or decrease their uncertainty about the diagnosis and prognosis of dementia. The model also illustrates that couples

experience an oscillating process of adjustment over time of acknowledging the difficulties and loss but also finding ways to carry on and cope together.

In conclusion, the analysis suggests that changes in roles and identity for most may be the most difficult challenge in the early stages of dementia as they occur so gradually over time and may be rarely thought about, as they are integrated into the relationship as both partners try to adapt. The analysis further revealed some variations between couples and between people with dementia and their partners in responses to receiving a diagnosis of dementia. These included their understanding and acceptance about what might be happening before and after they receive the diagnosis, and differences between people with dementia and their partners in the perceived benefits of receiving the diagnosis. Future research is needed to examine these differences and also explore psychological reactions to a diagnosis of dementia in a wider range of people with dementia, living in other social contexts.

Finally, the analysis revealed that couples are generally dissatisfied by the support offered by services after they have received a diagnosis of dementia and tend to feel hopeless about their situation. This study has provided an increased understanding of the needs of people with dementia and their spouse and has made recommendations about the ways services will need to adapt to meet these needs as well as alternative ways services can facilitate couples to make sense and adjust to receiving a diagnosis of dementia.

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APPENDIX I

Invitation letter for participants



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NEW PSYCHOLOGICAL RESEARCH PROJECT ABOUT COUPLES WITH ONE PARTNER WHO HAS MEMORY DIFFICULTIES

PRIVATE AND CONFIDENTIAL

Dear Mr and Mrs

We are writing to invite you to take part in a new research project investigating the impact of memory difficulties on couples. We are keen to talk to couples where one partner has been experiencing memory difficulties and has been to see Dr. for an assessment of these difficulties at Hospital.

We are interested in finding out more about how couples experience, manage and talk to each other about the memory difficulties and how they feel about the impact the memory difficulties have had on them. We hope the research will increase our knowledge about the best ways to help and support couples where one partner is experiencing memory difficulties. We have enclosed an information sheet about the project which tells you about the purpose of the study in more detail.

Participating in the research would involve talking to a researcher about your experiences which would take place at a location and time convenient for you.

We will contact you by telephone in about a weeks time to find out whether you would be willing to take part in the research, and answer any questions you may have. If you decide not to take part we will not contact you again after this.

In the meantime, if you would like to talk to someone about the research please call and leave a message on 0207 6791844 and a member of the research team will contact you. The research team are Linda Clare, Kathryn Evans, Lucie Robinson and Jenny Griggs.

Yours Sincerely

Dr Lucie Robinson
Trainee Clinical Psychologist

Jenny Griggs
Trainee Clinical Psychologist

Information sheet for participants



Sub-Department of Clinical Health Psychology
UNIVERSITY COLLEGE LONDON
GOWER STREET LONDON WC1E 6BT

The experience of couples where one person has memory difficulties

You are being invited to take part in a research study. Please read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part. Thank you for reading this.

- **Aims of the study**

The study has two main aims. First, it aims to explore how couples talk to each other when one person experiences memory difficulties. Second, it aims to explore what impact memory difficulties have on couples and how these affect daily life and relationships.

- **Your involvement**

You have been invited to take part in this study because you have seen one of the Clinical Psychologists at either the Whittington hospital or St Pancras hospital due to concerns about memory. **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 affect the care you receive. This invitation to take part will be followed up by a telephone call approximately one week after you receive the letter. If you decide not to take part, we will not contact you again.

If you decide to take part, you will meet the researchers on two occasions, each meeting lasting approximately one hour. These meetings will take place somewhere that is convenient for you, either at your house, or at St. Pancras hospital, the Whittington hospital, or at University College London. The interviewer will talk to you about your experiences of memory difficulties and will ask you to fill in a questionnaire and hold a conversation together as a couple. We hope that you will find this a helpful and perhaps enjoyable experience. However, if you find any aspect at all distressing, we would offer to meet with you again to give you a chance to discuss these feelings further.

We hope that taking part in this research will be of benefit for you, although we cannot guarantee it. The information we get from this study will help us to improve the support we can offer to couples who come to see us in the future with similar problems.

We do not expect that taking part in this research would do you any harm. We need to point out though that if you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

- **Confidentiality**

All the information you give us during the course of the research will be kept strictly confidential. Any written or recorded information about you will have your name and address removed so that you cannot be recognised from it.

- **What happens when the study is complete?**

Once the study is complete we will give you some information about the findings and ask for your views and comments. These will be incorporated into the final reports. We aim to write about the findings in scientific journals and we will be happy to let you have copies of any publications.

- **Ethical approval**

All proposals for research using human participants are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Camden and Islington Ethics Committee.

- **Further information**

For further information about this study, or to address any questions or worries you may have, please contact either Lucie Robinson, Jenny Griggs or Linda Clare by telephone on 020 7679 1844, or by post at the Sub-department of Clinical Health Psychology, UCL, Gower Street, London, WC1E 6BT.

- **Research team involved in this study:**

Linda Clare
Lecturer and Clinical Psychologist

Kathryn Evans
Clinical Psychologist

Jenny Griggs
Trainee Clinical Psychologist

Lucie Robinson
Trainee Clinical Psychologist

Linda, Jenny and Lucie are all based at University College London. Kathryn is based at the Whittington Hospital.

Thank you for taking the time to read this information sheet and for agreeing to take part in this study.

APPENDIX II

Consent form for participants

Title of Project: The experience of couples where one person has memory difficulties

Name of Researchers: Linda Clare (Lecturer), Jenny Griggs (Trainee Clinical Psychologist),
Lucie Robinson (Trainee Clinical Psychologist)

Please initial box

1. I confirm that I have read and understand the information sheet dated..... ☐
(version) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw ☐
at any time without giving any reason, without my medical care or legal rights being
affected.

3. I understand that sections of any of my medical notes may be looked at by ☐
responsible individuals from [company name] or from regulatory authorities where
it is relevant to my taking part in research. I give permission for these individuals to
have access to my records.

4. I agree to take part in the above study. ☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 for patient; 1 for researcher; 1 to be kept with memory clinic notes

APPENDIX III

Ethical approval letters

Camden & Islington Community Health Services LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre

St Pancras Hospital, London NW1 OPE

tel: 020 7530 3376 fax: 020 7530 3235

e-mail: ayse.all@camdenpct.nhs.uk

Chair: *Stephanie Ellis* Administrator: *Ayse All*

21 November 2002

Dr Linda Clare
Sub-Department of Clinical Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Dr Clare

LREC Ref. 02/41

Title: Communication, mutual support and psychological reactions to a diagnosis of dementia in couples

Thank you for your letter dated 29 October 2002 outlining an amendment to the information sheet for the above study, I apologise for the delayed response. I am please to inform you that the Committee has no ethical objection to these amendment being included. Please note that the conditions set out in out letter dated 25 June 2002 still apply.

Please forward any additional information or amendments to the ethics committee administrator at the above address.

Yours sincerely


Stephanie Ellis
Committee Chair

Victory House
170 Tottenham Court Road
London W1T 7HA
Tel: 020 7756 2500
Fax: 020 7756 2502

Chair Marcia Saunders
Chief Executive Christine Outram

13 November 2002

Dr Linda Clare
Sub-Department of Clinical Psychology
University College London
Gower Street
London W1CE 6BT

Dear Dr Clare

138/02 – (C&I number 02/41) Communications, mutual support and psychological reactions to a diagnosis of dementia in couples

Acting under delegated authority I write to inform you that the Barnet, Enfield & Haringey LREC sub group considered in full the locality issues relating to the above application at the meeting held on 12th November 2002. The issues reviewed were as follows:

- The suitability of the local researcher (Dr J Newby)
- The appropriateness of the local research environment and facilities
- Any specific issues that may relate to this local community

The LREC members on behalf of the LREC consider the locality issues have been adequately addressed and the proposed research can be conducted within the boundary of this Health Authority on the understanding that you will follow the conditions set out below:

- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been granted as set out in the framework for Research Governance in Health and Social Care.
 - You do not deviate from, or make changes to, the protocol without prior written approval of the MREC and notifying the LREC of this approval, except where this is necessary to eliminate immediate hazards to research participants, or when the change involves only logistical or administrative aspects of the research.
 - You notify this LREC when you have completed your research, or if you decide to terminate it prematurely.
 - You advise your sponsor of any unusual or unexpected results that raise questions about the safety of patients taking part in the research.
-

Although LREC approval has been given for the above study I have been asked to point out the following:

1. The term partner and mate are used in the Dyadic Adjustment Scale, suggest they stick to partner as could be confusing.
2. Short CVs with dates are required for all researchers listed on annex D but particularly Katheryn Evans who will no doubt be seeing Haringey patients as part of this study.

Please quote LREC number 138/02 on any future correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'C Hamilton'.

Christine Hamilton
Barnet, Enfield & Haringey
LREC Co-ordinator

APPENDIX IV

Semi-structured interview

The interview will be guided to cover the following topics:

- **When the couple first realised one of them had memory difficulties.**
Prompts: *who noticed first, what did they notice, what (if anything) did they do?*
- **What thoughts each person had at the time**
Prompts: *as an individual, as part of a couple, what was going through your mind?*
- **What each person felt at the time of this realisation.**
Prompts: *as an individual, as part of a couple, how do they think their partner felt?*
- **How these thoughts and feelings have changed over time?**
Prompts: *as an individual, as part of a couple, how do they think their partner's thoughts and feelings have changed?*
- **Whether the couple have sought a diagnosis.**
Prompts: *who's idea was it? how did they find out?, were they in agreement? what were their expectations before they contacted services?*
- **How the couple received a diagnosis.**
Prompts: *who gave you the diagnosis? who was present? what do you remember about what they told you? was the feedback you received clear or unclear?*
- **How each person reacted to the diagnosis.**
Prompts: *what was it like to hear the news? was the diagnosis helpful or unhelpful? did the diagnosis confirm the expectations you had or was the news a surprise? how did you feel when you received the diagnosis?*
- **How the diagnosis/illness has affected each partner since the diagnosis has been received.**
Prompts: *has the diagnosis had any impact in theirs as individuals or partners? what has changed and what are some of the things that may not have changed?*
- **How the diagnosis/illness has affected the couple's relationship?**
Prompts: *immediate effects, changes that have evolved over time?*
- **What reactions have other family members/friends had to the diagnosis?**
Prompts: *Have they noticed any changes in the way others treat them?*
- **What impact (if any) has the diagnosis had on the couple's involvement in activities?**

APPENDIX V

Individual level analysis of a transcript.

- Theme 2a)
- losing things beginning (6) D: Well as I said, it started and um ...she was um putting things down and forgetting where they was, didn't yer? Do you remember? you used to lose things, I'd put something down and then you'd forget were it was losing things
- (3) R: Oh yes mm
- separate apart at 1st (8) D: That was a few years ago now and gradually we got on and we went up there a couple of years before that, but I didn't go in there with you, but when we went down, back, the first time a couple of years ago... few years on going to hospital
- beginning to pick up sense of interview - re in previous (9) R: (interrupts) I told the lady that one, it was that one about getting the food and..... remembers previous interview
- turn taking (10) R: And he was always, we always buy... I buy...and you buy.... to get food and things like that shopping/buying
- L: Yep
- corrects R (11) D: But that's... that's nothing to do with what your asking is it? exasperated pushes out his mistake
- apologetic (12) R: Oh sorry (12) exasperated (12) apology
- L: No it was something I was just asking a minute ago wasn't it?
- (13) R: Oh yes
- R not realise (14) D: No when you first realised, I don't think you did so much as me (realise) didn't realise. D realised
- L: Right
- beginning to make sense interview - re in previous (15) R: I think I told that lady about the things I was doing activities she does
- beginning to make sense interview - re in previous (16) D: That's right you was mislaying things and gradually it got on and on and we had to go up to the Whittington didn't we gradual progression
- beginning to make sense interview - re in previous (17) R: I don't remember no memory of what
- beginning to make sense interview - re in previous (18) D: So when we went up there, they tested you, didn't they and asked you questions? tests/qs.
- beginning to make sense interview - re in previous (19) R: I didn't I didn't... disinterested
- beginning to make sense interview - re in previous (20) D: Do you remember going up there?
- beginning to make sense interview - re in previous (21) R: None of that at all no memory
- beginning to make sense interview - re in previous (22) D: You don't now, but at the time you was going up there, and er..... used to remember
- beginning to make sense interview - re in previous (23) R: I used to be very happy D used to be happy

Key

Theme 2: You don't notice straight away, 2a) *Anyone can forget*, 2b) *Gradually creeps up*.

Theme 1: I can't say I just can't remember, 1b) *I don't remember*

Theme 7: Used to be happy, 7b) *Used to go out*,

both used to be: *Theme 7a)*
 "happy" (24) D: I know you was we both was wasn't we, we used to be very happy, laugh and joke didn't we? all the time *both used to be happy, laugh/joke all the time*

echos (25) R: Mmm, all the time *Theme 7a)* *all the time*

L: R has been telling me.....

used to: "go out" (26) D: (interrupts) We used to go out a hell of a lot together didn't we? pictures and whatever *Theme 7b)* *going out*

echos (27) R: That's right pictures *Theme 7c)* *activities done together*

never used to "drink" (28) D: We never really used to drink or nothing *Theme 7d)*

agrees (29) R: D didn't *Theme 7e)*

(30) D: I used to drink at work, maybe a few drinks with the men from the market, not with R, we'd go to the pictures *activities not R*

never used to "dance" (31) R: But you never used to dance with me *R + D talking together here* *activities not D*

agrees (32) D: I wasn't a dancer no, I'm a bit too clumsy *Theme 7f)*

L: Mmm

pride (33) R: I was a great dancer *Theme 7g)* *emphasis still*

agrees (34) D: She was a good dancer *Theme 7h)* *dancing*

(35) R: Yes I was...

L: ...So when you first started noticing R's memory difficulties it was because she was misplacing things

beginning (36) D: That's the start..... *start*

L: And was that when you decided to go up to the Whittington?

silly R? (37) D: It was a long time after that, I mean just because you misplaced something, you don't go straight away, it gradually creeps up and things must have happened, I can't think *Theme 7i)* *gradual progression* *creeps up* *not clear* *expl?*

corrects R (38) R: (interrupts) Your mum died didn't she she..... *D corrects R / stops her*

(39) D: No that was a long time ago, well we, no er I can't really say why we went up there, something must have happened, but I can't think now. Because it comes up on you so slowly *corrects R* *no expl why hosp* *so slowly* *Theme 7j)* *not remember why* *slowly comes up*

L: Yes

Key

Theme 2: You don't notice straight away, 2a) *Anyone can forget*, 2b) *Gradually creeps up*.

Theme 7: Used to be happy, 7a) *Happy go lucky*, 7b) *Used to go out*, 7c) *I've done very well*.

used to be:
laughing
coping
a giggle
no reason to
go quiet

Theme 2a)

D: You know I mean when she was mislaying things at the start, we used to laugh and joke about it didn't we? I mean it was a giggle Oh yer haven't lost it again you know and all that lot.... and I can't see for what reason we went.....

used to
laugh/joke
when probs
no reason to
go

L: So it was over time that things happened, and there was more and more you were noticing

weeping
slow

Theme 2b)

D: I creeps up on you very very slowly

creeps up
slowly

L: Yes

denial?
takes time
to notice if
together

Theme 2c)

D: And you don't notice it, I s'pose someone who don't see yer for a while, then then they'd notice straight away.

not noticing
straight
away

L: Yes

Theme 2b)

D: But when your continually there all the time....

L: So you think it kind of crept up on you

not know
no 1st
- normalise

Theme 2a)

D: Oh it does it does, you don't know straight away, I mean anyone can forget where they put something, even you, young as you are

anyone can
forget

L: Yes

repeatedly
→ gives ppl
to go to limit

Theme 2b)

D: But I mean I s'pose it got to so many times it happened, ...probably that's how it was, that it happened so many times that we probably went to the doctor and he might have suggested er we go up there.

repetition
or forgetting
doctor's advice

L: Before you went up to the Whittington, did you have ideas about what might be going on?

no ideas
R had AD

Theme 2a)

D: No

R was to pin in
D makes her

no ideas what
going on

no idea
what is going
on in conversation

Theme 2a)

R: What was going on?

confusion topic conversation

expls

Theme 2a)

D: No no she's talking about your memory

L: About your memory R, did you have any ideas about what might be going on?

answers 4 R

Theme 2a)

D: No no I don't think so

D answers for R

Theme 2a)

R: You said you weren't....

not let her
speak

Theme 2b)

D: No you don't... I say, probably it happened so many times that I probably thought well we'll go and see if there can be something we can't do about it, but I can't really remember to be honest with yer, I know that the last couple of years, that's when things have got harder since we found out it was AD, but it must have started a long

not remember
why went

hard times
since dia AD

Theme 2a)

AD - got
harder since
that time
back time

Key

Theme 2: You don't notice straight away, 2a) Anyone can forget, 2b) Gradually creeps up, 2c) Passing it off, 2d) We'll go and see.

- started by this the one 2c)
time before that. A year or two before, you went up there, I went up there, but you
denial memory went in on your own, and you passed it off at that time
The one 2a)
- remembers what visits (52) R: I used to go there for the, for the.... 12 hours to prison
reflection started 100% by 12 minutes, then pass
- guesses (53) D: Oh you been up there for all things over the years, this is er what's it called now, many trips to hospital
the one at the er Whittington, the place where you go?
? doubt & know which called about now
- L: The Charterhouse building?
- (54) D: Nah... it's called something else... I can't think of the name, well there you go
- L: So what was it like when you found out about R's memory difficulties given that you'd had a bit of an explanation
- unwilling to (55) D: Well all they do is er sort of give her tablets didn't they? sort of like to arrest it, but she had violent reactions on both of them didn't yer?
The one 3) tablets to arrest it
violent reactions
- (56) R: Mmm
- not sure (57) D: So we spent six hours up the er hospital.....
spent at hospital bad time, painful exchange
- L: You were telling me, about R's personality I guess changing a little bit at that time
- Everything changed (58) D: Everything changed.... yeah definitely.... R became very ill, she was really sick, everything changed
illness/paranoia and R became very paranoid and thought that I was stealing things from her and even that I wanted to kill her, and that was very difficult considering what a good relationship we had..... paranoia
bad times as past relat
- pride dancing (59) R: I was a good good dancer, I used to do always wanted to.....
The one 4) R emphasises strengthens
D corrects R
- corrects R (60) D: But this is something to do with your memory loss R
happy when younger corrects R
- happy when younger (61) R: I was a happy girl
The one 5) happy as a girl
agrees agreement
- (62) D: Yes in your younger days
- L: R are you saying you can't remember a lot about what we're talking about?
- confusion who is 4? (63) R: Who D?
- L: About going up to the Whittington
- (64) R: Mmm
- (65) D: Can you remember much R?
- memory of (66) R: (interrupts) My mum was living at the hospital
while confused but connection made about Whittington
- L: Was she?

Key

Theme 2: You don't notice straight away, 2c) *Passing it off*, 2d) *We'll go and see*.

Theme 3: What can you do?

Theme 5: Things have got harder, 5a) *R became ill*.

Theme 7: Used to be happy, 7a) *Happy go lucky*, 7c) *I've done very well*.

**Impressions/reflections upon the experience of meeting and interviewing R and D
(20/11/02)**

- D underestimates R's abilities: memory; conversations skills, e.g. D says there is no point talking to her as she doesn't remember anything – Kitwood's MSP framework seems relevant.
- D has a sense of hopelessness about the situation, e.g. "nothing can be done?".
- R is able to talk about how she feels and respond to conversations in a way that makes sense in the context of what is being said or what was said previously.
- R is aware of how D has changed and is concerned about these changes, what they could mean and why he is unhappy now.
- R's memory for past events is better than for recent events, she told me she thought she was in her 40s.
- R has very little memory about receiving a diagnosis of AD.
- D talked about the loss of previously shared and enjoyed activities.
- Both R and D talked about the loss of laughter in their relationship and how much they had enjoyed their marriage and times spent together in the past.

APPENDIX VI

Complete list of themes from two interviews

Interview one

Themes

1) I can't say [r92] I just can't remember [r94]

Refers to R and D's shared belief that R won't have anything to say during the interview and can't remember anything anymore.

a) I don't know what I'm gonna say [r1] b) I don't remember [r17]

2) You don't notice it straight away [d42, d44]

Refers to D's descriptions of his gradual realisation that R had memory problems and deciding to go and see someone about it. R doesn't really remember much about what D is saying.

a) Anyone can forget [d44] b) Gradually creeps up [d37] c) Passing it off [d51]
d) We'll go and see

3) What can you do? [d74]

Refers to D's thoughts and feelings that nothing can be done to help R or change their situation. D appears to feel quite hopeless about the situation and refusing to consider help that was offered, but is also being realistic about the reality of AD being an incurable disease.

4) I'm fed up [r92]

Refers to R and D's feelings of depression and frustration

a) I used to be happy [r23] b) Frustration [d100]

5) Things have got harder [d51]

Refers to the things D is finding hard now he is R's carer. D no longer appears to have an identity as R's husband (or she his wife).

a) R became very ill [d58] b) All I am now [d112]

6) Carrying on [d112]

Refers to R and D's continued love, commitment and respect for one another

a) We're happy with each other [r107] b) R has her independence [d145]

7) Used to be happy [r23]

Refers to R and D's reminiscing about the happy life they have had together

a) Happy go lucky [d110] b) Used to go out [d26] c) I've done very well [r113]

Interview two

Themes

1) Something went wrong [CL589]

Refers to E's experience of being in hospital and the changes C noticed at that time. Both are still confused about what was going on with E

- a) I'm in prison [e272] b) It's a puzzle [CL241] [e391] c) No-one seemed to know [CL253] d) Don't have the answers [CL554]

2) I'll ignore it [CL143]

Refers to C's gradual realisation that the changes in E she noticed while he was in hospital were permanent

3) E's position [CL3]

Refers to E and C's descriptions of E's memory loss and what it's like for E having memory difficulties

- a) Grasping it [e312] b) I've Forgotten [e507] c) Memories [e362] d) Frustrating [e502]

4) Trying to do everything [CL166]

Refers to C's descriptions of how her life has changed and the specific things about her daily life with E that she finds stressful. C now has to do everything for her and E which puts her under considerable pressure and leaves her feeling resentful.

- a) Fitting it all in [CL490] b) Taking over the reins [CL121] c) Restricted [CL550]

5) Gets me down [CL190]

Refers to E and C's experiences of psychological distress since E started having memory difficulties

- a) Depressed [e648] b) Panic [e160] c) A bit resentful [CL548] d) Getting cross [CL550]

6) Trying to get through [CL315]

Refers to C's denial that E's memory problems are permanent and her persistent attempts to get through to him

7) That's your life [CL74]

Refers to C's acceptance and adjustment to E's memory loss and the changes to her life since E started to experience memory problems

- a) He's looked after [CL552] b) I know he can't help it [CL192] c) He's living in the past [CL585] d) Getting on with it [CL598]

8) Learning to relax [CL400]

Refers to C's descriptions about activities and people which help C and E cope with their feelings of distress

- a) My time out [CL476] b) Relaxation [CL400] c) Occupy his mind [CL298] d) My daughter [CL47]

9) You have to laugh [CL139]

Refers to C's attitudes about coping with distressing situations

- a) Have to laugh [CL604] b) Strong minded [CL480] c) Persons that got no-one [CL675]

10) That place [CL7]

Refers to C and E's mixed views about the helpfulness of E going to the day centre

- a) A Marvellous idea [CL7] b) Is it worth the effort? [CL35] c) A sheer waste of time [e21]

11) The story of my life [e185] [CL186]

Refers to the E and C reminiscing about their lives

- a) Free agents [CL325] b) Seen some sights [e408] c) Person he was [CL294] d) This Age [CL200]
e) Missed my daughter [CL606]

Appendix VII

Final list of themes, highlighting where each interview's themes have been condensed.

Higher order theme: Not quite the same person [JN3], tell me what actually is wrong [m61]

Theme One: You don't notice it straight away [d42, d44]

a) Anyone can forget [d44]

MPR1 THEME 2) You don't notice it straight away [d42, d44] a) Anyone can forget [d44] b) Gradually creeps up [d37] c) Passing it off [d51] d) We'll go and see [d53]

MPR2 THEME 2) I'll ignore it [CL143]

MPR3 THEME 3) Took me some time [p3] a) Disbelief and anger [p194]

MPR6 THEME 1) Not quite the same person [JN3] b) Where does it cross over [JN17] c) Something to put your finger on [CE25]

MPR7 THEME 1) People no longer flawless in their memories [g27]

b) Gradually creeps up [d37]

MPR1 THEME 2) You don't notice it straight away [d42, d44] b) Gradually creeps up [d37]

MPR6 THEME 1) Not quite the same person [JN3] a) A slow process of change [JN13] c) Something to put your finger on [CE25]

MPR7 THEME 2) Took quite a while [g27] a) More serious than the general case [g33]

Theme two: Coming to the conclusion [p3]

a) Noticed there had been some changes [j7]

MPR3 THEME 3) Took me some time [p3] b) Coming to the conclusion [p3] c) I don't remember a lot about it [c76]

MPR4 THEME 3) I was really surprised [M124] a) Knew she'd lost it a bit [M16] c) He noticed more than I did [M49]

MPR7 THEME 2) Took quite a while [g27] b) Something should be done [g33]

MPR8 THEME 1) Knew something was wrong [ru167] a) It added up [j170]
b) Something to read [ru56]

MPR9 THEME 4) No surprises [k11] a) Knew myself [k123] b) No particular revelations [k15]

b) Anyone would wonder [K113]

MPR3 THEME 5) My problem [c68]

MPR4 THEME 3) I was really surprised [M124] b) Didn't know what was wrong [M59]

MPR4 THEME 6) I heard it was hereditary [M128] a) Her mother had it [M126]
b) I am thinking about it [M150]

MPR8 THEME 1) Knew something was wrong [ru167] a) It added up [j170]
b) Something to read [ru56]

MPR9 THEME 4) No surprises [k11] c) Anyone would wonder [k113]

c) Deciding to go [CE57]

MPR1 THEME 2) You don't notice it straight away [d42, d44] d) We'll go and see [d53]

MPR3 THEME 2) Explaining to others [p9] and trying to explain [p46] a) I informed the doctor [p194] b) Giving information [p18] neither accuse or praise [p20]

MPR3 THEME 3) Took me some time [p3] b) Coming to the conclusion [p3]

MPR6 THEME 2) Deciding to go [CE57] a) Talking and reading together [CE57]
b) Frustration and working hard [CE78] c) I can't think what happened [JN50]

MPR7 THEME 2) Took quite a while [g27] b) Something should be done [g33]

MPR8 THEME 1) Knew something was wrong [ru167] c) Sorting it out [j220]

MPR9 THEME 1) A dilemma [k55] a) What to know and what not to know [k55]
b) Hopeful in a sense [k13] c) Fear [k125]

Theme three: I quite accepted it [JN88]

a) Of course I realise [c193]

MPR2 THEME 7) That's your life [CL74] b) I know he can't help it [CL192] c) He's living in the past [CL585]

MPR3 THEME 4) I realise [c168] a) Of course I realise [c193] b) I know what is happening [p212] she doesn't realise [p192] c) Abnormal becomes normal [c189]

MPR3 THEME 5) My problem [c68]

MPR4 THEME 5) I know the mind's going [M66] b) The brain's not there [M198]

MPR6 THEME 5) Now I have an excuse for it [JN32] a) From a possibility to a definite [JN73] b) I quite accepted it [JN88] c) Stopped driving [JN98]

MPR6 THEME 7) I assume everybody knows [JN134] a) Do tell people [CE135] b) Don't talk nonsense [JN15]

MPR8 THEME 4) What can you do? [ru25] a) This is my problem [ru85]

MPR9 THEME 5) There's no way round it [k59] a) The falsity has gone [k53] b) It's been resolved [v129] c) I suffer from memory loss [k89, k155]

b) No-one can do anything [ru91]

MPR1 THEME 3) What can you do? [d74]

MPR3 THEME 6) No solutions to my problem [c215]

MPR4 THEME 5) I know the mind's going [M66] a) Can't do nothing [M116]

MPR8 THEME 4) What can you do? [ru25] b) No-one can do anything [ru91]

MPR9 THEME 5) There's no way round it [k59] d) There isn't any help [k13]

c) I'm not any worse [k22]

MPR2 THEME 6) Trying to get through [CL315]

MPR3 THEME 4) I realise [c168] b) I know what is happening [p212] she doesn't realise [p192] d) I don't think about it [c45]

MPR4 THEME 1) I feel OK [A4] a) I haven't got memory difficulties [A2] b) He says it but I don't [A10]

MPR7 THEME 4) I don't remember [h39] a) I don't know that I have specific memory difficulties [h9]

MPR8 THEME 5) Don't mention the word [ru197] a) I don't think about it [ru180] b) Prefer others not to know [ru197]

MPR9 THEME 6) I'm not any worse [k22] a) That's not new [v23] b) The aging process [k15]

Theme four: It did nothing for me [ru152]

a) Hoped for something more [v115]

MPR2 THEME 10) That place [CL7] b) Is it worth the effort? [CL35] c) A sheer waste of time [e21]

MPR4 THEME 4) Isn't helpful [M107] c) I don't know why we go [A82] d) Doesn't do anything for her [M98]

MPR6 THEME 4) A pretty positive experience c) A pretty depressing experience [CE198]

MPR8 THEME 2) It did nothing for me [ru152] a) Nothing from it [ru162] b) Assessment only [j115] c) Nothing followed [j154] d) Sit and wait [ru5] e) Tests horrifying [j103] f) Resent no choice [j165] g) Parking hell [j220]

MPR9 THEME 2) Hoped for something more [v115] a) Absolutely negative [v18] b) A mere chat [k73] c) Forgot about us [v47] d) Haunted castle look [v171]

MPR9 THEME 4) No surprises [k11] a) Knew myself [k123] b) No particular revelations [k15]

b) Explained to me but didn't explain [M61]

MPR2 THEME 1) Something went wrong [CL589] b) It's a puzzle [CL241] c) No-one seemed to know [CL253] d) Don't have the answers [CL554]

MPR4 THEME 4) Isn't helpful [M107] a) Explained to me but didn't explain [M61] b) Should have told me more [M66] c) I don't know why we go [A82] d) Doesn't do anything for her [M98]

MPR5 THEME 1) Not as thorough as they used to be [Jm78] a) Don't tell you much [Em79] b) Just gave you tablets [Jm83]

Theme five: Coming here helped [v19]

a) Caring [ru40] and supportive [v33]

MPR2 THEME 10) That place [CL7] a) A Marvellous idea [CL7]

MPR6 THEME 4) A pretty positive experience b) Advice and practical suggestions [CE106]

MPR7 THEME 3) Doing some good [g45] b) Nice people [g49]

MPR8 THEME 3) A feeling someone cares [j65] a) Caring [ru40] b) Enjoyed being here [ru10] c) Benefits [j113]

MPR9 THEME 3) Coming here helped [v19] a) Supportive [v16]

b) A problem clearly defined [k15]

MPR3 THEME 3) Took me some time [p3] c) I don't remember a lot about it [c76]

MPR6 THEME 4) A pretty positive experience a) Relieved [CE82]

MPR6 THEME 5) Now I have an excuse for it [JN32] a) From a possibility to a definite [JN73]

MPR8 THEME 4) What can you do? [ru25] c) Got what we expected [j234]

MPR9 THEME 3) Coming here helped [v19] b) A problem defined clearly [k15]

MPR9 THEME 5) There's no way round it [k59] a) The falsity has gone [k53] b) It's been resolved [v129]

c) Some medicine from the doctors [c80]

MPR1 THEME 5) Things have got harder [d51] a) R became very ill [d58]

MPR3 THEME 6) No solutions to my problem [c215]

MPR5 THEME 1) Not as thorough as they used to be [Jm78] b) Just gave you tablets [Jm83]

MPR7 THEME 3) Doing some good [g45] a) Little change on the tests [g45]

Higher order theme: Everything's changed [d108], we have to go from there [K59]

Theme six: I would say I have changed [JN19]

a) I don't remember [h39] [Em60] [c68]

MPR1 THEME 1) I can't say [r92] I just can't remember [r94] a) I don't know what I'm gonna say [r1] b) I don't remember [r17]

MPR2 THEME 3) E's position [CL3] a) Grasping it [e312] b) I've Forgotten [e507]
c) Memories [e362]

MPR3 THEME 5) My problem [c68] a) I don't remember [c68] b) Forgetting things [p3] and becoming slow [p12]

MPR5 THEME 2) I'm not the same person [Em60] a) I don't remember [Em65] b) Remember things from years back [Em135] c) I used to have a good memory [Em22]
d) She's got worse [Jm37]

MPR7 THEME 4) I don't remember [h39] b) Two people with memory problems [g3]

MPR8 THEME 4) What can you do? [ru25] a) This is my problem [ru85]

MPR9 THEME 5) There's no way round it [k59] c) I suffer from memory loss [k89, k155]

b) I'm fed up with it [r92]

MPR 1 THEME 4) I'm fed up [r92] a) I used to be happy [r23] b) Frustration [d100]

MPR2 THEME 3) E's position [CL3] d) Frustrating [e502]

MPR2 THEME 5) Gets me down [CL190] a) Depressed [e648] b) Panic [e160]

MPR3 THEME 7) Depressed [c32]

MPR6 THEME 3) Quite depressed [CE55]

Theme seven: Taking over the reins [CL121]

a) Trying to do everything [CL166]

MPR1 THEME 5) Things have got harder [d51] a) R became very ill [d58] b) All I am now [d112] c) Don't see friends now [d135]

MPR2 THEME 4) Trying to do everything [CL166]

a) Fitting it all in [CL490] b) Taking over the reins [CL121] c) Restricted [CL550]

MPR8 THEME 6) Carer understands more [j26] a) The carer too [j119]

b) Lose your patience [CL472] my temper comes right out [M45]

MPR2 THEME 5) Gets me down [CL190] c) A bit resentful [CL548] d) Getting cross [CL550]

MPR4 THEME 8) My temper comes right out [M45] a) Give me something hard that I can hit her with [M209] b) Can't she be taken to a home [M196] c) She doesn't do anything [M42]

MPR8 THEME 6) Carer understands more [j26] b) More patient [j209]

c) It gets me down [CL190]

MPR1 THEME 4) I'm fed up [r92] a) I used to be happy [r23] b) Frustration [d100]

MPR2 THEME 5) Gets me down [CL190]

MPR3 THEME 8) I get stressed [p139]

MPR6 THEME 6) Living my ordinary life [JN96] b) There are losses

MPR9 THEME 7) Feeling sorry [v64]

Theme eight: Take it as it comes [j211]

a) We carry on [d112]

MPR1 THEME 6) Carrying on [d112] a) We're happy with each other [r107]

MPR2 THEME 7) That's your life [CL74] b) I know he can't help it [CL192] c) He's living in the past [CL585]

MPR4 THEME 9) I go downstairs [M185] a) A routine together [M247]

MPR5 THEME 3) It's just one of those things a) Take it as it comes b) Some days are worse than others [Jm39]

MPR5 THEME 4) We've got on alright [Jm156] a) Not really changed [Em164]
b) Only changed because of our age

MPR6 THEME 6) Living my ordinary life [JN96] a) Things our relationship was based on [CE119]

MPR8 THEME 4) What can you do? [ru25] d) Take things as they come [j211]

MPR9 THEME 9) A minor irritation [v108] a) It doesn't matter [v108]

b) Living my ordinary life [JN96]

MPR1 THEME 6) Carrying on [d112] b) R has her independence [d145]

MPR2 THEME 7) That's your life [CL74] d) Getting on with it [CL598]

MPR9 THEME 9) A minor irritation [v108] b) Not in a coma yet [k147] c) Things to offer people [k77]

Theme nine: Coping very well [p212]

a) My way of relaxing [CL484]

MPR2 THEME 7) That's your life [CL74] a) He's looked after [CL552]

MPR2 THEME 8) Learning to relax [CL400] a) My time out [CL476] b) Relaxation [CL400] c) Occupy his mind [CL298] d) My daughter [CL47]

MPR2 THEME 9) You have to laugh [CL139] a) Have to laugh [CL604] b) Strong minded [CL480] c) Persons that got no-one [CL675]

MPR3 THEME 9) Coping very well [p212] a) Coping [p212] b) Looking after her [p255] c) Changing the subject [p143] and controlling emotions [p141] d) Going out [p185] i) Exercise [p71] and entertainment [p177] ii) My day off [p202]

MPR4 THEME 9) I go downstairs [M185] b) Go downstairs [M183]

MPR8 THEME 6) Carer understands more [j26] c) I'm glad he's there [ru207]

MPR9 THEME 9) A minor irritation [v108] d) I can cope with that [k111]

b) Try not to tell him [CL520]

MPR2 THEME 8) Learning to relax [CL400] c) Occupy his mind [CL298]

MPR3 THEME 9) Coping very well [p212] c) Changing the subject [p143] and controlling emotions [p141]

c) Someone else to talk and worry with [CE131]

MPR3 THEME 10) Good friends [c45] a) Makes C happy [p120] b) Friend of mine [c45] c) Not enough [p122]

MPR4 THEME 10) I find them OK [A220] a) Ask how she is [M222] b) They do know [M218]

MPR6 THEME 6) Someone else to talk and worry with [CE131]

Theme ten: Wouldn't mind doing it all again [Em230]

a) We used to be happy [d110]

MPR1 THEME 7) Used to be happy [r23] a) Happy go lucky [d110] b) Used to go out [d26]

MPR2 THEME 11) The story of my life [e185] [CL186] a) Free agents [CL325] b) Seen some sights [e408] e) Missed my daughter [CL606]

MPR3 THEME 1) A hopeless case [c245] a) Bully boss man [c149] b) Don't give me that rubbish [c25, c120] c) A funny idea about love [c251] d) She shouts at me and I shout back [p220] e) Thinks I'm criticising [p18] f) My wife and I love her [p255]

MPR5 THEME 5) Lovely times [Em24]

b) The story of my life [E185] [CL186]

MPR1 THEME 7) Used to be happy [r23] c) I've done very well [r113]

MPR2 THEME 11) The story of my life [e185] [CL186] c) Person he was [CL294]
d) This Age [CL200]

MPR3 THEME 11) A perfectionist [p52] and an excellent linguist [p48]

MPR4 THEME 2) Love [A42] and Hate [A145]

MPR8 THEME 7) Been a happy person [ru21]

c) This age [CL200]

MPR2 THEME 11) The story of my life [e185] [CL186] d) This Age [CL200]

MPR7 THEME 1) People no longer flawless in their memories [g27]

MPR9 THEME 6) I'm not any worse [k22] b) The aging process [k15]

MPR5 THEME 4) We've got on alright [Jm156] b) Only changed because of our age

Appendix VIII

Final theme two, with all relevant extracts

2) Coming to the conclusion [p3]

Refers to coming to the conclusion that there was a problem, this includes couple's insight, awareness and explanations at the time for what was happening before they sought a diagnosis.

a) Noticed there had been some changes [j7]

This sub-theme includes couple's descriptions of how aware they were of what was happening, what insight they had that one of them was in the early stages of dementia

i) I knew myself [k123]

Partner quotes

MPR3(m) - she was forgetting things [p3] - we noticed or I noticed that C is getting upset very quickly [p5] - C being an exceptionally organised person that she is doing things which were not in her character and it was repeating itself [p7] - Like putting the cutlery in the wrong place whatever all the plates or like filling the dishwashing machine in the order she used to do it or like putting the pans in the right place and so on or like forgetting erm several items of her own property and then asking me to find it [p9] - I did complain about her er the she fills we used to fill in the dishwasher once er a day she fills it she uses it twice a day two half loads [p22] - the mistakes she was making I just simply it was out of character [p135] - I was aware so I was the first to notice but it took me some time to come to the conclusion [p3] - when I discovered that this these things are happening I came to the conclusion that this must be Alzheimer's [p9] - I suggested that this is the situation [p9] - then I came to the conclusion that well this was repeating itself so it must be Alzheimer's [p135] - I came to the conclusion that she is OK she has changed [p194] - I have discovered recently in the last year [p93] In my case I know what is happening [p212] - I have always been the one who takes decisions [p150] - when I find out that things are going wrong I immediately abruptly change and insist that this has to be done like this because it's time wasting I am always aware of time [p150]

MPR4(m) - I knew she'd lost it you see just a bit I didn't know it was a lot just a bit [M16] - there was a lot of things different a lot of things I can't remember now but there was a lot of things the cleaning the dressing everything everything [M26] - I know she always does... perfect table but that's when I noticed it [M16] - No not a perfect table to me it wasn't a perfect table [M16] - we got the table ready and ...without salt and pepper and I know she always puts salt and pepper on the table the right way..... and that got me that got me [M16] - but er but she wasn't doing the things properly er she wasn't making the it wasn't my idea of a ... home [M24] - everything was alright but not my idea cos I knew she can do better I knew she can do better [M24] **MPR8(m)** - I'd noticed changes in my wife and she'd noticed [j7] - changes in her personality [j18] - I'd noticed there had been some changes [j7] - I didn't know what to think I'd noticed loss of memory loss of confidence it seemed to add up I knew what Alzheimer's disease was it added up [j170] - I expected it [j168] **MPR6(f)** - you were obviously aware that you couldn't remember things [CE2] - I know you were making a lot of the comments that people tend to make about ah my Alzheimer's you know [CE2]

MPR7(f) um but er in general that you you didn't remember things as clearly [g27] - I began to realise there was a difficulty [g43] **MPR1(m)** No when you first realised, I don't

think you did so much as me [d14] **MPR8(m)** the carer understands more what's happening [j26] **MPR2(f)** - I see the actions more than anybody [CL29] – I'm gonna notice it more because I know what he was like [CL249]

PWD quotes

MPR8(f) - I don't know how it was but I must have seen it [ru210] - Knew something was wrong at the time [ru167] - I would see the word Alzheimer's so I realised that was something to do with me [ru180] - I wrote away [ru60] — I did write away [ru130] - understand more what's happening [ru56] **MPR9(m)** - dare I sound narcissistic, of what I had more or less comprehended by myself [k163] - neither better or worse than my own personal self evaluation [k165] - I knew it about myself before that [k209] - I made some remark about it [k185] - there weren't any surprises [k11] – I really knew myself before that [k123] – I more or less comprehended it myself [k94] **MPR6(m)** - I knew by then what was going on [JN90] - we're both well educated people [JN92]

ii) I didn't know what was wrong [M59]

Partner quotes

MPR4(m) - No idea no idea no I didn't even know I didn't know [M59] - I didn't know what was going wrong know what I mean? didn't know not at all [M61] - we went in our minds and it was a blank you know what I mean it was a surprise I I was really surprised [M124] **MPR9(f)** – before I thought K was angry about having to move [v16] **MPR2(f)** – it was very very hard [CL486] – he didn't know what it was all about [CL345] - he couldn't make out why [CL206] **MPR5(m)** - when she used to go in she used to go to see him and I used to say what did he say when she come out oh she said he didn't say a word really she don't remember it [Jm102] **MPR3(m)** - with C she has just taken it for granted well I mean she doesn't realise there are changes taking place [p192] – she doesn't realise that these things are not normal that there is a change in any way [p175] – you just take it for granted [p194]

MPR4(m) - he noticed the changed as well he noticed more than I did in a way [M49] - she kept kissing him and cuddling him and all this and that that was the change [M53] - G said to me go and see someone I wasn't going to take her but he said to me take her cos he saw that she'd I see her everyday know what I mean I there was no change for me then it wasn't then but to him it was a change and er she er she was what her name it he said to me well you'd better take her to the hospital or something [M47]

PWD quotes

MPR8(f) - I had the paper from the Alzheimer's disease and I kept that but I didn't realise at that stage that it was me what I had [ru138] **MPR2(m)** – all I know is that my lung collapsed [e85] - has something happened? What am I doing here? What am I doing [e352, e162] – what's happening to me? [e162] – I thought that's it I've got it [e167] cancer [e169] – to me I was as fit as a fiddle [e591] – I just couldn't grasp it [e112] – I can't grasp it [e173] – all these things but I just couldn't make out what it was all about [e286]

b) Anyone would wonder [K113]

This sub-theme includes couple's explanations of why one of them was experiencing memory problems, genetics and old age.

i) The process if why me [j183]

Partner quotes

MPR4(m) - someone told me it was “heradetary” I don't know if I don't know if it's true or not I don't know if it's true or not is it true? [M128] - well that's what I heard [M130]

- I did hear it was [M135] - her mother had it her mother had it the same thing and she had it something bad... she did she was bad 'cos we had her for a couple of months well couple of years and er she was really bad [M126] - Now I'll tell you what's happened I know it's bad and I know it's rude she used to go to the loo.... and put things in it like her cardie 'cos I found it so I know [M142] - She was so I know she was [M144] - I don't know how it goes because she's got three sisters two other sisters and she was the one to get it [M133] - her mother had it so why didn't the other two the other two get it one of them instead of her know what I mean? I'm not knocking them or anything like that but that's how I felt cos she doesn't speak to the others [M137] - I know via relations of hers he's got it her her cousin of hers er her husband's got it and he's very bad he's away for three days a week and er he's really bad a smashing fella [M118] - he was he is a smashing fella (...) and er he's got it but he's just in the hospital the home for three days [M118] - my mother had it. [M145] - at the moment me I haven't and my sister hasn't so whether it goes to somebody else I don't know [M148] - I am thinking about it I tell you [M150] - I hope my sister don't get it cos she's younger than I me ...and my mother got it late [M150] - very late in life [M151] - my sister I hope my sister don't get it [M152] **MPR8(m)** - we went through the process of why me why has is happened [j183]

PWD quotes

MPR9(m) - the condition of unknowing why I came to encounter the condition [k13] – it wasn't my style of life [k55] - men's memory problems a minority in a way [k25] – lifestyles of men and women differ [k27] – the two sexes have different lifestyles [...] the biology is different [k27] – sections of society [k28] more socially aware who seek services[k30]

MPR3(f) - I suspect that I got my problem from my mum because I remember many years ago noticing [c78] – instead of behaving like what you would expect a granny to behave [c78] – completely withdrawn my mum and I realise that she probably had the problem that I now have [c78] - I'm probably not as bad as my Mum was [c80]

ii) Our age [g27]

Partner quotes

MPR7(f) - I refer collectively to our age which is in my case is 70 and H is 84 now but erm you notice amongst all your friends that erm those who used to to have (...) one notices that people like that are no longer absolutely flawless in their memories [g27] - We have a clear number of friends who are about my age or a few years younger (...) so amongst them and other contemporaries of H's one noticed um [g31]

PWD quotes

MPR6(m) - I suppose everybody says it as they get older oh I forget [JN11] **MPR9(m)** - Is it just old age- that's part of the aging process anyway [k15] – this situation could arise simply through the aging process [k113] – surely this is something that comes very much with people's age [k131] – part of the human condition they way in which people respond to varied circumstances [k33] – there may be a million and a half old codgers my age who are slowly going batty don't all come to see a psychiatrist [k13] – I saw my behaviour replicated by dozens and dozens of old dears [k134]

c) Deciding to go [CE57]

This sub-theme describes couples making a decision to go and see a professional about the memory difficulties. A sense that it would be useful to see someone, but also a reluctance to face what might be happening.

i) A feeling there was help [k13]

Partner quotes

MPR1(m) - I probably thought well we'll go and see if there can be something we can't do about it [d51]- That's right you was mislaying things and gradually it got on and on and we had to go up to the Whittington didn't we? [d16] **MPR7(f)** comes a point when you think that something perhaps should be done about this [g33] - there a question how do you agree that it's necessary to have something done [g33] **MPR8(m)** - we'd decided we got in touch we came along [j9] - we went through the process [j183] - we went to sort it out [j220] - we'll give it a try [j65] - we did get some of that [j65] - she went to see him on her own [j7] - We have the same situation [j119] - carer understands more what's happening [j26] - come to hospital to sort it out [j220] **MPR6(f)** - I think I remember it you and H and I talking about it together it was at the point where you know I suppose you had been reading you'd both been reading about medication in the BMJ and thinking that it could be beneficial if it was Alzheimer's and um and having a conversation together really about whether it would be a good idea to get a referral...to get a diagnosis to get you on some medication... so I would think that would have been part of it you yourself were reading about it and then deciding to go [CE57] **MPR9(f)** - if you can get help whatever it is it's good to do [v60] **MPR5(m)** - we went when it started [Jm100]

MPR4(m) - we went to the G.P. first didn't we went to him er her doctor first and he referred us to the hospital [M47] **MPR1(m)** - can't see for what reason we went [d40] - Dr suggested [d45] **MPR6(f)** - you initially went off to your G.P. Dr (..) and um.... and it was pretty typical really she asked you the the sort of stupid obvious questions about the Prime Minister and that and on that basis said you were alright [CE78]

PWD quotes

MRP9(m) - I had a feeling there was help for memory problems [k13] - we were hopeful in a sense that there could be something in me that wouldn't be lost [k27]- I thought this was probably wise [k102] - it's important to talk about how things have been [k115] - some perspective perhaps of the way in which your condition might diminish [k31] - No I don't think I did, I don't think I felt I had any particular expectations.. [k27] - there was all this fuss [k198] - it came to the point that anything that helped us to understand it was going to be a plus [k202]

ii) Reticence [v144]

MPR9(f) - I was pleased to come K wasn't [v32] - reticence about talking [v144] - Alzheimer's disease is a scary word [v152] - it's scary for a lot of people when they can't cure it with chemicals [v144] **MPR8(m)** - keen for the assessment [j113] - I have an analytical kind of mind and knew what Alzheimer's did and what needed to be looked at so I was very keen to do that with a professional [j113] - my question was what could be done about it and what were the implications of it [j139] **MPR7(f)** - Nothing what so ever until I think I said I think you need to go and talk to someone . but I did persuade you eventually but not having said anything about it before in other words you were quite happy when I suggested you might go and see these people [g35]

PWD quotes

MPR9(m) - I don't know, this is a dilemma that arises in many other aspects of my existence what to know and what not to know [k104] - having it confirmed you're slowly going round the bend it not a very helpful situation to be in [k125] - I wasn't sure if that would be supportive but on the other hand you know I thought this is probably wise.. so I don't know [k102] - when it comes to the mind it's a bit more woolly [k114] **MPR8(f)** - I didn't know really what I'd gain from it [ru216]

Appendix IX

**Letter sent to participants inviting feedback and comments from one of the couples
who were given details of the results**



Sub-Department of Clinical Health Psychology
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GOWER STREET LONDON WC1E 6BT

Date

Dear.....

Please find enclosed a summary of the themes that I developed from your interview, to describe your experiences since’s memory problems began.

The summary is divided into three sections:

- Experiences before you received the diagnosis
- Experiences of receiving the diagnosis
- Experiences since you have received the diagnosis

In each section the main themes are presented, followed by quotations from your interview that relate to each theme.

A description of each theme is also presented based on my interpretations of the comments you made during the interview.

I would appreciate your feedback about my interpretations and the themes that I have developed to describe your experiences.

I will telephone you in about a week to find out whether you would like to make any comments about my analysis.

Best Wishes

Dr. Lucie Robinson
Trainee Clinical Psychologist

A summary of the themes developed from your interview

1) Experiences before you received the diagnosis

Themes one and two

- **A slow process of change**

“In a way it’s all been a slow process and a slow process of change not a sudden one”

- **Where does it cross over?**

“It’s difficult to think when it’s normal and when it’s abnormal really when you have reached that point”

“It’s quite difficult putting a finger on it, in some ways is an exacerbation of how you were previously before it started”

These themes appear to describe a process of gradually realising that J had memory problems, and finding it hard to retrospectively identify exactly when J’s memory problems became a cause for concern.

Themes three and four

- **Talking and reading together**

“Reading about medication in the BMJ and thinking that it could be beneficial if it was Alzheimer’s and having a conversation together really about whether it would be a good idea to get a referral”

- **Frustration and working hard**

“A struggle to get it confirmed, the second time you went you took H with you and managed to get a referral”

These themes appear to describe how the decision was made to seek a diagnosis, and highlighted that you had some difficulties obtaining a referral from J’s GP at first.

Theme five

- **Depression**

“My memory was that you were quite depressed”

This theme appeared to describe that J was feeling depressed before he received his diagnosis.

2) Experiences of receiving the diagnosis

Themes six and seven

- **Relief**

“There was a marked improvement really in your condition in that you became much less withdrawn really and seemed quite relieved that the whole thing had been diagnosed”

- **Advice and practical suggestions**

“Advice ideas and practical suggestions about things which we might do”

These themes appeared to describe that seeking the diagnosis was a positive experience, leading to feelings of relief and helpful advice.

Themes eight and nine

- **From a possibility to a definite**

“Told me that I had Alzheimer’s and that made it change from a possibility to a definite”

- **I quite accepted it**

“I would say I have changed and there is a problem and that I have what plenty of other people have”

These themes appeared to describe that the diagnosis helped you accept that J had Alzheimer’s disease.

3) Experiences since you have received the diagnosis

Themes ten and eleven

- **Things our relationship was based on**

“But other than that things have been ordinary really living my ordinary life”

“I think things have changed but um it’s quite difficult putting a finger on it”

- **There are some losses**

“It’s much more difficult to share now in terms of memories”

These themes appeared to describe how on the whole you are both carrying on leading an ordinary life since the diagnosis has been received despite the losses involved.

Theme twelve

- **Someone else to talk and worry with**

“It still makes it possible to do things that otherwise we might find were difficult”

This theme appeared to describe how useful it is to have J’s brother around and how his support helps you both cope with the things that have changed in your lives.

Theme thirteen

- **Do tell people**

“I just assume that everybody knows, well tell me who doesn’t know and I’ll tell them”

“One issue actually has been whether um whether um to leave it to J to tell people or whether for me to tell them and I think that’s often a very difficult one to judge”

This theme appeared to describe that you prefer your friends to know about J’s diagnosis and highlighted an issue of how you decide who will tell them.

Comments from the couple who received the correspondence described above

The wife without dementia gave the following comments over the telephone.

“We have no quarrels about what you have said in your summary. We agree that it seems a fair summary of our interview and we have no objections with your descriptions of our experiences. Thank you for sending it.”

APPENDIX X

Additional examples of the two categories of social interaction²

1) Partners silencing or disagreeing with their spouse with dementia

MPR1(m), MPR2(f), MPR4(m), MPR8(m)

a) Taking the lead in answering the interview questions

MPR8(m) J gives long full answers to questions rarely consulting Ru about her view.

MPR1(m) D answers for R without giving her a chance to try to answer again. He also tells R how she feels and doesn't let her answer questions about herself.

Also MPR2(f) and MPR4(m)

i) Ignoring their spouse's comments during the interview.

Instead the partner carries on talking rather than responding to the aspect of conversation their spouse has introduced

MPR8(m)

Ruby " well the same questions you've had already had before" [ru13]

Jake "and it takes ten minutes and then goodbye" [j14]

Ruby "it's just not on" [ru15]

Jake " and then see you in three months..... Etc". (Jake talks on) [j16]

MPR2(f) CL talks while is E talking/trying to talk [CL150] [CL627]

MPR4(m) M ignores A

- when she starts to talk to G and remains focused on the interview and what he wants to say [M65] [M106] [M145]
- when A attempts to join in the interview, again remaining focused on the interview and what he wants to say [M112] [M120] [M168] [M258] [M260]
- When she disagrees with what he's saying [M126]

ii) Taking over answering from their spouse

MPR8(m) and MPR1(m) throughout the interview.

MPR2(f)

- CL answers for E when he is asked to comment on what she has been saying
- [CL54] [CL154]
- CL takes control of the conversation back from E when he starts to get muddled [C294] [C345] - *Oh I'll tell the lady about that [CL387] – right I'll tell you this quickly [CL614]*
- CL talks while is E talking/trying to talk [CL150] [CL627]

MPR4(m) M takes the lead back from A when she starts talking about his other women [M45] - *now I'll tell you what's happened [M142]*

iii) Interrupting their spouse to silence them

MPR8(m)

Ruby "He did nothing as far as I'm concerned.. I..." [ru142]

Jake "Darling...." [j143]

² Line references from individual transcripts are listed to indicate a point in a couples interview when the interaction occurred.

MPR1(m) - *But that's... that's nothing to do with what your asking is it? [d10] - she's talking about your memory [d47]*

Also **MPR2(f)**

iv) Correcting what the spouse says

MPR8(m) - *darling she was also at the Whittington [j39] - darling yes but you could enjoy going to the cinema [j88]*

MPR1(m) - *but that's... that's nothing to do with what your asking is it? [d10] - we're not talking about that... recent times [d68]*

MPR2(f) CL corrects E when he muddles up names or facts and generally at these points takes the lead once again in the interview and E is silenced.

b) Personal distraction

Talking about their spouse's problems in front of them

MPR8(m) - *Ru's memory is getting worse [j16]*

MPR1(m) D tells R that she doesn't remember rather than encouraging her to answer or validating what she can remember - *no she won't remember [d72] - you can't remember that can yer? [d70]*

Also **MPR2(f)**

c) Disagreements and arguments during the interview

MPR4(m) M shakes his head rather than verbally disagreeing with what A is saying and/sighs [M42] [M159]

Also **MPR1(m)** and **MPR2(f)** raise their voices during the interview.

2) Partners supporting and facilitating their spouse with dementia to have a voice

MPR5(m), MPR7(f), MPR9(f)

a) Allowing their spouse to speak first/take a lead

MPR9(f) V takes the lead in answering some of the interview questions [v61] [v84] [v148] [v211] but more often K answers first.

MPR5(m) Em and Jm take a more or less equal lead in the conversation

MPR7(f) G lets H lead in responding to the interview questions, G only leads when she is asked a question directly [h5], [g27]

i) Not interrupting their spouse when they are talking

MPR9(f) V allows K to interrupt her and lead the conversation but V doesn't interrupt K and lets him finish his answer before she responds

MPR5(f) Jm allows Em to answer questions which are directed at her [Jm12]

Also **MPR7(f)**

ii) Allowing their spouse to interrupt and then take the lead

MPR5(m) Jm lets Em take over the lead at several points in the interview [Em12] [Em56] [Em60]

Also **MPR9(f)**

iii) Including their spouse in what they are saying

MPR5(m) Jm includes Em when he is speaking, inviting her opinion in what he is saying

MPR7(f) G explains to H what/who she is talking about [g27]. At times she is more talking to H checking out with him that he agrees than talking to the interviewer [g35]

iii) Asking their spouse whether they agree with what they are saying

MPR7(f)

b) Cuing and prompting their spouse to talk

i) Restating the interview questions

MPR5(m) Jm talks very patiently to Em when she can't remember something and keeps cuing her until she appears to remember

ii) Asking their spouse what they can remember

MPR5(m) Jm cues Em to help her participate in the interview [Jm97]

- *well he just gave you tablets didn't he really?* [Jm83]

MPR7(f) G cues H to help him talk during the interview

- *what I call the IQ tests do you remember? I call the IQ tests where you have to do sums and arrange things and so on* [g38]

iii) Talking about the past

MPR5(m) Jm and Em reminisce together about their lives, this is something that Jm knows Em can join in with to talk about

iv) Having conversations

MPR5(m) Jm holds conversations with Em during the interview [Jm46]

v) Providing information (when asked)

MPR5(m) Jm answers Em's questions [Jm96]

MPR7(f) G explains to H what is going on and answers H when he asks her to explain, which allows him to have a role in the interview [g24] [g31]

vi) Encouraging them to talk

MPR5(m) Jm shows an interest in what Em is talking about - *what's that dear?* [Jm134]

MPR7(f) G cues H so he can carry on talking - *as a pose to?* [g10]

c) Pointing out the strengths of the person with dementia

i) Currently

MPR9(f) - *he is a good teacher* [v243] - (...) *K can still draw like an angel* [v132]

ii) In the past

MPR7(f) G talks of H's achievements/strengths - H has always been physically very fit compared with his contemporaries [g31]

iii) Minimising the memory problems

MPR7(f) G minimises H's memory problems and appears reluctant to talk about H having memory problems. Is she deliberating trying to avoid personal distraction, talking about H as if he is no longer there.

- G presents it as a joint problem - *(laughing) Two people having memory problems [g3] - we've both never been about to remember names [g27]*
- G refers to her faults - *a more registering mind of some sort would maybe [g32]*
- G refers to age/other people – *one notices people like that are no longer absolutely flawless in their memories so same thing with H [g27]*
- G makes excuses for H not remembering - *the trouble is you've been to the RF under so many different headings [g49]*