"I don't know whether you should talk to them about it." Talking about memory difficulties in couples where one partner has early-stage dementia.

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ABSTRACT

This exploratory qualitative study was designed to investigate the way that couples talk to each other when one partner has early-stage dementia. It specifically set out to explore whether there was evidence of Kitwood's positive and negative elements of interaction in conversations between couples, as utilised in Dementia Care Mapping, what concerns couples raise with one another with regards to memory difficulties, and whether couples find it helpful to discuss their concerns. Seven couples participated in this study. They were asked to hold a conversation about any concerns they had regarding the memory difficulties experienced by one of them. Following this conversation each member was interviewed separately to explore their experience of this conversation, and whether they found it generally helpful to discuss concerns with their spouse. The data were analysed using content analysis and Interpretative Phenomenological Analysis. Evidence of some of Kitwood's negative and positive elements were found throughout the conversations though differing patterns of elements were shown between different couples, and between the people with dementia and their spouses. During the conversations there was great variation in the amount that the couples focused on the memory difficulties and their concerns, with some couples appearing to avoid this topic to a greater or lesser extent. Through the conversations and the interviews it was found that the majority of the couples involved in this study did not discuss their concerns about dementia with one another, and a number of different reasons were given for this. The findings are discussed in relation to the existing literature, and a speculative model is proposed linking the observations with social constructionist theories in relation to dementia. Clinical implications and methodological limitations of the study are considered.

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CHAPTER ONE

INTRODUCTION

This study aims to explore the ways in which couples talk to each other when one of them has early-stage dementia, and the conversational support they may or may not provide to one another. This is an area that has previously been neglected by research. It is an important area to investigate as dialectical models and social constructionist theories of dementia have shown that interactions with other people can influence the well-being of a person with dementia, and other research has shown that in the context of various illnesses and disabilities the support offered by spouses can be extremely beneficial. The findings from the current study might be clinically relevant in thinking about ways to help couples where one partner has received a diagnosis of dementia.

In this chapter the literature relevant to this study will be presented. Firstly, the literature relevant to dementia, particularly early-stage dementia, will be described, and issues relating to the impact on marriage and communication will be considered. Secondly, the existing literature on mutual support in couples where illness is present will be discussed.

The review will begin with an overview of recent research on dementia and advances in theory, along with a discussion of the impact this has had on research, and a consideration of practical issues surrounding research with people with dementia.

Background

Until relatively recently dementia was viewed mainly from the perspective of a medical model in which the experience of the person with dementia was accredited purely to a disease process and seen as a physical condition (Kitwood, 1997). With this view came statements about people with dementia being "unable" to communicate (p.15, Killick and Allan, 2001). The result of this paradigm was that psychological research into dementia focused primarily on the perspectives of, and effects of dementia on, caregivers, and little attention was given to the person with dementia.

Recent developments in the literature on dementia have questioned the traditional medical model and encouraged a new paradigm in which the "personhood" of the individual with dementia is considered important. This has largely arisen from the work of Kitwood (e.g. 1997) who argued that neurological changes cannot wholly explain how dementia manifests in specific cases. Kitwood developed a dialectical model which accredited the process of dementia to a number of different aspects, each of which interact and account for a person's specific presentation at any given time. These aspects include neurological impairment; however, they also include malignant social psychology, individual coping mechanisms, environmental support and the personality of the person with dementia. This interactive process highlights the importance of personhood and sense of well-being. Kitwood has suggested that with optimum conditions, i.e. by preventing a situation in which malignant social psychology occurs, a process of *rementia* may arise – whereby the effects of dementia may be reduced or slowed down. Based on this, research is beginning to look at the means by which well-being and personhood might be maintained. The focus should be on "the person, who they are, how they understand and experience their world and what they need to maintain their sense of self" (Killick & Allan, 2001). Kitwood (1997) states that the one encompassing need people with dementia have is for love, and that arising from this is a need for comfort, attachment, inclusion, occupation, and identity. As a result of the emergence of this person-centred approach to dementia, more and more research is now beginning to look at the experience of those with dementia as well as their carers (Cotrell & Schulz, 1993). As Cotrell and Schulz (1993) write:

> "Much can be gained from changing our view of the person with dementia from someone to be studied to someone whose perspectives can help us understand AD" (p.210)

A further development in dementia care has been the emergence of acetylcholinesterase-inhibiting medication, which has been shown to slow down the deterioration of organic functioning in people in the early stages of dementia (e.g. Corey-Bloom, Anand & Veach, 1998). The combination of anti-dementia medication and the emergence of person-centred perspectives have led to a focus on early detection and to increasingly frequent disclosure of diagnosis to people with dementia. These two aspects are promoted in the UK within the National Service Framework (Department of Health, 2001) which was developed with a focus on older adult care (Clarke & Keady, 2002). Although there is still reluctance amongst some professionals and carers to disclose the diagnosis (Pratt & Wilkinson, 2001), in general this has meant that there are now many more people with early-stage dementia who are aware of their diagnosis. In turn this has led to an increase in psychological research exploring the experience of dementia from the perspective of the person with early-stage dementia, as well as that of the partner, or family member.

The perspective of people with dementia

With the emergence of research focusing on the person with dementia as well as the caregiver, questions have arisen over whether this is a worthwhile way of exploring dementia, and whether it is ethical to do so.

Wilkinson (2002) explores research looking at the perspectives of people with dementia, and considers aspects including whether this is a worthwhile exercise, how it is best approached, and ethical considerations. She states that conducting research involving the perspectives of people with dementia is important since we need to develop our understanding of the experience of living with dementia. Her rationale for this is that if we can improve our understanding of a person's experience we are in a much better position to provide adequate and appropriate care, based on a person's actual needs rather than their perceived needs. Within this book Clarke and Keady (2002) also talk about the importance of viewing people with dementia as "experts" from whom we can learn a great deal.

In terms of interviewing people with dementia, Cohen and Eisdorfer (1986) present case studies and suggest that individuals in the early stages of dementia are fully capable of articulating their feelings and concerns. Cotrell and Schulz (1993) report that in-depth interviewing and administration of psychological tests are fully possible in the early and moderate stages of dementia.

Having considered the general background to the area of early-stage dementia and research, this literature review will now focus on some of the previous research which relates more specifically to the present study. This will begin with a consideration of relationships and people with dementia. These topics are central to this study which focuses on the marital relationship.

Personhood and the importance of relationships and communication

As mentioned above, with the emergence of Kitwood's work researchers are endeavouring to explore the concept of personhood and how this may be maintained or undermined in people with dementia. Personhood has been described as being essentially social in nature as it refers to people in relation to other people (Cheston & Bender, 1999a). In relation to this, Killick & Allan (2001) have looked specifically at communication in people with dementia with one of the authors spending a great deal of time communicating with adults with dementia in residential care settings. The authors conclude that to maintain a sense of well-being and personhood people with dementia have a need to continue in relationships with others. Killick and Allan (2001) state:

> "..the quality of personhood is made real through relationships with others…central to the business of relationships is communication" (p.18)

and

> "We cannot be truly in relationships with others if we are not in communication with them" (p.18)

Though Killick and Allan focus mainly on working with people with dementia in the later stages, what they are saying applies to people with early-stage dementia, and indeed to anyone who is in relationships with others.

In another piece of research Harris and Stein (1999) explored the concept of the definition of self in people with dementia, and furthermore how this might be preserved. They concluded that the social interactions people with dementia experience impact on their sense of self.

Therefore, central to the concept of personhood and self-esteem in people with dementia is the nature of their relationships with those they come into contact with. The focus of this study is the marital relationship. This relationship is a key relationship in the lives of many people, where individuals have a role as husband or wife. If people can maintain a sense of belonging in this role, and continue to function within the marital relationship, it would be hypothesised, from what has been outlined above, that this could have extremely beneficial effects on personhood as well as on the marriage.

This recognition of the importance of interactions and communication in maintaining or disrupting personhood links both with the dialectical model of dementia and with social constructionist theories. These will be presented in turn, firstly with a more in-depth focus on Kitwood's dialectical model of dementia and his notion of a "malignant social psychology" which is centred around a focus on interactions.

The dialectical model of dementia and "malignant social psychology"

As outlined in the previous section personhood is said to be demonstrated, and to arise, through interactions with others (Kitwood & Bredin, 1992). Kitwood (1997) examined interactions between people with dementia and caregivers. He identified seventeen elements that may contribute to a "malignant social psychology" and damage the personhood and well-being of the person with dementia. These include disempowerment, infantilisation and intimidation. In contrast to this he also identified twelve elements of positive interaction that can help maintain, or improve, the personhood of the person with dementia. These include recognition, negotiation and validation. The negative and positive elements are listed in Table 1 and Table 2 (overleaf). Kitwood suggested that all these forms of interaction represent forms of care, with the person with dementia at the receiving end. He also identified two types of interaction where the person with dementia takes the lead role and the caregiver is offering an empathic response. These types of interaction are listed in Table 3.

Kitwood (e.g. 1990, 1997) was largely concerned with how carers could be helped to stop using negative ways of interacting, which contribute towards a malignant social psychology, and how more the positive ways of interacting could be encouraged, and positive person work created. Kitwood (1990) suggests four possible reasons why dementia seems to create a situation of malignant social psychology. These are: good caregiving requires high levels of empathy, imagination and flexible thinking and these are aspects which are "lacking in the everyday world" (p.185); the pressure that many caregivers face means that they cannot give their best to people with dementia; there is a tendency to not acknowledge people with dementia as persons and as having value, and so people with dementia do not get treated with the respect given to other people; being with a person with dementia may arouse a person's own fears about their own future and immortality and a malignant social psychology may arise as a result of wanting to keep people who remind us of our fears at a psychological distance.

Table 1: Negative interactive elements as defined by Kitwood (1997)

Element	Definition
Treachery	Using forms of deception to distract or manipulate a person, or force them into compliance.
Disempowerment	Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated.
Infantilisation	Treating a person very patronisingly, as an insensitive parent might treat a very young child.
Intimidation	Inducing fear in a person, through the use of threats or physical power.
Labelling	Using a category such as "dementia", as the main basis for interacting with a person and for explaining their behaviour.
Stigmatisation	Treating a person as if they were a diseased object, an alien, or an outcast.
Outpacing	Providing information, presenting choices, etc., at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear.
Invalidation	Failing to acknowledge the subjective reality of a person's experience, and especially what they are feeling.
Banishment	Sending a person away, or excluding them, physically or psychologically.
Objectification	Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained.
Ignoring	Carrying on (in conversation or action) in the presence of a person as if they were not there.
Imposition	Forcing a person to do something, overriding desire or denying the possibility of choice on their part.
Withholding	Refusing to give asked for-attention, or to meet an evident need.
Accusation	Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.
Disruption	Intruding suddenly or disturbingly on a person's action or reflection; crudely breaking their frame of reference.
Mockery	Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense.
Disparagement	Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self-esteem.

Table 2: Positive interactive elements as defined by Kitwood (1997)

Elements	Description
Recognition	The person with dementia is acknowledged as a person, known by name, affirmed in his or her uniqueness.
Negotiation	The person is consulted about his / her preferences, desires and needs, rather than being made to conform to others' assumptions.
Collaboration	Two or more people are aligned on a shared task, with a definite aim in view. Working together.
Play	Play has no goal outside the activity itself, it is simply an exercise in spontaneity and self expression.
Timalation	Forms of interaction in which the prime modality is sensuous, for example through aromatherapy or massage.
Celebration	The form of interaction in which the division between caregiver and cared-for comes nearest to vanishing completely as all are taken up in a similar mood. Any moment in life which is experienced as intrinsically joyful.
Relaxation	This form of interaction has the lowest level of intensity and the slowest pace.
Validation	Acknowledging the reality of a person's emotions and feelings, and giving a response on the feeling level.
Holding	To provide a safe psychological space, a "container"; hidden trauma and conflict can be brought out, areas of vulnerability exposed.
Facilitation	Enabling a person to do what otherwise he or she would not be able to do. To enable interaction to get started, to amplify it and to help the person gradually fill it out with meaning.

Table 3: Types of interaction where the person with dementia takes the leading role, as defined by Kitwood (1997)

Interaction	Description
Creation	The person with dementia spontaneously adds something to the social setting from his or her stock of ability and social skill. Common examples are beginning to sing or dance.
Giving	The person with dementia expresses concern, affection or gratitude; makes an offer of help or presents a gift.

Kitwood (1990) suggests that each of the negative interactive elements contribute towards a malignant social psychology because they damage the self-esteem of the person with dementia and diminish personhood. Therefore it is important to explore situations in which there may be a development of a malignant social psychology, and to find ways to combat this. The interactive elements defined by Kitwood and outlined in Tables 1 and 2 have been utilised for this purpose with the development of Dementia Care Mapping (e.g Bradford Dementia Group, 1997; Brooker, Foster, Banner, Payne & Jackson, 1998), whereby interactions in residential care settings are observed and recommendations made to remove any aspects of malignant social psychology that may be impacting on people with dementia in these settings. Cheston and Bender (1999a) advocate that there should now be a focus on addressing the ways people with dementia and their carers can be helped to develop effective ways of interaction in their own family homes, since this is where the majority of people with dementia reside.

Social constructionism and dementia

Related to Kitwood's dialectical model are social constructionist theories about dementia (e.g. Sabat, 2001; Sabat & Harré, 1992). Social constructionism explores "how we make our worlds and are in turn made by our worlds" (Harding & Palfrey, 1997, p.9). Central to social constructionism is a focus on discursive practices, with conversation being crucial.

Sabat (2001) describes social constructionist theory and how this relates to dementia in detail. Social constructionist theory posits not one single fixed entity that is the self but that there are multiple selves, which are constructed in the context of social interactions and relationships. Sabat suggests that “selfhood” is manifested in a number of ways, termed as Self 1, Self 2 and Self 3. Self 1 is a sense of personal identity, with all of us experiencing ourselves as the same person from moment to moment – this is expressed linguistically through the use of personal pronouns such as “I” and adjectives such as “Mine”. Self 2 relates to the unique set of attributes that each of us has which makes us different to others, and our beliefs about these attributes. These attributes are mental and physical, and may be stable or change over time. Self 3 relates to the way people present themselves in the world, which fluctuates in different social situations. For example the way we present ourselves to colleagues at work is generally different from the way we present ourselves to our friends. What is important, and highly relevant to the present study, is that to be able to present a particular Self 3 persona, e.g. loving wife, the co-operation of others is required, in this case the spouse. Sabat concludes that in people with dementia the Self 3 persona is particularly vulnerable because of this reliance on others and interpersonal interactions. The person with dementia must be “positioned” by the other as a loving spouse in order for him/her to continue to uphold this role. Unfortunately many people with dementia are often positioned in terms of their illness and as “patients”, and people respond to them as such. Therefore it is hard for people with dementia to uphold any other Self 3 personae, with the danger being that as a result of this process their sense of self, and therefore their self-esteem, may be greatly undermined.

Sabat (2001) goes on to link this theory in with Kitwood’s notion of a malignant social psychology. He suggests that caregivers may show behaviour and interactions that undermine the personhood of the individual with dementia, and that this may not be intentional but may arise as a result of how the person with dementia has been positioned by the caregiver, e.g. as a patient, defective, weak, etc. Sabat suggests that one way to combat this is for carers to be able to see what remains intact in the person with dementia:

> "By attending to and supporting those remaining intact abilities, caregivers can avoid positioning the afflicted incorrectly, decrease the likelihood of engaging in forms of malignant social psychology, and minimise excess disability" (p.108)

Therefore Kitwood's theory of a malignant social psychology and social constructionist theories as applied to dementia are both relevant to this study. The focus of this study is on the ways in which people with dementia and their spouses talk to each other about the memory difficulties, with an exploration of which types of interactions might be helpful and which might be damaging to a person's sense of self and therefore his/her personhood. The conversational interactions between people with early-stage dementia and their spouses is an area which has been largely neglected. However, there have been a number of studies which look at interactions between caregivers and people with more advanced dementia, and these will be the focus of the following section.

Studies of interactions with people with dementia

In light of the dialectical model and social constructionist theories of dementia a number of studies have looked at the quality of interactions between people with dementia and their carers, largely focused on professional caregivers (e.g. Bohling, 1991), though a few studies have looked at communication between people with dementia and their informal caregivers, who mostly tend to be family members (e.g.

Gallagher-Thompson, Dal Canto, Jacob & Thompson, 2001; Small, Geldart & Gutman, 2000). However, these studies have focused mainly on the losses in communication skills as a result of the dementia, and on negative interactions, rather than also looking at conversation and communication as a potential support, or as a coping strategy for dealing with the diagnosis and impact of dementia. They have also tended to focus on people with more severe dementia rather than those in the early stages, and have used somewhat artificial tasks to explore their questions. This study aimed to explore an area previously neglected, through looking at the interactions between people with early-stage dementia and their spouses. There was a focus on how people may or may not support each other, rather than focusing on deficits in communication, with an aim of exploring how people with dementia and their relatives can "be helped to develop effective and sustainable patterns of interaction within their own homes" (Cheston & Bender, 1999b, p.144).

Shakespeare (1998) has extensively studied verbal interactions between 'confused' and 'normal' speakers, mainly by examining interactions during interviews between professionals and people with dementia ('confused' speakers) and their caregivers. She has identified a number of problems which arise in talk between these speakers, and that there are many variations in the way that those who are 'confused' talk, distinguishing between minimally, moderately and very active speakers. She draws on the work of Goffman (e.g. 1983) who explores what kind of self emerges in everyday social interactions, and the implications for individuals of their success or failure in interaction, with the idea that people will attempt to present as ordinary when their identity is impaired in some way. Shakespeare looks at some of the ways people with dementia make attempts to maintain 'face' during their interactions with others, and says that because of the problems ‘confused’ people may have in their talk with others (such as being unable to remember biographical details of their lives and answer specific questions) the act of talk can put a person’s sense of self as a valued person in a precarious position. Shakespeare also states that some problems in these interactions may result from people with dementia having been placed in a degraded position by others and therefore when ‘normal’ speakers talk to ‘confused’ speakers they sometimes do unusual things, such as asking questions testing the person with dementia, and interrupting them, which in turn leads to further threats to the person with dementia’s sense of self, and as a result they may engage in defensive or evasive talk in order to try and save face. Shakespeare also identifies that some people with dementia take little part in the development of conversational topics, and therefore often ‘normal’ speakers must work hard to maintain a conversation through the introduction and development of topics.

More recently a study was designed to explore task-oriented talk between people with early-stage dementia and their spouses (Clare and Shakespeare, in press; Shakespeare and Clare, submitted). In the context of a wider study of the subjective experience of developing dementia, couples who consented, and where individual interviews had revealed no evidence of significant marital difficulty that might be exacerbated by participating, were asked to hold a five-minute conversation and to come up with a short statement that summed up their current situation. It was found that the spouses of the people with dementia established more ‘interactional rights’ through various conversational means; however, there was also evidence of the people with dementia making various attempts to be heard, with differing responses from the spouses. The authors conclude that the way couples manage the conversational process may be an early factor which can help maintain well-being and avoid the development of a malignant social psychology. They propose that there is a need to attend to relationships and interactions from the earliest stages of dementia, and that there should be a focus on looking at the process of conversation in couples where one has early-stage dementia to explore the potential supports or hindrances which couples may provide to each other during conversation. The current study sought to explore these issues further.

Having introduced the idea of the importance of relationships, and in particular the importance of communication and the marital relationship, this chapter will now turn to a focus on each of these areas in turn, and consider how each of these may be affected by dementia.

Marital relationships and the impact of dementia

Research has shown that, following declines in marital satisfaction in middle age, marriages generally become stronger and more positive as couples enter older age (Carstensen, Gottman & Levenson, 1995). However, dementia is a serious, terminal condition, the onset and progression of which can cause a great deal of distress for both the person who is affected and their spouse, and may negatively affect the marital relationship, as with any major crisis. In particular dementia may disturb the established balance and interfere with continuity and meaningful interactions in married couples (Ingebretsen & Solem, 1997). There has been much research on the impact on dementia on familial caregivers, including partners of people with dementia, since the largest group of familial caregivers of people with dementia are spouses, with wives as the predominant caregivers (Jansson, Nordberg & Gratstrom, 2001; Pollitt, Anderson & O'Connor, 1991). O'Connor (1993) states that though only one person in the relationship has dementia there are two victims, the person with dementia and his or her spouse.

Research has found that communication difficulties in people with Alzheimer's disease are a major source of caregiver strain because of the psychological and interpersonal burden they present (Hendryx-Bedalov, 2000), though other research has noted that individuals with dementia are able to engage in meaningful communication which can be interpreted by others (Acton, Mayhew, Hopkins & Yauk, 1999). Some research has found that strain in the caregiver is more related to the quality of the marital relationship (Morris, Morris & Britton, 1988) and to social support (Zarit, 1986) than to the symptoms and behaviour shown by the person with dementia.

Other research has explored the impact of dementia on the marital relationship, focusing on the losses and negative aspects resulting from the illness (e.g. O'Connor, 1993; Bull, 1998). Bull (1998) looked at the losses spouses experienced when their partner had dementia, and found through content analysis a number of loss themes, these being loss of the "person", loss of sharing or interaction, loss of contact (with the outside world), loss of family functioning, loss of a way of life, and loss of role functioning. To combat these losses, Bull found that families employed a number of strategies to maintain their sense of belonging together and of functioning as a family, these being keeping in touch, sustaining the partner relationship, changed role performance and changing family boundaries. This research focused only on the losses and coping of the caregiver and did not consider the perspective of the person with dementia (at the time of the research the partners with dementia were in residential care and in the later stages of dementia). In another study exploring the main difficulties and rewards faced by spouse caregivers, the main difficulty-related themes to emerge were: loss of companionship through diminished quality of communication; loss of reciprocity as carers experienced their partners' growing dependency; and deterioration in the partners' social behaviour. In terms of satisfactions, the main themes were: a feeling of job satisfaction; continued reciprocity and mutual affection; companionship; and the fulfilment of a sense of duty (Murray, Schneider, Banerjee & Mann, 1999). Therefore, if the marital relationship, in terms of reciprocity and affection, can be maintained, this can lead to greater well-being and less carer strain.

Other research has explored levels of depression in people with dementia and their spouses. Depression in people with early-stage dementia has been shown to contribute to variance in cognitive impairment and functioning, including the realm of communication (Fitz & Teri, 1994). Research has also shown that carers of people with dementia are at increased risk of mental health problems (Schneider, Murray, Banerjee & Mann, 1999) and that for husband carers a closer marriage is associated with depressive symptoms (Tower, Kasl & Moritz, 1997). Psychological morbidity in caregivers is associated with depression in people with dementia (Brodaty & Luscombe, 1998). Therefore, if ways to reduce depression in people with dementia and their spouses can be found this would improve well-being in both partners, and this in turn could improve communication which would help the relationship, and enhance the sense of well-being for both partners, further.

Throughout much of this research communication difficulties in the person with dementia have been identified as a cause of stress and sense of loss of relationship. Communication may be affected in early-stage dementia in a number of ways which will be outlined in the next section.

Early-stage dementia and communication

During the early stages of Alzheimer's disease there are a number of language impairments which arise and which affect communication. Predominant among these are word-finding difficulties and naming difficulties, which can lead to circumlocutory discourse, with people talking around the word they cannot find (Morris, 1999).

In one study (Chesla, Martinson & Muswaswes, 1994) spouses reported that the biggest challenge facing them following the diagnosis of Alzheimer's disease in their partner was communication with their spouse. Common problems reported by spouses include the person with Alzheimer's disease having difficulty finding words, understanding directions or sustaining conversations, and frequent repetition. However, research has also found that people in the early and middle stages of Alzheimer's disease are able to uphold the requirements of orderly conversations, i.e. they can abide by turn-taking rules (Ripich, Carpenter & Ziol, 1997).

Therefore people with early-stage dementia may show some aspects which may cause some annoyance to their spouses during interactions; however, they remain capable of conducting conversations.

Having considered the impact of dementia on the marital relationship and communication, the focus of this chapter will turn to ways in which people may cope with their memory difficulties, as this study also aims to consider how couples cope and adjust.

Coping in dementia

Dementia, as with any serious illness or disability, places enormous demands on coping resources (Cottrell & Lein, 1993) and the development of coping mechanisms is essential in order to optimise well-being in dementia. Many researchers have stated that a psychological understanding of dementia needs to take into account how an individual copes with the changes which arise (e.g. Cottrell & Schultz, 1993; Woods & Britton, 1985; Clare, 2002a). In contrast, this study is also designed to explore how couples cope with the changes, and, specifically, whether they can help each other to cope by supporting each other effectively. However it is important to think about how individuals may cope, since this will impact on how people may cope together.

There have been a number of studies exploring individual coping mechanisms in dementia. The importance of investigating coping mechanisms in dementia is that a better understanding will provide a basis for developing effective psychological interventions to help maximise well-being and personhood, particularly for those who have the greatest difficulty in adjusting and developing efficient coping mechanisms. This will be true at an individual and at a couple level.

Cotrell and Lein (1993) interviewed caregivers of people with dementia and asked how they felt the person with dementia had coped. They found that in the early stages of dementia people were inaccurate about their deficits. Furthermore in all but one person a realistic perception was correlated with depressive symptomatology. If confronted with their difficulties the people with dementia would employ strategies where they would react strongly and blame others, withdraw from social contact or deny their problems. However, this study explored coping in the person with dementia by asking their spouse, rather than asking the person with dementia directly, and therefore cannot be wholly reliable as it is based on secondary sources.

Clare (2002a; 2003) interviewed people with early-stage Alzheimer's disease and their partners and identified the coping mechanisms they employed. She proposed a model of awareness and coping in early-stage dementia involving the processes of registering changes, reacting to changes and trying to make sense of them, experiencing their emotional impact, and adjusting. Within these processes, responses fell on a continuum ranging from 'self-maintaining' responses on the one hand to 'self-adjusting' responses on the other. Self-maintaining styles of coping included 'holding on' and 'compensating' - strategies employed to help maintain the prior self-concept and a sense of normality. Self-adjusting coping styles included 'fighting' and 'coming to terms' - strategies involving confronting the threats of dementia head on, viewing them as a challenge, and allowing the self-concept to change in response. She found that most respondents used strategies tending more towards self-maintaining rather than self-adjusting styles. In terms of reactions, explanations and emotional responses to dementia there was a tension between needing to "put on a protective coating" (self-maintaining) and "spend time in the depths" (self-adjusting). This model highlights the individuality of coping mechanisms – some people seem to cope by avoiding the issue of the dementia and normalising their experiences, whilst others cope by confronting the dementia, and many may use a combination of the two approaches. The tensions between these two positions had also been noted in previous studies (Keady & Nolan, 1995; Keady, Nolan & Gilliard, 1995).

Pearce, Clare and Pistrang (2002) investigated coping in men with early-stage dementia and specifically explored whether there were differences in coping shown by men from different occupational backgrounds. They conducted semi-structured interviews with twenty men and their wives and used Interpretative Phenomenological Analysis to identify themes relating to coping with early-stage dementia. As had been found previously, and as outlined above, they found that the men were balancing a wish to maintain their sense of self with a need to reappraise and construct a new sense of self. Furthermore they found that the individual strategies people used were based on their own personal resources, but also on their social environment, their interpersonal relationships and socio-political factors. Relevant to the current study, they found that the wives of men with dementia expressed confusion about how they and their husband should cope as a couple. Some consciously tried to reassure their husbands that their difficulties were normal, whilst others would not share the diagnosis at all or preferred not to remind their husbands of their illness and seemed to collaborate in the denial. Some of the coping strategies employed by the men to try and maintain their sense of self involved reconstructing their role in relation to their wives and devising ways of feeling needed in relationships.

As mentioned above, all of these studies have explored coping in the individual, and how each partner copes separately, rather than looking at dyadic coping. Pearce et al (2002) found that couples were unsure how to cope together, and the present study was designed to think about support and ways of coping that may be evident in couples.

Having considered the literature relevant to early-stage dementia and coping this chapter will now turn to the other area of research which has guided the present study, with a review of the literature on coping in couples where one person is ill, and studies of social support in general and in the context of ill-health.

Social support in couples

Away from the dementia field, some research has focused on investigating coping in couples in general, with an emphasis on social support and help-intended communication. Cutrona (1996) has written extensively on this subject. She writes that the spouse is often the first person to whom one turns in times of crisis, and that relationships function to provide, amongst other things, emotional support, esteem support, information support and tangible assistance. Importantly, and highly relevant to this study, she argues that the primary benefit of social support is as a protection against deterioration of health and well-being. Support within the marital relationship may promote a positive emotional tone and prevent the acceleration of negative interactions, and well-timed and sensitive support from a spouse can provide a way for the couple to remain in emotional contact. As evidence of this, Cutrona cites research that found spousal support can lead to a decrease in rates of depression (Brown & Harris, 1978).

Cutrona goes on to examine social support in couples when they are facing serious illness. She states that chronic illness changes the context in which social support is given and received, since the ill spouse is placed in a position of dependence, and the well spouse is placed in a carer role which may overwhelm him or her. As the illness progresses, so do these imbalances, which may lead to heightened tensions, and the role of appropriate support becomes even more crucial. Research has shown that the onset of illness is a time of crisis for married couples, and both the ill and well partners have an equal risk of developing psychological distress (e.g. Thompson & Sobolew-Shubin, 1993). Open communication has been found to be a critical component in maintaining high quality relationships within the context of serious illness; however, support from the spouse can also backfire and may interfere with the extent to which a person with illness regains strength or functional capabilities. Therefore Cutrona concludes that the partners need to find ways of interacting which do not reinforce helplessness, but equally do not ignore the patient's need for love and nurturance.

It would seem that the marital partner can be a great source of support in times of stress, and this has been shown to be helpful for people who have been diagnosed with serious illness, depending on issues such as the nature of the relationship. Open communication and disclosure of concerns have been shown to be helpful for those suffering from a number of serious illnesses, such as breast cancer, myocardial infarction, and rheumatoid arthritis (e.g. Manne & Zautra, 1989; Pistrang & Barker, 1995; Pistrang, Clare & Barker, 1999). Specifically, the marital relationship has been shown to be crucial to adjustment and psychosocial recovery following a heart attack (e.g. Coyne & Smith, 1994), and in breast cancer good communication with the partner has been shown to be associated with the psychological well-being of the woman with cancer (e.g. Pistrang & Barker, 1995). Furthermore social support has been shown to increase survival time in patients with cancer (Funch & Marshall, 1983). Therefore, open communication and social support can improve emotional functioning and well-being, but can also improve physical functioning.

This is an area which has previously been unexplored within the literature on dementia, specifically looking at the support that married couples may provide to each other following a diagnosis of dementia. Open communication has been shown to be helpful to partners where one of them is suffering from a chronic illness; however, we do not know whether the same can be said for people with dementia and their spouses. Indeed there may be a number of aspects which hinder couples from talking about this diagnosis and their concerns. It has already been mentioned that many carers feel the diagnosis should be withheld from the person with dementia. If this is so, it would seem likely that these same people may shy away from talking to their partners about their concerns surrounding the dementia. Previous research, not specific to dementia, has shown that chronic illness can have negative effects on open communication, since the well spouse may fear harming the ill spouse by focusing on and talking about unpleasant topics (Dunkel-Schetter & Wortman, 1982), or may believe that talking about death can lead to a worsening of disease (Lichtman, Taylor & Wood, 1987). Therefore some well spouses have a tendency to avoid conversations involving negative emotions and information. This may be compounded in dementia by a person's own fears about this illness – for many the prospect of "losing one's mind" may be an ultimate fear and so something to shy away from to avoid facing one's own feelings. Furthermore, spouses may know little about dementia and therefore be reluctant to open up discussion about it as they may feel unable to answer questions. However, Cohen and Eisdorfer (1986) suggest that creating an open environment for the person with dementia can often lead them to a stage of greater openness and acceptance. They state that many individuals in the earlier stages of the disease often welcome the chance to discuss their experiences of dementia, and express needs that can be met by supportive open discussion. Cheston and Bender (1999b) also explore this idea and suggest that the use of denial in the person with dementia may be an indication of an impoverished psychosocial environment where the person with dementia is unable to explore his or her experiences. They state that if the person is given a supportive context they may be able to move through this stage of denial, as has been shown to be the case for people who have been bereaved.

The aims of the current study

As mentioned above, to date it seems there has been very little research looking at the conversational support that the couple may provide to each other when one of them has early-stage dementia, and whether this kind of support functions as a coping mechanism in dementia, or whether some communication between partners may have a negative impact. This is an area that may also be of considerable interest now because there is a move towards earlier diagnosis of dementia. This means that more people are being given their diagnosis when communication skills are still relatively intact, and so are in a position to be capable of both giving and receiving social support from their spouse, which in turn may enhance the well-being of both partners. Conversely, some communication may have a negative impact and decrease the sense of well-being of either partner. The aim of the current study was to explore these ideas and to look at communication between couples where one partner has early-stage dementia, particularly looking at how they may or may not support each other with concerns about the illness.

The purpose of this study

There were a number of reasons for developing this study. The first was, as already mentioned, that this is a previously neglected area. It was hoped that this study would provide an insight into how spouses talk to each other when one has early-stage dementia, and in particular how they talk about memory difficulties. The aim of this was to find out what couples may do to help each other, and in turn what may not be so helpful and may damage the personhood of the person with dementia. It was hoped that, by understanding the processes that are more supportive and less supportive, ways could be found by clinicians to promote more positive interactions between people with dementia and their spouses, thereby lessening any malignant social psychology. As Sabat (2001) states:

> "There is, at present, no medical intervention which can prevent or stop the progress of brain damage produced by Alzheimer's disease. If, on the other hand, we can identify problems whose origin is not the disease itself, but can be found in dysfunctional social interactions which are fuelled by incorrect assumptions about the afflicted person, it may be possible to minimise those dysfunctional interactions and thereby improve the lives of the afflicted and caregivers alike." (p. 2-3)

The research questions

This study is designed to look at the conversational support spouses may or may not provide to each other following the diagnosis of dementia, and their conversations about the diagnosis of dementia and impact of memory problems. It aims to explore a number of aspects of couples' communication:

Whether there is evidence of Kitwood's elements of interaction in the conversations between people with early-stage dementia and their spouses. This study aims to look at the process of conversations and to see how partners interact when talking about issues related to the onset of dementia or memory problems, exploring how personhood may be being maintained or damaged. Kitwood's ideas of positive and negative interactions will be utilised to explore whether the significant elements he identified can usefully be applied to couples where one partner has early-stage dementia, as they have been applied to people with later-stage dementia, and in institutions, through Dementia Care Mapping. However, in contrast to the emphasis of this work on quality of care interactions, the present study will assume reciprocity, i.e. that the person with dementia, as well as the carer, may show some or all of Kitwood's aspects of interaction.

What concerns couples raise with regard to the dementia and the impact of memory problems. The study will explore what topics people raise with their partners and wish to discuss, and what concerns people voice about their own or their partner's memory problems.

Whether couples find it helpful to have these conversations. As previously mentioned, open communication and disclosure of concerns has been shown to be helpful in some cases of serious illness. It will be interesting to explore with couples whether this is true for people with dementia and their spouses, particularly since, as outlined above, denial has been highlighted as an important coping strategy for some people, whilst facing up to difficulties is a strategy used by others.

This chapter has introduced the literature relevant to the current study, and presented the aims and the research questions being asked. The following chapter will focus on the design of this study and the methods that were employed to answer these specific research questions.

CHAPTER TWO

METHOD

This is a qualitative study which aims to look at conversations between people with early-stage dementia and their spouses. Specifically, the study has been designed to explore whether there is evidence of Kitwood's interactive elements in conversations between such couples, what concerns couple raise with regards to memory difficulties and, if the couples talk about such concerns, whether they find these conversations helpful.

This study was part of a programme of research looking at the impact of developing dementia, and took place in conjunction with another study which was also looking at couples where one member had early-stage dementia. The authors of these two studies were both involved in recruitment and visited participants together, each taking responsibility for a separate aspect of data collection as required by the two distinct components of the research programme. This chapter will mainly focus on aspects relevant to the study presented in this thesis.

The following sections will consider the participants who took part in this study, ethical issues, the procedures followed and the methods of analysis, and ways in which the quality of the research was ensured.

Participants

The study included heterosexual couples aged between 65 and 85 where one member of the couple met diagnostic criteria for probable or possible Alzheimer's disease as defined by NINCDS-ADRDA (McKhann et al., 1984), or probable or possible vascular dementia as defined by NINDS-AIREN (Roman et al, 1993). People with dementia were in the early stages and showed only mild or minimal impairment, as indicated by a score of 18 or above on the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975).

To be included in the study, couples had to have been living together for at least five years. All the couples in this study were married. Though it was not necessary to be of UK origin, all the participants were required to have been living in the UK for a substantial amount of time, and to have a reasonable level of fluency in English, in order to ensure a relatively homogeneous group who had been exposed to the same cultural images of dementia.

Recruitment process

Participants were recruited from memory clinics and community mental health teams across the North Thames region. Clinicians identified potential participants known to their services. Those who met the inclusion criteria were then sent an invitation letter and information sheet detailing the study (see Appendix 1). This was followed up about a week later by a telephone call from one of the researchers to invite participants to take part. If couples agreed to take part a meeting was set up at the location of their choice (in practice, all couples chose to be seen in their homes) at which time the consent form was completed and the research conducted.

Characteristics of the sample

Seventeen couples were approached to take part in this study. Nine couples declined the invitation to participate and one couple changed their minds having initially agreed to take part. Proportionately more couples where the wife had received the diagnosis of dementia agreed to take part. Although the couples did not have to give a reason why they did not wish to take part, some people mentioned their partner not wanting to take part, or not wanting to take part because they were participating in some other research.

Seven couples took part in this study. In four of these couples the wife was the partner who had received the diagnosis of dementia. Details of the participants can be seen in Table 3 overleaf. For each couple, the name of the person with dementia is given first. Details have been changed to ensure anonymity. The MMSE scores given are those that were recorded by other professionals. All these scores were obtained within the four months before the researchers' visit. The scores represent a mark out of a possible 30. Scores ranged from 18 to 29 (mean = 22.29; SD = 3.95).

Table 4: Details of the couples who participated in this study

Ann and Ahmad	Ann and Ahmad have been married for over forty years and have two children. Ann is 74 and is Scottish. She worked as a history teacher. Ahmad is 76 and from the Middle East but has been resident in the UK for more than 40 years. He was an engineer. Ann and Ahmad reported having had a turbulent marriage. Ann has received a diagnosis of probable Alzheimer's disease and had an MMSE score of 23.
Bill and Betty	Bill and Betty have been married for more than fifty years and have one daughter. Bill is 75 and is English. He was in the army and then did a variety of skilled jobs. Betty is also 75 and English. She has held a number of part time jobs such as cleaning and waitressing. Bill and Betty reported being happily married but having led fairly separate lives until Bill became ill. Bill has received a diagnosis of probable vascular dementia and had an MMSE score of 23.
Clive and Charlotte	Clive and Charlotte have been married for less than ten years though they have known each other for much longer. Clive is 79. He was born in Germany but moved to the UK when young. He worked as a doctor. Charlotte is 69 and English. She still works part time as a therapist. They reported having a very happy marriage and sharing many interests and activities. Clive has received a diagnosis of probable Alzheimer's disease and had an MMSE of 29.
Doris and Donald	Doris and Donald have been married for over forty years and have two children. Doris is 73 and English. She worked in administrative jobs. Donald is 71 and also English. He worked as a baker. They reported having had a very happy marriage though Donald said that Doris' illness had changed all that. Doris has received a diagnosis of probable Alzheimer's disease and had an MMSE of 19.

Table 3: Details of the couples who participated in this study (continued)

Elizabeth and Edward	Elizabeth and Edward have been married for over fifty years and have two children. Elizabeth is 79 and English. She worked as a shop assistant. Edward is 81 and also English. He had worked as a hairdresser. It was hard to get a sense of how their relationship had been in the past. Elizabeth has received a diagnosis of probable Alzheimer's Disease and had an MMSE score of 25.
Fritz and Fran	Fritz and Fran have been married for over forty years. Fritz is 84 and was born in Austria but moved to the UK when young. Fran is 70 and English. They both worked as scientists, and Fran still works part time. They reported a good marriage but one in which they never discussed concerns. Fritz has received a diagnosis of probable Alzheimer's disease and had an MMSE score of 18.
Gill and George	Gill and George have been married for over sixty years and have one son. They are both English. Gill is 85 and worked doing jobs such as factory work and shop work. George is 80. He worked in the motor industry. They reported having had a very happy marriage. Gill has received a diagnosis of probable vascular dementia and had an MMSE score of 19. George had received low MMSE scores in the past (18 and then 23 a month later), over a year before we visited the couple. However his scores were attributed to physical health difficulties at the time, and on testing he was not found to have dementia.

Procedure

After couples had agreed to take part in the research, the two researchers visited them in their homes. At the beginning of the meeting the researchers explained the purpose of the visit and described the research, reiterating the information that participants had received from the information sheet in a clear and simple way. Following these explanations participants were asked whether they had any further questions, and their understanding of the procedure and what they were being asked to take part in was checked. Participants were then asked to sign the consent form (see Appendix 2) after confirming that they were both still willing to take part. It was reiterated at this stage that participants could withdraw from the research at any time.

Following this the couples were asked some questions about their background by both of the researchers – how long they had been married, whether they had children, where they had lived previously, and what occupations they had both followed. This conversation allowed the participants a further opportunity to become familiar with the researchers and ensure that they felt comfortable to proceed.

For the present study, the couples were then asked to hold a conversation which was followed up by separate individual interviews with each partner. The aims and procedures for the conversations and interviews are described in the sections below. These were conducted by the researcher within the context of the study reported here. The second researcher remained on the premises while the conversations and interviews were carried out, but did not actively participate in the procedures.

Couple conversations

The couples were asked to hold a conversation about any concerns they had relating to the impact of memory difficulties. The aim was to explore how couples talk to each other and to see, specifically, whether there is evidence of Kitwood's categories of interaction during their conversations, and whether couples openly discuss their concerns, as has shown to be helpful in other areas of health psychology (e.g. Pistrang and Barker, 1995). A similar approach has been used in previous research (Clare and Shakespeare, in press) where couples in which one person had early-stage dementia, were asked to hold a conversation of up to five minutes with the aim of coming up with a sentence or statement which summed up their current situation. In the present research it was decided to give couples up to fifteen minutes to hold the conversations as it was suggested (Clare and Shakespeare, in press) that somewhat longer conversations may have been useful for some couples. In that study, some couples finished their conversation before the five minutes was over, while others used the full five minutes and appeared likely to have continued for longer had this option been available. Fifteen minutes was therefore selected as an appropriate length of time; however, this was monitored throughout the course of the research and there was always the option to extend the time period if this had seemed appropriate. In fact most of the couples chose to have conversations which were shorter than the allocated fifteen minutes (see below).

In the present study the couples were asked by the researcher to hold a conversation about any concerns they had about the impact of memory difficulties. The task was explained to them by the researcher and they were also given a set of instructions on paper which they were left with whilst completing the task (see Appendix 3).

Participants were told that the researcher would leave the room whilst they had the conversation and that it would be tape-recorded. They were given fifteen minutes to have the conversation, after which time the researcher would re-enter the room; however, they were also told they could stop the conversation at any point before this, should they wish to. They were asked as far as possible to discuss their concerns in the same way they would usually discuss concerns. Couples were told that following the conversation the researcher would talk to each person individually.

Whilst having the procedure explained, a number of the spouses of the participants with dementia stated that they no longer had conversations or that conversations with their partners were difficult. When this happened they were asked to try completing the task all the same. All the couples attempted to have a conversation. Five of the seven couples stopped the conversation before the fifteen minutes were over.

Individual interviews

Following the conversations each member of the couple was interviewed individually by the researcher about his or her experience of the conversation and about discussing concerns with the partner generally. The aim of these interviews was to explore whether couples where one person has early-stage dementia find it useful to discuss their concerns about their difficulties, as has been shown to be the case for others with serious illness (e.g. Pistrang and Barker, 1995).

The interviews lasted between five minutes and twenty-five minutes and were tape-recorded. To aid recall of the couple conversation the participants with dementia were interviewed first whilst their spouse waited in another room and had an informal chat with the other researcher. Before the interviews were conducted participants were asked again whether they were happy to carry on with the research.

The interviews followed a semi-structured format based on a pre-planned interview schedule (see Appendix 4). The interview schedule was produced following the guidelines of Smith (1995). The interview included the following topics:

- How the person had found having the conversation and how typical this conversation was, i.e. whether they had spoken about the memory difficulties at other times.
- Whether they found the conversation helpful or unhelpful and what aspects were helpful or unhelpful.
- Whether the couple generally discussed concerns, and if so how they usually went about this.
- Whether they generally found it helpful or unhelpful to discuss concerns.

During the interviews, the terms dementia or Alzheimer's disease were not used unless these were first introduced by the person being interviewed, and the language chosen followed that used by the participants as closely as possible.

Following the completion of the interviews, the participants were interviewed as part of the other study being conducted (after being asked whether they were happy to carry on). Both researchers remained in the room while this interview was conducted, although it was conducted by the second researcher. This interview lasted between ten minutes and one hour. Following this participants were asked how they had found the experience of the task and interviews, and asked whether they had any further questions. They were reminded of the contact details of the researchers and invited to contact them if they had any further concerns or queries as a result of taking part. There was no further contact from any of the couples following these meetings.

Ethical considerations

Ethical approval was granted for this project from Camden and Islington Local Research Ethics Committee and Barnet, Enfield and Haringey Local Research Ethics Committee (see Appendix 5).

Research has suggested that people in the earlier stages of dementia should be capable of giving informed consent. However it was thought that people with dementia might have difficulty in understanding and retaining the details of the study, and also that there was a possibility some might become distressed when taking part because of the content of the conversations and interviews. These factors were taken into account when designing the study. The information sheet was written in straightforward language and in a large font with the information divided into relevant sections. This was done to make the sheet more accessible to potential participants. In the meeting with participants before the data collection got underway the researcher checked that the participants had read and understood the information sheet and explained the process again before asking participants to read and sign the consent form. Participants were reminded that they could withdraw from the research at any time. During the meeting both members of the couple were asked at regular intervals, at each stage of the research, whether they were happy to carry on. One couple chose to complete the research over two meetings, with the conversations and individual interviews which were part of this study being completed in an initial meeting, and the joint interview which was part of the other study being conducted a week later.

The protocol included measures aimed at minimising discomfort during the meeting and ensuring that any distress which may have arisen was dealt with appropriately. Interviews were conducted at the pace of the participants and followed their language, and the terms 'dementia' or 'Alzheimer's disease' were not used unless previously introduced by the person being interviewed, since it was possible that participants either had not been informed of their diagnosis, or did not accept it. It was decided that if a person became distressed they would be offered a follow-up meeting, and in all cases it was agreed that professional help would be made available from the agency where they had been assessed. In addition, information was given about the Alzheimer's Society if it was considered appropriate.

Analysis of the data

All the conversations and interviews were transcribed verbatim. Transcripts excluded any details which might lead to identification of participants, such as the real names of the participants, family members' names and places of employment. The transcripts were then analysed using two different approaches. The different approaches were employed since this was an innovative study and there was not one single method which could be employed to do justice to the issues being explored and questions being asked, and furthermore because the data incorporated both couples' conversations and individual interviews. The conversations were analysed using content analysis to explore the presence or absence of the Kitwood categories outlined in Tables 1 and 2 above, and Interpretative Phenomenological Analysis (IPA) to explore thematically what the couples talked about during their conversations. The individual interviews were analysed using IPA to explore thematically whether couples talk about memory difficulties and whether they find it helpful to do so. Each of these techniques will be described in turn below.

Content Analysis

Content analysis provides a way of combining quantitative and qualitative approaches as it applies a quantitative analytic approach to verbal, qualitative material (Barker, Pistrang and Elliott, 1994). Content analysis offers a means of examining social communication, which typically includes recorded verbal communications, and the technique has been identified as being particularly helpful in looking at processes in social groups, and in exploratory or descriptive studies (Berg, 1989). Therefore this method of analysis was suitable to use in analysing the couple conversations, and was appropriate for this exploratory study. Content analysis involves developing categories and looking at the data to determine the frequency of occurrence of these categories. Defined categories should be consistently applied so that other readers of the research would obtain the same or comparable results (Berg, 1989). In this study a deductive approach was employed in that the categories to be applied were the interactive elements previously identified by Kitwood as forming positive and negative interactions with people with dementia. These elements have been usefully employed in Dementia Care Mapping to look at the quality of care that people with dementia in residential settings experience from professional caregivers. The aim of this study was to utilise these same categories and see if they could be applied to people with early-stage dementia in communication with their spouses, and to explore whether there was evidence of factors which may contribute to a malignant social psychology or whether there were aspects which are more positive and could contribute to a more positive sense of self. In order to establish whether each of Kitwood's elements were contained within the couple conversations it was necessary to further operationalise each of the elements individually with regard to their expression in this context (see below). Following the operationalisation of the elements, content analysis involved studying the conversations to explore the presence or absence of the defined categories.

In this study quantitative and qualitative aspects of content analysis were utilised. A quantitative approach was used to determine which categories were present in the conversations, taken as a whole data set, and which were absent. The categories which were found to apply were then explored further to determine which categories appeared in each individual conversation, and how often. A further qualitative component of the analysis consisted of describing and illustrating the ways in which the categories are exemplified in the conversations, using extracts from the transcripts. Two researchers studied all transcripts and independently rated them for the presence or absence of the Kitwood categories. Inter-rater reliability was calculated.

Interpretative Phenomenological Analysis

As outlined above, the conversations and interviews held with participants were analysed by a process of Interpretative Phenomenological Analysis (IPA), an approach described by Smith (e.g. 1996, 1997) as:

> "an attempt to unravel the meanings contained in.....accounts through a process of interpretive engagement with the texts and transcripts"
>
> (p.189, Smith, 1997)

The aim is to explore in detail a participant's view of what is being investigated. IPA is concerned with a person's perceptions or accounts of objects and events, rather than with trying to produce an objective statement of the object or event itself (Smith, Jarman & Osborn, 1999). This method aims to understand what a participant thinks or believes about the topic being explored (Smith et al, 1999).

Willig (2001) suggests that IPA is an approach which is informed by some of the principles drawn from a branch of philosophical thinking called phenomenology. This is concerned with the ways in which individuals gain knowledge of the world around them, within particular contexts and at particular times. Interpretative Phenomenological Analysis is a method which recognises the impossibility of getting direct, unbiased access to a participant's life world and recognises that in exploring a participant's experience the researcher's own view will be implicated, as will be the interaction between the researcher and participant. Therefore what is produced in analysis is an interpretation of experience.

This approach was deemed appropriate for this study for a number of reasons. Firstly, it is considered particularly suitable for issues relating to health psychology and the study of illness (Smith, Flowers & Osborn, 1997). Secondly, it is specifically to be used for the interpretation of data generated by semi-structured interviews. Thirdly, this approach fitted with my own beliefs, and those within clinical psychology thinking, about the importance of peoples' perceptions and their interpretations of their experiences as being much more crucial than the actual experience itself.

As mentioned above, IPA has specifically been designed for use in interpreting material drawn from semi-structured interviews. In the current study IPA was also utilised in looking at the conversations between the couples, as a method of discovering the themes which were talked about within these conversations. This method was employed to answer the first research question about what the couples talk about with regards to memory difficulties, and was intended to supplement the content analysis described above.

The actual method of employing IPA has been described in a number of papers (e.g. Willig, 2001) and is described below when the steps of analysis are presented (p.52).

The process of analysis

The process of analysis took part in two main stages, firstly with the analysis of the conversations, and secondly with the analysis of the individual interviews. Each of these will be described in turn.

Analysis of the conversations

The analysis of the conversations utilised two methods, as described above, and the procedures involved in both the content analysis and the Interpretative Phenomenological Analysis will be described in turn.

Content analysis

The initial stage of the content analysis involved operationalising the elements defined by Kitwood (1990, 1997) to identify what would indicate the presence of each element within the conversations. Though Kitwood has previously provided definitions of each element, these are aimed more at the kind of interactions one would see in a residential care setting, and include a wider range of behaviour rather than just conversational interactions. Therefore it was necessary to further consider how each category would be operationalised in conversations between couples where one partner had early-stage dementia. Each of the elements and its definition was looked at and a consensus was reached about a valid and practically applicable operationalisation of the concept in the context of the conversations, drawing on existing studies (Clare and Shakespeare, in press; Shakespeare, 1998) and clinical experience. The operational definitions which were used in the present study are detailed in Tables 5 and 6 below.

This study assumed reciprocity in the sense that both the spouses and the people with dementia could show Kitwood's positive and negative elements of interaction. Therefore, the two types of interaction he identified where people with dementia take the lead role, creation and giving (outlined in Table 3 in Chapter One), were not operationalised and employed in this study as it was felt that aspects of these would be shown through the positive interactive elements, for example facilitation and validation.

Table 5: Negative interactive elements as defined by Kitwood (1990, 1997) and operationalised for the present study

Element	Definition	Operationalised
Treachery	Using forms of deception to distract or manipulate a person, or force them into compliance.	One person in conversation telling lies or manipulating the truth to get other person to comply with their wishes.
Disempowerment	Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated.	During the conversation doing things or talking about doing things which the other person could do for themselves. Jumping in or talking over, not allowing the other person to make the contribution they are able to.
Infantilisation	Treating a person very patronisingly, as an insensitive parent might treat a very young child.	During the conversation talking to the other person as if they are a small child or behaving in the conversation as if the other person is a small child.
Intimidation	Inducing fear in a person, through the use of threats or physical power.	Making verbal threats to the other person in the conversation, to which they respond in a fearful way.
Labelling	Using a category such as "dementia", as the main basis for interacting with a person and for explaining their behaviour.	During the conversation attributing a persons actions or remarks to the memory problems. Treating the person in a different way to how they would be treated in the absence of memory problems. Referring to the person as "patient" or "person with dementia" (or similar) during the conversation.
Stigmatisation	Treating a person as if they were a diseased object, an alien, or an outcast.	Treating the person with memory problems as if they are a diseased object, excluding them. Making comments about problem reflecting how the other person cannot do things / contribute / participate.

Outpacing	Providing information, presenting choices, etc., at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear.	During the conversations interacting at a pace too fast for the other person to understand. For example bringing in more information than the other person can take in or respond to, and using the resulting confusion to secure agreement or compliance.
Invalidation	Failing to acknowledge the subjective reality of a person's experience, and especially what s/he is feeling.	During the conversations ignoring or overlooking the subjectivity of the other person. For example contradicting what the other person describes (e.g. if the other person says s/he is worried, the partner responds with "No you're not" or fails to respond at all).
Banishment	Sending a person away, or excluding them, physically or psychologically.	Not holding a conversation with the other person, excluding them entirely. Or making 'asides' directed to the tape-recorder / researcher about the person.
Objectification	Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained.	During the conversation talking to the other person as if they are an object with no human qualities.
Ignoring	Carrying on (in conversation or action) in the presence of a person as if they were not there.	During the conversations ignoring the other person completely, not responding to them or speaking to them at all. Refusing to engage in conversation at all – being willing to speak only to the researcher about the person, not with the person.
Imposition	Forcing a person to do something, overriding desire or denying the possibility of choice on their part.	During the conversations forcing a person to do or say something which they have said or demonstrated they are clearly reluctant to do or say. Imposing the

Imposition (continued)		subject matter on the other person, not allowing negotiation over what to talk about.
Withholding	Refusing to give asked-for attention, or to meet an evident need.	Not responding to the other person, for example not answering their questions, or if the other person asks for something / expresses a need not responding to this.
Accusation	Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.	During the conversation making statements blaming the other person for their actions / failures of actions. Blaming the person themselves, rather than memory problems, e.g. "You're so stupid". Making direct accusations.
Disruption	Intruding suddenly or disturbingly on a person's action or reflection; crudely breaking their frame of reference.	Over-talking the other person's attempts to speak and make comments. Also disrupting by refusing to follow the direction of the conversation the other person wishes to take and bringing them back to another topic, e.g. back to the subject of their memory problems.
Mockery	Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense.	During the conversation making fun of the other person, making comments which could humiliate the other person.
Disparagement	Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self esteem.	During the conversation making comments about the other person being incompetent or useless, or acting in a way which would lead other person to feel incompetent or useless. For example, continually asking a question that the other person has said they do not know the answer to.

Table 6: Positive interactive elements as defined by Kitwood (1997) and operationalised for the present study

Elements	Description	Operationalised
Recognition	The person with dementia is acknowledged as a person, known by name, affirmed in his or her uniqueness.	During the conversation mentioning attributes, achievements or positive characteristics specific to the other person.
Negotiation	The person is consulted about his / her preferences, desires and needs, rather than being made to conform to others' assumptions.	During the conversation the other person is consulted about his / her preferences, desires and needs, rather than being made to conform to others' assumptions.
Collaboration	Two or more people are aligned on a shared task, with a definite aim in view. Working together.	Both agree to take part in the conversation and carry out a conversation.
Play	Play has no goal outside the activity itself, it is simply an exercise in spontaneity and self expression.	Making playful remarks within the conversation, which both members of the couple experience as playful. Using humour in a shared way.
Timalation	Forms of interaction in which the prime modality is sensuous, for example through aromatherapy or massage.	Demonstration of physical affection, e.g. through the use of touch.
Celebration	The form of interaction in which the division between caregiver and cared-for comes nearest to vanishing completely as all are taken up in a similar mood. Any moment in life which is experienced as intrinsically joyful.	Both members of the couple showing joy within the conversation. Using tones of voice which suggest happiness, and talking about joyful aspects of their lives.
Relaxation	This form of interaction has the lowest level of intensity and the slowest pace. Showing signs of relaxation.	Shown through a companionable silence, or evident after a successful resolution of the conversation. Making contented sounds / sighs.
Validation	Acknowledging the reality of a person's emotions and feelings, and giving a response on the feeling level.	Responding to a persons subjective comments in a way which acknowledges and validates the emotions that appear to be expressed.
Holding	To provide a safe psychological space, a "container"; hidden trauma and conflict can be brought out, areas of vulnerability exposed.	During the conversation being able to share difficult feelings and talk about areas of vulnerability,

Holding (continued)		showing that they feel safe to express these to their partner.
Facilitation	Enabling a person to do what otherwise he or she would not be able to do. To enable interaction to get started, to amplify it and to help the person gradually fill it out with meaning.	Helping the other person to achieve what he or she would not be able to do alone, e.g. helping conversation to start / helping other person to express themselves if these are aspects the other person finds difficult. Providing support and cues in the conversation which provides a structure that helps the person to participate. Helping the conversation to continue, for example by breaking a long silence.

Once the operational definitions had been agreed, the researcher and the supervisor independently rated two of the couple conversations. The unit of analysis was specified as a talking turn. This has been defined by Shakespeare (1998) as "the utterance that one person makes before another person takes over the floor" (p.104), though, in addition, for the purposes of this study, if there was a large silence following one person's talking turn in which they appeared to be waiting for the other participant to speak, but ended up filling the silence themselves, this was counted as two talking turns. The raters studied each talking turn and identified whether one of the Kitwood categories applied. For talking turns where it was felt that both a positive and a negative element applied, both were coded. If it was felt that a talking turn contained more than one positive or negative element the raters independently assigned the category that they felt best matched their observations. Following the rating of the initial two conversations the researcher and the supervisor met to check the reliability of the categorisations, and to discuss any discrepancies in opinion as well as issues arising in applying the codes. Upon completion of this process the researcher and supervisor independently rated the remaining conversations. Appendix 6 lists ratings made for each talking turn within each of the conversations. On the basis of these ratings inter-rater reliability was calculated. Lists of the number of couples for whom each element was present were produced. Lists were also produced of all the examples which fitted into each of the element categories for all of the couples (see Appendix 7). The information in these lists provided the basis for a descriptive overview of the content analysis. The lists containing these extracts were produced following discussion leading to consensus between the two raters, and present the consensus that was reached about the extracts and the categories which were felt to be most applicable to each.

Interpretative Phenomenological Analysis

Each of the couples' conversations was taken in turn. It was read and then re-read a number of times and any emerging thoughts or observations were noted. These included questions, comments on language use, general observations about the conversation, etc. These were noted in the left-hand margin of the transcript. Following this a number of steps were followed for each conversation. Each of the steps was followed firstly looking at the transcript from the point of view of the person with dementia, and then repeated while reading from the perspective of the spouse. The researcher followed the process of IPA and went through the transcript and noted down any relevant ideas and statements. The statements / ideas were written in the participants' language and not modified in any way, and recorded on the right-hand side of the transcript. A list of these ideas was then produced and studied, and they were then grouped under general themes and sub-themes. In labelling each of the themes the language of the participants was adhered to in order to capture the sense of the theme and not impose the language of the researcher. For each conversation, a full list of themes with all relevant extracts was produced.

Once this process had been completed for all the conversations, the researcher began cross-analysis over all the conversation transcripts. This involved taking all the themes that had been generated, grouping these into a coherent arrangement looking for similarities and differences, and producing a hierarchical list of themes and sub-themes with all relevant extracts, again using the language of the participants to label each of the themes. This method was employed in turn with the themes for the people with dementia and then their spouses. The researcher then went back and forth between the lists of extracts and ideas and the original transcripts to check that everything had been assigned in the best possible way. The list of themes and extracts were reviewed by the supervisor in detail to check that they followed logically, and any questions were discussed until consensus was reached.

Examples of some of the steps in the IPA analysis are contained in Appendices 8-10.

Analysis of the interviews

In analysing the interviews the transcripts were similarly read and re-read and any initial thoughts recorded in the left-hand margin of the transcript. Following this the researcher made a list of statements and ideas produced by the participants. This list was then analysed and grouped into themes and sub-themes. Again all examples and instances of a given theme were recorded and the themes were labelled using the words of the participants. Following this the themes arising across all the interviews were extracted and grouped into a hierarchical list of themes and sub-themes. Full lists of themes with relevant extracts were produced, and again these lists were checked against the original transcripts. As with the conversations, at each stage of the analysis (the analysis of individual interviews and the cross-analysis) the results were discussed with the supervisor in order to gain another perspective and to pick up on anything which did not seem to fit.

Validity in qualitative research

Since qualitative methodologies have been utilised more and more within psychological research there have been attempts to define how to maximise the validity of qualitative research (e.g. Elliott, Fischer & Rennie, 1999; Yardley, 2000). It has been recognised that the majority of the guidelines for assessing the validity and reliability of quantitative research cannot be applied to qualitative methodologies, and fortunately guidelines more appropriate to qualitative research are now available.

Elliot et al (1999) have produced a list of guidelines which will be introduced here, and discussed in turn in relation to this study which utilised both quantitative and qualitative methods of analysis. Elliott et al state that there are a number of guidelines which are common to both quantitative and qualitative methodologies, these being: having an explicit scientific context and purpose; using appropriate methods; respect for participants; specification of methods; appropriate discussion; clarity of presentation; and contribution to knowledge. They also list guidelines which are pertinent specifically to qualitative research. Each of these is discussed below:

- *Owning one's perspective* – qualitative researchers should specify their theoretical orientations and personal thoughts, both those that were in existence before the research and during it. They should "recognize their values, interests and assumptions and the role that these play in the understanding" (p. 221, Elliott et al, 1999). My perspective is outlined above, and in the following section, and is reflected upon further in Chapter Four.

- *Situating the sample* – the research participants and their life circumstances should be described to help the reader judge to whom the findings might be relevant. In this study the details of the participants (whilst protecting anonymity) are given in Table 4.

- *Grounding in examples* – examples of the data should be provided to the reader to show the fit between the data and the author's interpretations, and to allow the reader to think about possible alternative interpretations. In Chapter Three examples of data will be given to support the researcher's interpretations, both for the Interpretative Phenomenological Analysis and the content analysis.

- *Providing credibility checks* – several methods may be employed to do this, for example: checking the understanding of the data with the original participants; using multiple qualitative analysts; comparing two or more qualitative perspectives; triangulation with external factors (e.g. outcome) or quantitative data. Throughout this study a number of techniques were employed to try and maximise the credibility and the trustworthiness of the analysis. At each step a supervisor who was highly experienced in the areas of qualitative analysis and dementia care was consulted and asked for feedback on the analyses, and as part of the content analysis the supervisor independently rated the conversations to check for the presence or absence of the Kitwood categories. There was also discussion with the other researcher who had met the couples and been present at the meetings with participants. In addition, throughout the process reflective memos were kept which were helpful in keeping a check on any biases which may have emerged on the part of the researcher. These memos were shared with the supervisor and discussed in supervision. Also, there was triangulation between the use of differing methods of data collection (i.e. the conversations and the interviews). Lastly, the use of more than one method of analysis may provide a credibility check (Willig, 2001) by exploring whether the interpretation produced by one method of analysis fits with the interpretations offered by other methods. Within this study methods from content analysis and Interpretative Phenomenological Analysis were drawn upon in order to build an interpretation of the data.

- *Coherence* – the understanding should fit together in a cohesive, integrated way, and the analyses should be presented with a framework, or an underlying structure (Willig, 2001). In the Chapter Three of this study the analyses are presented within a framework that follows the original research questions.

- *Accomplishing general versus specific research tasks* – if a general understanding of the phenomenon being studied is the aim it should be based on an appropriate range of instances, and limitations of generalisation identified. If the goal is in understanding a specific case it should be explored systematically and comprehensively enough. In the current study seven couples participated, providing a range of examples of how couples talk to each other when one of them has early-stage dementia. Limitations on the generalisability of the findings are discussed in the final chapter.

- *Resonating with the reader* – readers should feel that the research has enhanced their understanding of the subject being studied (Willig, 2001). It is hoped that the current study enhances an understanding of the ways in which couples talk to each other when one has early-stage dementia, and the ways in which these may or may not be helpful in maintaining personhood and well-being, though the real test of this may not come until this work is disseminated more widely.

Having considered the methods used in this study and the procedures employed to maximise the validity of the findings this chapter will lastly turn to a description of the perspective of the researcher.

Researcher's perspective

I embarked on this research project with very little personal or professional experience of people with dementia. As a young girl, around ten years of age, I remember an old lady who lived on my road who would keep wandering from her house, in her nightdress and slippers, who I was told was "senile". At the time I found this frightening, fearing what this lady who I perceived as "mad" might do next. Other than this as I was growing up I had no other experience of people with dementia. As a teenager I applied for a job in a residential home for older adults but on visiting the home found the stench and the atmosphere too unbearable and chose to work in a shop instead. Throughout these experiences I developed my own beliefs and fears, and the prospect of losing my mind, and ending up like that old lady, was almost too frightening to imagine - I, like many others, developed the idea that I would rather die with my mind intact.

Before I embarked on the Doctorate training course my own grandmother died following years of having Parkinson's disease. It was only right at the end of her illness that she suffered with dementia and I saw little of her at this stage; however, I have no doubt that this has influenced my decision to explore coping in dementia. She had a very close relationship with my grandfather who is still alive, and who, with his positive and inspirational outlook on life, goes against many of society's prejudices towards older adults.

During the time of choosing research projects I was involved in organising my own wedding and, therefore, getting married. My mind was very much focused on thoughts of marriage and being with someone for the rest of my life, which included thoughts of growing old together and facing adversity along the way. I have no doubt that it was the combination of this event, and the experiences of my grandparents, which influenced me to embark on this piece of research looking at communication in couples and how much they may, or may not, discuss their concerns about dementia.

Up until this point I still had very little personal experience of people with dementia. Shortly after choosing this project I began a placement working with older adults within the context of a Community Mental Health Team. During this placement I worked in a memory clinic where I was involved in assessing whether clients had dementia, and I also co-facilitated a Reminiscence Group on an inpatient ward, which included clients in the later stages of dementia. Through these experiences I learnt that people with dementia were certainly not the frightening people I had imagined from my youth, but were human beings who were often frustrated by their difficulties and often made various attempts to cover these up, sometimes through the process of denial.

Around this time I saw the film "Iris" based on the life of Iris Murdoch who died following developing Alzheimer's disease. I found the film very upsetting and it really struck a chord in me, no doubt because of a combination of my thoughts of my marriage, grandparents, this research project, clients I was seeing, and my own fears and mortality.

What has really struck me as I have read the research in the area is the lack of consideration of the support couples may provide to each other around the time of the development and diagnosis of dementia. There was a sense, as I read the literature, that once someone has dementia they are almost redundant, no longer capable of providing support to anyone, or communicating anything particularly meaningful. Although there is now much more research exploring the perspective of the person with dementia, it still seemed that little attention was paid to the marital relationship and the role of husband or wife in interaction with the individual with dementia. This further supported my decision to focus on this topic exploring meaningful, supportive communication between husbands and wives regarding the impact of difficulties.

The implications of my own thoughts and motivations for embarking on this piece of research were that I expected, and hoped, to find couples being extremely supportive towards each other and sharing their worries and concerns with each other. These thoughts, and their possible impact on this study, are considered in Chapter Four.

This chapter has focused on the design of this study and the methods employed in collecting and analysing the data. It has also described my perspective, which is important in the context of qualitative research as it could influence the interpretation of data. The following section will turn to the results of the analysis of the conversations and interviews, and offer a presentation of the findings.

CHAPTER THREE

RESULTS

This chapter presents the findings from the couple conversations and the individual interviews with each person. There were many variations between couples as well as some similarities, and this chapter will attempt to reflect both the similarities and differences.

Each of the initial research questions will be taken in turn as a focus for presentation of the analyses. However, before discussing each of the questions a brief description of each of the conversations will be presented, with qualitative information about the general content and process of the conversations, and a more quantitative description in terms of how many talking turns each of the participants in the conversation had, and how many questions each of them asked. Shakespeare (1998) found that there is huge variation in the activity shown by 'confused' and 'normal' speakers, and in how balanced their conversations are. In particular she found a strong emphasis on questioning on the part of the 'normal' speaker to try and elicit responses from the 'confused' speaker. In light of these observations it was decided to focus on this aspect for the purposes of this study. This qualitative and quantitative information provides a context for the detailed presentation of results which follows.

During this chapter the word spouse (if not described as the spouse with dementia) refers to the member of the couple who had not been diagnosed with dementia.

Brief descriptions of the conversations

Table 6 provides quantitative information about the number of talking turns and questions asked by the people with dementia and their spouses in each of the couple conversations, and following this are qualitative descriptions of the conversations.

Table 7: Number of talking turns, and number of talking turns which contained questions, in the couple conversations for the people with dementia and their spouses

	Number of talking turns	Of which questions	Percentage of talking turns which included a question
Ann (pwd)	122	18	14.8%
Ahmad	122	49	40.2%
Bill (pwd)	37	7	19.0%
Betty	34	8	23.5%
Clive (pwd)	21	1	4.8%
Charlotte	22	6	27.3%
Doris (pwd)	36	3	8.3%
Donald	38	17	44.7%
Elizabeth (pwd)	21	1	4.8%
Edward	21	14	66.7%
Fritz (pwd)	22	14	63.6%
Fran	21	7	33.3%
Gill (pwd)	10	3	30%
George	9	3	33.3%

Ann and Ahmad

Ann and Ahmad spoke for the full fifteen minutes. The conversational topics were largely imposed by Ahmad and he seemed to be trying to generate a list of the times when Ann forgot things, which involved him questioning Ann about her difficulties. At times she fought against this and denied some of the things Ahmad said she forgot, and as a result there were many points when the two became entrenched in what Ann described as an argument.

Bill and Betty

Bill and Betty ended their conversation before the fifteen minutes was over. They began talking about a visit from their daughter at Bill's instigation; however, later Betty turned the conversation to a focus on Bill's difficulties and some of her frustrations. Towards the end of the conversation Bill started raising some of his own concerns but the conversation was drawn to a close by Betty shortly after this.

Clive and Charlotte

Clive and Charlotte spoke for the full fifteen minutes. During this time there were a lot of silences and pauses in which Charlotte seemed to be giving Clive room to speak and think. During this conversation each member of the couple raised their own concerns about the impact of Clive's memory difficulties.

Doris and Donald

Donald and Doris did not talk for the whole fifteen minutes and decided jointly to end the conversation after about five minutes. During this conversation Donald seemed at times to be imposing his understanding of the task and trying to get Doris to talk about what she could and could not remember, and at other times Doris steered the conversation to talk about the past and her achievements. Both members of the couple talked about some of their frustrations with each other.

Elizabeth and Edward

Elizabeth and Edward did not talk for the whole fifteen minutes and Edward decided to end the conversation whilst Elizabeth was still speaking. During this conversation the topic of memory difficulties was avoided altogether and Edward directed the conversation throughout by asking Elizabeth what she wanted to do during the day.

Fritz and Fran

Fritz and Fran ended their conversation before the fifteen minutes were up. During their conversation Fran tried to explain the task and facilitate conversation; however, Fritz repeatedly said that he did not understand what he was meant to be doing.

Gill and George

Gill and George had the shortest conversation and ended this well before the allocated fifteen minutes. Both of them struggled to think about what to talk about, and said that they did not have any concerns.

Summary about the general descriptions of the conversations

There was huge variation between the conversations in a variety of aspects, such as length and content. In terms of talking turns and number of questions there was a roughly equal number of talking turns shown by the people with dementia and their partners; however, on the whole the spouses asked many more questions than the people with dementia, which seemed to reflect attempts to both direct the conversation and aid the contribution of the person with dementia.

The focus of this chapter will now turn to exploring what was found in relation to each of the initial research questions.

The presence of Kitwood's elements of interaction in the conversations

Throughout the couple conversations there were aspects of the conversations which fitted with some of the Kitwood categories. The tables below detail which of the negative and positive elements were identified within the conversations, and in which couples. Tables 8 and 9 show, respectively, the negative interactive elements observed within the conversations on the part of the people with dementia and the spouses, and Tables 10 and 11 show, respectively, the positive interactive elements observed within the conversations on the part of the people with dementia and their spouses.

Table 8: Identification of Kitwood's negative interactive elements within the conversations in the talking turns of the participants with dementia

Negative elements	Ann	Bill	Clive	Doris	Eliza-beth	Fritz	Gill	Total
Treachery								0
Disempowerment								0
Infantilisation								0
Intimidation								0
Labelling								0
Stigmatisation								0
Outpacing								0
Invalidation								0
Banishment								0
Objectification								0
Ignoring								0
Imposition								0
Withholding								0
Accusation	Yes			Yes				2
Disruption	Yes	Yes		Yes				3
Mockery								0
Disparagement								0

Table 9: Identification of Kitwood's negative interactive elements within the conversations in the talking turns of the spouses of people with dementia

Negative elements	Ahmad	Betty	Charlotte	Donald	Edward	Fran	George	Total
Treachery								0
Disempowerment	Yes	Yes			Yes			3
Infantilisation	Yes	Yes		Yes	Yes			4
Intimidation								0
Labelling								0
Stigmatisation	Yes							1
Outpacing								0
Invalidation	Yes	Yes		Yes				3
Banishment				Yes				1
Objectification								0
Ignoring								0
Imposition	Yes			Yes	Yes			3
Withholding								0
Accusation		Yes						1
Disruption	Yes	Yes		Yes				3
Mockery	Yes							1
Disparagement	Yes	Yes		Yes				3

Table 10: Identification of Kitwood's positive interactive elements within the conversations in the talking turns of the participants with dementia

Positive elements	Ann	Bill	Clive	Doris	Eliza-beth	Fritz	Gill	Total
Recognition			Yes	Yes				2
Negotiation					Yes		Yes	2
Collaboration	Yes	Yes	Yes	Yes	Yes	Yes	Yes	7
Play	Yes	Yes						2
Timalation								0
Celebration								0
Relaxation								0
Validation								0
Holding			Yes					1
Facilitation		Yes					Yes	2

Table 11: Identification of Kitwood's positive interactive elements within the conversations in the talking turns of the spouses of people with dementia

Positive elements	Ahmad	Betty	Charlotte	Donald	Edward	Fran	George	Total
Recognition	Yes	Yes	Yes	Yes				4
Negotiation		Yes	Yes	Yes	Yes	Yes	Yes	6
Collaboration	Yes	Yes	Yes	Yes	Yes	Yes	Yes	7
Play	Yes	Yes						2
Timalation								0
Celebration								0
Relaxation								0
Validation		Yes	Yes	Yes				3
Holding			Yes					1
Facilitation			Yes	Yes		Yes	Yes	4

Reliability calculations

Inter-rater reliability was calculated for overall agreement across the conversations and elements, and for each of the elements individually. Overall percentage agreement in rating each talking turn for the presence or absence of the Kitwood categories was 93.7%, and when adjusted for Cohen's kappa was 0.9. Percentage agreement on rating each of the individual elements is shown, for the negative and positive elements respectively, in tables 12 and 13 below. Agreement for each of the identified elements ranged from 50% to 100%. The agreement ratings in these tables only refer to positive identification of the categories, i.e. they only refer to the talking turns where one or both of the raters identified Kitwood's categories, and do not include the talking turns where it was agreed each element did not appear (the overall percentage agreement above includes the talking turns where elements were identified, but also those turns where no elements were observed).

Table 12: Reliability calculations for each of the negative elements identified in the conversations

Element	Number of talking turns where identified	Number where raters agreed	Number where only one rater rated	% agreement
Disempowerment	3	2	1	67%
Infantilisation	14	5	9	63%
Stigmatisation	2	1	1	50%
Invalidation	11	8	3	73%
Banishment	1	1	1	100%
Imposition	7	5	2	71%
Accusation	4	3	1	75%
Disruption	20	16	4	80%
Mockery	3	2	1	67%
Disparagement	37	33	4	89%

Table 13: Reliability calculations for each of the negative elements identified in the conversations

Element	Number of talking turns where identified	Number where raters agreed	Number where only one rater rated	% agreement
Recognition	14	14	0	100%
Negotiation	19	16	3	84%
Play	6	3	3	50%
Validation	4	2	2	50%
Holding	9	7	2	78%
Facilitation	22	18	4	82%

The following sections detail each of the elements which were identified in the couple conversations, with examples from the data, and proceed to further discussion of the elements. Lists of all the identified examples of each element are contained in Appendix 7. These lists, and the examples used in the following descriptions, were produced after discussion and represent the consensus reached by the two raters. It is important to note that the following descriptions represent the interpretations that were made by the raters, and, though presented as specific extracts, were considered within the context of the entire conversation each couple had. It is also important to acknowledge that some of the findings were likely to be a product of the conversational task, and this is discussed further in the following chapter.

Negative interactive elements

Disempowerment

Within three of the conversations there were examples of disempowerment occurring, with the spouses of the people with dementia appearing to disempower the people with dementia. This involved the spouses not allowing the people with dementia to make a contribution or complete an action which they would be able to with the input of their spouse.

In the following extract Edward completely disregarded the fact that Elizabeth had started to say something and decided to end that task and call the researcher back into the room, not allowing Elizabeth to make the contribution to the conversation which she wished to:

> *Edward: Yes, oh yes we've got to go downstairs and do some washing, yes we have, yes you're right you're right there we must go and do that washing. Erm what else?*
> *Elizabeth: Or if not we could do it tomorrow.*
> *Edward: No no we'll do it today. Erm, right that's it.*
> *Elizabeth: We'll take the...*
> *(Edward gets up and goes to get researcher)*
> *Edward: (Directed to researcher) Okay luvvie.*

In the next example Ann made a comment about asking for Ahmad's help in getting some shoes from the shops (as she earlier said that she has forgotten how to get to the shoe shop). Her statement suggests that Ahmad is failing to help her carry out actions she has asked for help with, and his comment following her request is also disempowering in that he completely disregarded her request, and suggested something which she has already said she is unable to do:

> *Ahmad: I see, okay then, err (laughs) what about going and buying yourself a pair of shoes, you have been telling me that you need to buy a pair of shoes.*
> *Ann: I asked you to come with me and you haven't done it yet, so I I haven't got any shoes.*
> *Ahmad: (over-talking) Why don't you go yourself?*

Infantilisation

Four of the spouses also made comments and acted in a way which seemed infantilising towards the people with dementia. At times the spouses talked to the people with dementia in a way which seemed to place the person with dementia in an inferior role, as if they were a parent speaking to a small child, either through the questions they asked or the way they responded to their partners. For example, in the following extract Ahmad responded in what seems like a rather patronising way to Ann's comments about a strategy she has developed to help cope with her memory difficulties, and furthermore then goes on to test her on another aspect of her memory:

> *Ahmad: ...Do you forget the day you have to bath?*
> *Ann: No because I write it in the book.*
> *Ahmad: That's very good, that's very good. And your hair wash?*

In another section of the conversation between Ann and Ahmad, Ahmad insisted on asking her to spell words, which is reminiscent of the kind of thing a parent might do with a small child. Even more patronisingly, although she correctly spelt the words, he then decided to make the task easier:

> *Ahmad: Yeah. Okay let's ask you smaller words. Spell chaos.*

Betty also makes a comment which seems patronising towards Bill, and which seems to completely disregard his concerns. In this extract Betty brought up Bill's attendance at a day centre which she knows upsets him, but she does so in what seems to be a patronising way:

> *Betty: ....ahhh, now this (name of day centre), 'cos this is what we have a little go about don't we.*
> *Bill: Yeah. Well I think it's a waste of time.*
> *Betty: Well you only go for four hours, four five hours, and it is not just to take a blood test, it's to to observe you so they can work out exactly what is wrong. Nothing to do with just a blood test.*

Throughout the conversation between Edward and Elizabeth, Edward appeared to treat his wife in a very childlike way, as if she is incapable of making decisions for herself. Taken on their own, some of the extracts between Edward and Elizabeth could be seen to represent caring interactions, however the interpretations presented here have been made considering the context of the entire conversation, as well as the tone of voice used by the speakers. In the following extract Elizabeth gave an answer but Edward insisted on checking this with her, as if her first response could not be trusted:

> *Edward: You'll have a fish ball, right, okay then. Erm, is there anything else you want to do today?*
> *Elizabeth: Not particularly.*
> *Edward: Nothing else, sure.*
> *Elizabeth: Yeah.*
> *Edward: Now you're positive?*

Stigmatisation

One of the spouses made a comment which was interpreted as stigmatising. Ahmad opened up the conversation with this question, which immediately identifies Ann as having problems, and being unable to do certain things:

Ahmad: Hello Ann so what is your memory problems now? Let me know.
Ann: Well, erm, I don't remember the names of all your friends, that's my main problem.
Ahmad: Yeah.

Invalidation

During the conversations three of the spouses appeared to respond to their partner in what could be seen as an invalidating way. This involved overlooking the subjectivity of the other person, either by completely contradicting what the other person was saying in terms of what they can do, or how they felt, or failing to respond to the comments the other person made about how they were feeling, or the subjective concerns that they raised. In the following extracts Ann tried to tell Ahmad that she cannot answer his questions because she cannot remember; however, Ahmad completely disregarded this and insisted that she can remember, contradicting what she has said on two occasions:

Ann: (over-talking) Well I don't remember that actually.
Ahmad: You do!
...
Ann: I don't remember that actually.
Ahmad: You do!

In the following example Bill talked about being unable to sleep, suggesting he has some concerns. However Betty stopped his line of conversation and completely ignored the issues he was raising:

Bill: I mean I toss and turn in bed, and.... you know I...
Betty: Yeah....well.....not much more really I can say on this.

In his conversation with Doris, Donald failed to validate much of what she said. Right from the beginning of the conversation he completely overlooked Doris's feelings in order to get on with the task:

> *Doris: You know I hate things like this.*
> *Donald: Yeah..well it's only research Doris. If it helps other people that's the main thing. Innit. Eh? Well I mean how's your... What I'm saying is how...do you think your memory is now?*

In another example Doris stated that she feels the same as she always has; however, Donald then made a comment which again disregarded this. He suggested she was wrong and that she cannot possibly still feel the same:

> *Doris: I still feel the same.*
> *Donald: No, I mean at this time....now you're losing your memory...how do you feel?*

Banishment

One of the spouses made a comment which was suggestive of banishment in that it seemed to exclude the person with dementia. In the following extract Donald used the term "we" in a way which linked himself with the researchers and separates both from Doris, as if Doris has been excluded in some way, and she is the subject to be tested:

> *Doris: I'm losing my memory.*
> *Donald: I know you're losing it, and errrr **we** want to see how what you can remember at the moment.*

Imposition

Three of the spouses appeared to show imposition within their conversations, and imposed their interpretation of the task and their chosen subject matter on the people with dementia, often leading them to force a person to talk about a subject they have said they are reluctant to talk about. In the following extracts Ann and Doris stated that they do not know the answers to questions asked yet their partners continued trying to get them to answer their questions. In the example between Doris and Donald, Doris has already explained that she does not want to continue taking part, yet Donald kept on asking questions despite her protests, and imposed on her his interpretation of the task which has been set:

> *Doris: I don't know how is my memory.*
> *Donald: Well, I mean, can you remember anything now? Is it long ago or recent time?*

Similarly, Ahmad kept pressing Ann for the answer to a question which she stated she does not know the answer to:

> *Ann: I don't know but I don't pay any attention...*
> *Ahmad: (over-talking) Well you watched the news.*
> *Ann: I pay no attention to what the government says.*
> *Ahmad: But you watched the news, the news, the, John Prescott was in the parliament and and you commented...*

In another example of imposition, Ahmad asked Ann if she wishes to ask him anything. He then allowed her to lead the conversation for two of her talking turns before turning the conversation back to a discussion of her memory problems, and testing her memory, once again imposing his interpretation of the task on her:

> *Ahmad: Well what do you think had happened happened to my father?*
> *Ann: No I won't draw that one. It just came into my mind all of a sudden.*
> *Ahmad: Alright then, well you tell me how many pairs of glasses have you got?*

In the conversation between Edward and Elizabeth the entire subject matter (talking about the day ahead) was imposed by Edward, who, by asking constant questions about the day ahead, allows no room for any other topic to be spoken about. He also imposed on the conversation by deciding when it will end:

> *Elizabeth: Or if not we could do it tomorrow.*
> *Edward: No no we'll do it today. Erm, right that's it.*

Accusation

One of the spouses without dementia made an accusatory comment towards her spouse, blaming and accusing him for his actions, which have arisen from a concern. Betty accused Bill of keeping asking questions about her whereabouts when his family come to take care of him:

> *Betty: Yeah you say this Bill but even when they've been here its urr "what time's she coming back?", "when's she coming back?" you you you can't do that. What is your fear of me going out?*

Two of the people with dementia made accusatory comments towards their spouses during the conversations. In the first of these extracts, Ann accused Ahmad of failing to help her get some shoes:

> *Ahmad: I see, okay then, err (laughs) what about going and buying yourself a pair of shoes, you have been telling me that you need to buy a pair of shoes.*
> *Ann: I asked you to come with me and you haven't done it yet, so I I haven't got any shoes.*

In the second example, Doris accused her husband of failing to take her out, something which she has previously said she enjoys:

> *Doris: But you getting now, you don't take me out anymore.*

Disruption

During the conversations three of the spouses disrupted their partner at times, either through over-talking their partner's attempts to speak or disrupting the direction of conversation that the other person wished to take. In the conversation between Ahmad and Ann this was shown when Ahmad over-talked Ann's attempts to speak, often in order to continue with a different line of conversation or questioning:

> *Ann: (Over-talking) I warn I warned these ladies...*
> *Ahmad: (Over-talking) Let me ask you you were good in spelling, let me ask you if you remember how to spell jeopardy.*

In other conversations the spouse disrupted the other person by changing the direction of the conversation, and not following the line of conversation of the other person:

> *Bill: But as I say it's ummm...*
> *Betty: Should have put this on first thing in the morning when you was asking me all them questions...*
>
> *Doris: When we were married, in the young...*
> *Donald: Yeah, well we're not know, we're old now Doris:, and errr your losing your memory and they want to know how far it's gone, I s'pose.*

Three of the people with dementia also disrupted their partners at times during the conversation. This seemed to serve a different purpose from the disruption shown by the spouses. Whereas the spouses seemed, at times, to use disruption to bring the conversation back to the task (as they had interpreted it), the people with dementia seemed to use disruption to avoid talking about certain elements of conversation, to keep talking about elements they wish to focus on, or to make a point and dispute what their partners had said. For example Ann used disruption to clearly dispute what her husband said:

> *Ahmad: Very good. What about sometimes you lose your glasses and things like that. Why don't you...*
> *Ann: (over-talking) I've never lost my glasses.*
> ...
> *Ahmad: (over-talking) No but sometimes you take it off to say powder your err err nose.*
> *Ann: (over-talking) Rubbish I reject that totally, 'cos I can't see without my glasses. The first thing I do in the morning is put my specs on obviously.*

In another example of disruption by the person with dementia, Betty tried to air some of her frustrations about Bill's constant questions, and Bill quickly cut in to try and change the subject:

> *Betty: No, you know...*
> *Bill: (interrupts) Oh yeah what's all them plugs over there? What's...?*

In a third example Doris disrupted Donald's reflection to try and keep the conversation focused on her own past and love of dancing:

> *Donald: I was too clumsy.*
> *Doris: I always, if I wanted to go dancing I'd go dancing.*

Mockery

There was evidence of mockery being shown by one of the spouses in the conversations, with the spouse talking to the person with dementia in a humiliating way which seemed to make fun of the difficulties the person with dementia has. Ahmad seemed to mock Ann on a few occasions. Firstly, Ann was protesting about something he has said, and defending herself, and in response Ahmad laughed, and responded in a seemingly mocking way with "I see", appearing to making light of her protests:

> *Ann: I leave the torch on, never*
> *Ahmad: Sometimes, not every time*
> *Ann: Never, never.*
> *Ahmad: I see, okay then, err (laughs) what about going and buying yourself a pair of shoes, you have been telling me that you need to buy a pair of shoes.*

At another point in the conversation Ahmad seemed to mock Ann by making a humiliating comment which implied that though she should be good in spelling she is not:

> *Ann: I was top of the school in English, French and German.*
> *Ahmad: Yeah so you should be very good in spelling then.*

<u>*Disparagement*</u>

Three of the spouses made comments or acted in ways during the conversations which appeared disparaging towards the people with dementia, and implied that the person with dementia is useless or incompetent in some way. Throughout his conversation with Ann, Ahmad continually asked Ann questions trying to get her to "admit" to the things he feels she struggles with. He seemed to be trying to produce a list of her deficits and therefore made comments and asked questions which imply Ann is incompetent in some ways, for example:

> *Ahmad: But then sometimes you forget your dressing gown you took it in the wardrobe and then come and tell me I've lost it and and err and also the jacket you use for washing your hair, yeah? When did you develop this err difficulty? We have to continue because they are recording.*

In other conversations some of the spouses mentioned difficulties and struggles the person with dementia had, but often this was not disparaging because the person with dementia had mentioned their struggles first – in the conversation between Ann and Ahmad, Ahmad wanted to bring up all the deficits and seemed intent on pushing Ann to own up to these despite her protests against this:

> *Ahmad: You also lost your way on the way back to Hampstead.*
> *Ann: When was that?*
> *Ahmad: Same day.*
> *Ann: No, no, I got back alright.*
> *Ahmad: Well you went twice. The second time you found your way out of Hampstead.*
> ...
> *Ahmad: But do you make mistakes and forget for instance to put the fire on and the...*
> *Ann: No never, I have never done that.*
> *Ahmad: Twice you did that.*
> *Ann: The fire. You're the one who left the bloody fire on the other day.*

> *Ahmad: No no, when you were cooking on your own and I was out you forgot the cooking and once you forgot to put the chicken in and the next time you forgot to switch off the electricity so the bottom of the pan was burnt.*

He also continued to push Ann to answer his questions even when she has said she does not know the answer, which could serve to damage her self-esteem and make her feel more incompetent:

> *Ann: (over-talking) The figures? I don't remember the figures. Most people support the strike, most people are quite happy to give money to the strikers, I don't know how much or errr whether they're still doing that.*
> *Ahmad: According to John Prescott just yesterday in parliament said that to increase the salaries of the firemen they have to sack some people. How many did he suggest?*

During her conversation with Bill, Betty made comments that suggest Bill is so irritating that she has felt like murdering him. Although in the second extract she used humour and made a joke about her comments, to imply that she could have killed Bill for his irritating ways does seem disparaging:

> *Betty: Should have put this on first thing in the morning when you was asking me all them questions...*
> *Bill: Yeah.*
> *Betty: and I could have strangled you.*
> ...
> *Betty: Not much else we can say....Except (laughs) well, for the first time I could have murdered you. Nah, I wouldn't do that.*

During his conversation with Doris, Donald also made some comments which seem to imply Doris is incompetent, and which could be damaging to her self-esteem. These included comments relating to the past and their current situation:

> *Doris: (protesting) I used to sing.*
> *Donald: Yeah but not really. You wasn't much of a singer.*
> ...
> *Doris: Ummmmm.....Just...just like to get around and do things.*
> *Donald: No, you can't do a lot now can you.*

Summary of the findings related to Kitwood's negative interactive elements

During some of the conversations both the people with dementia and the spouses showed evidence of some of the negative interactive elements identified by Kitwood. It is interesting to note, however, that the people with dementia and their spouses showed differing constellations of elements. The people with dementia showed evidence of fewer of the negative interactive elements, with only disruption and accusation showing up in the conversations. The spouses showed evidence of greater numbers of the elements, and there was evidence of disempowerment, infantilisation, stigmatisation, invalidation, banishment, imposition, accusation, disruption, mockery and disparagement. The presence of greater numbers of negative elements in the spouses' talk may have, in part, been a reflection of the fact that they often took the lead role in the conversations (reflected in the greater numbers of questions asked by many of the spouses); however, the different constellations of elements remain interesting.

It is important to note that in rating the conversations the decision was taken, for each talking turn, to identify the element which seemed to fit best with what was observed. For some talking turns this was quite difficult and there seemed to be some overlap between some of the categories. For example, disruption and imposition seemed to be closely linked, as did disempowerment, infantilisation and stigmatisation.

A further important finding was that different conversations in different couples yielded very different results, and whilst in some of the conversations there was evidence of many of the negative elements, in three of the conversations there was no evidence of these elements on the part of the spouse or the person with dementia. This would suggest that different processes are operating for different couples.

The next section will focus on a description of the positive interactive elements which were identified in the conversations.

Positive interactive elements

Recognition

During the conversations four of the spouses showed recognition and mentioned attributes, achievements and positive characteristics specific to the other person. For example, Ahmad mentioned Ann's past achievements:

> *Ahmad: O-S you said. Something like that. Anyway C-H-A-O-S. My spellings going as well but my spelling was never good. Don't forget you got a gold medal for English at school, and you did English together with French and German at University.*

Betty and Donald both mentioned past interests of their partners:

> *Betty: You've just actually umm you was loved football or err the racing, boxing.*
>
> *Donald: (Laughs)……Ah, right…Yeah I know you used to like dancing, I know that.*

Charlotte also made reference to things that Clive partners can currently achieve:

> *Charlotte: And that there clearly isn't a whole, aspects of your functioning that are still fine.*

Two of the people with dementia also showed recognition of their spouses during the conversations. Doris recognised that Donald was never good at dancing, and Clive talked about his recognition of how wonderful Charlotte is:

> *Donald: So it's a shame that I wasn't a dancer, wasn't it?*
> *Doris: You never was.*
>
> *Clive: …………….You're marvellous, essential.*

Negotiation

During the conversations six of the spouses negotiated with their partner and consulted them about their preferences, desires and needs. In some of the conversations this involved negotiating over the actual conversation, for example asking whether there was anything the other person wanted to talk about, or whether to end the conversation:

> *Fran: (laughing) I don't know, what would you like to talk about?*
>
> *Betty: ...I think that's about it, don't you?*
>
> *Donald: Is that the finish? You don't want to talk anymore?*

In other conversations there were questions designed to negotiate and ask specific questions:

> *Charlotte: I was wondering for you what feels like the most difficult part of the illness?*
>
> *Edward: Right, where do you want to go today?*

Interestingly the conversation between Edward and Elizabeth consisted of Edward asking many questions aimed at negotiating the activities the two would partake in over the day. However at times these questions had a patronising, infantilising feel (as described in infantilisation above), and as a result some of Edward's talking turns could be viewed as showing both a positive and a negative interactive element. Although he seemed to be negotiating, this was not being done in a way that seemed hugely positive.

Two of the people with dementia were also observed to be negotiating during their conversations. Gill simply checked how her partner was, whilst Elizabeth mentioned and made a statement wanting to negotiate a household chore:

> *Gill: You okay duck? Oh I ain't got me glasses on.*
>
> *Elizabeth: We haven't got any washing to do today?*

Collaboration

Collaboration was operationally defined as being present if both members of the couple agreed to take part and hold a conversation. All of the couples held a conversation; therefore collaboration was evident for all of them. In view of the operational definition and the fact that by its very nature collaboration is a process which must involve two people (at least), this element could not be found in any one talking turn, and therefore could not be rated in the same way as the other interactive elements. However, though collaboration was evident in all the conversations, by virtue of them being conversations, it appeared that some conversations, and some sections of the conversations, were more collaborative than others, with the sense that some of the couples seemed to be working together and seemed much more aligned than other couples. Certainly the conversation between Edward and Elizabeth did not appear very collaborative since Edward led the conversation from start to finish – this is perhaps why his negotiations did not appear as though they were truly positive in their nature. On the other hand some conversations appeared highly collaborative. For example at the beginning of the conversation between Gill and George there was a lovely process where they settled themselves down and checked each other was alright before focusing on the task. There was a sense that they were very much working together:

> *George: Alright?*
> *Gill: You okay duck? Oh I ain't got me glasses on.*
> *George: You want your glasses? Where are they?*
> *Gill: In that room.*
> *George: Alright, hold up (George leaves to get glasses)*
> *Gill: Okay love....Yeah I've read it now.*

The conversation between Charlotte and Clive also seemed very collaborative in that they both contributed in various ways, and together built up a picture of how the situation was for them and how they felt – each listening to what the other person was saying and then expanding on this and presenting their views. This process is demonstrated in the following extract:

> *Clive: In what way?*
> *Charlotte: Well say we're in Yorkshire it takes longer to re-orientate yourself, remember where things are. And, when we go away, particularly abroad, umm...you find it quite difficult to find your way around and it takes, you do eventually but it takes you much longer.*
> *Clive: Yes, yes that's true when I'm away from somewhere and I don't remember that place as well as somewhere I see everyday.*
> *Charlotte: I mean I I sort of ask myself from time to time do I get terribly worried that your Alzheimer's might get much worse and you might get really confused and on the whole the answer I give myself is that I don't think it will happen and I think that it's progressing very very slowly.*
> *Clive: Yes.*
> *Charlotte: And that there clearly isn't a whole, aspects of your functioning that are still fine.*
> *Clive: (jovially) I'm hoping the same. Sometimes sometimes I sometimes I think it is getting worse.*
> *Charlotte: In in what particular way?*
> *Clive: On occasions where I have forgotten something and I've forgotten something, where something was or forgetting things when, my glasses*

> *somehow which I know all people do to some extent, sometimes that sort of things get worse and worse.*

In contrast to this, the conversation between Ahmad and Ann seemed fairly uncollaborative at times, and seemed to descend into battles in which each person was trying to get their own point across or direct the conversation, rather than the two of them being aligned and working together on the task. The following extract highlights this process:

> *Ahmad: You also lost your way on the way back to Hampstead.*
> *Ann: When was that?*
> *Ahmad: Same day.*
> *Ann: No, no, I got back alright.*
> *Ahmad: Well you went twice. The second time you found your way out of Hampstead.*
> *Ann: Well you weren't there.*
> *Ahmad: You told me. Yeah?*
> *Ann: All I remember is that I got back anyway, then I then I, it wasn't really difficult getting back because once I was in Euston I know I knew which direction to go.*

<u>Play</u>

There seemed to be playful exchanges in two of the conversations, which were shown by laughter in both members of the couple, following playful, jovial comments:

> *Ann: Well I don't know what to ask you. When did you last see your, no, that's an old Scottish joke (both laughing).*
> *Ahmad: (laughing) What is it, what is it? Ann: well I don't know what to ask you. When did you last see your, no, that's an old Scottish joke (both laughing).*
> *Ahmad: (laughing) What is it, what is it?*
> *Ann: (laughing) When did you last see your father?*

> *Betty: Right...yeah (as researcher was leaving the room)*
> *Bill: Well don't strangle me (laughs).*
> *Betty: (laughing) What if he strangles me.*

Validation

Three of the spouses validated the experiences of their spouses during the conversational task, and responded to subjective comments of the person with dementia in a way which acknowledged and validated the emotions which were expressed. In the first example Bill expressed a concern that what he wanted to do may be 'illegal' (refusing to go to a day centre). In response Betty acknowledged this concern, and gave him information to try and reassure him:

> *Bill: No, but what umm what happens if I don't go, do I you know am I breaking a law or somethin'?*
> *Betty: No you're not breaking a law because it's to go there is partly voluntary but it's no good you saying ohh you know "why am I like this". They are trying to find out. And if you don't allow, to you it might all seem silly, what they're doing, but it isn't. There's, there's behind each thing they do there's something to find out how your mind is ...so ummm...no-one can make you do anything you don't want to, it's not, you ain't committed to go anywhere, this is all to help you.*

In another example, Clive expressed the aspect he finds most irritating about his memory difficulties, which Charlotte heard, acknowledged, and expanded on:

> *Clive: The irritating thing is shared experiences of something...I can't recollect.*
> *Charlotte: Yes yes I mean I was having similar thoughts in terms of erm you can't for example remember a holiday we've both been on, something like that so....*

Donald also, at times, heard and validated Doris's statements of her feelings:

> *Doris: I don't like being indoors on my own that's why I go out walking with you.*
> *Donald: Yes, I know...*

Holding

In rating the conversations for evidence of holding it was observed that this aspect needed to be rated in some sense indirectly, because evidence of one member of the couple "holding" the experiences and vulnerabilities of the other person tended to be reflected in the talking turns of the other person; that is to say, "holding" on the part of one participant could only be judged to be evident where the nature of the other participant's responses suggested that s/he felt held.

Given this caveat, there was evidence of holding during one of the conversations, in that both members of the couple were able to express difficult feelings or conflicts and expose areas where they felt vulnerable. This took place in the conversation between Charlotte and Clive:

> *Charlotte: I mean I I sort of ask myself from time to time do I get terribly worried that your Alzheimer's might get much worse and you might get really confused and on the whole the answer I give myself is that I don't think it will happen and I think that it's progressing very very slowly.*
>
> ...
>
> *Charlotte: I mean I suppose there is an element certainly of sadness for me and I'm sure for you that things like going to the theatre together, aren't able always to follow the jist.I suppose I see that as quite a loss because you can't, we can't discuss it.*
>
> ...
>
> *Clive: (jovially) I'm hoping the same. Sometimes sometimes I sometimes I think it is getting worse.*
>
> ...
>
> *Charlotte: No no no well you get sort of umm helpless and angry and anxious all at once....and really what I want to do is just takeover and that's fine if you let me (laughing) but you often won't............*
>
> *Clive: It probably is a struggle within me too to try and be in control when I've forgotten.*
>
> *Charlotte: No, I'm sure.*

Facilitation

Four of the spouses showed evidence of facilitation during the conversations, and helped the conversation to fill out, or continue. Sometimes this involved asking the other person questions to allow the 'story' being told during the conversation to develop:

> *Donald: What about urm years ago? You can remember.*
>
> *George: No not really....... (Long silence). Any concerns to discuss?*

At other times this involved encouraging the other person to ask questions, or give their opinions:

> *Donald: So is there anything you errrr want to ask me?*
>
> *Charlotte: No, I'm sure. But I suppose you're meant to be telling me where I'm not at all helpful or your concerns.*

During the conversation between Fritz and Fran the majority of Fran's talking turns were attempts to facilitate the conversation through explaining to Fritz her perceptions of the task, which he repeatedly said he did not understand:

> *Fran: They're doing a research thing into seeing whether specifically they can do anything about problems which arise between couples when one half has some memory difficulty.*
> ...
> *Fritz: I don't know what you are on about. What am I supposed to do?*
> *Fran: Tell me if you find it a problem that you forget things, particularly in interacting between us?*

Two of the people with dementia also made attempts to facilitate the conversation. Bill responded to Betty saying she does not know what to talk about by opening up discussion by means of a question:

> *Betty: ....Umm let's have a look...uhh...right....ok now, don't know what to say really.*
> *Bill: What what was (daughter) wanting this morning?*

Gill also facilitated conversation with George by breaking a long silence with a statement which requests a response:

> *Gill: (following long silence) There's nothing to discuss is there really? Just sort of make do with things don't we.*

Summary of the findings related to Kitwood's positive interactive elements

As was the case for the negative interactive elements, during the conversations both the people with dementia and the spouses showed evidence of some of the positive interactive elements identified by Kitwood. Interestingly, however, the constellations of the positive elements employed were similar for the people with dementia and their spouses, with both of these groups using recognition, negotiation, collaboration, play, holding and facilitation. The only difference was that it was only the spouses who showed evidence of validation.

It was observed that in rating for positive elements there seemed to be less overlap between the different elements, and therefore less decision-making had to be employed in decoding which category applied to individual talking turns. Perhaps the only exception to this was in exploring negotiation and facilitation, as there seemed to be some overlap between the two, perhaps because both involved questions, which at times could both be seen as facilitating additional conversation, or asking for the other person's views and opinions.

Again, as with the negative interactive elements, a further finding was that different couples showed very different results with regards to the type and amount of positive elements seen within their conversations. Encouragingly, all of the couples were observed to show some of the positive elements; however, in some couples these were seen rarely, while in others almost every talking turn contained a positive element.

This chapter will now turn to a consideration of the results in relation to the second research question being asked.

The concerns couples raise with regards to dementia and the impact of memory problems

As mentioned previously, during the conversations the couples, at times, spoke about memory difficulties, but at other times also chose to speak about different topics.

In relation to this research question, IPA was used to identify the themes expressed by participants during their conversations. The process of applying IPA to the conversations between the couples yielded a number of themes which reflected what was talked about in response to the task. Themes were extracted for the people with dementia and their spouses separately, though many of these themes overlapped, as would be expected within a conversation. The themes will be presented in turn.

The analysis led to the identification of nine themes in total. The themes were not mutually exclusive and some of the participants' comments fell into more than one theme. The themes were grouped into three categories, "Talking about the difficulties", "Talking about positive aspects" and "Talking about the task". Each of these categories is presented below with the themes which fit into it. Each theme is illustrated with quotations from the participants, with the identity of the speaker given. An indication has also been given of how common each theme was across participants.

Talking about the difficulties

Within this category are themes relating to the memory difficulties and concerns about these.

Theme One: I can't remember

In this theme, in response to the task, the people with dementia talked specifically about their memory difficulties and what some of their current struggles were as a result of these difficulties. Five of the seven people with dementia mentioned aspects which fell into this theme. The people with dementia spoke about their memory difficulties in a number of ways. Different aspects of dementia seemed to be more of a concern for different people. Ann talked about having difficulties recalling names:

> *I don't remember the names of all your friends, that's my main problem.*
> *The only thing that bugs me a lot is forgetting names.*

For Bill his concern centred around his loss of concentration, and the way this had resulted in him not being able to enjoy some of the activities he used to:

> *I can't concentrate and read a paper, I can't get a newspaper.*
> *I didn't even look at the newspaper, the racing results...*

For Clive his main concern was forgetting, and specifically forgetting things that he and his wife had shared:

> *On occasions where I have forgotten something and I've forgotten something, where something was or forgetting things when...*
> *The irritating thing is shared experiences of something I can't recollect.*

Other aspects that the people with dementia talked about were being unable to find their way, and not wanting to go too far away from home or to unfamiliar places.

Interestingly, only one of the people with dementia, Clive, mentioned the emotional impact of his difficulties, saying they cause him to get agitated and irritated.

Theme Two: You're losing your memory

Here the spouses of the people with dementia also vocalised how they saw the memory difficulties. All but one of the spouses mentioned the memory difficulties in some way during the conversation. The spouses' comments about the memory difficulties fell into a number of categories which identified: what they see the memory difficulties as being, strategies to help, what they perceive the impact is on their spouse, and the emotional and practical impact on them.

Some of the spouses stated what they perceive the memory difficulties to be. This included different aspects, many of which tied in with what the people with dementia talked about. Many of the spouses' mentioned their partners' forgetting – forgetting where they have placed things, forgetting the way, forgetting names, and forgetting during tasks.

A few of the spouses mentioned aspects that they perceived as being helpful for the people with dementia. Ahmad mentioned strategies which he and Ann have devised and suggested some new ones:

> *Writing in the book helps to keep your memory going.*
> *Why don't you practice putting your glasses and torch and things like that also in a bowl...*

Betty talked about the day centre which Donald attends, saying that it is important he goes so that people can observe him and work out what is going on with his memory:

> *If they can't really see how you are, I mean it's like the things they do you think it's all silly but that is to see how your reactions are and how your mind works...*
> *This is something you've got to have, if you don't go they'll say "Well that's it we won't bother with him" and you won't get better will you.*

Some of the spouses also talked about what they perceived some of the effects of the difficulties to be on the people with dementia. For example, there is mention of a loss of interest in previously enjoyed activities:

> *You was, loved football or err the racing, boxing. You're not interested in any of it now are you. (Betty)*

Other aspects which were mentioned were an increase in worrying by the person with dementia, agitation, anger and helplessness:

> *You sort of get umm helpless and angry and anxious all at once. (Charlotte)*

In talking about the memory difficulties, two of the spouses referred to the effects the memory difficulties have had on them, more in emotional terms than in practical terms. For Betty there was a sense of extreme frustration in what she said when she mentioned that she could have "murdered" and "strangled" Bill at times.

Charlotte on the other hand talked about a great sense of loss and sadness:

> *There is an element of sadness for me and I'm sure for you that things like going to the theatre together, aren't always able to follow the gist. I suppose I see that as quite a loss because you can't, we can't discuss it.*

Some of the spouses also mentioned how the memory difficulties have impacted on them in practical terms. Three of the spouses mentioned things which related to this. The changes they mentioned included having to "do work here", and having to "go and find it for you". There was also mention of them needing to have a break because of the pressure of the increase in work and support which they felt they were providing:

> *It's to give me five minutes, give me a few hours on my own. (Betty)*

Three of the spouses spent part of the conversations questioning the people with dementia as to whether they saw any problems in their memory. However the way these questions were worded and spoken suggests they were being asked for different reasons. For example, two of the participants seemed to be asking questions which they appeared to be genuinely curious about:

> *I was wondering for you what feels like the most difficult part of the illness? (Charlotte)*
> *Tell me if you find it a problem that you forget things, particularly in interacting between us? (Fran)*

In contrast, Ahmad seemed to be asking questions to which he already knew the answer, because he seemed to want Ann to spell out what her difficulties were:

> *Do you ever forget names or err numbers or or your way or err a combination?*
> *Do you forget the day you have to bath?*

Talking about positive aspects

In this category the people with dementia and their spouses talked about a number of aspects which were more positive or which normalised their difficulties, as if to counterbalance what is not so good. Themes are split between normalising the difficulties, talking about just getting on with the difficulties, talking about what has not changed, and mentioning past achievements.

Theme Three: I know all people do to some extent

In this theme two of the people with dementia normalised their experience of memory loss through slightly different means – Clive stated that everyone loses their memory, saying “I know all people do to some extent” and Doris talked about her age, saying “I’m too old”, as a justification for not being able to remember things.

Theme Four: I can do

Over half of the people with dementia mentioned what they are still able to do and achievements they have made in the past, as if to highlight that it is not all bad.

Four of the people with dementia talked about what remains intact and how things have not changed. Part of this included minimising the impact of memory difficulties, for example Ann stated that “it doesn’t disturb my daily life actually”, and Doris said that she “still feel[s] the same”. People also mentioned things which are not a problem, saying that they can still do things, and that things they enjoy they have no difficulty with.

Two of the people with dementia talked about the past and their previous achievements. Ann mentioned that she was "top of the school" and Doris talked about the past and her singing and dancing, saying she "could do anything" and that she "loved it".

Theme Five: Aspects of your functioning are still fine

This theme reflects how the spouses of the people with dementia talk about similar things to those their partners had mentioned and that were linked under the previous theme. Again, they talked about what their partners can still do and still remember, and also what some of their past achievements have been.

Three of the spouses mentioned things that their partners can still do and which have not been affected by their memory problems. One of the spouses summed this up:

> *There clearly isn't a whole, aspects of your functioning are still fine... (Charlotte)*

Aspects which were mentioned as remaining intact were remembering familiar places, listening to music, reading, and remembering past times.

Also, as the people with dementia did, some of the spouses talked about the past achievements made by their partners. The two people who did this were, as would be expected, the two spouses of the people with dementia who talked about past achievements, with Ahmad emphasising Ann's successes at school, saying, "You got a gold medal for English", and Donald saying to Doris, "You was a good dancer".

Theme Six: Just sort of make do with things don't we

This theme reflects how the people with dementia talk about day-to-day life and how, to some extent, they just get on with things in spite of their memory difficulties. This extends from Elizabeth who, with her husband, talked about nothing other than the day ahead and their plans for the day, to Ann who stated that the memory problems "don't affect my daily life actually", and Gill who stated that she and George "just sort of make do with things". There is a sense here that things carry on regardless of the memory difficulties and again this seems to relate to minimising the difficulties.

Theme Seven: Where do you want to go today?

Some of the spouses talked about day-to-day activities during the conversation task. As mentioned above the most extreme example of this was seen where Edward spent the entire conversation questioning Elizabeth about how their day should unfold – this was the only topic of conversation between the two of them. Other people spent part of the conversation talking about day to day subjects.

> *Is there anything else you want to do today? (Edward)*
> *You know we're going to___ on Friday, I hope that meets with your approval? (Fran)*

Talking about the task

The final category relates to what the participants spoke about in relation to the research and, specifically, the task they had been given. In this context the people with dementia seemed to be looking to their spouses for guidance in the task, whilst the spouses were trying to respond at the same time as wondering how to proceed.

Theme Eight: What can we discuss?

This theme relates to the task and some of the people with dementia not being sure what they should do, and hence asking for some guidance from their partners. Three of the people with dementia were concerned about this. Issues that they mentioned ranged from not being "used to this" and feeling "very self-conscious" to not knowing what to do or stating "there's nothing to discuss is there really".

Theme Nine: Doing a research thing

In this theme the spouses also voiced concerns about how to proceed with the task, but also made statements as to how they perceived the task as they tried to guide their partners.

As did the people with dementia, the spouses also said that they were unsure what to talk about and that they were struggling with the task; again reasons varied between feeling self-conscious and not knowing what to say. One of the spouses also expressed the view that it was not the task itself but actually having a conversation which felt quite alien:

> *We never did have much conversation because you were busy looking at the sports. (Betty)*

However, in addition, the spouses explained their perception of what the task was and made statements guiding their partners to stick to talking about memory. There were a number of explanations for the task:

> *We are conversing so that these people understand what we forget and when we don't forget. (Ahmad)*

> *Doing a research thing into whether specifically they can do anything about problems which arise between couples where one half has some memory difficulty. (Fran)*
> *What they're after is [reads out task]... (George)*

Summary of what was found in relation to what the participants talked about

IPA yielded a number of themes which related to what the couples talked about during the conversation they were asked to have. These themes related to three broad categories – firstly talking about their difficulties, secondly talking about aspects which had not changed and past achievements, and thirdly talking about the task itself. There were huge variations in how much the couples talked about the memory problems, from those who did not mention memory at all to those whose entire conversation was centred on memory difficulties and their concerns about this. It was interesting that for the majority of the couples who did talk about memory difficulties the conversation was centred around naming the specific deficits that were present (themes one and two). There was very little talk about what were the specific concerns surrounding these difficulties and limited mention of practical and emotional concerns.

It was interesting that for a number of the couples, as well as talking about the memory difficulties, there was a focus on previous achievements and what functions remained intact. The talk of past achievements may have been an attempt to maintain a sense of self in the face of the memory difficulties, though it may also have been a way of emphasising current difficulties in comparison to the successes of their past.

The focus on the task and questions about what should be discussed suggested that many of the couples found this a hard conversation to have. There may have been a number of possible reasons for this. For example, the task may have presented an unfamiliar situation for many of the participants, and talking itself may have been fairly unusual for some of the couples who may not have tended to converse very much generally. The themes relating to the task, with the people with dementia questioning and the spouses showing that they were giving some guidance, suggests the importance of the roles each of them took, with, on the whole, the spouses taking the lead position.

Concerns raised in the individual interviews

The individual interviews were designed to explore with participants whether they found it helpful to discuss concerns with their partner in relation to the third research question. However, during the course of these interviews the people with dementia and their spouses also raised some of their concerns and worries about the memory difficulties. It was of interest that much of what they said had not been mentioned in the conversations with their partners, and this was especially true for the partners who did not have dementia. IPA elicited a number of themes relating to the memory difficulties, and those which stood out as being additional information, and were not also discussed in the conversations, are presented below.

Theme Ten: I'd like to have my old memory back

This theme reflects how the people with dementia talked again about their specific memory difficulties, and what specifically for them caused the most problems, as outlined in theme one from the conversations. Within the individual interviews all the people with dementia, except for Elizabeth, mentioned having difficulties in their memory. Two of the people with dementia also talked about a sense of loss and sadness in relation to the memory difficulties which they had not spoken about with their spouses:

> *It gets me down as well. (Bill)*
> *Doesn't seem possible when I had a good memory like that, just one of those things love... (Gill)*
> *I'd like to have the old memory back... (Gill)*

The sense of loss in these words was not reflected in the conversations that these two people with dementia had with their spouses.

Theme Eleven: The core emotional level

In this theme the spouses of the people with dementia talked about the emotional impact of the dementia on themselves and on their partner. There was little sense of this being mentioned in the conversations at all, but it came up on a number of occasions during the interviews. There was a split between talking about a sense of depression and sadness, and a sense of anger and frustration.

A number of the spouses talked about there being a sense of loss for both themselves and their spouses. A number of them considered this from their partner's perspective:

> *She's not taking part, that makes her, I feel, a bit sad. (Ahmad)*
> *I don't know what it does to her because she is sad already. (Ahmad)*
> *I think this depression seems to run in his family... (Betty)*
> *There are times when Clive will bring something up to do with his Alzheimer's, and I think actually get much more to the core of it than I do, and say something incredibly direct and very painful. (Charlotte)*

A number of them talked about their own sadness or used words which implied a sense of loss and sorrow:

> *It does make me sad. (Ahmad)*

> *It's no compensation. (Donald)*
> *I'd sooner have it, I've got, I've had everything else, I'd sooner have it than her. (Edward)*
> *I wish she would [remember]... (Edward)*

In addition, over half the spouses talked about the frustration they and their partners felt with the impact of the memory difficulties. The majority of them mentioned their own frustration:

> *Eventually I lose my temper and scream... (Ahmad)*
> *It is frustrating because I am seeing to things and I can't keep saying to him he's not to worry because I am seeing to it all... (Betty)*
> *My cool goes and I get very het up and anxious and we get into an escalating spiral... (Charlotte)*
> *I also freely admit that I get absolutely furious. (Fran)*

Just one of the spouses talked about the frustrations of the person with dementia:

> *She has gone very bad tempered. (Ahmad)*

Therefore, in the interviews some of the participants talked about the emotional impact of the memory difficulties, a topic which was seldom raised within their conversations. This would suggest that the couples largely avoided talking about their sense of loss and frustration with one another when talking about their concerns.

Finally, this chapter will consider the third research question.

Whether couples find it helpful to have these conversations

The third research question asked whether the couples found it helpful to discuss their concerns about the memory difficulties. During the conduct of this study it became clear that a further question that needed to precede this one was whether the couples ever talked about the memory difficulties in the first place, as it emerged that for some couples this was a topic which was largely not spoken about, and indeed some did not seem to converse much at all anymore.

These questions were addressed during the individual interviews with the people with dementia and their spouses. IPA produced a number of themes relating to talking about memory difficulties, and about talking in general. These seemed to fit into two categories relating to talking about difficulties and not talking about difficulties. These will be presented below.

Not talking about difficulties

This category will be presented first, since it emerged that the majority of the couples did not talk about memory difficulties and their concerns relating to these. This was true of almost all of the couples. It is interesting to note, however, that, with the exception of one of the couples, all the participants said that they had talked through any other kinds of concerns they had in the past and found this helpful and important.

Theme Eleven: What do we say?

In this theme the spouses discussed not wanting to talk about the memory difficulties and also gave varying reasons for this.

Some of the spouses stated that they do not generally talk about the memory difficulties and so the task presented an unusual situation for them:

> *We don't talk about her memory. (Ahmad)*
> *I've never really spoke to Doris about it... (Donald)*
> *We never really talked about that... (Fran)*

A number of the spouses also talked about the reasons for the lack of conversation about the memory difficulties. Some of them explained the reason as being that their spouse is no longer capable of conversation, saying they have "passed that stage" and they "don't know what you are talking about". Another reason mentioned was that conversations become "repetitive" with the sense that there is no point having these conversations as they will not be remembered anyway.

Other reasons for not talking about the memory difficulties linked more with the reactions of the people with dementia. Some of the spouses said that they do not talk about the memory difficulties or concerns because their partners deny these:

> *She just puts two fingers up to me or goes ahh, you're mad or something like that, that's it, finished. (Edward)*
> *So there's sort of an awareness but not a particular willingness to reflect on it. (Fran)*

Finally some of the spouses talked about how they think discussing the memory difficulties might impact on their partners emotionally. Some stated that it might "hurt" their partners to talk about the difficulties and that they would not talk about them "in front of her". One spouse stated:

> *I don't know whether you should talk to them about it because I think it frightens them. (Donald)*

Theme Twelve: We don't often have conversations

In this theme the people with dementia discuss how they do not generally talk about the memory difficulties and give some of their reasons for this. A number of them mentioned that they have "never really discussed" the memory difficulties, echoing their partners' words; however, the reasons they gave for this were generally different from the reasons given by their partners.

One of the people with dementia clearly said that she is capable of conversation but that her spouse mocks her in a way which prevents her from talking at times:

> *He says I don't have conversation but I do.*
> *He takes the mickey out of me and laughs at me. (Elizabeth)*

Others talked about having never really been great talkers ("it's always been like that") or not finding it "particularly helpful".

A lot of the people with dementia also talked about just having to get on with the situation of having dementia. This seems to involve two elements. Firstly there was the idea that because they and their partner are so used to one another they no longer need to talk about things:

> *When you are living with one another all the time you take so much for granted and, you know, you don't think about it... (Ann)*
> *By the way we carry on he knows my memory is not as good as it used to be... (Gill)*

Secondly there was the idea that there is nothing that can be done about dementia so they just have to get along with it, with the sense that there is no point in talking about it as it is "just one of those things":

> *Well we just, we just get on with it you know. (Elizabeth)*

Talking about difficulties

Although very much in the minority one of the couples talked about how they discuss the memory difficulties.

Theme Thirteen: We certainly do talk about it

Charlotte was very clear that she and Clive often discuss the memory problems and that this is about "sharing" and "acknowledging" difficulties. She talked about how important this is to their relationship:

> *Particularly when Clive's able to name something or really get to the core emotional level, what it's like and what he's afraid of, what he's afraid it might be like for me for example, it's well, it's the essence of what a relationship is about.*

In turn, Clive also talked about discussing the memory difficulties with his wife. He finds this "helpful" because it "brings it up and tries to analyse".

In conclusion it seems that for the majority of the couples the topic of memory difficulties was an avoided area, though the reasons given for this varied from person to person, and between those who had dementia and those who did not.

In the final part of this chapter the main findings of the analyses will be summarised.

Summary of the main findings

- There was evidence of Kitwood's elements of interaction within the conversations. These included positive interactive elements, but there was also evidence of some of the elements identified by Kitwood as potentially contributing to a malignant social psychology in many of the conversations.

- Although all of the conversations contained at least one of Kitwood's positive interactive elements, not all the couple conversations contained evidence of the negative elements.
- There was a different constellation of negative elements found relating to the utterances of people with dementia and of their spouses.
- The majority of the couples talked about memory difficulties in the conversation they were asked to have; however, the main focus seemed to be on producing a list of deficits rather than on what concerns there may have been in relation to these. This contrasted with the individual interviews where participants spoke more openly about some of their emotional concerns.
- As well as discussing the difficulties, in many of the conversations there was also a focus on more positive aspects, such as what the person with dementia could still do and what they had previously achieved.
- The majority of the participants reported that they do not talk about the memory difficulties and gave varying reasons for this. The spouses who do not have dementia talked about their partners being unable to hold conversations, being in denial, or not wanting to upset them, and the people with dementia talked about not talking about the difficulties because they just have to get on with things.

These results will be discussed further in the following chapter, with ideas proposed as to how the results fit with the existing literature and research, what the findings of the current study add to previous knowledge, and how the findings may contribute to supporting people with early-stage dementia and their families.

CHAPTER FOUR

DISCUSSION

Overview of the study

This exploratory, qualitative study was designed to look at how couples talk to each other when one partner has early-stage dementia. In particular it aimed to explore what concerns couples raise with regards to memory difficulties, and how they talk to each other about these. It also aimed to explore whether there is evidence of malignant social psychology, and whether these couples find open communication helpful.

Seven couples, where one partner had early-stage dementia, were involved in the study and each couple was asked to hold a conversation about any concerns they had about the memory difficulties. Following this, each member of the dyad was interviewed individually to explore how they had found having this conversation, and whether they found it useful or otherwise to talk about their concerns with their partner. The data from the conversations and the interviews were analysed quantitatively and qualitatively by using content analysis and Interpretative Phenomenological Analysis. Content analysis revealed that many of Kitwood's negative and positive elements of interaction were present in the couples' conversations, though different patterns of elements were observed in different couples, and there were also differences between the negative elements shown by the people with dementia and their spouses. The themes identified by IPA from the conversations showed that whilst the majority of the couples talked about the memory difficulties in the conversations, the focus seemed to be on talking about specific deficits, rather than a focus on what peoples' concerns about these were. The extent to which the couples talked about the memory difficulties varied largely from couple to couple, with some focusing more on day-to-day issues, and with many of the couples talking about aspects that remained intact and past achievements of the person with dementia. During the individual interviews the majority of the participants reported that they do not openly discuss the memory difficulties with their spouses and a number of reasons were given for this.

The findings will now be discussed in more detail with regards to previous research and theory.

Exploring how couples talk to each other when one has early-stage dementia

The results of this study supported and added to much of the existing literature on dementia, particularly with regards to the dialectical model and social constructionist theory. Again, as in the previous chapter, each of the initial research questions will be taken in turn and explored with regards to what was found in light of existing research and theory.

Is there evidence of Kitwood's elements of interaction in the conversations between people with early-stage dementia and their spouses?

Many of Kitwood's elements of interaction were observed to be present within the couples' conversations. The use of the Kitwood categories in this study shows that these categories can be usefully applied to looking at interactions with people with early-stage dementia, and interactions between people with dementia and their spouses. These are both areas where Kitwood's categories of interaction have not previously been applied, as his categories were devised mainly to look at people in the moderate to severe stages of dementia, in interaction with professional caregivers, as operationalised in the innovative Dementia Care Mapping approach (e.g. Bradford Dementia Group, 1997; Brooker et al., 1998).

Different couples showed very different patterns of elements; for example, whilst all of the couples showed evidence of some of the positive elements not all of the couple conversations contained negative elements, and therefore whilst some of the couples were seen to be creating situations in which there was evidence of a malignant social psychology this was not true for all of the couples. This would seem to suggest that there were different processes operating within different couples. In addition, with regards to the negative interactive elements it was observed that different constellations of elements were shown by the people with dementia and their spouses, again suggesting that different processes were operating in the two different sets of people. Social constructionist theory, as outlined in Chapter One, provides a useful framework for thinking about a possible explanation for the findings in relation to Kitwood's elements of interaction. Sabat (2001) has suggested that a situation of malignant social psychology may arise because of the way the person with dementia has been positioned, and that if a caregiver positions the person with dementia as a patient, and as weak and defective, they are likely then to respond in such a way that a situation of malignant social psychology occurs. One possible model of the results found in the current study based on this theory is that some of the spouses of the people with dementia had positioned their partners as weak and defective and responded to them in a way which reflected this positioning, and therefore showed evidence of the negative interactive elements. On the other hand it appeared that within other couples this positioning had not occurred, and the partners treated each other in more of an equal way, and with no evidence of the negative interactive elements.

This concept of positioning also provides a possible explanation for the finding that the people with dementia and their spouses showed differing constellations of the negative interactive elements. The spouses were observed to show evidence of a greater number of the negative interactive elements, which, based on this model, would be expected as these elements related to having positioned the other person in a lesser role, and having labelled the other person as being defective due to the presence of dementia. Many of the elements which were shown by the spouses but not by the people with dementia seemed to highlight this process, as, for example, disempowerment, infantilisation, and disparagement all seem to be highly related to having placed the other person in an inferior role, and as being defective in some way. Furthermore, the two elements shown by the people with dementia, disruption and accusation, seemed to serve a different function when being used by the people with dementia in comparison to their spouses. Whereas the spouses seemed to use these two elements to keep the person with dementia on task and keep themselves in charge, the people with dementia seemed to show these negative elements when they were trying to get their voice across and be heard. Often this was to interrupt the conversation and turn things around from a focus on their deficits, or, in the case of accusation, to show in some way that they were not the only person who was flawed. Therefore it appeared that in the couples where the spouse had positioned the person with dementia in a weaker role and as defective the person with dementia made attempts to assert himself or herself against this.

The evidence from this study, showing the presence of negative interactive styles, suggests that malignant social psychology can arise early on in the dementia process and is not just limited to the later stages where people with dementia have more extensive difficulties. This finding highlights the need for research to explore the interactions between people with early-stage dementia and their spouses (and others) to try and understand the processes creating the malignant social psychology, and identify possible ways in which the situation could be ameliorated. It is important to note that for some couples there was no evidence of any of Kitwood's negative elements of interaction, which suggests that the processes which lead to the creation of a malignant social psychology, hypothesised here to arise because of positioning, are not inevitable in all couples, which would suggest that ways to prevent this process from occurring are possible.

It was also observed that whilst many of Kitwood's interactive elements were observed to be present within the conversations there were a number of elements for which no evidence was found. This may, in part, have been due to the fact that this study was based on a limited sample, so that further research may reveal the presence of more of these categories, however it also appeared that some of the categories were not present because they were not very applicable to people with early-stage dementia conversing with their spouses. Objectification, ignoring and withholding were all absent, all of which seemed to refer to not treating the other person as human and not responding to them – by the very fact all the couples had a conversation the presence of these elements would seem to be excluded. Treachery was also absent; however, this would be very hard to assess in that it would be impossible to know for sure whether one partner was lying or not. Finally, in relation to the negative elements no examples were found of labelling. This was interesting since it appeared that many of the findings, and the presence of the negative elements seemed to be due to a process of labelling of the person with dementia. Therefore, although there were no direct labels applied during the conversations labelling would seem to represent a process which could be hypothesised, based on the model suggested here, to have taken place between all the couples for whom there was evidence of Kitwood's negative interactive elements. In terms of the positive elements, the absence of evidence of timalation and relaxation seemed to be a reflection that these primarily refer to the senses, and to behaviours which could not really be measured or observed in tape-recorded conversations, whereas the absence of celebration was likely to have been more a response to the nature of the task, which meant there was a focus on concerns.

The concerns couples raised with regards to the dementia and impact of memory problems

Within the conversations many of the couples talked about the memory difficulties; however, very few actually spoke about the impact of these and their specific concerns, and instead there was a tendency to just list what deficits were present. We know, from previous research, that dementia has a huge impact on peoples' lives and can lead to a number of negative aspects for both partners (e.g. O'Connor, 1993; Bull, 1998) so it is interesting that many of the couples avoided these topics in their conversations with each other. It could have been suggested that perhaps in early-stage dementia there are fewer aspects of concern for people with dementia and their spouses as many functions remain intact and deficits are less than in the later stages of the illness. However, in the individual interviews there were a number of concerns and emotions which were raised which had not been raised within the conversations, for example talking about a sense of sadness and frustration about the dementia. Again, it was interesting that the participants would often talk about their concerns with the researcher but chose not to talk about these with their spouse. There was also, within the conversations, a tendency amongst many of the couples to talk about issues other than the memory difficulties. One of the couples avoided the topic of memory difficulties altogether by talking about the day ahead, whilst others spent more or less time talking about aspects unrelated to the memory difficulties. In other couples there was a tendency to talk about more positive aspects, for example what aspects had not changed with the impact of memory difficulties and what some of the people with dementia had achieved in the past. These seemed to be a way of avoiding talking about the memory difficulties or counterbalancing some of the more negative issues which surrounded the memory difficulties. It would seem here that couples were fluctuating between the coping strategies which have been identified in previous research relating to individuals with dementia (e.g. Clare, 2002a; Pearce et al., 2002). Within the conversations there seemed to be a tension between facing up to the difficulties and talking about the concerns, and talking about aspects which avoided the topic of memory difficulties, which would seem to be an attempt to preserve self-esteem. It seemed that the couples varied in how much they mirrored each other with regards to the use of strategies aimed at avoiding the topic of memory difficulties; at times, both members seemed to collude together and avoid talking about the difficulties, whilst at other times it appeared the spouses with dementia would try and encourage their partners to talk about the memory difficulties.

An interesting feature was that the level of denial shown by different participants again seemed to link with the way that they were positioned within the conversations, particularly in relation to the people with dementia. It is important to note here that in using the term denial it is not the intention to imply that the people with dementia were not aware of their difficulties themselves; though unawareness may have a neurological basis in some circumstances, this was not felt to be the case for the people with early-stage dementia who took part in this study since all but one of the people with dementia made comments either within the conversations or the interviews in which they talked about having memory difficulties. The term denial as used here then generally refers to attempts by the person with dementia to deny their difficulties to *others* (to their spouse). This aspect is discussed in more detail below.

In thinking about a possible model to explain the findings in relation to what was talked about during the conversations it is again useful to think about social constructionist theory and Sabat's ideas about positioning in relation to dementia. As mentioned above, the existence of the negative elements which contribute towards a malignant social psychology have been suggested by Sabat to arise when the caregivers of people with dementia position themselves as the stronger person with their partners being seen as weaker, a positioning which seemed to be occurring within many of the couple conversations in this study. In response, the way in which the people with dementia seemed to position themselves seemed to fluctuate in response to where they were positioned by their spouse. It appeared that the more they were positioned as the weaker partner within the conversation the more they tried to position themselves as an equal and would try to deny their memory difficulties and present the appearance of being normal. The more the people with dementia were categorized by their spouses the more they tried to fight against this. This was shown through what they would say, with a focus on what remained intact, and a denial of difficulties. During the conversations many of the people with dementia tried to turn the conversation away from their difficulties to a focus on what was intact, and this may have been an attempt to get their spouses to place them in a different position, i.e. not just as a defective person.

Therefore, for the people with dementia, being positioned in an inferior role seemed to lead to a need to prove their normality in some way or accentuate positive aspects of themselves as a way of holding on to a positive identity, whereas the people who were given a positive identity by others, as more of an equal partner, were able to talk explicitly about their difficulties.

This possible model adds to the models of individual coping which have been developed (e.g. Clare, 2002a; Pearce et al., 2002) as it would seem that one factor in affecting the coping styles developed by an individual would be the way they are positioned by those around them, particularly their spouse. In other words, the social context the person with dementia is in will affect whether s/he faces up to the dementia and try and incorporate it into his/her existing picture of self, or whether s/he tries to minimise or deny the difficulties. Clare (2003) has developed ideas about awareness and denial in dementia and suggests that denial, or unawareness, is not a symptom of early-stage dementia, which it has been conceptualised as in some medical research and models, but is a possible response which may be shaped by pre-existing psychological factors and social factors, which include relationships. The current study supports the notion of the impact of social context in shaping a person's response to having early-stage dementia, and suggests that acceptance and adjustment to memory difficulties are largely influenced by the way the person with dementia is positioned by those around them. Therefore, it would seem that as well as people's individual coping styles affecting the way people will cope together as a couple, the way they interact as a couple will also affect how they will cope as individuals.

The other themes to emerge in looking at the transcripts of the conversations centred around the task itself, with some of the people with dementia asking for guidance about how to proceed with the task, and the spouses providing this guidance and presenting their interpretations of the task. These findings seemed to follow some of the ideas of Shakespeare (1998) who found that some 'confused' speakers had little involvement in the development of conversational topics, and that, for some, topic progression largely depends on the input of 'normal' speakers. This may also account for the large proportion of questions generally asked by the spouses of the people with dementia, which could often be seen as attempts to generate conversation, and keep the people with dementia to the spouses' perceived interpretation of the task. For some it seemed that the people with dementia were asking for their partners to manage the conversation, and for others it seemed that the spouses assigned themselves this task (not all of the people with dementia showed concerns about what to discuss, yet most of the spouses took the lead role in the conversations and made attempts to direct the conversation). The role that many of the spouses took, to develop the topic of conversation, may also go some way to explaining some of the findings of the content analysis. For example there are times when the spouses disrupted their partner, or made some invalidating comments when they felt their partners were not keeping to task. Therefore it must be acknowledged that the task, and the spouses' attempts to develop the topic may have played a role in some of the findings, contributing towards the observation of some of the Kitwood categories.

Whether couples find it helpful to have these conversations

The last of the questions looked at whether the couples found open communication helpful with regards to memory difficulties. The majority of the couples said that they did not often talk about the memory difficulties, and the IPA analysis produced a number of themes which related to why the couples did not engage in these conversations. For the couples where there was evidence of Kitwood's negative interactive elements, the spouses who did not have dementia gave reasons such as that their partners were no longer capable of conversation or that their partners may not be able to cope with these conversations. This would fit within a model which suggests that these spouses had positioned the people with dementia as being weak and defective in some way, and fitted with Kitwood's (1990) idea that one of the reasons dementia can create a situation of malignant social psychology is that there is a tendency not to recognise people with dementia as persons and as having value and capability. This idea was encapsulated by one of the people with dementia who gave one of her reasons for not talking as being because her husband took the "mickey" out of her. There also seemed to be the sense, in some of the reasons given by the spouses without dementia, that there was a risk of harming the person with dementia more by discussing their difficulties, as highlighted in previous research (Dunkel-Schetter & Wortman, 1982). However, for the couples where they consistently appeared to position each other as more equal partners, and there was no evidence of Kitwood's negative interactive elements, there were different stories about talking or not talking. For the three couples to whom this applied, one of the couples stated that they openly communicated about the difficulties and found this helpful, while in another couple there was open communication but also a sense that they just had to get along with things, and the third couple talked about having never spoken about their concerns with one another in the past, and so that it was not the presence of the memory difficulties which stopped them discussing their concerns about these.

The finding that few couples discussed their concerns about dementia or found this helpful contrasts with previous work exploring support and open communication in couples more generally. For many illnesses open communication has been shown to have positive effects and can promote well-being (e.g. Pistrang & Barker, 1995). It would seem that one possible explanation for this contrast may lay, again, in the way that the people with dementia were positioned by their spouses. For the couples where the person with dementia was positioned as defective, talking about the memory difficulties would not seem appropriate for the spouses who did not feel their partners were capable of such discussions, or worried that it might damage them more. For the people with dementia open communication would pose the threat of leading them to be labelled as defective even more and this is an aspect they seem to be battling against.

It would seem, therefore, that acceptance and openness in people with dementia and their spouses might be fostered by reducing elements which may contribute to a malignant social psychology. If this could be reduced and open communication encouraged then some of the benefits of support which have been shown in other illnesses may occur for people with dementia; in particular there may be a better sense of well-being and, indeed, a process of *rementia* may occur, as demonstrated in the case of people with more advanced dementia when there are positive changes in their social environment (Sixsmith, Stilwell & Copeland, 1993). On the other hand, for the couples where the person with dementia is positioned primarily as "patient" and the spouse primarily as "carer", the resulting interactions and roles will reduce the well-being of both partners, with, for the spouse without dementia, the perceived loss of their partner, and for the person with dementia, the loss of role.

The concept of positioning

The tentative model which has been proposed here suggests that the way that the people with dementia were positioned was central to determining which of Kitwood's elements were present within the conversations, what the couples would talk about, and how open they were about their concerns, or how much there was evidence of denial. It is helpful here to think of Sabat's model of self (e.g. Sabat, 2001), as previously described in Chapter One, to further outline a possible explanation for this. On receiving a diagnosis of dementia and experiencing memory difficulties a person is faced with the challenge of incorporating these new features into his or her existing picture of self (Self 2) and combining this with his or her previous history and attributes. In this study one of the important self-attributes would be as a husband or wife. Within the marital relationship the person with dementia will try to continue to act as a wife or husband (Self 3), but will need the interaction of their spouse to achieve this. If their spouse treats them now as a diseased entity rather than as a shared partner then it would seem natural for the person with dementia to assert him or herself and employ techniques to try and re-establish him or herself in the previous, more desirable role, and minimise the unwanted part of themselves with respect to which they are being labelled. The more they are labelled the more they will attempt to have their voice heard. However, on the other hand, if the spouse of the person with dementia still treats them as a husband or wife within more of a shared partnership then it is more likely that the memory difficulties will be able to be incorporated into the picture of self and there would be more willingness to discuss the memory difficulties and any concerns. This supports some of the notions of Cheston and Bender (1999b):

> "The task of the person with dementia, then, is to position themselves within relationships in a way that allows them to assert a continuity with the past and to continue to be seen as the person that they have been. By creating positions for themselves within the world that are consistent with valued aspects of their lives, people with dementia can create an identity for themselves which can accommodate the existence of the illness without being overwhelmed by it"
> (p179)

The creation of a malignant social psychology

It is important to note here that I am not suggesting that the contribution to the development of a malignant social psychology is intentional in any way, just as Kitwood (1990) emphasises that there is "no suggestion here of a general pattern of conscious, deliberate, malicious intent of the part of family members" (p.186). Social constructionist theory highlights the importance of the construction of society and indicates that "'society' gives us our various and varying roles and the accompanying roles" (p21, Harding & Palfrey, 2001).

Within UK society the dominant model of dementia still remains the medical model, with dementia viewed as a disease. Though this model is beginning to be challenged, it is likely that within general society the medical model still dominates. Alongside the concept of dementia being a disease has been the idea of people with dementia not being able to communicate and being defective and weakened by the process of dementia. Furthermore it is a relatively short time since the emergence of anti-dementia medication and the development of a focus on early detection and diagnosis. Therefore, another aspect which is lacking is a picture or model within society of early-stage dementia. The images that many people may have in their minds when thinking of the illness may be images of those in the later stages of dementia where impairments are greater. These images, certainly, were those that I held before embarking on this piece of work and coming into contact with people in the early stages of dementia. If the only models and pictures that people have are of a disease which leaves people unable to communicate and significantly impaired then it is perhaps of very little surprise that people with early-stage dementia will be positioned in undermining ways as has been found for some of the participants in this study. These images that society gives us may be held by the person with dementia and their spouse, and it would appear that the more the partner without dementia transfers these pictures onto their partner the more the partner, who may not feel as disabled as these images would suggest, will deny their difficulties in an attempt to maintain their feelings of self worth. It is not surprising then, that in the couple where there was open communication and an absence of malignant social psychology, their occupational backgrounds meant that they were educated about dementia, and advances in dementia, and in the benefits of open communication (they were a doctor and a therapist).

It is also important to note that although in early-stage dementia the impairments are less than those in the later stages there are, nevertheless, some significant impairments, particularly in the realm of communication (e.g. Morris, 1999). Previous research has highlighted this as being one of the biggest difficulties which the spouses of people with dementia have identified (e.g. Chesla et al., 1994; Hendryx-Bedalov, 2000). We cannot doubt that at times it is frustrating living with people with dementia, and there are many practical and emotional difficulties which have to be contended with by caregivers, as has been found in previous research (Zarit & Edwards, 1999). A sense of frustration was a theme that was echoed by many of the participants within this study. With this increase in frustration it would be very difficult not to, at times, be guilty of negative interaction and creating a malignant social psychology. In conducting this work I found that conversation was sometimes difficult, as has been found by previous researchers (e.g. Shakespeare, 1993). In transcribing the interviews with the people with dementia I was appalled to see how, on a number of occasions, I seemed to have missed some of the messages they were giving me and had not picked up on some of their concerns. Therefore, I too was guilty of some of Kitwood's negative elements. It would seem that at times it is hard not to inadvertently position the person with dementia as being in a weaker position in some way because of some of the changes that occur in their communication, and also the challenges this creates for people wishing to communicate effectively with them.

Therefore we need to be careful not to lay blame with the spouses of people with dementia and accuse them of intentionally creating negative conditions and positioning their partners in an inferior role since, for the large part, it would seem that this process emerges from society's views of dementia, and from the difficulties in communication, and other caregiving demands, that the process of dementia creates.

Methodological considerations

The following section focuses on the limitations of this study and the appropriateness of the conclusions.

Limitations of the study

There are a number of limitations which mean that the results of this study need to be considered with some caution. Firstly, there are some issues relating to the design of the study. The couples were asked to have a conversation with a prescribed focus which meant that the resulting conversations were not naturally occurring. Some of the results could perhaps, at least in part, be attributed to the task which was set. For example, the person with dementia generally being the focus of the conversation and the list of deficits which was produced by some couples may have been a reflection of the task, which asked people to talk about their concerns about the memory difficulties. Furthermore the way the task was designed with the couples asked to talk about the difficulties being experienced by one of them meant that the people with dementia were automatically placed in the position of having problems, and as being inferior in some way, which may have impacted on the conversations and interviews and led to some of the results which suggested that they were positioned as defective. Although the study was designed to have value in aiding our understanding of the ways in which people with dementia and their spouses talk about dementia, we cannot be sure how much these conversations represented naturally occurring conversations. The presence of the tape recorder and the researcher may also have made people feel uncomfortable and self-conscious (as highlighted by some of the participants) and therefore may have made it more unlikely that these conversations would replicate what would occur naturally. However, despite this, it would seem that the extent to which the people spoke about the memory difficulties in their conversations was generally supported by what they said in the individual interviews, i.e. those who said that they rarely talked about the memory difficulties spoke less about these and showed more attempts to avoid these in their conversations than those who said that they did talk about the difficulties. In addition it could be hypothesised that by being told that the research was being conducted to look at how couples talk to each other and what support they might provide to one other there would have been a bias on the part of participants to be seen in a positive light. It would therefore seem unlikely that they would show signs of negative interactions during this process if these were not an aspect of their normal communications. Furthermore the fact that different processes and results were observed in different couples, particularly the finding that not all the couples showed evidence of Kitwood's negative interactive elements, would suggest that the task set and the design of the research could not be accountable for all the results. However the limitations in the design of this study mean that the conclusions and hypotheses can only remain tentative, and further work would be required to provide additional evidence for their validity.

A second limitation is that this study only explored the interactions of these couples at one point of time, and following the diagnosis of dementia. Although some information was gained during meeting with participants which gave some insight into the quality of their relationships prior to the development of the memory difficulties, it is hard to gauge a real sense of what the history of the couples' communication is, and the types of communication seen may have reflected long-standing patterns of interaction. Although most of the couples reported having previously being in happy relationships, and things having changed greatly since the onset of dementia, it would be impossible to be sure that this was indeed the case, as this is reliant upon self-report. Therefore it may have been the case that had we met with these couples before the onset of dementia much of what was observed may have been present beforehand, for example it may have been that some of couples who showed evidence of Kitwood's negative interactive elements may have always shown similar interactions, for example some of the spouses without dementia may have always treated their partners in disempowering ways.

A further limitation, as highlighted by various methods within qualitative research, is that it was the same researcher who both collected and analysed the data, and therefore throughout this process there was the threat of the biases of the researcher affecting the results. Various methods were employed to try and combat this. In the content analysis, two people were involved in independently rating the conversations. For the IPA, each stage of the analysis was discussed with a supervisor, and reflective memos were kept and discussed in order to try and keep a check on any biases that may have affected the interpretations of the data. However, it would be impossible to entirely rule out that biases may have influenced the data collection and analysis. My own biases may have played a part at all stages of this study. For example in the design of the task which asked people to have a conversation about the memory difficulties there was an assumption on my part that married couples would discuss their difficulties (be these related to memory or other issues). Throughout, there was also the thought, and hope, that couples would discuss their difficulties and would find it helpful to do this. This may have affected the analyses in that there may have been a bias towards seeing those couples who discussed their difficulties in a more favourable light, and to have a more critical stance when it came to those who were more reluctant to discuss the memory difficulties. This bias may also have had an effect in that it may have made me, unconsciously, more or less favourable to participants when conducting the research. This may have been reflected in my behaviour and therefore may have made people more or less willing to engage in the task and talk about their communication with their spouses. However, though these biases may have played a part they are biases which are supported by the literature on couples (e.g. Cutrona, 1996) in that for the large part it has been shown that it is helpful for couples to discuss their difficulties, and that many couples do this. Furthermore, in terms of the biases playing a role when with the participants, the study was conducted in the presence of a second researcher who would have made comments had she noticed any differences in my response to different couples. The presence of the second researcher also allowed for additional reflection as a result of her observations, and this was a strength of the study.

Part of the bias in expecting couples to openly communicate their concerns and have an equal relationship may have arisen from my age and occupation. I am of a relatively young age and brought up in a generation where talking about problems is generally encouraged and seen as an important method of dealing with difficulties. I am also entering the profession of clinical psychology where there is a huge emphasis on talking. In contrast, the participants in the study were from an older generation who, it is likely, have received different messages. Many of them would have been brought up within the culture where it was considered important to retain a "stiff upper lip". People were not encouraged to talk through problems and there were well-defined gender roles. There is a potential danger in trying to transfer the messages of one culture onto another, and the absence of open communication in the sample may be as much a reflection of their culture and generation than a result of the positioning of people with memory difficulties. However, again there were various ways of trying to deal with this. Firstly, there was discussion with a supervisor at all points in the design, conduct and analysis of this study. The supervisor involved was of an older generation than the researcher and so the research was not only designed from the point of view of a younger generation. Secondly, all of the couples, with the exception of one, said that they had discussed concerns as a couple in the past and found this a helpful way of coping with difficulties. Therefore it would seem that couples from an older generation do talk through problems; however, in this situation many chose not to talk about the memory difficulties. In other words, the avoidance of talking about their concerns in this study is more likely to be a reflection of the topic area than a reflection of a lack of talking generally.

Another methodological limitation was the small size of the sample. Only seven couples took part in this study and this may have been the reason why there was only one couple who really perceived open communication as beneficial. For these conclusions to be established as valid there would need to be similar results shown in a larger number of people. However, the lack of a picture of couples where there are more positive ways of interacting and talking about the difficulties would also seem to reflect the current lack of positive communication with people with dementia. Therefore although this can be seen as a weakness of this study it is also an important finding in suggesting how the majority of couples are dealing with the early stages of dementia.

Methods of Analysis

This was an exploratory study into an area previously neglected by research. As a result there was no obvious single method to draw on in analysing the transcripts. In order to answer the research questions this study drew on a combination of techniques and paradigms to give a structure to the analysis. The use of qualitative techniques allowed an in-depth focus on the interactions between the couples, and allowed reflexivity in thinking about the issues which may have impacted on the research, and, therefore, how these might be changed in the future. The specific methods that were used gave an insight into the way that couples talk to each other when one has early-stage dementia, and what they talk about in relation to the memory difficulties. The findings from each of the analyses fitted together in a coherent way, and provided a triangulation of methods, allowing a further credibility check of the results.

However, the use of these specific methods also produced some constraints regarding the imposition of structure on the analyses. These constraints may have meant that there were aspects in the conversations which were missed. For example in using the Kitwood categories as a basis for the analysis, limitations were imposed as to what would be observed and what would not because of the imposition of structured categories. It was also found that at times it was hard to distinguish between the categories as many of the talking turns seemed to fit into more than one category, particularly when considering the negative interactive elements. It was found that a number of the negative categories overlapped and they might be more usefully joined together when being applied to conversations. For example, disruption and imposition seemed to share a lot of qualities, in that they involved cutting across the other person's frame of reference; and disempowerment and infantilisation also seemed fairly similar in that both involved treating the other person in a disempowering, patronising way which seemed to ignore the abilities of the other person. It would appear then that in thinking about Kitwood's categories some refinement would be required if they are consistently to be applied to the conversations of couples where one has early-stage dementia. There may be scope in the future for refining this approach and developing a more extensively elaborated method for examining interactions between people with early-stage dementia and their spouses, building on the Dementia Care Mapping approach to studying interactions between carers and people with dementia in the later stages (e.g. Bradford Dementia Group, 1997).

Representativeness of the participants

A number of couples were contacted and invited to take part in this study and only a proportion of these agreed to participate. It is possible that there were differences between the couples who agreed to take part and those who did not, and there may have been differences in the way that those who did not take part talk to each other. It may have been that those who agreed to take part did so because they were feeling more frustrated and facing more difficulties and looking for help, or it may have been that those who did not take part were facing more difficulties but did not want these to be exposed. However, despite this issue, this study is important in helping to build up an understanding of how couples may be talking to one another, and has suggested some ways couples can positively interact, and how some others might benefit from help to reduce their negative interactions.

The method of recruitment may also have biased the sample. The participants had all attended out-patient clinics in hospitals as a result of their memory difficulties. Previous studies have indicated that only a small number of people with dementia come into contact with health services (e.g. Cooper & Fearn, 1998). It is likely that those who do not come into contact with health services cope with their difficulties in different ways from those who do. Therefore, those who did participate in this study may not have been representative of all couples where one partner has early-stage dementia. However, this limitation applies to most of the clinically-based research with people with dementia.

This study focused only on couples who had been married for a certain period of time and required that participants had been resident in the UK for a substantial period of time. Therefore the results found can only be considered directly relevant to heterosexual married couples and UK residents. Homogeneity of the participants was important in this study because of the small sample size; however, it is important to acknowledge that many people with dementia do not live as part of a couple and further work would be needed to explore whether this kind of approach could be applied to people with dementia in the context of other relationships and interactions.

Implications for further research

This exploratory study has begun to develop a model of how couples talk to each other about their concerns when one partner has early-stage dementia. It has been tentatively suggested that the way that the person with dementia and their spouse are positioned affects the way they talk to each other and how much they talk about the memory difficulties. Further research would be required to enhance the validity of these findings and explore the generalisability of the results, and to develop a more fully elaborated model of talking in couples where one has early-stage dementia.

As outlined in the preceding section, this study focused on a specific group of people. The study looked at heterosexual married couples who had been residing in the UK for a substantial period of time. Further research could look at whether the results found with this sample would be found in other groups of people, for example homosexual couples, and people from different cultures. A focus on couples in different cultures would be particularly interesting. One of the conclusions suggested in this study is that it is the messages about dementia within British society which in part affect how people with dementia are positioned by their spouses. Therefore it would be predicted that in other societies where the messages were different people would in turn be positioned differently. Producing similar studies with different cultural groups would support or disprove this hypothesis, and would therefore highlight how much of a role the messages we receive from society might play in shaping interactions between individuals, lending further support or otherwise to social constructionist theory.

It would also be interesting to conduct longitudinal studies and look at how couples interact over a period of time and with the progression of dementia. It would be interesting to explore whether with time, as people become more accustomed to the deficits, they feel less frustration and therefore there are less negative interactions or whether the negative interactions increase over time as the dementia worsens. It would also be useful to explore whether there are various other factors which influence interaction styles, such as the amount of professional support received. In addition it would be useful to conduct longitudinal studies which explored interaction styles prior to and following the development and diagnosis of dementia in order to assess whether there were changes in interaction styles as a result of the memory problems, or whether these reflect long-standing communication patterns in couples.

Furthermore, in thinking about the generational effects and ideas about the benefits of talking it would be interesting to look at younger couples where one of them has early-stage dementia (early-onset dementia) to see whether there are differences in talking and interactions which may be produced by generational differences.

Ethical issues

Some of the findings from this research are important to consider from an ethical point of view. The people with dementia in this study were considered capable of consent in that they had been given information, had the capacity to understand it and voluntarily took the decision to take part (Medical Research Council, 1991). However, it may have been that some of the people with dementia did not feel able to voice their preference not to take part and felt disempowered in relation to their partners, and the researcher. Indeed, it is clear from some of the conversations that some of the people with dementia were, at times, when the conversations got underway, not entirely happy about participating, or unclear about their participation, but these messages seem not to have been heard by their partners, and at times some of the spouses seemed to completely override the preferences of the people with dementia (for example when Donald continues despite Doris saying she hates "things like this"). Therefore it would seem important in future studies for researchers to ensure, when seeking consent to participate, that the person with dementia is given a chance for their voice to be heard independently of their partner. It would also be important to view consent as a process, and for consent to be checked and rechecked, as has been highlighted by others (e.g. Pratt & Wilkinson, 2001), since in this study it seemed that people were initially happy to consent, and happy taking part in many aspects of the study, but some felt differently during the actual conversations. In future research it would be important to consider ways in which this may be avoided, for example, it may have been that the researcher could stand out of view of the participants but so that s/he was able to hear, and therefore able to step in if it seemed that participants were unhappy about taking part at any stage. For example, it may be possible to set the research up so that the researcher could listen from another room whilst the conversation was taking place and being recorded. Another alternative could also be to allow the participants to try out the task first, and then re-check consent, and understanding, after this experience.

Clinical implications

The results of this study looking at conversations between people with early-stage dementia and their spouses suggest that in many couples there is evidence of the development of a malignant social psychology, shown through the presence of Kitwood's negative interactive elements. This has been emphasised as being damaging to well-being and personhood, and in this study seems to be related to a reduced likelihood of open communication which has been shown to improve well-being in people with chronic conditions. Therefore, these findings have clinical implications and suggest that we should be seeking ways in which to help couples following a diagnosis of early-stage dementia in order to prevent the development of a malignant social psychology and so prevent excess disability and maximise well-being in both partners.

There has been a debate within the literature on whether people with dementia should receive their diagnosis (e.g. Pratt & Wilkinson, 2001) and this research can add to that debate. It seems that receiving a diagnosis may be important now, particularly with the emergence of anti-dementia medication and with person-centred approaches. Early detection of dementia has also been highlighted as important, as it may make it possible to develop help to maintain well-being (Clare, 2002b). However it seems that one of the drawbacks of giving people with dementia and their spouses a diagnosis in the early stages is that, in many couples, a process of labelling occurs and husband and wife may become positioned as patient and carer, or weak and strong.

Therefore, if people are to be given a diagnosis of dementia in the early stages it would seem important to provide couples with education and support around this time to try and minimise the possibility of malignant social psychology entering their interactions. The importance of support around the time of diagnosis has been highlighted previously (Husband, 2000) and, specifically, therapeutic interventions for family caregivers have been identified as being important for the well-being of both the person with dementia and their caregivers (Marriott, Donaldson, Tarrier & Burns, 2000). This research emphasises the importance of such support and therapeutic intervention. It would seem important to educate couples about the impact of early-stage dementia and specific deficits involved, but also to educate them in the person-centred model and highlight the importance of specific interactions for maintaining well-being and personhood. Couples who are struggling and who have positioned themselves as carer and patient could be offered some couple work to help them think about their roles and the way they interact, and allow the voice of the person with dementia to be heard and a more equal relationship to be re-established.

However, on a much wider scale, in terms of clinical implications this study also highlighted that there may be a need to move away from looking only at what therapeutic work may be done with couples where one has early-stage dementia, to looking at ways of changing society's perceptions and responses to dementia. It has been proposed that it is the views and images from society which play a large part in how people with dementia are positioned by others, and in order to change this positioning, and thereby open the way for couples to discuss their concerns, there would need to be a change at a societal level. It would seem, therefore, that the 'quiet revolution' (Clare, Baddeley, Moniz-Cook & Woods, 2003) which is currently taking place, and promoting a person-centred model of dementia, needs to become louder, and information needs to be disseminated to society as a whole.

Conclusion

In conclusion, the seven couples who participated in this study showed a great deal of variation in the extent to which they talked about memory difficulties and in the way they interacted. Most of the couples said that they did not openly communicate their concerns about dementia, and this was suggested to be related to the way the couples positioned themselves in their interactions. The findings suggest that there would be benefits in helping couples to find more positive ways of interacting and fostering an environment which would promote the discussion of concerns, which in turn would increase well-being, and help to maintain personhood for people with early-stage dementia and their spouses.

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APPENDIX ONE
INFORMATION SHEET AND INVITATION LETTER FOR PARTICIPANTS

INFORMATION SHEET FOR PARTICIPANTS

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 hospital or 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 a 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 hospital, the 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.

August 2002

INVITATION LETTER FOR PARTICIPANTS

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, Alison Pearce, Lucie Robinson, Jenny Griggs and Mike van Dijkhuizen

Yours sincerely

Jenny Griggs	Lucie Robinson
Trainee Clinical Psychologist	Trainee Clinical Psychologist

APPENDIX TWO
CONSENT FORM

CONSENT FORM FOR PARTICIPANTS

of Project: The experience of being in a couple where one person has memory uities

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

Please initial box

onfirm that I have read and understand the information sheet dated .... ersion ....) for the above study and have had the opportunity to ask questions. ☐

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

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

gree to take part in the above study. ☐

of Patient	Date	Signature
of Person taking consent erent from researcher)	Date	Signature
archer	Date	Signature

APPENDIX THREE
COPY OF SHEET DETAILING CONVERSATIONAL TASK LEFT WITH PARTICIPANTS

TASK

We would like you to have a conversation about any concerns you may have about the impact of memory difficulties. Please try and discuss this in the same way you would generally discuss concerns. You will have fifteen minutes to discuss this, and we will leave the room during this time. Following this I will talk to you individually about your experience of this conversation.

APPENDIX FOUR
INTERVIEW SCHEDULE

How did you find having that conversation?

Do you think this was a fairly typical conversation?
Prompt – have you had this kind of discussion before? Do you talk about your concerns about your / your partner's memory difficulties? Did you / your partner discuss your concerns when you first noticed the memory difficulties?

Did you find the conversation helpful or unhelpful? What made it helpful or unhelpful?

(If it was helpful) Was there anything that was unhelpful / (If it was unhelpful) Was there anything which you found helpful?

Have you found it useful to talk about the memory difficulties with your partner in the past?

How do you generally discuss concerns as a couple?
Prompt – have you found it useful to talk about difficulties with your partner in the past? / In the past how have you, as a couple, dealt with difficulties?

Do you generally find it helpful or unhelpful to talk about concerns with your partner?

Would you find it helpful to talk about the memory difficulties with your partner?

APPENDIX FIVE

COPIES OF LETTERS GRANTING ETHICAL APPROVAL FOR THIS STUDY

Copies of letters from:

1) Camden and Islington Local Research Ethics Committee
2) Barnet, Enfield and Haringey Local Research Ethics Committee

Camden and Islington Community Health Service
LOCAL RESEARCH ETHICS COMMITTEE
Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NWI OPE
tel: 020 7530 3376 fax: 020 7530 3235
e-mail: ayse.ali@camdenpct.nhs.uk
Chair: ***Stephanie Ellis*** **Administrator:** ***Ayse Ali***

25 June 2002

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

Dear Dr Clare

LREC Ref: 02/41 (please quote in all further correspondence)
Title: Communications, Mutual Support and Psychological Reactions to a Diagnosis of Dementia in Couples

Thank you for your letter dated 17 June 2002 addressing the points raised by the committee. I am pleased to inform you that after careful consideration the Local Research Ethics Committee has no ethical objections to your project proceeding. This opinion has also been communicated to the North Central London Community Research Consortium.

PLEASE NOTE THAT THIS OPINION ALONE DOES NOT ENTITLE YOU TO BEGIN RESEARCH.

Camden and Islington Community Health Service LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility to decide whether or not the project should go ahead, taking into account the ethical advice of the LREC[1]. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management, who will need to be assured that the researcher holds an appropriate NHS contract, and that indemnity issues have been adequately addressed.

N.B. Camden and Islington Community Health Service LREC is an independent body providing advice to the North Central London Community Research Consortium. A favourable opinion from the LREC and approval from the Trust to commence research on Trust premises or patients are **NOT** one and the same. Trust approval is notified through the Research & Development Unit.

The following conditions apply to this project:

- You must write and inform the Committee of the start date of your project. The Committee (via the Local Research Ethics Committee Administrator or the Chair at the above address) must also receive notification:

    a) when the study commences;
    b) when the study is complete;
    c) if it fails to start or is abandoned;
    d) if the investigator/s change and
    e) if any amendments to the study are made.

- The Committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.

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[1] Governance Arrangements for NHS Research Ethics Committees, *July 2001 (known as GAFREC)*

- It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee and management approval from the body hosting the research.

- The Committee will require a copy of the report on completion of the project and may request details of the progress of the research project periodically (i.e. annually for longer projects).

- If data is to be stored on a computer in such a way as to make it possible to identify individuals, then the project must be registered under the Data Protection Act 1998. Please consult your department data protection officer for advice.

- Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

Please forward any additional information/amendments regarding your study to the Local Research Ethics Committee Administrator or the Chair at the above address.

Yours sincerely

Stephanie Ellis
Chair, LREC

North Central London NHS
Strategic Health Authority

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

C A Hamilton

Christine Hamilton
Barnet, Enfield & Haringey
LREC Co-ordinator

APPENDIX SIX
RATINGS GIVEN BY EACH RATER FOR EACH TALKING TURN IN ALL THE CONVERSATIONS

Couple: Ann (pwd) and Ahmad

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	Positive	Negative	Positive
1	Ahmad	Stigmatisation		stigmatisn	
2	Ann				
3	Ahmad				
4	Ann				
5	Ahmad	Disruption		disruptn	
6	Ann				
7	Ahmad	Disruption		disruptn	
8	Ann				
9	Ahmad	Disparagement		disparagemt	
10	Ann				
11	Ahmad	Disparagement		disparagemt	
12	Ann	Disruption		disrupn	
13	Ahmad				
14	Ann				
15	Ahmad				
16	Ann				
17	Ahmad	Disparagement		disparagem	
18	Ann				
19	Ahmad				
20	Ann				
21	Ahmad				
22	Ann				
23	Ahmad				
24	Ann				
25	Ahmad				
26	Ann				
27	Ahmad				
28	Ann				
29	Ahmad				
30	Ann				
31	Ahmad				
32	Ann				
33	Ahmad				
34	Ann				
35	Ahmad	Disparagement		disparagem	
36	Ann				
37	Ahmad				
38	Ann				
39	Ahmad				
40	Ann				

41	Ahmad				
42	Ann				
43	Ahmad				
44	Ann				
45	Ahmad	Disparagement		disparagem	
46	Ann				
47	Ahmad	Disparagement		disparagem	
48	Ann				
49	Ahmad				
50	Ann	Disruption		disrupn	
51	Ahmad	Disparagement		disparagem	
52	Ann				
53	Ahmad	Imposition		imposition	
54	Ann				
55	Ahmad	Imposition		imposition	
56	Ann				
57	Ahmad	Disparagement		disparagem	
58	Ann				
59	Ahmad	Disparagement		disparagem	
60	Ann				
61	Ahmad	Disparagement		disparagem	
62	Ann				
63	Ahmad	Disparagement		disparagem	
64	Ann				
65	Ahmad				
66	Ann				
67	Ahmad				
68	Ann	Disruption		disrupn	
69	Ahmad	Imposition		disparagem	
70	Ann				
71	Ahmad	Disparagement		disparagem	
72	Ann				
73	Ahmad				
74	Ann				
75	Ahmad	Disparagement			
76	Ann				
77	Ahmad	Disparagement		disparagem	
78	Ann				
79	Ahmad	Disparagement		disparagem	
80	Ann				
81	Ahmad			mockery	
82	Ann				
83	Ahmad				
84	Ann				
85	Ahmad				
86	Ann				
87	Ahmad	Imposition		Imposition	
88	Ann				

89	Ahmad	Infantilisation		infantilisn	
90	Ann				
91	Ahmad				
92	Ann				
93	Ahmad	Infantilisation		infantilisn	
94	Ann	Disruption		disrupn	
95	Ahmad	Disparagement		disparagem	
96	Ann				
97	Ahmad				
98	Ann				
99	Ahmad	Disparagement		disparagem	
100	Ann				
101	Ahmad	Disparagement		disparagem	
102	Ann				
103	Ahmad				
104	Ann				
105	Ahmad				
106	Ann				
107	Ahmad	Disparagement		disparagem	
108	Ann				
109	Ahmad	Mockery			
110	Ann	Accusation		accusation	
111	Ahmad	Disempowerment		disempower	
112	Ann				
113	Ahmad	Infantilisation			
114	Ann				
115	Ahmad				
116	Ann				
117	Ahmad			disparagem	
118	Ann				
119	Ahmad				
120	Ann				
121	Ahmad				
122	Ann				
123	Ahmad	Disparagement		disparagem	
124	Ann				
125	Ahmad				
126	Ann				
127	Ahmad	Infantilisation		infantilisn	
128	Ann				
129	Ahmad				
130	Ann				
131	Ahmad				
132	Ann	Disruption		disrupn	
133	Ahmad	Disruption		disrupn	
134	Ann				
135	Ahmad				
136	Ann				

137	Ahmad				
138	Ann				
139	Ahmad				
140	Ann				
141	Ahmad				
142	Ann				
143	Ahmad	Disparagement		disparagem	
144	Ann				
145	Ahmad				
146	Ann				
147	Ahmad	Disparagement		disparagem	
148	Ann	Disruption		disrupn	
149	Ahmad	Disparagement		disparagem	
150	Ann				
151	Ahmad	Infantilisation			
152	Ann				
153	Ahmad	Disparagement		disparagem	
154	Ann				
155	Ahmad	Infantilisation			
156	Ann				
157	Ahmad	Infantilisation			
158	Ann				
159	Ahmad				
160	Ann				
161	Ahmad				
162	Ann				
163	Ahmad				
164	Ann				
165	Ahmad		Recognition		recognition
166	Ann				
167	Ahmad	Mockery		mockery	
168	Ann				
169	Ahmad			mockery	
170	Ann				
171	Ahmad				
172	Ann				
173	Ahmad				
174	Ann				
175	Ahmad				
176	Ann				
177	Ahmad				
178	Ann	Disruption		disrupn	
179	Ahmad	Invalidation		disparagem	
180	Ann				
181	Ahmad				
182	Ann				
183	Ahmad				
184	Ann				

185	Ahmad	Invalidation		disparagem	
186	Ann				
187	Ahmad				
188	Ann				
189	Ahmad				
190	Ann				
191	Ahmad				
192	Ann				
193	Ahmad	Disparagement		disparagem	
194	Ann				
195	Ahmad				
196	Ann				
197	Ahmad				
198	Ann				
199	Ahmad				
200	Ann				
201	Ahmad	Disruption		disparagem	
202	Ann				
203	Ahmad				
204	Ann				
205	Ahmad			disparagem	
206	Ann				
207	Ahmad				
208	Ann		Play		
209	Ahmad		Play		
210	Ann		Play		
211	Ahmad				
212	Ann				
213	Ahmad	Imposition			
214	Ann				
215	Ahmad				
216	Ann				
217	Ahmad	Disparagement		disparagem	
218	Ann				
219	Ahmad				
220	Ann				
221	Ahmad	Disruption		disrupn	
222	Ann	Disruption		disrupn	
223	Ahmad	Disparagement		disparagem	
224	Ann			stigmatisn	

Agreement on 191 out of 224 talk turns = 85.27% agreement

Couple: Bill (pwd) and Betty

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	Positive	Negative	Positive
1	Betty				
2	Bill		Play		play
3	Betty		Play		play
4	Bill				
5	Betty				
6	Bill		Facilitation		
7	Betty				
8	Bill				
9	Betty				
10	Bill				
11	Betty				
12	Bill				
13	Betty				
14	Bill				
15	Betty				
16	Bill				
17	Betty				
18	Bill				
19	Betty	Disruption			
20	Bill				
21	Betty				
22	Bill				
23	Betty	Disruption		accusation	
24	Bill				
25	Betty	Disparagement		disparagemt	
26	Bill				
27	Betty				
28	Bill	Disruption			
29	Betty	Infantilisation		infantilisatn	
30	Bill				
31	Betty	Invalidation		invalidation	
32	Bill				
33	Betty	Disempowerment		disempower	
34	Bill				
35	Betty		Validation		validation
36	Bill				
37	Betty				
38	Bill				
39	Betty	Accusation		accusation	
40	Bill				
41	Betty	Invalidation		invalidation	
42	Bill				
43	Betty	Invalidation		invalidation	
44	Bill				

45	Betty				
46	Bill				
47	Betty				
48	Bill				
49	Betty	Invalidation		invalidation	
50	Bill				
51	Betty		Recognition		recognition
52	Bill				
53	Betty				
54	Bill				
55	Betty				
56	Bill				
57	Betty		Recognition		recognition
58	Bill				
59	Betty	Disparagement		disparagemt	
60	Bill				
61	Betty		Negotiation		
62	Bill				
63	Betty	Disparagement		disparagemt	
64	Bill		Play		play
65	Betty				
66	Bill				
67	Betty				

Agreement on 62 out of 67 talk turns = 92.54% agreement

Couple: Clive (pwd) and Charlotte

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	Positive	Negative	Positive
1	Charlotte				
2	Clive				
3	Charlotte		Facilitation		facilitation
4	Clive				
5	Charlotte		Facilitation		facilitation
6	Clive				
7	Charlotte		Holding		holding
8	Clive				
9	Charlotte		Recognition		recognition
10	Clive		Holding		holding
11	Charlotte				
12	Clive				
13	Charlotte				
14	Clive				
15	Charlotte		Holding		holding
16	Clive				
17	Charlotte		Holding		holding
18	Clive		Holding		holding
19	Charlotte		Facilitation		facilitation
20	Clive		Recognition		recognition
21	Charlotte				
22	Clive		Recognition		recognition
23	Charlotte				
24	Clive				
25	Charlotte		Holding		holding
26	Clive				
27	Charlotte		Recognition		recognition
28	Clive				
29	Charlotte				
30	Clive				
31	Charlotte				
32	Clive				
33	Charlotte		Negotiation		facilitation
34	Clive		Holding		
35	Charlotte		Validation		holding
36	Clive				
37	Charlotte		Negotiation		
38	Clive				
39	Charlotte		Recognition		recognition
40	Clive				
41	Charlotte		Holding		holding
42	Clive				
43	Charlotte		recognition		recognition

Agreement on 39 out of 43 talk turns = 90.7% agreement

Couple: Doris (pwd) and Donald

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	Positive	Negative	Positive
1	Doris				
2	Donald	Invalidation		Invalidation	
3	Doris				
4	Donald	Imposition		Imposition	
5	Doris				
6	Donald	Invalidation		Invalidation	
7	Doris				
8	Donald	Banishment		Banishment	
9	Doris				
10	Donald	Disruption		Disruption	
11	Doris				
12	Donald				
13	Doris				
14	Donald		Facilitation		Facilitation
15	Doris				
16	Donald				
17	Doris				
18	Donald				
19	Doris				
20	Donald		Recognition		Recognition
21	Doris				
22	Donald				
23	Doris				
24	Donald				
25	Doris				
26	Donald	Disparagement	Recognition	Disparagement	Recognition
27	Doris				
28	Donald	Disparagement		Disparagement	
29	Doris				
30	Donald		Recognition		Recognition
31	Doris				
32	Donald				
33	Doris		Recognition		Recognition
34	Donald				
35	Doris	Disruption		Disruption	
36	Donald				
37	Doris	Disruption		Disruption	
38	Donald		Recognition		Recognition
39	Doris				
40	Donald				
41	Doris				
42	Donald	Infantilising		Infantilising	
43	Doris				
44	Donald	Disruption	Validation	Disruption	Validation

45	Doris				
46	Donald	Invalidation		Invalidation	
47	Doris				
48	Donald	Disparagement		Disparagement	
49	Doris				
50	Donald	Invalidation			
51	Doris				
52	Donald				
53	Doris				
54	Donald				
55	Doris				
56	Donald	Invalidation		Invalidation	
57	Doris				
58	Donald				
59	Doris	Accusation		Accusation	
60	Donald				
61	Doris				
62	Donald		Validation		
63	Doris				
64	Donald				
65	Doris				
66	Donald				
67	Donald		Facilitation		Facilitation
68	Doris				
69	Donald				
70	Donald				
71	Doris				
72	Donald		Negotiation		Negotiation
73	Doris				
74	Donald				

Agreement on 72 out of 74 talk turns = 97.3% agreement

Couple: Elizabeth (pwd) and Edward

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	**Positive**	**Negative**	**Positive**
1	Edward		Negotiation		negotiation
2	Elizabeth				
3	Edward				
4	Elizabeth				
5	Edward		Negotiation		negotiation
6	Elizabeth				
7	Edward				
8	Elizabeth				
9	Edward		Negotiation		negotiation
10	Elizabeth				
11	Edward		Negotiation		negotiation
12	Elizabeth				
13	Edward				
14	Elizabeth				
15	Edward	Infantilisation			
16	Elizabeth				
17	Edward	Infantilisation	Negotiation		negotiation
18	Elizabeth				
19	Edward		Negotiation		negotiation
20	Elizabeth				
21	Edward				
22	Elizabeth				
23	Edward				
24	Elizabeth				
25	Edward		Negotiation		negotiation
26	Elizabeth				
27	Edward		Negotiation		negotiation
28	Elizabeth				
29	Edward				
30	Elizabeth				
31	Edward		Negotiation		negotiation
32	Elizabeth				
33	Edward	Infantilisation			
34	Elizabeth				
35	Edward	Infantilisation			
36	Elizabeth				
37	Edward				facilitation
38	Elizabeth		Negotiation		negotiation
39	Edward	Imposition			
40	Elizabeth				
41	Edward	Disempowerment			

Agreement on 34 out of 41 talk turns = 82.93% agreement

Couple: Fritz (pwd) and Fran

Talking turn	Speaker	Rater 1 (JG)		Rater 2 (LC)	
		Negative	Positive	Negative	Positive
1	Fran		Facilitation		Facilitation
2	Fritz				
3	Fran		Facilitation		Facilitation
4	Fritz				
5	Fran		Facilitation		Facilitation
6	Fritz				
7	Fran		Facilitation		Facilitation
8	Fritz				
9	Fran		Facilitation		Facilitation
10	Fritz				
11	Fran		Facilitation		
12	Fritz				
13	Fran		Negotiation		Negotiation
14	Fritz				
15	Fran		Facilitation		Facilitation
16	Fritz				
17	Fran				
18	Fritz				
19	Fran		Facilitation		Facilitation
20	Fritz				
21	Fritz				
22	Fran				
23	Fritz				
24	Fran				
25	Fritz				
26	Fran		Negotiation		Negotiation
27	Fritz				
28	Fran		Negotiation		Negotiation
29	Fritz				
30	Fran				
31	Fritz				
32	Fran		Facilitation		Facilitation
33	Fritz				
34	Fran				
35	Fritz				
36	Fran				
37	Fritz				
38	Fran				
39	Fritz				
40	Fran				Facilitation
41	Fritz				
42	Fran				

Agreement on 40 out of 42 talk turns = 95.24% agreement

Couple: Gill (pwd) and George

Talking turn	**Speaker**	**Rater 1 (JG)**		**Rater 2 (LC)**	
		Negative	**Positive**	**Negative**	**Positive**
1	George		Negotiation		negotiation
2	Gill		Negotiation		negotiation
3	George		Facilitation		facilitation
4	Gill				
5	George		Facilitation		facilitation
6	Gill				
7	George				
8	Gill				
9	George		Facilitation		facilitation
10	Gill				
11	George		Facilitation		facilitation
12	Gill				
13	George				
14	Gill				
15	George				
16 silence between this and 17	Gill				
17	Gill		Facilitation		
18	George				
19	Gill				

Agreement on 18 out of 19 talk turns = 94.74% agreement

APPENDIX SEVEN
LISTS OF ALL THE EXTRACTS IDENTIFIED FOR EACH INTERACTIVE ELEMENT

Negative categories - spouses

Disempowerment

Ann: I asked you to come with me and you haven't done it yet, so I I haven't got any shoes
Ahmad: (over talking) Why don't you go yourself?

Bill: Cos I still say I can go down Pond Street
Betty: You can't go down Pond Street, not just for a blood test, you could go to your own doctors for a blood test. Up there it's just to observe you.....and if you don't, if if they can't really see how you are, I mean it's like the things they do you think it's all silly but that is to see how your reactions are and how your mind works.....so this is something you've gotta have, if you don't go they'll say "well that's it we won't bother with him" and you you won't get better will you

Elizabeth: We'll take the...
(Edward gets up and goes to get researcher)
Edward: Okay luvvie.

Infantilisation

Ahmad: ...Do you forget the day you have to bath?
Ann: No because I write it in the book
Ahmad: That's very good, that's very good. And your hair wash?

Ahmad: So in other words writing in the book helps you to keep your memory going
Ann: Yes
Ahmad: Very good. What about sometimes you lose your glasses and things like that. Why don't you...

Ahmad: Yeah. You don't find difficulties in finding your way say
Ann: To the food hall. No.
Ahmad: No.Very good. But you do forget your way to shoe shops.

Ann: Cos I don't know where the bloody shops are, that's why
Ahmad: Do you think you have forgotten the shops?

Ahmad: Spell architecture

Ahmad: (Over talking) Okay spell acknowledge

Ahmad: Yeah. Okay lets ask you smaller words. Spell chaos

Betty: ....ahhh, now this camden mews, cos this is what we have a little go about don't we.

Donald: I know you did..yeah
Doris: well
Donald: but I'm just talking to you about it

Elizabeth: Yeah I don't mind
Edward: (over talking) You sure?
Elizabeth: I'm positive
Edward: Err what do you like, fish or meat

Elizabeth: Not particularly
Edward: Nothing else, sure
Elizabeth: Yeah
Edward: Now you're positive?

Stigmatisation
Ahmad: Hello Ann so what is your memory problems now? Let me know.

Invalidation
Ann: (over talking) Well I don't remember that actually
Ahmad: You do!

Ann: I don't remember that actually
Ahmad: You do!

Bill: Yeah. Well I think it's a waste of time
Betty: Well you only go for four hours, four five hours, and it is not just to take a blood test, it's to to observe you so they can work out exactly what is wrong. Nothing to do with just a blood test

Bill: Don't know, well say she, say something happens to you while your out
Betty: Well, that is the chance you take in this life

Betty: I've been out every day of my life, shopping and one thing or another and all of a sudden you're worrying in case something happens while I'm out.

Bill: I mean I toss and turn in bed,and.... you know I...
Betty: Yeah....well.....not much more really I can say on this

Doris: You know I hate things like this
Donald: Yeah..well it's only research Doris. If it helps other people that's the main thing. Innit. Eh? Well I mean how's your... What I'm saying is how..do you think your memory is now?

Doris: No, I'm too old
Donald: It's not, nothing to do with being old. It's with asking about your memory.....Can you think of things

Doris: I still feel the same
Donald: No, I mean at this time....now you're losing your memory...how do you feel?

Doris: I can do things
Donald: No…I mean

Doris: Who does the cleaning?
Donald: I do
Doris: I do
Donald: No Doris, you haven't done that for years…… But errrr you go out for your little walks dontcha in the morning

Banishment
Doris: I'm losing my memory
Donald: I know you're losing it, and errrr **we** want to see how what you can remember at the moment.

Imposition
Ann: I don't know but I don't pay any attention..
Ahmad: (over talking) Well you watched the news
Ann: I pay no attention to what the government says
Ahmad: But you watched the news, the news, the, John Prescott was in the parliament and and you commented

Ann: (over talking and raising voice) All I know, all I know is, and all I'm interested in is that I support the firemen. End of story.
Ahmad: (over talking) Yeah well that, that is nothing to do with memory, and I am trying to test your memory. You see, err

Ahmad: (laughing) Yeah. Well warning them or otherwise has nothing to do with memory, you have to stick to the memory.

Ahmad: Well what do you think had happened happened to my father?
Ann: No I won't draw that one. It just came into my mind all of a sudden
Ahmad: Alright then, well you tell me how many pairs of glasses have you got?

Doris: I don't know how is my memory.
Donald: Well, I mean, can you remember anything now? Is it long ago or recent time?

Elizabeth: Or if not we could do it tomorrow
Edward: No no we'll do it today. Erm, right that's it.

Accusation
Betty: Yeah you say this Bill but even when they've been here its urr "what time's she coming back?", "when's she coming back?" you you you can't do that. What is your fear of me going out?

Disruption
Ahmad: (over talking) What else don't you remember?

Ann: (continuing whilst P interrupting) that keep turning up, and I...
Ahmad: What else don't you remember?

Ann: (Over talking) I warn I warned these ladies
Ahmad: (Over talking) Let me ask you you were good in spelling, let me ask you if you remember how to spell jeopardy

Ann: Oh we probably went to the pub as well
Ahmad: (over talking) Captains Captains Captains Wife

Ann: When did I lose my, I can't, I can't walk anywhere without my glasses
Ahmad: (over talking) No but sometimes you take it off to say powder your err err nose

Bill: So she'll be coming here first
Betty: Yes..umm.....what talk about, never really been great converla..converla

Bill: But as I say it's ummm
Betty: Should have put this on first thing in the morning when you was asking me all them questions..

Doris: When we were married, in the young
Donald: Yeah, well we're not know, we're old now Doris:, and errr your losing your memory and they want to know how far it's gone, I s'pose

Doris: I loved it
Donald: I know you did......so how, this, how are you getting on now, at this time?

Mockery
Ann: Never, never
Ahmad: I see, okay then, err (laughs) what about going and buying yourself a pair of shoes, you have been telling me that you need to buy a pair of shoes

Ann: I was top of the school in English, French and German
Ahmad: Yeah so you should be very good in spelling then

Disparagement
Ahmad: I told them that jokes jokes I forget names all the time. Often they say hello to me in the street and I say hello and I recognise them but I don't know their name. Errr what about losing your way, do you ever lose your way?

Ahmad: But you also forget things you placed somewhere, like your torch and err

Ahmad: But then sometimes you forget your dressing gown you took it in the wardrobe and then come and tell me I've lost it and and err and also the jacket you use for washing your hair, yeah? When did you develop this err difficulty? We have to continue because they are recording

Ahmad: You also lost your way on the way back to Hampstead.
Ann: When was that?
Ahmad: Same day
Ann: No, no, I got back alright.

Ahmad: Well you went twice. The second time you found your way out of Hampstead.

Ahmad: No you buy it and then you read it. Do you remember what you read?
Ann: I don't know I can't give you a report.
Ahmad: Well what did you read last time in the newspapers?
Ann: I didn't have a newspaper yesterday.
Ahmad: The day before? Did you read anything about the fire strike, firemen's strike.

Ann: (over talking) The figures? I don't remember the figures. Most people support the strike, most people are quite happy to give money to the strikers, I don't know how much or errr whether they're still doing that.
Ahmad: According to John Prescott just yesterday in parliament said that to increase the salaries of the firemen they have to sack some people. How many did he suggest?

Ann: Well I I don't agree with anything the government says
Ahmad: I know but err how many did he say would lose their jobs?
Ann: Well I don't remember that. You tell me.
Ahmad: So do you ever forget names or err numbers or or your way or err a combination? Or other aspects?
Ann: What do you mean numbers?
Ahmad: Well I told you how many how many were err Prescott suggested that should lose their jobs, you forgot the numbers
Ann: What do you mean I forgot them? I never
Ahmad: (over talking) You don't know how many they

Ahmad: What about remembering to cook. You you know how to cook? Like you used to

Ahmad: But do you make mistakes and forget for instance to put the fire on and the..
Ann: No never, I have never done that
Ahmad: Twice you did that
Ann: The fire. You're the one who left the bloody fire on the other day
Ahmad: No no, when you were cooking on your own and I was out you forgot the cooking and once you forgot to put the chicken in and the next time you forgot to switch off the electricity so the bottom of the pan was burnt

Ann: (over talking) I've never lost my glasses
Ahmad: Why don't (raising voice and laughing) I had to go and find it for you

Ann: My torch is in the same place every night
Ahmad: Okay then but sometimes you switch turning it off switching it off. What about that?
Ann: Never
Ahmad: You do forget and I go and switch it off.
Ann: I leave the torch on, never
Ahmad: Sometimes, not every time

Ann: I never went to Waitrose
Ahmad: Ah you used to go and use your Switch card in Waitrose. But you don't..

Ahmad: Yeah you are very good at it, so I am trying to, well, we have to show you are good at something and you are not so good at other things, so how do spell jeopardy
Ann: J-E-O-P- I don't know if it's an e or an o, O-R-P
Ahmad: (Over talking) But you used to tell me you never made a mistake in the with any spelling

Ahmad: (Over talking) Do do you think do you think your ability to spell has gone down

Ahmad: No I'm just I'm just trying to find some awkward words that are difficult difficult to spell

Ann: Where was I? Don't know where I was
Ahmad: (over talking) Where was we, where were we, both of us?

Ann: I've never lost this one
Ahmad: You did and you had to go and find the other one, and because you haven't had the glasses I have to go and look for them

Ann: (over talking) Rubbish I reject that totally, cos I can't see without my glasses. The first thing I do in the morning is put my specs on obviously
Ahmad: Yeah well that's why you you leave it somewhere and then in the morning you can't find…(researcher into room)

Betty: Should have put this on first thing in the morning when you was asking me all them questions..
Bill: Yeah
Betty: and I could have strangled you.

Betty: I mean really and truly we were just saying about a conversation, well we never did have much conversation because you were busy looking at the sports.
Betty: Not much else we can say….Except (laughs) well, for the first time I could have murdered you. Nah, I wouldn't do that

Doris: (protesting) I used to sing
Donald: Yeah but not really. You wasn't much of a singer.

Doris: Ummmmm…..Just…just like to get around and do things
Donald: No, you can't do a lot now can you

Negative categories – people with dementia

Accusation
Ahmad: I see, okay then, err (laughs) what about going and buying yourself a pair of shoes, you have been telling me that you need to buy a pair of shoes
Ann: I asked you to come with me and you haven't done it yet, so I I haven't got any shoes

Doris: But you getting now, you don't take me out anymore

Disruption
Ahmad: But then sometimes you forget your dressing gown you took it in the wardrobe and then come and tell me I've lost it and and err and also the jacket you use for washing your hair, yeah? When did you develop this err difficulty? We have to continue because they are recording
Ann: (over talking) Well I don't know

Ann: (over talking) The figures? I don't remember the figures. Most people support the strike, most people are quite happy to give money to the strikers, I don't know how much or errr whether they're still doing that.

Ahmad: Very good. What about sometimes you lose your glasses and things like that. Why don't you..
Ann: (over talking) I've never lost my glasses

Ann: (over talking and raising voice) All I know, all I know is, and all I'm interested in is that I support the firemen. End of story.

Ahmad: Okay let me let me ask you
Ann: (Over talking) I warn I warned these ladies

Ann: (Over talking) I never used that bloody word, when when when did I use jeopardy

Ahmad: Which, where were we living when you lost them
Ann: (over talking) Well I don't remember that actually

Ahmad: (over talking) No but sometimes you take it off to say powder your err err nose
Ann: (over talking) Rubbish I reject that totally, cos I can't see without my glasses. The first thing I do in the morning is put my specs on obviously

Donald: I was too clumsy
Doris: I always, if I wanted to go dancing I'd go dancing

Donald: I know, well that's it.
Doris: (over talking) I used to work with…

Betty: No, you know….
Bill: (interrupts) Oh yeah what's all them plugs over there? What's..

Positive elements – spouses

Recognition
Ahmad: O-S you said. Something like that. Anyway C-H-A-O-S. My spellings going as well but my spelling was never good. Don't forget you got a gold medal for English at school, and you did English together with French and German at University

Betty: You've just actually umm you was loved football or err the racing, boxing.

Betty: Well you'd always used to sit and read a paper, and and read it actually read it til the print was coming off

Donald: Yes I know, you worked up til your sixties. Sixty five…

Donald: …..You was a good dancer.

Donald: Laughs……Ah, right…Yeah I know you used to like dancing, I know that

Donald: I know, you used to go dancing when you was younger

Charlotte: And that there clearly isn't a whole, aspects of your functioning that are still fine

Charlotte: You think it will? You can hear the words……..I mean I when it comes to things like appreciating art I don't think you are any different to how you have been

Charlotte: Yes. Hear, hear……………I mean you still you still seem to enjoy reading

Charlotte: Well no, I think when I first knew you (researcher into the room) You've come to rescue us! Shall I turn it off?

Negotiation

Betty: …I think that's about it, don't you?

Donald: Is that the finish? You don't want to talk anymore?

Edward: Right, where do you want to go today?

Edward: Now do you want to go downstairs at all?

Edward: Yeah, and when you go downstairs and come up do you want to go into the bed, do you want to lie down or something like that

Edward: (over talking) Maybe later on, right. Err, What do want for lunch?

Edward: (over talking)You're not bothered. Right erm then do want after that do you want erm a apple peeled

Edward: Err what do you like, fish or meat

Edward: Right. Then what what do want for tea later on?

Edward: Biscuit, and what about later on tonight?

Edward: You'll have a fish ball, right, okay then. Erm, is there anything else you want to do today?

Fran: I hope that meets with your approval?

Fran: (laughing) I don't know, what would you like to talk about?

Fran: You want to continue doing the crossword?

Charlotte: I mean what I wanted to know, how it felt to you with Henry not having the same

Charlotte: I was wondering for you what feels like the most difficult part of the illness?

George: Alright?

Play
Ann: Well I don't know what to ask you. When did you last see your, no, that's an old Scottish joke (both laughing).
Ahmad: (laughing) What is it, what is it? Ann: well I don't know what to ask you.
When did you last see your, no, that's an old Scottish joke (both laughing).
Ahmad: (laughing)What is it, what is it?

Betty: (laughing) What if he strangles me.

Validation
Bill: No, but what umm what happens if I don't go, do I you know am I breaking a law or somethin'?
Betty: No you're not breaking a law because it's to go there is partly voluntary but it's no good you saying ohh you know "why am I like this". They are trying to find out. And if you don't allow, to you it might all seem silly, what they're doing, but it isn't. There's, there's behind each thing they do there's something to find out how your mind is ..so ummm…no-one can make you do anything you don't want to, it's not, you ain't committed to go anywhere, this is all to help you

Doris: I loved it
Donald: I know you did……so how, this, how are you getting on now, at this time?

Doris: I don't like being indoors on my own that's why I go out walking with you
Donald: Yes, I know…

Clive: The irritating thing is shared experiences of something..I can't recollect
Charlotte: Yes yes I mean I was having similar thoughts in terms of erm you can't for example remember a holiday we've both been on, something like that so….

Holding
Charlotte: I mean I I sort of ask myself from time to time do I get terribly worried that your Alzheimers might get much worse and you might get really confused and on the

whole the answer I give myself is that I don't think it will happen and I think that it's progressing very very slowly

Charlotte: And I know that I I'm at my worst, at least I think I'm at my worst with you, when you when you get het up about certain things umm.....I don't on the whole ?????? but umm if it's sort of something financial I get, suppose cos I get anxious then and I feel that things might get out of control.........and then I think we get into a spiral ???? and that makes you worse

Charlotte: No no no well you get sort of umm helpless and angry and anxious all at once....and really what I want to do is just takeover and that's fine if you let me (laughing) but you often won't...........

Charlotte: I mean I suppose there is an element certainly of sadness for me and I'm sure for you that things like going to the theatre together, aren't able always to follow the jist.I suppose I see that as quite a loss because you can't, we can't discuss it

Charlotte: Right, yes. I mean it's harder, yeah.....................I suppose for me I sometimes wish that you were able to take the initiative, on where you might want to go for a holiday or what you might want to do, cos that seems to be something that is quite difficult

Facilitation
Donald: What about urm years ago? You can remember

Donald: So is there anything you errrr want to ask me?

Charlotte: No, I'm sure. But I suppose you're meant to be telling me where I'm not at all helpful or your concerns

Fran: Have you sort of got the general

Fran: They're doing a research thing into seeing whether specifically they can do anything about problems which arise between couples when one half has some memory difficulty

Fritz: They are looking for a solution?
Fran: Yeah, if you like. I mean do you see any problems arising because you forget sometimes?

Fritz: I don't know what you are on about. What am I supposed to do?
Fran: Tell me if you find it a problem that you forget things, particularly in interacting between us

Fritz: ...Anyway I'm totally lost, I don't know what I am supposed to do
Fran: As part of this exercise the idea is to find out how do we normally, I think, converse with each other. I suggested earlier we just shout at each other (both laugh) but that's not....I mean you don't find any particular problem in that you forget what I said or something like that?......No......Ah well, change of subject

Fritz: Umm?
Fran: I said then we if we are to have a conversation we can talk about something else. You know we're going to ___ on Friday? I hope that's, umm

Fritz: um. I still don't know what's it all about, however
Fran: Well as I think the young lady tried to explain they're doing research into whether, let me put it that way round, memory problems can be helped by looking at the two of us, because I am the person you mostly are with.

Fran: You're more, in other words, when it comes to, when memory problems arise I suppose they are most likely to arise because we make arrangements, we do things, and so on, and I mean, do you find there is a problem there?

Fritz: I don't understand. What, she hopes that we will come back to her remembering something
Fran: Not necessarily and, no, no, no, this is not what I call the IQ test type thing, no, this is longer term looking at the situation. This isn't your please arrange these pieces of cardboard to make an elephant or something, no, this is to see, I suppose maybe in a way to see whether, err how can I put it, umm, what I do makes things better or worse as far as memory is concerned

Clive: I'm not used to this
Charlotte: Yeah, ummm........yeah.........I mean I I think I I notice your memory difficulties more when we're away from here, in that..

Clive: In what way?
Charlotte: Well say we're in Yorkshire it takes longer to re-orientate yourself, remember where things are. And, when we go away, particularly abroad, umm...you find it quite difficult to find your way around and it takes, you do eventually but it takes you much longer
George: You want your glasses? Where are they?
Gill: In that room
George: Alright, hold up (George leaves to get glasses)

George: Yeah, what they're after is – READS OUT TASK

George: No not really....... (long silence)
Any concerns to discuss?

Positive elements – people with dementia

Recognition
Donald: So it's a shame that I wasn't a dancer, wasn't it
Doris: You never was

Clive: You are on the whole very very ideal

Clive: ....You're marvellous, essential.

Negotiation
Gill: You okay duck? Oh I ain't got me glasses on

Elizabeth: We haven't got any washing to do today?

Collaboration
All conversations = collaborative, by very nature of being a conversation. Though some "feel" more collaborative than others (those with more positive elements).

Play
Ann: well I don't know what to ask you. When did you last see your, no, that's an old Scottish joke (both laughing).
Ahmad: (laughing)What is it, what is it?
Ann: (laughing)When did you last see your father?

Bill: Well don't strangle me (laughs)

Betty: Not much else we can say….Except (laughs) well, for the first time I could have murdered you. Nah, I wouldn't do that
Bill: (jovially) Ahh, I've got it on tape

Holding
Clive: (jovially) I'm hoping the same. Sometimes sometimes I sometimes I think it is getting worse.

Clive: It probably is a struggle within me too to try and be in control when I've forgotten

Clive: The irritating thing is shared experiences of something..I can't recollect

Facilitation
Betty: ….Umm let's have a look..uhh…right….ok now, don't know what to say really
Bill: What what was (daughter) wanting this morning?

Gill: (following long silence) There's nothing to discuss is there really. Just sort of make do with things don't we.

APPENDIX EIGHT
STEPS OF THE IPA ANALYSIS
EXCERPT OF A TRANSCRIPT TAKEN FROM A CONVERSATION

This section contains part of the conversation which took place between Doris (person with dementia) and Donald. In the margins are the notes made by the researcher in the first two steps of the analysis – the left hand margin contains notes which reflected my initial thoughts and reflections when reading the transcript, and the right hand notes identify the initial themes which emerged during the IPA analysis, pertaining to what Doris was saying.

Transcription notation:
… = short pause during speech / trailing off or incomplete sentence
(interrupting) = notes in brackets reflect tones / actions which were picked up from listening to the conversation.
(*or now?*) = notes in italics in brackets indicate queries about what has been said

This transcript begins at the beginning of the conversation between Doris and Donald following the researcher leaving the room.

	Doris: You know I hate things like this	*I hate things like this*
Invalidating *Straight into task*	Donald: Yeah..well it's only research Doris. If it helps other people that's the main thing. Innit. Eh? Well I mean how's your… What I'm saying is how..do you think your memory is now?	
	Doris: I don't know how is my memory.	*Don't know how is my memory*
	Donald: Well, I mean, can you remember anything now? Is it long ago or recent time?	
	Doris: No, I'm too old	*I'm too old*
Invalidating *Focusing on task*	Donald: It's not, nothing to do with being old. It's with asking about your memory…..Can you think of things	
States she is losing her memory	Doris: I'm losing my memory	*Losing my memory*
We=aligns himself with researchers. Doris and us	Donald: I know you're losing it, and errrr we want to see how what you can remember at the moment. Can you, I mean, if I ask you something can you remember it in a little while later?	
Ignores his question, moves to focus on the past	Doris: When we were married, in the young	*When we were married* *In the young*

Invalidating	Donald: Yeah, well we're not know, we're old now Doris, and errr your losing your memory and they want to know how far it's gone, I s'pose	
	Doris: Well that's it	
	Donald: So you can't remember anything now	
	Doris: No	
Imposing his ideas, what he thinks is going on. But also turning to positive	Donald: What about urm years ago? You can remember	
	Doris: Long time ago when we was getting…	*Long time ago*
Both interrupting – trying to get point across	Donald: (interrupts) When we was getting	
	Doris: (interrupts) Working….working. That was the most things	*Working*
What she can remember	Donald: Yeah well you can remember them sorts of times can you	
	Doris: I was working from school to late…to late	*Working from school to late*
Validating	Donald: Yes I know, you worked up til your sixties. Sixty five…	
	Doris: Yes	
	Donald: Sixty six	
Disputes / protests	Doris: No (*or now?*)..just cut it out	
Back to the present	Donald: And now your retired……..urm..	
Leads conversation back to focus on the past – happier times?	Doris: I used to be one of the theme persons that could do anything from dancing to singing. I could do….	*Used to be* *Could do anything from dancing to singing*
	Donald: Well you could, you was never a singer Doris. You was a good dancer.	
Protesting, asserting	Doris: (protesting) I used to sing	*Used to*
Arguing point. Correcting.	Donald: Yeah but not really. You wasn't much of a singer.	

Doris: Just as good as anybody else. *As good as anybody else*

APPENDIX NINE
STEPS OF THE IPA ANALYSIS
EXAMPLE OF THE ANALYSES DRAWN FROM ONE OF THE PARTICIPANTS

In this section the themes produced using IPA as identified for Doris are presented. These notes represent the analysis of the conversation between her and Donald.

Theme: Long time ago
Doris refers a lot to the past and past achievements

- *In the young*
  When married
  In the young
  Working
  Working from school to late
  Used to be
  Used to
  Used to work with
  For years and years

- *As good as anybody else*
  Could do anything from dancing to singing
  As good as anybody else

- *If I wanted to go I'd go*

- *Loved it*

Theme: Still feel the same
Doris talks about her current situation and how she can still do things

- *Still feel the same*

- *I can do*
  Like to get around and do things
  I can do things
  I do

Theme: I'm too old
I'm too old

Theme: Memory
Don't know how is my memory
Losing my memory

Theme: Going out
We like those [walks]
You don't take me out anymore
Don't like being indoors on my own that's why I go out walking with you

APPENDIX TEN
STEPS OF THE IPA ANALYSIS
EXAMPLE OF ONE OF THE THEMES PRODUCED DURING CROSS - ANALYSIS OF THE CONVERSATIONS

In this section one of the IPA themes produced by the cross-analysis of the conversations is presented, with all the instances of the theme taken from each of the conversations. After each instance the speaker is identified in brackets.

Theme One: I can't remember

I don't remember the names of all your friends, that's my main problem (Ann)
The only thing that bugs me a lot is forgetting names (Ann)
I was in a terrible mess. I was completely lost. (Ann)
I don't remember where I was going (Ann)
Twice I asked and I still got lost (Ann)
I didn't know where I was (Ann)
I don't remember the figures (Ann)
You know my memory is bad so there's no use testing me (Ann)
I don't know where the bloody shops are (Ann)
It's sort of umm, what's the word, it's not working too well (Ann)
I don't remember that actually (Ann)
I don't even look at the football, the racing results (Bill)
I can't concentrate and read a paper, I can't get a newspaper (Bill)
I can't remember (Bill)
What's all them plugs over there? (Bill)
What was L wanting this morning? (Bill)
What did L want this morning? (Bill)
Is that what L said this morning? (Bill)
On occasions where I have forgotten something and I've forgotten something, where something was or forgetting things when (Clive)
When I'm away from somewhere I don't remember that place as well as somewhere I see everyday (Clive)
Sometimes that sorts of things get worse and worse (Clive)
The irritating thing is shared experiences of something I can't recollect (Clive)
I can remember something that we've been somewhere but erm not much of the details (Clive)
Sometimes I have to go back (Clive)
I get agitated (Clive)
I tend to shut up (Clive)
A struggle within me to try and be in control when I've forgotten (Clive)
I'm losing my memory (Doris)
If I'm near home I can get along with it but not at a long distance (Gill)