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**“We don’t like to use the ‘A’ word”  
Couple’s experiences of living with Alzheimer’s disease; An exploratory study**

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## Abstract

Research has shown that often individuals who have received a diagnosis of dementia are living within a spousal relationship. Despite this, it is only recently that researchers have begun to explore the couple's experiences of this, and in turn relatively little research has interviewed couples together to explore their lived experience of the illness. In this study, Interpretative Phenomenological Analysis was used to analyse the data from interviews with five couples, whereby one member of each couple had a diagnosis of Alzheimer's disease. Four themes were identified around relating to Alzheimer's, living and relating, facing the future, you, me and "it". These themes along with quotes to illustrate them are presented and discussed within this paper. The results showed that couples used a variety of strategies to cope with the Alzheimer's, in particular, many of the couples actively avoided thinking about the future. The presence of congruence was seen as an important factor in helping to maintain a sense of 'couplehood'. Dynamics between the couples and the Alzheimer's were also explored. Clinical Implications include the importance of the role of psychologists in teaching and disseminating knowledge around couples and Alzheimer's', and the importance of providing support to maintain a sense of personhood for the individual with Alzheimer's. Follow up studies would be useful to explore the couple's relationship as the illness progresses and also to look at the dynamics of the couple using different forms of analysis.

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## **Statement of Contribution**

To complete this piece of research I contributed towards the project design, applying for ethical approval, writing the literature review, recruiting participants, collecting data, data analysis and writing up of the data,.

Throughout the process regular advice was sought from Dr Shirley Thomas and Dr David Connelly.

I also sought qualitative methodological support from Dr Jennifer Clegg.

## **“We don’t like to use the ‘A’ word”**

### **Couple’s experiences of living with Alzheimer’s disease: An exploratory study**

**Abstract** Research has shown that often individuals who have received a diagnosis of dementia are living within a spousal relationship. Despite this, relatively little research has been conducted around interviewing couples together to explore their lived experience of the illness. In this study, Interpretative Phenomenological Analysis was used to analyse the data from interviews with five couples, whereby one member of each couple had a diagnosis of Alzheimer’s disease. Four themes were identified around relating to Alzheimer’s, living and relating, facing the future, you, me and “it”. Results indicated some of the strategies utilised by couples to cope with the illness and also highlighted the importance of maintaining ‘couplehood’ and the factors involved in this. Clinical Implications along with areas for future research are discussed.

**Keywords:** Alzheimer’s; couplehood; experience; IPA; spousal relationships

#### **Introduction**

The medical (organic) model of dementia has long been a framework for research, with clinicians focusing on the biomedical aspects of the illness. Consequently there has been much progress in explaining the neuropathology, biochemistry and genetics of dementia. It is argued that within this medical model people with dementia are seen as existing outside a social world; that is, their problems are attributed to brain damage with the effects of the world in which they live being discounted (Cheston & Bender, 1999). This single medical model of dementia was challenged by Kitwood (1990, 1993) who stated that dementia not only involves a change in brain function, but also a change in the social-psychological environment, that is in patterns of relationships and interactions. As such, the medical paradigm explains dementia in a technical way and may not take into consideration the individualistic experience of living with dementia. Kitwood (1997) uses the concept of ‘personhood’ to describe “a standing or status which is bestowed upon one human being, by others, in the

context of relationship and social being, implying recognition, respect and trust” (p 8). Within this concept, Kitwood (1997) used the term ‘malignant social psychology’ to describe the ways in which people with dementia are treated by others, which can result in a loss of ‘personhood’ and lead to them becoming depersonalised (see Appendix A for more details). These perspectives highlight that dementia cannot be fully understood in terms of being either an organic illness, or a social or psychological problem, rather that these need to be integrated to provide a holistic view of dementia.

Early research into the experience of dementia primarily focused upon caregivers’ experiences of living with someone with dementia; in particular eliciting and examining the concept of caregiver burden. Informal caregivers have generally been defined as persons who help a relative or friend, without pay, with one or more basic activities involved in daily living (Bertrand, Fredman & Saczynski, 2006). Some research has found that spouses caring for patients with dementia, stroke and Parkinson’s disease, perceive a similar type and high level of burden, independent of the disease (Thommessen et al., 2002), whilst Connell, Janevic and Gallent (2001), have commented that the evidence which links dementia caregiving to negative mental health outcomes is compelling and consistent. McConaghy and Caltabino (2005) also found that carers were at a high risk of developing psychological and physical health problems due to the complexities of dementia care. Further studies comparing caregivers of adults with and without dementia have supported these findings (Bertrand et al., 2006).

Considerable research has been conducted around carer’s experiences, yet receiving a diagnosis of dementia can be distressing for the individuals themselves. Despite this, due to the dominance of the medical model of dementia, little research

was conducted around the individual subjective experiences of dementia until the 1990s. Initial research was based on observation of behaviour in clinical settings and it is only relatively recently that researchers have begun to use qualitative methods to explore the ways in which individuals experience dementia. This was seen as an important advancement as a better understanding of this experience helps to inform the development of services which are sensitive to peoples' changing needs (Pearce, Clare & Pistrang, 2002). Clare, Roth and Pratt (2005) proposed that how an individual copes with the onset of dementia will be influenced by their personality, along with their previous experiences of coping with difficult situations and hence their preferred coping styles. An individual's understanding of dementia and its implications have been identified as strong factors which are likely to influence coping strategies (Pearce et al., 2002), whilst studies have indicated that an individual's ability to utilise adaptive coping strategies is crucial to optimise their well being (Clare, 2002; Pearce et al., 2002; Robinson et al., 2005). Pratt and Wilkinson (2003) identified that the social context is integral in terms of understanding the experience of a person with dementia, whilst Harman and Clare (2006) highlighted the importance of psychosocial factors in relation to the individual's awareness of their illness.

Davies and Gregory (2007) identified that over the past 20 years, up to 80 percent of dementia care has often been provided by spouses in the family home. Social context is seen as integral to the experience of dementia, with many people who are diagnosed with dementia living as part of a couple. Yet few studies have explored the experiences of spouses or the combined perspectives of couples during the early stages of dementia. There is growing recognition that the concept of personhood cannot generally be maintained individually, and that the relationship

between the individual with dementia and their partner is a key factor in maintaining this sense of self (Hellström, Nolan & Lundt, 2005a; Kitwood, 1993). Throughout the dementia illness, both members of the couple will engage in constructing both an individual and a shared sense of identity which fits in with their social context (Robinson et al., 2005). In accordance with this, engagement in activities also provides interaction with others which in turn can impact upon an individual's sense of personhood.

Research into the dynamic interpersonal relationships of people with dementia and their carers has identified that the way spouses interact with one another is crucial in determining the dynamics of dementia. Keady and Nolan, (2003) identified four patterns of 'working relationship' within couple relationships - working alone, working separately, working together and finally working apart. Research by Hellström et al., (2005a, 2005b) supports these stages, although they found that often the process of working together involved some aspect of working individually on behalf of the individual not affected with dementia in order to cope with their emotions. Research has also identified that the process of maintaining involvement with each other was increasingly dependent upon the efforts of the spouse without dementia as the dementia progressed. The concept of 'couplehood' has been proposed (Hellström et al., 2005a) which suggests that rather than the person coming first (personhood) the couple are the primary focus. Consequently this "potentially provides a more nuanced understanding of the ways in which spouses 'do things together'" (p.19).

The idea of congruence can also be seen to affect the ways in which individuals work together. Hellström et al., (2005b) proposed the term 'nurturative relational context' to describe how couples may adapt to the diagnosis of dementia.

Within this context, couples seek to sustain the personhood and the agency of the person with dementia. Such a process can be seen as involving a balance between maintaining important elements of the former relationship, yet adapting to and creating a shared meaning for the new relationship which incorporates the degenerative and unsettled nature of the dementia.

The experience of loss has been seen as being an important aspect for both members of the couple, although it was recognised that each member of the couple may experience this differently (Robinson et al., 2005). Similarly, in relation to this loss, Montgomery and Williams (2001) highlight the importance of reorganisation and adaptation to the illness amongst couples, after diagnosis and during the early stages.

Couples are more likely to be able to develop a shared construction of the illness and its meaning by addressing the concepts of change. This fits with research by Robinson et al., (2005) who interviewed couples and found that they described a period of joint negotiation and adjustment which developed over time. Accounts from these couples suggested a “cyclical process of denial, minimisation, and gradual realisation” (p.344) as they began to realise that these changes were permanent.

Current research indicates that loss, understanding, and social interactions all contribute towards how an individual experiences dementia. Much of the research supports early work by Kitwood whereby the individual’s sense of self and self-identity is maintained by relationships, and as dementia progresses, it increasingly becomes the responsibility of those unaffected by dementia to maintain this.

The explored ‘lived experience’ of dementia has been considered as central in helping to develop effective proactive care, with emphasis on involving individuals as ‘active and dignified participants’ (Steeman, Casterle, Godderis & Grypdonck,

2006). Spousal studies have focused upon interviewing couples separately (Hellström et al., 2005; Vernooj-Dassen, Derksen, Scheltens & Moniz-Cook, 2006; Clare 2002) in order to allow for free expression of thoughts and feelings, and so that triangulation of participant and carer perspectives could be used to provide a “credibility check” (Clare, 2002). However, when examining the process of coping it can be informative to interview the couple together as this allows the researcher to gain an insight into the couple’s shared construction of the dementia diagnosis. Davies and Gregory (2007) emphasise the importance of understanding how the marital relationship influences the way in which dementia enters the lives of couples. Despite this, only a few recent studies have begun to interview the couples’ together (Robinson et al., 2005).

Research into coping styles has indicated that the process of coping and adjustment in dementia is somewhat fluid, whereby couples regularly review and evaluate their situation in order to adapt their relationship accordingly (Clare, 2005; Hellström et al., 2005a; Vernooj Dassen et al., 2006).

It can be seen from the increasing body of research that individuals adjust differently to the diagnosis of dementia and that more often than not this is within the context of a relationship. Research into how couples psychologically adapt to this process along with the exploration of their experiences of the dementia is paramount in helping us to identify the needs of couples in relation to maintaining both the wellbeing of the person with dementia and their partner. Steeman et al., (2006) state that “more research is needed to refine and deepen our present understanding of living with dementia” (p.736). Hence understanding the experience of how couples cope with dementia increases our evidence base for the development of effective proactive care which focuses and builds upon these adaptive strategies.

The aim of the current study is to explore the lived experiences of couples whereby one of them has received a diagnosis of Alzheimer's disease. The couples were interviewed together to help facilitate our understanding of the concept of 'couplehood', whether this exists, and if so how it manifests itself within different relationships. A thematic framework will be offered to help understand the psychological experiences of the couples as they live with the dementia and the impact this has on their relationship.

## **Method**

The methodology in this study was qualitative and used Interpretative Phenomenological Analysis (IPA) (Smith, 1996) to explore the experiences of a small sample of participants who had been diagnosed with Alzheimer's disease and were part of a couple. IPA aims to characterise participant's experience from their own subjective perspective but recognises that the researcher's views and relationships with the participants will influence any such exploration. As a result the phenomenological analysis produced by the researcher is always an interpretative account (Willig, 2004).

Following approval from the local research ethics committee and the relevant NHS Research and Development department, participants were recruited through a memory clinic service. Participants were considered appropriate for the study if they fulfilled the following inclusion criteria:

- Diagnosed with dementia of Alzheimer's type and could be approached within four weeks of their last clinic appointment.
- Living with a spouse or partner within a relationship, who does not have any form of dementia.

- Classified as being within the mild or minimal range of severity with a Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) score of 18 or above.
- Able to give informed consent.
- Able to speak fluent English (as assessed by the psychiatrist).

Participants were then excluded from the study if they were deemed to be experiencing clinically relevant levels of major psychiatric disorder as defined by the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders – 4th edition; American Psychiatric Association, 1994) as assessed by the psychiatrist.

Participants meeting these criteria were identified by their psychiatrist at their memory clinic appointment and approached to take part in the study. The diagnosis of Alzheimer's disease was used as it is the most common form of dementia, and all individuals had received a comprehensive neuropsychological assessment. By restricting the study to this diagnosis, a homogenous sample could be obtained. The GPs of the individuals with Alzheimer's disease were informed of their patient's interest in the study and asked to state whether they had any concerns regarding their involvement. Ten couples were identified; five declined and five couples participated in the study.

Participants comprised of five couples; three females and two males with Alzheimer's disease along with their partners. All participants were White British and the couple itself was identified as the unit of participation.

See table 1 for demographics information. All names of participants have been changed to preserve anonymity.

**Table 1 Demographic Information**

Individual with Alzheimer's	Age	Name of partner	Age	Length of marriage
Joan	74	David	75	52years
Rosemary	77	Todd	76	51years
Mary	70	John	71	20years
Michael	76	Sandra	75	54 years
Keith	78	Margaret	75	51 years

Qualitative information was collected through semi-structured interviews with the couple at their home. The initial meeting took place around four weeks after their latest memory clinic appointment and its purpose was twofold. It allowed for the collection of written consent and also demographic data from the couple, but was also a useful way of building up a rapport with the participants. The second meeting was an interview and explored the couple's experience of living with Alzheimer's within the context of their relationship. Interviews lasted between 30 and 50 minutes and followed a semi structured format that included topics around their understanding of Alzheimer's, and their relationship. Care was taken within the interviews to use participants language or preferred vocabulary particularly in reference to their diagnosis. All interviews were tape recorded and subsequently anonymised and transcribed. (see Appendix B for interview schedule and extended analysis).

Interviews were analysed using IPA (with the couple being the unit of analysis) and then subject to various stages of coding and analysis (Smith, 2008; Larkin, Watts & Clifton, 2006). The first stage involved line by line analysis of the

interview content for each transcript to identify the ideas and meanings being expressed. The next step involved identifying 'objects of concern' for the participants, for example anything which was important to the participants according to the researcher. The claims made about these objects were then explored, for example, the object of 'Alzheimer's disease' is understood as "not easy to live with". This information was organised into a table for each transcript.

Several 'objects of concern' were relevant for many of the couples and so were integrated. Object descriptors were then examined in relation to one another. Descriptors that could be interpreted as relating to an overall theme were then clustered and these themes were descriptively defined. Five initial themes were generated. During this stage it was important to continually refer back to the original transcripts so that the connections that had been made were accurately reflected in the experience of the participants.

The final stage involved consideration of the initial themes in order to generate super-ordinate themes that encapsulated the range of experiences. Four super-ordinate themes were generated, with two of those being further divided into three and two sub-ordinate themes. Separate themes were not identified for each member of the couple, as the joint interview meant that the separate narratives were not distinguishable.

The validity of the interpretative process was checked through frequent reference back to the original transcripts to justify the interpretation, and by including verbatim quotations within the study to demonstrate to the reader the source of the interpretation. Credibility checks with members of the research team were also undertaken at all stages of the analysis to validate the credibility of any claims being made. A reflective journal of the process was also written.

## **Results of Analysis**

The results are presented by theme and are ordered through a logical progression in the data. Four super-ordinate themes were identified from the data: Relating to Alzheimer's disease; living and relating; facing the future; and you, me and "it". The primary focus of this paper is to explore couples' experiences of living with Alzheimer's disease. For this reason, the paper will focus mainly on the themes of living and relating, and 'you, me and "it"' as it was felt that these most effectively captured the essence of the research. The remaining themes will be summarised in less detail (for an extended discussion of all themes see Appendix G)

### **Relating to Alzheimer's disease**

Within this theme the participants offered a range of perspectives on Alzheimer's and its connotations for them as a couple in relation to their understanding, Alzheimer's as a disruption, and day to day life with Alzheimer's.

#### *1. (i). Understanding Alzheimer's*

This subtheme highlights couples' understanding of what Alzheimer's disease is.

John provides a comprehensive and medical understanding of the disease.

“...the outer surfaces of these nerves become coated with a protein, which inhibits the actual electrical flow or the memory flow and that's obviously ... and that causes ... the bit that that's connected to in the brain, that's the bit that dies, which is really what Alzheimer's is.”

John, (45-51)

John explains Alzheimer's in a purely objective and biological sense, with little or no emotion attached, and no sense of the way in which it is likely to affect their life.

In contrast to this, Joan and David use a simile to help them try and understand the disease.

“...like a five shelved bookcase. The top one being the most recent memories and the farther down, the older memories. One day the end falls off the bookcase and so the shelves fall down and the top memories slide off very quickly. In other words, the short-term memory just goes. But the one underneath lasts longer, until they gradually slide off and so it goes on over the years. And eventually, all memory is lost, which is the frightening thing.”  
David, (25-39)

David gives a very non-medicalised view of Alzheimer’s, and within this is able to assimilate how the illness is likely to progress whilst in turn acknowledging his fear about this happening.

Alongside this was the idea that some couples had little or no understanding (or desire to understand) what Alzheimer’s disease is.

*1. (ii). Alzheimer’s disease as a disruption*

This subtheme emerged through examining the couples’ different accounts of how they viewed Alzheimer’s. Within this, the couples’ accounts all described Alzheimer’s disease as being disruptive.

Rosemary and Todd’s feelings towards the Alzheimer’s disease express it as being something which is unmentionable and stigmatising.

“it’s almost as if you’ve got the plague or something”  
Rosemary, (62)

The notion of it being like the plague also conveys thoughts about it being socially isolating, almost shameful and something no-one would want. Margaret and Keith stated from the very start of the interview:

“we don’t like to use the ‘A’ word”  
Margaret.

This was an important statement for them to make as it clarified their feelings about the disease and demonstrated a total rejection and refusal to acknowledge its name, almost as if saying it out loud would make it more real.

1. (iii) *'being swept along by the Alzheimer's'*

Within this subtheme, the narrative suggests many of the couples feel that they have a lack of control over what is happening to them, and it is very much apparent that they are feeling swept along by the illness with no say over how it affects them.

“It horrifies me because I just sort of feel it bubbling up and shouting and slinging things around occasionally, but I’m going to try and get out the way you know, to go through that phase”  
Rosemary, (322-326)

Rosemary implies that the Alzheimer's leaves her feeling helpless and out of control over the symptoms. Rosemary's behaviour is out of character and thus elicits feelings of being completely horrified by the way she is acting. She tries to regain some control by indicating motivation to go through that phase and onto the next one, which she implies won't be as bad. In this quote Rosemary indicates that movement through the stages of Alzheimer's is a good thing and that change can be in a positive direction. Rosemary also appears to be a good observer of her own behaviour.

Mary has a static view of her Alzheimer's:

“it is stressful for both of us and I really don't know what to do (cries).”  
Mary, (713-714)

Mary implies a helpless stance, whereby they are completely at the mercy of the Alzheimer's, and do not know how to cope with this. Within this quote there is no indication that Mary's symptoms will decline or progress through different stages.

Sandra and Michael's account was in stark contrast to the other accounts. Although Alzheimer's has unwelcome and unpleasant effects, they tried to reframe it in a positive way:

“the nice part is he doesn't remember the nasty bits”  
Sandra (663-664)

This reframing appeared to be important for Sandra and Michael because they did not want to address many of the negative aspects that the Alzheimer's brings with it, for example getting 'het up' and emotional.

### **Living and Relating**

This theme encompasses several concepts which encapsulate the couple's experiences of living with Alzheimer's disease.

Embedded in this theme are two further subthemes specifically around 'relating to each other', and 'relating to others'. Within this paper only the first subtheme will be discussed as it was felt to relate more clearly to the aims of the study that is, the relationship of the couple. For further discussion on the context and background of the couples' relationships, and also the subtheme of relating to others (see extended analysis in appendix G)

#### *2. (i) Relating to each other*

Within this subtheme, it can be seen that the couple's ideas about their relationship have at times been forced to change as a result of the Alzheimer's. During analysis of this theme, it was felt that several components were central to the relationship and how it functioned. These components included the couple, the individual with Alzheimer's, the partner, roles and responsibilities.

A key concept within this subtheme focuses around change. The change was apparent in many different areas of the couples' life, and included the loss of their relationship as they knew it.

"I suppose it's still there but it's.. the relationship but it's getting a bit frayed isn't it?" Rosemary, (612-614)

"I don't think we're quite so close as we have been...this has just overwhelmed us, that's what it is and everything's altered."  
Rosemary, (629-634)

Rosemary's quotes highlight the changes which have occurred within her and Todd's relationship and gives the sense that the Alzheimer's is 'all encompassing'. Despite having Alzheimer's, Rosemary still shows an insight and awareness of how the relationship is now different.

Joan and David's discussion of change is slightly different from Rosemary and Todd's.

"you knew if Joan was going to do something she'd do it and so would I. I think that's the biggest thing I miss and I know it sounds awful but I can't rely on Joan anymore."  
David, (179-183)

Within this context, David highlights that reliance on each other was an important factor within their relationship, and this has now gone. From this quote one gets the sense that David feels like the Alzheimer's has robbed him of the "old Joan" who was a personification of a more reciprocal relationship.

The changing of roles within the relationship was identified across all interviews. When asked how these roles had changed, the majority of couples stated that the partner without the Alzheimer's took more of a leading role in everyday life. As well as domestic roles within the relationship, it became clear from the interviews

that many of the partners had also had to adapt to the role of being a carer and a loving husband or wife. John articulated this when he said;

“I feel now that I’m ... my life ... I wear two hats; you know, I wear the hat of a hopefully loving husband but I also wear the hat of a carer. And I think this is where Mary may think I’m being hard but sometimes I think as a carer you’ve got to ... if you’re going to do it successfully, you’ve got to be detached in some respect.”

John, (784-787)

John’s quote is a good example of the difficulties faced by partners as they realise that they have to adopt a new role in addition to their role as a partner. John is able to acknowledge this, but appears unsure as to what his primary role is for example whether he is still the loving husband, or now more of a carer. John makes it clear that it’s hard to find a balance and he is unable to wear both hats at once. He later goes on to state:

“I’ve got to you know ... if I get too involved, I’ll get nothing done. So that’s ... I think that is the way it’s going to go and probably the caring role, if things deteriorate, will become a larger proportion. That’s how I deal with it. It may not be the right way, it may be that other people are better equipped to handle it, I don’t know, but that’s me.”

(824-833)

It is important for John to look after Mary well, and he almost implies that in order to survive he has to detach himself from her emotionally. Within this quote, John recognises that he is likely to become more of a carer than a husband, although he does not state that this is inevitable, but rather softens the inevitably by using the word ‘if’ in relation to Mary deteriorating.

Following on from the changing of roles, the partners of the individuals with Alzheimer’s had begun to experience increased levels of responsibility towards their partner. This responsibility centred on increasing levels of dependence upon them by their partner (this included feeling responsible for checking that their partner had turned things off and done what they said they had), and a sense of responsibility to

remain the healthy one in order to care for their partners as well as they possibly could. Another aspect of responsibility which arose from the interviews was the idea of being more responsible for them and their partner's safety. Sandra describes how she is constantly vigilant of Michael:

“I watch him an awful lot and it annoys him. That's something, ‘don't keep watching me, I'm alright’. But if I don't watch him, he'll do something wrong and then I'm looking round for something you know, ‘where have you put it?’”

Sandra, (224-231)

Change in some cases was seen as a positive thing:

“I think we've become closer”

Sandra, (508)

Alongside change being both a negative and positive concept, some couples experienced potential change as a scary prospect. Explicitly couples would discuss how they would not allow certain aspects of their relationship to change, however underneath, there was an awareness that whatever plans they made, these may be futile in the end. The lack of control over the Alzheimer's was again highlighted with a sense of potentially losing out to it in the end. Below is a section of dialogue between Joan and David where they are talking about their relationship, (and which highlights this observation).

D “well it'll change obviously if Joan gets worse, but I can't see me loving her any less or...

J I'm not going to get worse, you look at it that way.

D Well yeah, we ... I mean I dread the thought if you did, love. But I can't see that I would ...

J We'll survive.

D I couldn't stop feeling the way I do about her.

J No, no way. Nor me you, love.

D No. But we have spoken about what if you forget me, haven't we and you've said you never will ...

J No.

D But I mean we don't know, do we?

J Well you don't know but ...”

Many of the changes led to sources of tension within the relationships, and thus highlighted strategies used by the couples to cope with this.

Much of the conflict seemed to arise out of the individual with Alzheimer's forgetting or losing items and reflected feelings of frustration by both parties. Sandra explained that when Michael has lost or forgotten something then he is likely to blame her for it and subsequently they developed their own strategy for diffusing such situations.

“Well mainly when he's forgotten something and he blames ... turns round and says it's my fault you know, that sort of thing. 'Oh you did it, I didn't; no, not me'. And I say 'well there's nobody here only me' and the one-eyed bloke we call it now. We say now when things go awry or things go missing, 'oh it's the one-eyed bloke's been again'. And we pass it off like that; we have to joke about it. You have to laugh or else you cry.”  
Sandra, (178-189)

Sandra's experience of conflict encapsulates the poignancy of the changes occurring within the relationship. Sandra's last sentence tells us that for them (and maybe her in particular) this is the only way she can deal with these difficulties. The quote highlights how the couple have worked together to diffuse the conflict by passing blame onto a non-sensical third person. By doing this, neither of the couple are made to feel at fault, and they can neatly side step around the painful issue of Michael's Alzheimer's.

In relation to coping with the changes, the couples seemed to use strategies of needing to 'be normal', minimisation, and humour to normalise their experience:

“there is a change but the change is so gradual and you're getting older so you sort of just accept things really”  
Margaret, (267-269)

Many of the couples appeared reluctant to talk about how the Alzheimer's may affect them later on. Casual language was often used to state that the Alzheimer's *might*

get worse. By doing this, it allowed the couples to retain some hope that things just might not get that bad.

“If we can stay no worse than this then we could cope very happily”  
Margaret, (706-707)

The concept of humour arose frequently within the interviews. Couples appeared to use humour to soften the blow of the symptoms of the Alzheimer’s, for example the forgetfulness, and was also used by those with Alzheimer’s to joke about their partners increased responsibility.

“we get over a lot of things with humour don’t we...  
...it helps to keep it light hearted. I suppose its chickening out of accepting that something is going to happen really “  
David, (789, 805-808)

### **Facing the Future**

It became apparent that each couple had their own outlook on life which seemed to influence how they thought about their future. This was best captured by the idea of a continuum; at one end the future is described positively, whilst at the opposing end there is no future.

Keith and Margaret described that a positive attitude and a positive outlook were important for their wellbeing and to help them cope. It was felt that Keith and Margaret had mixed feelings and reactions about the Alzheimer’s as they were accepting of the Alzheimer’s on a very small level, but rejecting of it in many ways. Their positive outlook felt like it helped them to take control over the illness and subsequently they did all they could within their power to try and fight the illness so it did not become a bigger part of their life.

“You’ve got to be positive haven’t you?”  
Keith, (1103)

In contrast to this Rosemary and Todd described that they did not really have much of a future:

“I don’t think either of us see much long-term future as things are going. I don’t mean together but managing our lives, helping each other; I don’t think it’s going to last very much longer quite honestly. Maybe a year but I can’t see it for much longer than that”

Todd, (616-623)

From this quote it feels as though Rosemary and Todd are being forced to confront the finality of life and their relationship as they know it. They appear to have resigned themselves to the fact that they can’t carry on and that their life together is almost over.

### **You, Me and ‘It’**

This theme describes the relationships between the couple and the Alzheimer’s disease. Within this theme there are two subthemes which focus on the positioning between the individual with Alzheimer’s and their partner, and the couple with the Alzheimer’s. By nature of interviewing the couple together, dynamics and positioning (i.e. their concept of orientation to and involvement in the lived world) were identified within the dyad and considered to be important.

#### *4 (i) – Two’s company*

The analysis of the positioning and dynamics between the partners in one relationship provoked this theme. The parent and child dynamic was so apparent that it was felt necessary to explore this further.

In relation to this dynamic, the partner with Alzheimer’s was talked to as if they were a child, with their partner taking on the parental role. An example of this can be seen

within Rosemary and Todd's relationship. In relation to Rosemary not going out much, Todd states:

"I mean she's very good on sort of a one to one. We have this sitter now that comes"

Todd, 169-170

Within this quote it feels as though Todd has taken on a parental role, with the word 'sitter' implying she needs looking after, perhaps like a baby sitter would look after a child.

Rosemary appears to have sensed the shift in positioning between her and Todd as some of her quotes are from the viewpoint of being like a child: for example when discussing Todd leaving her on her own in the house, she states:

"And I've stayed in the house and I've felt quite safe and I've not done any damage or anything. I just sort of read or do something or other"

Rosemary, 385-388

One gets the sense that Rosemary wants validation from Todd for being a 'good girl' and causing no trouble. In much the same way a child may seek validation from their parent for being well behaved.

Similarly later on, Rosemary thinks her husband views her like a child, and in relation to not going shopping, states:

"I haven't been coming lately because I think he gets on better without me there, I think he thinks I'm going to be like a little kid."

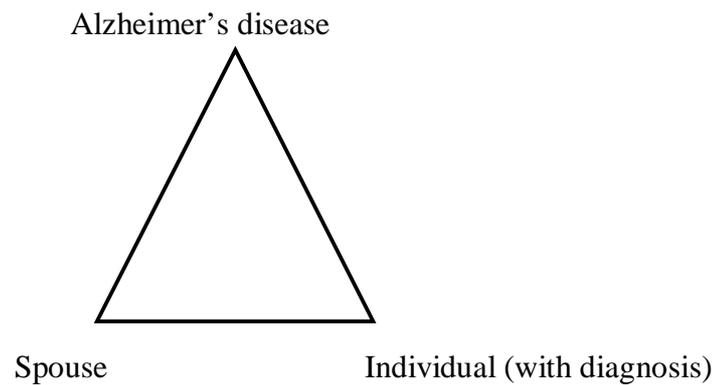
Rosemary, 496-499

From this quote, Rosemary appears to feel that she is a burden to Todd, and relates this to being like a child. One wonders whether the situation has arisen before, and Rosemary's experience is that Todd is not always able to stay within the role of a husband, having made references to her acting childlike in the past.

4 (ii) *'Three's a crowd'*

It was noticeable that Alzheimer's was identified as a third object alongside the couple's relationship. This subtheme is best represented in figure 1 (overleaf):

Figure 1: **Diagrammatical account of the positioning between both partners and the Alzheimer's**



Throughout the interviews, there appeared to be three main patterns emerging.

- The Alzheimer's was seen as completely external to the couple,
- The Alzheimer's was seen as part of the individual who had the diagnosis,
- The partner without Alzheimer's was unable to assimilate the Alzheimer's with their partner (all three points were fragmented).

In the first instance, couples would externalise the Alzheimer's so that it was not part of them or their relationship. These responses can be thought of on a continuum whereby couples externalise and deny its existence. This continuum ranges from not wanting to even say the word 'Alzheimer's' and referring to Alzheimer's as "it", through saying it but not using the proper name, for example "the problem" or the

“A word”, and finally acknowledging the Alzheimer’s by using its name, but still not wanting anything to do with it.

An example to illustrate this last point comes from Sandra who states:

“I’m the sort of person that if I’d got cancer, I wouldn’t want to be told you know, I’d rather not know. So it’s the same with this really.”  
Sandra, 620-623.

Within this instance, the symptoms of the Alzheimer’s were also seen as separate from the individual. David gives an example of this:

“It’s not because Joan couldn’t do it or can’t, it’s because this blessed memory lets you down”  
David, 312-314

David implies that Joan is separate to the Alzheimer’s and it is the Alzheimer’s and not Joan who is at fault.

In the second instance, the Alzheimer’s and the individual with the diagnosis were seen as congruent. In such cases, the person with the Alzheimer’s would be held responsible for their difficulties, and likewise, the person with Alzheimer’s would also assimilate themselves with the disease. Todd and Rosemary illustrate these two points:

“I mean I realise, you’ve got a problem”  
Todd, 352-354

“It’s not so bad when you learn to live with it”  
Rosemary, 940-941

Finally, the relationships appeared fragmented whereby the partner of the spouse with Alzheimer’s was unable to assimilate them with the Alzheimer’s and so all three components became separate. This was best highlighted through several quotes made by the partners of individuals with Alzheimer’s and became so prominent they have been named ‘unmentionables’ during the analysis. Within these

'unmentionables' the partners would often begin to talk to their partner about their difficulties and then be unable to complete the sentence:

"Now, you just ... it's all gone, you know and it's horrible, that's all I can say really."

John, 480-481.

"I can't, I have to double check everything pretty well, bless her, because you just can't...well you..."

David, 191-193

Both John and David experience difficulties talking directly to their partner about what has changed or what they can't now do.

Another unmentionable was when partners would begin to talk to their partner and then turn and finish the sentence of by talking to the interviewer.

"I mean you're not as relaxed as you were and you can't ... Rosemary used to enjoy reading and doing a lot of things didn't you."

Todd, 453-456

From Todd's perspective it feels too painful for him to directly say to her what she can't do, and so instead it is easier for him to externalise this and talk about Rosemary rather than to her.

The couples experiences arising from this subtheme appeared to reflect an inability by partners to engage within a fractured world.

## **Discussion**

The interpretative analysis describes the lived experience of dementia, and how couples understand Alzheimer's. In turn, a range of perspectives surrounding how the couples constructed the changes, adaptations and implication of the disease were identified.

The importance of the understanding of Alzheimer's and in turn the impact this has on how the couples assign meaning to the illness has been highlighted. Couples had contrasting definitions of the illness which allowed them to conceptualise it between themselves.

The process of loss and change was also identified from the interviews. This highlighted changes around couples' roles and responsibilities within the relationship which often led to an increase in inequalities of power (Robinson et al., 2005; Rolland, 1998). Similarly, work by Clare et al., (2005), found that whilst some couples explicitly confronted the changes they would be facing, the majority of the couples in the study made it clear that they did not wish to discuss or think too much about the future or their current situation.

Many of the couples described the importance of focusing on day to day life and remaining positive. This seemed to be an important strategy for coping with everyday difficulties and often involved a minimisation of the impact of the Alzheimer's. This process appeared to be different from that of denial and more of an adaptive coping strategy as the couples had all accepted the Alzheimer's (on some level) but seemed to make a conscious decision not to engage in the rumination of what may happen. Other studies have produced similar findings, with Hellström et al., (2005a) suggesting this was a conscious decision to make life as meaningful as possible whilst the opportunity existed. Robinson et al., (2005) also made similar observations and suggested that this joint construction gave both partners permission not to worry about the changes they were experiencing. Similar strategies to those used by couples with dementia have been used by spouses whereby one of them had been diagnosed with a brain tumour. Salander and Spetz, (2002) proposed that this was not about pretending not to know, or knowing but ignoring the fact, rather there

was a “mutually accepted judgment that the disease might be fatal, but an agreed understanding that it would not form the dominant discourse.” (Hellström et al., 2005b, p.278).

Many of the participants appeared to demonstrate levels of congruence in relation to their relationship and views on life, for example using ‘we’ often, and producing a similar narrative around certain topics. Whitlach (2001) identified congruence between the partners as an important factor in maintaining the personhood of the individual with Alzheimer’s. Congruence can be seen as dynamic and multidimensional and instrumental in maintaining the person’s sense of identity and self. Other research has commented that failure to achieve this congruence is likely to result in interpersonal conflict and the couples are likely to begin to drift apart (Salander & Spetz, 2002). The concept of ‘working together’ (Keady & Nolan, 2003), for example to make the best of the situation was also seen as an important factor within the research in maintaining couplehood and fitted with the notion that couples generally ‘worked together’ when they had congruence. Within this study, many of the couples could be seen to ‘work together’. However in some of the couples it was felt that they had started to ‘work apart’, for example when the relationship became fraught and it was difficult to reach a mutually agreed way forward, which in turn led to relationships becoming strained with an increase in conflict.

The interviews indicated that couples developed adaptive coping strategies for difficult situations (Robinson et al., 2005) for example not responding or use of humour when items went missing or tasks had not been completed. This fits with the idea of sustaining couplehood (Hellström, Nolan & Lundh, 2007) and has been identified as an important component in the development of the ‘nurturative

relational context'. In some couples adaptive coping strategies did not seem to be used and as a consequence it was felt that they had become so overwhelmed by the Alzheimer's that all they could do was think about the future and worry. Within these relationships, conflict appeared to be a prominent feature.

Hellström et al., (2007) identified four interrelated sets of activities for maintaining couplehood (talking things through, being appreciative and affectionate, making the best of things and keeping the peace). Within this study the activity of 'making the best of things' was clear, whereby the couples searched for the positives and took each day at a time. Talking things through and keeping the peace, were prevalent to a lesser extent, and being appreciative and affectionate was not noticeable. One reason for this may have been because the current participants were only interviewed at one time point and so had not experienced any of the changes associated with some of these other activities yet.

In relation to discussing the future, Hellström et al., (2005a) suggest that often deliberately sustaining a degree of uncertainty was preferable to openly acknowledging the future impact of the disease. Kuhn (1998) also found this, but commented that some carers were frankly pessimistic about how they would meet the future needs of their relatives with Alzheimer's. This could be seen within Rosemary and Todd, and to a lesser extent with John and Mary, although in John's case, he had experienced the death of a previous spouse and so seemed more aware of the realities he would have to face.

The ways in which the couples positioned themselves and the dementia was an interesting observation. Exploring the concept of 'positionality' can help us to capture the concept of orientation to and involvement in the lived world (Palmer, Larkin, de Visser & Fadden, unpublished). In this study 'positionality' was an

important aspect in maintaining couplehood whereby the strategy of externalising and distancing themselves from the disease allowed them to do this successfully. The decision to externalise the Alzheimer's could be seen as a healthy process as it allows the couple to engage with the reality of the situation, yet provides a mutually agreed way forward which promotes congruence and an increase in couplehood.

The study has highlighted many key areas which have implications for clinical practice. The way information is presented at diagnosis and through the course of the illness is important as professionals working in this field need to be able to adapt their style to permit alternative ways of understanding, for example medical terms or use of analogies. Many of the couples indicated that they did not want to discuss the future and this was identified as a useful strategy. Professionals need to be mindful of the information they tell couples and be respectful of the information they do or do not want to know. In practical terms it may be useful to make access to information a choice and thus give couples written information so that they can access this when they feel ready to. This could also be applied to the provision of support groups and the importance of tailoring treatment which is relevant to their levels of adjustment.

Sustaining couplehood has been highlighted as an important factor within couples. It is of huge importance to provide the necessary support to enable the members of the couple to play an active role within the relationship for as long as possible. Practically this could be through the promotion of the continuation of well rehearsed tasks for example in the case of Joan and David where Joan continued to make the toast and tea for breakfast, and also by including the person with Alzheimer's in decision making and keeping them an active participant within their own care for as long as possible.

As psychologists, this highlights the importance of disseminating such research across staff teams to facilitate improvements throughout services and also increases our awareness as clinicians of being flexible to the needs of couples throughout the illness.

The current study has aimed to provide further evidence for our understanding of how couples experience Alzheimer's. However, limitations should be acknowledged. Due to its qualitative nature and the limitations of time available, participants were only observed at one point in time. Interviews were conducted jointly with the couple which was a strength as it captured the dynamic experience between the couple within the same room and their co-constructed account. However, this did lead to more complex transcripts, and gave limited access to individual accounts. Individuals may have been more cautious and positioned themselves in certain ways within the conversation. Interviewing couples can be seen as a challenge to IPA as it encompasses a double hermeneutic, and it became apparent that the way the couples positioned themselves and used language to talk about their experience was an important factor. This highlighted the need for continued research into the use of IPA with more than one individual, and the potential for using other methods such as discourse analysis to add another dimension and gain a different type of understanding. It is also important to consider when researching relationships in this context, that we do not know what the dynamics of the relationship were like before the Alzheimer's.

A follow up study would be useful to observe how the couples adjust to the disease as it progresses, and to identify any changes in their awareness or the ways they work with each other. As mentioned previously it would also be interesting to analyse the same data from a different qualitative perspective such as discourse

analysis to observe more closely the discourse between the couple and their constructions, particularly within a joint interview.

Word count: 7999

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# Dementia –submission guidelines for authors

## The International Journal of Social Research and Practice

Editors:

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University of Manchester, UK

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John Carroll University, Cleveland, USA

### Manuscript Submission Guidelines:

#### Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.
2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.
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8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.
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11. *Figures*. Line drawings should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

12. *References in the text* should be presented in American Psychological Association (APA) style, i.e. the author's name and year of publication in brackets, together with the page numbers, e.g. 'As Kitwood (1997, pp 40-41.) has observed', or, in a more general reference: 'Kitwood (1997) appears to be saying ...'

13. *Reference list*. The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17(4), 597-607.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Morse, J. M. (1994). Emerging from the data: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.),

*Critical issues in qualitative research methods* (pp. 23-43). London: Sage.

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15. *Abbreviations*. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

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## North Nottinghamshire Research Ethics Committee

1 Standard Court  
Park Row  
Nottingham  
NG1 6GN

Telephone: 01159123344 Ext: 39368  
Facsimile: 01159123300  
25 March 2008

Miss Lindsay Flatman  
Trainee Clinical Psychologist  
University of Lincoln  
Department of Health, Life and Social Sciences  
Court 11, Satellite Building 8, Brayford Pool  
Lincoln, LN6 7TS

Dear Miss Flatman,

**Full title of study:**            **A qualitative exploration of the experience of adjusting to a diagnosis of dementia within couples, where one of them has recently been diagnosed with Alzheimer's.**

**REC reference number:**    **07/H0407/64**

Thank you for your letter of 28 February 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The Chair has considered the further information on behalf of the Committee.

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

### **Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		16 August 2007
Investigator CV	1	16 August 2007
Protocol	1	01 August 2007
Letter from Sponsor		17 January 2008
Interview Schedules/Topic Guides	1	01 August 2007
Letter of invitation to participant	2	01 December 2007
GP/Consultant Information Sheets	2	01 December 2007
Participant Information Sheet: Individual with Alzheimer's Disease	2	01 December 2007
Participant Information Sheet: Partner of individual with Alzheimer's Disease	2	01 December 2007
Participant Consent Form: Individual with Alzheimer's Disease	2	01 December 2007
Participant Consent Form: Partner of individual with Alzheimer's Disease	2	01 December 2007
Response to Request for Further Information		15 January 2008
Response to Request for Further Information		28 February 2008
Letter to Consultant Psychiatrist	2	01 February 2008
CV - Key Investigator		
CV - Educational Supervisor	2	13 August 2007

## **R&D approval**

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdform.htm>.

## **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.

- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nationalres.org.uk](mailto:referencegroup@nationalres.org.uk) .

**07/H0407/64**

**Please quote this number on all  
correspondence**

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

Yours sincerely

**Dr David Walsh**  
**Chair**

Email: [trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk)

*Enclosures: Standard approval conditions*

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R&D office for NHS care organisation at lead site - NHCT

## **Appendix A**

### **Additional background material**

#### *Dementia*

Dementia is an umbrella term which is used to describe a group of symptoms which comprise cognitive (communication, reasoning, and memory), and physical (loss of skills) decline. The ICD-10 (International Classification of Disease – 10th edition; World Health Organisation, 1988, 1994) defines dementia as a “syndrome due to the disease of the brain, usually of a progressive or chronic nature, in which there is a disturbance of cognitive functions, including memory, thinking, comprehension, language. These are commonly accompanied by deterioration in emotional control and social behaviour”. There are several different types of dementia, each of which are caused by different diseases of the brain. It is estimated that there are now 700,000 people with dementia in the United Kingdom (Knapp & Prince, 2007), with Alzheimer’s disease (AD) being the most commonly diagnosed type.

AD is a complex and progressive degenerative disorder (Paun, 2002) which changes the chemistry and structure of the brain causing brain cells to die. Two thirds of individuals with AD are living in the community, and it is estimated that family carers of people with dementia save the UK over £6 billion a year (Knapp & Prince, 2007). In the early stages of AD individuals may begin to experience forgetting or repeating themselves more often than usual. As the illness develops, individual’s memories will get worse, and recognition of people and places will worsen. Eventually individuals will become increasingly frail and dependent on others for help and may exhibit challenging behaviours and have difficulties with everyday tasks such as eating, communicating and toileting.

Medical models of dementia were the primary focus in dementia care for many years, with professionals focusing upon the neurological models of the disease. Within this context, the social and interpersonal nature of dementia was ignored. This was challenged by Kitwood (1993, 1997) who used the term ‘malignant social psychology’ to describe the ways in which people with dementia are treated by others and to highlight that losses due to dementia not only occur in relation to neurological functioning, but also within dementia sufferers relationships with other people. He proposed that the malignancy is part of our cultural inheritance whereby caregivers carry out most of their work with kindness and good intent, with little realisation of the impact the psychosocial environment can have on health. Consequently, dementia sufferers begin to lose their sense of ‘personhood’ and become depersonalised. Kitwood (1997) initially proposed ten elements of this, with a further seven being added at a later date. These elements included being disempowered (things are done for them that they are able to do themselves), labelled (using the category of ‘dementia’ as the main basis for interacting with a person and explaining their behaviour), infantilised (being treated like a child) and banished (physically or psychologically sending a person away or excluding them). See table 1 for a full description of Kitwood’s elements.

**Table 1: Kitwood’s proposed list of elements contributing towards malignant social psychology (1997)**

1	<i>Treachery</i>	Using forms of deception in order to distract or manipulate a person, or force them into compliance
2	<i>Disempowerment</i>	Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated
3	<i>Infantilization</i>	Treating a person very patronisingly as an insensitive parent might treat a young child
4	<i>Intimidation</i>	Inducing fear in a person, through the use of threats or physical power
5	<i>Labelling</i>	Using a category such a dementia, or ‘organic mental disorder’ as the main basis for interacting with a person and for explaining their behaviour
6	<i>Stigmatisation</i>	Treating a person as if they were a diseased object, an alien or an outcast
7	<i>Outpacing</i>	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.
8	<i>Invalidation</i>	Failing to acknowledge the subjective reality of a person’s experience, and especially what they are feeling
9	<i>Banishment</i>	Sending a person away or excluding them- physically or psychologically
10	<i>Objectification</i>	Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained
11	<i>Ignoring</i>	Carrying on in the presence of a person as if they were not there
12	<i>Imposition</i>	Forcing a person to do something, overriding desire or denying the possibility of choice on their part
13	<i>Withholding</i>	Refusing to give asked for attention, or to meet evident need.
14	<i>Accusation</i>	Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation
15	<i>Disruption</i>	Intruding suddenly upon a person’s action or reflection; crudely breaking their frame of reference
16	<i>Mockery</i>	Making fun of a person’s strange actions or remarks, making jokes at their expense
17	<i>Disparagement</i>	Telling a person that they are incompetent and useless; giving them messages that are damaging to their self esteem

### *Carer burden*

Much research has been carried out into carer burden and carer strain of those looking after family members with dementia. It has been suggested that caregivers to individuals with dementia have several areas to cope with. In particular they must cope with the reality that their loved one will continually deteriorate, and that dementia is an irreversible disease which will increasingly begin to “rob the caregiver of the intellectual and emotional reciprocity that they once shared” (Bertrand, Fredman & Saczynski, 2006, p. 547). Jansson, Nordberg and Gratström, (2001) found that protecting the care receiver from awareness of increasing decline, and preserving the past along with the individuals sense of self were considered to be important aspects of dementia care for spousal caregivers.

Research has focused more specifically on the impact of care giving when the caregiver has been a relative or spouse. Such studies have begun to identify coping strategies which are used by the caregiver as they go through the process of trying to adapt to not only the impact of the dementia on their lives, but the impact this will have with regard to their relationship and everyday life. Kuhn (1998) found that adjusting to changing responsibilities was a significant factor within the coping process, especially within spousal relationships. Stress process models have been used to identify risk and protective factors for carer well-being (Hayley, LaMonde, Han, Burton & Schonwetter, 2003), and Connell, Janevic and Gallant, (2001) identified that caregivers coping style related to the level of stress they experienced when caring for a relative with dementia. Typically two types of coping have been identified; emotion focused coping and problem-focused coping. Emotional coping strategies refer to the use of internal strategies which an individual may use to manage their emotions, for example, day dreaming, praying for a miracle and

avoidance. In their research into caring for a relative with dementia, Papastavrou, Kalokerinou, Papacostas, Tsangari and Sourtzi (2007) found that during the early stages of the disease when the symptoms of dementia are relatively mild, caregivers may use avoidance and denial strategies which are initially useful. However, they found that as the illness progresses, such emotional strategies become increasingly less effective. Consequently links have been made between high levels of depression and emotion focused strategies. McClendon, Smyth and Neundorfer (2004) also found that depression caused by such strategies could be related to lower patient survival rates, as the caregivers are less available for the patient. Problem focused coping strategies involve efforts to change the problematic and stressful situation in some way. Research has provided evidence that even in situations where little can be changed, attempts to problem solve, or re-frame the problem in a positive light can be seen to decrease carer stress (Connell et al., 2001). Work by Hayley et al., (2003) identified that less distress was found in caregivers with larger social networks and increased participation in social activities.

### *Individuals with dementia*

Morse and Johnson (1991) discussed a four stage model of chronic illness. This model highlights that individual adaptation to a chronic illness is dependent not only upon the individuals evaluation of the stressor, but the effectiveness of their coping behaviour, and the social support they will receive to help them gain control over this. Lazarus and Folkman's stress coping model (1984) is widely used to explain how individuals evaluate and adapt to stressors. Essentially, it is proposed that the ways in which stressors are evaluated will determine the emotional or behavioural reaction, and individuals will adopt a problem or emotion focused

approach (as mentioned previously). Although this model is widely used, Zeidner and Endler (1996) stated that it is more useful as a frame of reference, as it does not take into account the level of chronicity specific to different illnesses, which in turn may affect the coping strategies an individual uses.

The meanings individual's give to the term 'dementia', and their sensitivity towards others' reactions of their diagnosis are also important. Clare (2002) concluded that people in the early stages of dementia are capable of presenting coherent and insightful accounts of their experiences, and are sensitive to the responses of others to their diagnosis, as well as the strategies others may undertake to try and protect them. In light of this, social responses towards the diagnosed individual which fail to take into account their level of awareness, may serve to reinforce an individual's protective strategies such as concealment and denial in order to reduce the threat of marginalisation.

Clare (2003) conceptualised coping with dementia as falling upon a continuum, ranging from self-maintaining responses to self-adjusting responses. Within the self-maintaining responses it was hypothesised that individuals were likely to utilise self-protective strategies. These strategies can be seen as an attempt to preserve and protect the pre-existing self-concept in order to maintain normality and continuity in line with their personality before the onset of the dementia. Protective strategies may involve minimisation of problems (Clare, 2002), denial of problems and avoidance of activities (Gillies, 2000), and the use of humour to mask inability to remember or respond appropriately (Burgener & Dickerson-Putman, 1999).

In contrast to this, self-adjusting responses may be aimed at integrating new experiences and difficulties and adjusting ones sense of self in accordance with this.

Integrative strategies which may be used include finding out more about dementia, focusing on the good things (Clare, 2002), and taking a proactive stance through anticipating and preparing for future needs (Harris & Durkin, 2002)

Harman and Clare (2006) found that self-adjusting responses were more likely to be implemented once a diagnosis of dementia has been given. In contrast, self maintaining responses were more likely to be used before a diagnosis had been given, and used to normalise the changes experienced and attribute these to the process of aging.

Individuals diagnosed with dementia may be reported as 'losing interest in the world'. Cheston and Bender (1997) challenged the view that this is purely down to neurological degeneration, and highlight the importance of social factors in this process. In accordance with the levels of malignant social psychology proposed by Kitwood (1997), they support the notion that once the individual has been diagnosed and hence 'labelled', then their behaviour becomes in some way different from the norm. They therefore state "it may be useful to desist from seeing the person with dementia as withdrawn; and be more accurate to say that their social roles have been withdrawn from them, leaving only the roles of the patient and dementia sufferer" (Cheston & Bender, 1997, pp. 523).

### *Couples*

The diagnosis of dementia can often mean that individuals are thrown into a world whereby they are forced to adapt their ways of life, and "construct an individual and a shared sense of identity within their social context" (Robinson, Clare & Evans, 2005, p.337). It has also been proposed that the role of social interaction plays a significant part in influencing whether the newly diagnosed

individual copes positively with the transitional processes involved (Steeman, Casterlé, Godderis & Grypdonck, 2006).

Keady and Nolan (2003) proposed that the patterns of working among couples can affect the dynamics of the dementia within couples. Four patterns of working relationship were defined, the first of which is the concept of 'working alone'. In this situation one or other of the partners are seen as working individually. This situation is identified as occurring most frequently within the early and late stages of dementia. The second concept is 'working separately'. In this instance, both partners are actively engaged in the process, but often this consists of one partner 'covering their tracks', whilst the other becomes more vigilant towards any changes in the others behaviour. It was found that within this pattern of working, relationships often became strained. The pattern of 'working together' involves both partners actively opening up and discussing with each other their fears and views about what is happening. Within this pattern, couples can be seen to work together to make the best of their situation, which could include seeking appropriate help. The final pattern of working identified was that of working apart. In this instance, the relationship becomes unsettled, and the couple are unable to agree on a way forward.

Robinson et al., (2005) identified the experience of loss as being an important aspect for both members of the couple, although it was recognised that each member of the couple may have different experiences of this. Montgomery and Williams (2001) highlight the importance of reorganisation and adaptation to the illness amongst couples, after diagnosis and during the early stages.

Much research has also identified the concept of loss as being prevalent within the relationship, for both parties. For example, the individual who has been

diagnosed with dementia may experience depressive symptoms due to an awareness of their condition and the losses associated with this, whilst the spouse may experience losses in relation to the loss of a previous lifestyle, and the loss of their partner (Dempsey & Baago, 1998). Couples are required to adjust to the diagnosis, and the associated loss, and in turn consequently begin to reevaluate the social context in which their relationship is based. Montgomery and Williams (2001) identify that relational role loss is a consequence of care giving most prevalent amongst caregivers. Often the caregiver will grieve the loss of a living spouse, particularly when the dementia has progressed to the point where the relationship has been significantly altered.

#### *Gaps in the research*

Currently, research has been aimed at examining the impact of a dementia diagnosis over time, and as such attempted to provide models, which help to understand the adjustment process. Research into coping styles has indicated that the process of coping and adjustment in dementia is a somewhat fluid process, whereby couples are regularly reviewing and evaluating their situation in order to adapt their relationship accordingly. This has been supported by many studies including Clare, Roth and Pratt (2005) who found that through examining thematic accounts of change, the dynamic nature of evaluating change over time was captured. Hellström, Nolan and Lundh, (2005a) found that over time couples worked together to manage the awareness of dementia, and proposed the concept of ‘couplehood’ whereby for spouses the couple was the primary focus.

Interviewing couples separately to gain a qualitative understanding can be useful as it gives an insight into how each partner appraises the situation, their

associated feelings and coping strategies used, however, Forbat and Henderson (2003) have identified that this method can result in the interviewer feeling 'stuck in the middle' of the couple. Few studies have attempted to combine the perspectives of people with dementia and their partners. This method can be complex, as individuals may feel unable to say things in front of their partner and it is not without ethical consideration. Despite this, an integral part of the marital relationship is missed if the perspectives of both partners are not included as part of the analysis (Macquarrie, 2005). This research therefore aims to capture this dynamic and in turn explore the lived experience of couples with Alzheimer's disease (Robinson et al., 2005; Harris, Pistrang & Barker, 2006).

#### *Clinical relevance*

NICE (National Institute for Health and Clinical Excellence) provide comprehensive guidelines on the diagnosis and treatment of dementia, yet it is only recently that a person centred approach toward dementia care is being considered. Access to 'Structured group cognitive stimulation programmes' (1.6.11) is suggested for those with a dementia diagnosis, whilst 'carer's assessments seek to identify any psychological distress on the carer' (1.11.2.1).

This research can be seen as clinically relevant as it serves to enhance our knowledge of the psychological processes couples experience once a diagnosis of Alzheimer's has been given. Consequently it will contribute towards understanding what support may be required by couples not only to maintain their well being and relationship, but also to help us as clinicians gain an insight into how this can be integrated towards providing a person focused approach.

## **Appendix B**

### **Extended Methodology**

Interpretative phenomenological analysis (IPA) (Smith, 1996) has been used extensively to explore individual's subjective experience of physical illness and to get an 'insiders perspective' (Conrad, 1987), with many studies using this methodology to understand the impact of dementia (Clare et al., 2005; Langdon, Eagle & Warner, 2007, Robinson et al., 2005). IPA is phenomenological in that it aims to explore the participant's view of the topic being investigated. It is interpretative as it acknowledges that the participants description of their experiences are elicited through a dynamic process within which the interviewer's own beliefs and understanding influences the process of interpretation in order to make sense of the participants subjective world. IPA involves a double hermeneutic as "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith, 2008 pp.53). The use of IPA was chosen instead of other methods such as discourse analysis for the following reasons. The emphasis on language as a constructive tool is one of the core assumptions of discourse analysis. Language is the key function and is used to examine how people use it to construct objects and events within their worlds. In other words, by studying discourse and conversation we can explore how meanings are created and negotiated. However, after some consideration it was felt that this methodology may be too demanding upon the participants as some of them may have begun to experience a decline in their verbal abilities. This approach also does not attempt to explore the essence of individual's everyday experiences which was the primary aim of the research. It was therefore felt that although IPA recognises that

the context of language is important, the meanings and experiences behind this are seen as central to the interpretation. The couples' experiences of Alzheimer's disease was the primary focus of the research and it was decided that this would be best addressed through the use of IPA.

### *Recruitment*

In accordance with IPA methodology, purposive sampling was used to produce a homogenous sample. Five couples were recruited for the study. IPA studies are conducted on small sample sizes, and Smith and Osborn (2008) state that a sample size of between 5 and 6 is considered to be appropriate.

Participants meeting the inclusion criteria were identified by their consultant psychiatrist at their memory clinic appointment and asked if they would be willing to be contacted about the study by the Principal Investigator. Once couples agreed, the contact details for the potential participants were then passed on to the Principal Investigator, who wrote to the GP of the individual with Alzheimer's disease to clarify whether they had any objections to the individual participating in the study. If no objection had been received within a specified 10-day period, then the Principal Investigator wrote to potential participants, sending them a participant information sheet and an invitation letter, along with the Principal Investigators contact details. The invitation letter had a reply slip for potential participants to return to the Principal Investigator should they wish to proceed. This was returned to the Principal Investigator within a specified 10 day period if the participants were willing to take part. The participants were then contacted and an initial interview was then arranged.

Ten couples were identified to take part in the study, although five of these declined. Two stated their partners were already involved in other research, Two did not feel that they wanted to discuss the Alzheimer's, and the fifth declined with no reason.

### *Interviews*

The couples were seen twice by the Principle Investigator. During the first meeting, demographic details such as age, gender, marital status, education, past occupations, and family (e.g. number of children, proximity and contact) were collected.

The second meeting involved a semi structured interview. The interview schedules were developed to allow for the topic area to be explored flexibly but in detail. In accordance with IPA methodology, the semi-structured interview should allow the researcher to follow up and focus on any particularly interesting or important aspects of the topic discussed. The schedules were initially developed from themes identified within the literature on couples living with Alzheimer's disease. These were then discussed and piloted on research supervisors and colleagues. Through this process, the interview schedule was deemed to be too complex and attempted to guide the participants too much. The schedules also did not adhere to the principles of IPA methodology, as they did not allow for the participants to explore their own constructions of what had happened. Instead, the questions appeared too rigid and meant that the Principle Investigator was attempting to interpret the couple's experiences rather than facilitating the couples own exploration and interpretation of their experiences. In light of this, the interview questions became narrowed down to four main questions, with prompts to use if

necessary. These questions guided the participants onto the subject area being explored but were flexible enough to enable the Principle Investigator to try and explore the couples understanding of their experience (see Appendix F). The interviews were recorded to allow for transcription to take place to enable the data to be analysed.

All interviews were carried out with both members of the couple present.. Great care was taken to establish an atmosphere in which each member of the couple felt free to describe their own experience without either one feeling criticised or attacked.

The first meeting with the couple lasted approximately 60 minutes. During this time written consent was obtained from each member of the couple, and they were given the opportunity to ask questions about the research. The couple were then asked for demographic details and more information was given about the nature of the research along with arranging a date for the next interview.

The second meeting was a semi structured interview. This interview was tape recorded in order for later transcription to take place. In this interview the couple were asked to comment on their experience of living with Alzheimer's disease and in particular in relation to their relationship. Questions were only used as prompts and served to facilitate a free exchange within the discussion, with the principal investigator being guided by the narrative of the individuals. Care was taken within these interviews to use the participant's language or preferred language whenever possible, particularly in reference to their diagnosis.

The tapes from the interviews were destroyed once transcription had taken place, and the transcripts were anonymised and kept in a locked filing cabinet at the

university. A summary of the completed research was available to participants on request.

### *Ethical considerations*

Alongside obtaining ethical approval, it was felt that there were other important ethical considerations which needed to be acknowledged during this study. Below are details of these along with the measures taken to address them.

- Informed consent – Participants were fully informed about the research before any data collection took place. Due to the degenerative nature of Alzheimer’s disease, it is important that consent is obtained in a way that is ethically acceptable. The Mental Capacity Act (2005) states “a person must be assumed to have capacity unless it is established that he lacks capacity” (section 1.2). An individual is considered to be unable to make a decision if they are unable to understand information relevant to a decision, unable to retain the information in order to make a decision, or unable to communicate their decisions (section 3.1). If participants are able to do all these things then they will be considered to have the capacity to consent.
- Right to withdraw – Participants were informed in their information sheet that they could withdraw from the study up until the point their interviews became transcribed, without this having any effects on them or their care.
- Confidentiality – Information on participants was anonymised once the interviews had taken place, so that any information obtained remained confidential.

- Tiredness – Due to the nature of Alzheimer’s it was important to be aware that participants may get tired during the interviews and that if this happened then the interviews could have been rescheduled or adapted accordingly
- Interview difficulties – Due to the nature of the cognitive impairment, there was a risk that individuals may become marginalized in the interview process by a cognitively intact partner. Interviews were facilitated to allow equal opportunity for both research participants to talk. In the event that the researcher felt that this could not be attained, the interview would have been appropriately terminated.
- Distress – Due to the nature of the issue being discussed, it was possible that the individuals may have experienced some distress. If this had occurred then the individuals would have been offered the facility to speak to a member of the Mental Health team at the memory clinic.

*Personal standpoint*

At the point of completing this research project I was 28 years old and in the final year of Clinical Psychology training, I had had very little experience of working with older adults, and no personal or professional contact with Alzheimer’s disease. These were important reflexive considerations to be aware of whilst analysing the results as I felt I entered the research with few prior assumptions or expectations. Despite this some anxieties were present around how the couple would respond to being interviewed about something so personal and potentially distressing.

*Data Analysis and step by step coding:*

The majority of the interviews were transcribed by a professional transcriber who completed a University of Lincoln confidentiality agreement. Due to the nature of

the research, the couple was used as the unit of analysis throughout. Although this has been occasionally used before, the aims of IPA studies have usually been met through one to one interviews. Despite this, recent research has demonstrated the usefulness of IPA outside of the traditional one to one interview and also within focus groups (Palmer, Larkin, de Visser & Fadden, unpublished). Research has found that as long as the group remains a homogenous sample and the participants are able to discuss their own personal experiences in sufficient detail and intimacy, then IPA can be seen as a suitable tool. As with all IPA studies, the researcher also needs to be able to reflect upon and explore their own role within this dynamic and be attuned to interactional factors within the group.

#### Step 1 of analysis

The texts were read and re read during which process notes were jotted down. Objects of concern were then identified along with the participants' description of this and quotes to illustrate it. This process was repeated across all transcripts. (See table B.1 overleaf).

**Table B.1. Identification of objects of concern**

Transcript material	Location	Object of concern	Description
“And one thing we find, that other people are ... if Rosemary mentions Alzheimer’s, you don’t get a very good reaction, it’s almost as if you’ve got the Plague or something”	Rosemary & Todd, line 59-63	Alzheimer’s	Alzheimer’s is unmentionable and stigmatising.
“Well we don’t think about the future.”	Michael & Sandra, line 579	Future	They don’t think about the future.
“Well mainly when he’s forgotten something and he blames ... turns round and says it’s my fault you know, that sort of thing. ‘Oh you did it, I didn’t; no, not me’. And I say ‘well there’s nobody here only me’ and the one-eyed bloke we call it now. We say now when things go awry or things go missing, ‘oh it’s the one-eyed bloke’s been again’. And we pass it off like that, we have to joke about it. You have to laugh or else you cry.	Michael & Sandra, line 178-189.	Humour	Humour is used as a way of coping and minimising conflict..

**Step 2**

All objects of concern from the transcripts were collated into documents for each object.

**Table B.2 Collation of objects of concern**

Object	Location	Description
Roles	Sandra & Michael	Increased financial role
	Mary & John	Shift of domestic role
	Mary & John	Movement away from husband role into carer role
	Joan & David	Do all roles
	Keith & Margaret	My role has increased

### Step 3

The objects of concern were then grouped into clusters according to similarity of content. The clusters were then summarised and given a description.

Table B.3. **Organisation of clusters**

Item name	Cluster title	Cluster description
Alzheimer's disease	Alzheimer's	Participants understand Alzheimer's in broadly negative terms e.g. disruptive. Symptoms are difficult and impact on functioning. Medication instills hope.
Symptoms		
Medicine		
Cure		
Memory		
Individual with AD	Relationships	Both individuals in the couple experience change. Responsibilities increase for the partners of individuals with AD and roles are altered. Conflict is of concern to the couples.
Partner		
communication		
Roles		
Relationship		
responsibility		
Being alone		
Togetherness		
Change	Change	Change is inherent across all aspects of experience.
Acceptance	Coping	Couples' strategies vary and generally are directed towards maintaining normality and the continuance of everyday life.
Adaptation		
Insight		
Minimisation		
Humour		
Being normal	Positioning	Couples leave things unsaid.
Unmentionables		
Future	Future	Couples differ in how they manage thinking about the future.

### Step 4

The clusters were subject to an interpretative stage in order to determine the overarching ideas and constructs arising out of these (see table B.4 overleaf).

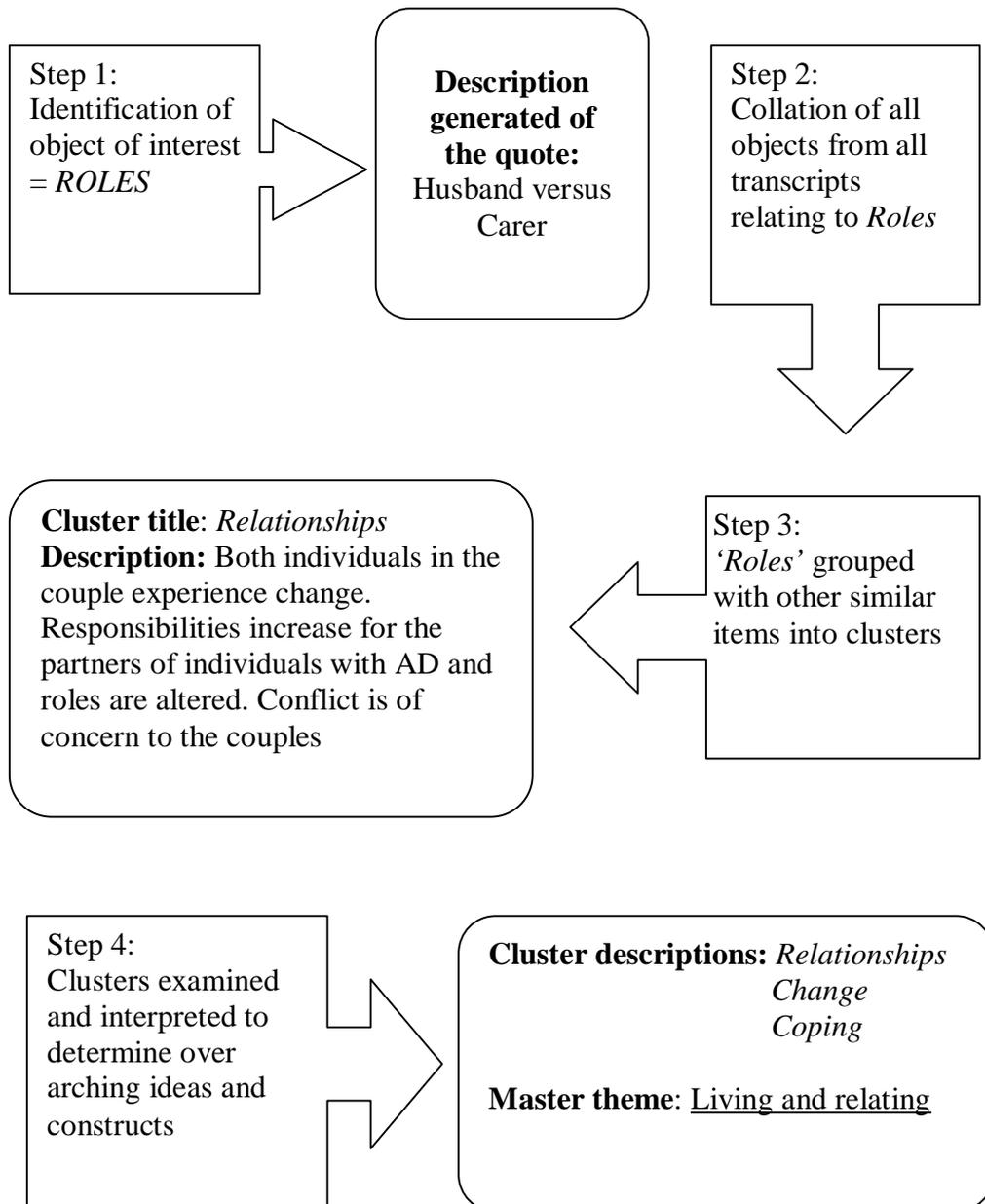
Table B.4. **Generation of a master theme**

Cluster description	Master theme	Sub themes
'Relationships': e.g. roles and responsibilities	Living and Relating	Relating to each other
Change		Relating to others
'Coping': e.g. humour and being normal		

See overleaf for a worked example of tracking a quote through to a master theme.

Figure 1. **Worked example of tracking a quote through to a master theme**

*“I feel now that I’m ... my life ... I wear two hats; you know, I wear the hat of a hopefully loving husband but I also wear the hat of a carer. And I think this is where Mary may think I’m being hard but sometimes I think as a carer you’ve got to ... if you’re going to do it successfully, you’ve got to be detached in some respect.”*  
*John, (784-787)*



The writing up of the research will be around translating these master themes into a narrative account, alongside considering how they relate to one another, to current literature and clinical practice.

Throughout the process of analysis, supervision was regularly sought and changes were made. Initially it was felt that some of the interpretations were more descriptive and as such they were re-read and made more explicitly interpretative. After discussion with my supervisors, some of the theme titles were also altered so that they were more representative of the theme being captured. It was important to utilise supervision within this process as it also allowed for any strong feelings (which had been elicited by the participants) to be discussed and addressed and in turn acknowledge the impact this may have upon interpretation of the data.

#### *Memo to self*

Memos were generated during the interpretation of the research as part of the continual reflexive process. Below is an extract from one of these memos.

*Was struck by the loneliness of this couple and them having no family. Spending all their time together, boredom? Wonder how this affects their coping with the illness. Husband seems to spend a lot of time thinking about the consequences. Wife doesn't seem too bothered.*



Lindsay Flatman  
C/o David Connelly – Clinical Psychologist  
Broxtowe Integrated Mental Health Team for Older People  
The Sheila Gibson Unit  
Bramwell  
Chilwell Lane  
Bramcote  
NG9 3DU  
Tel: 0115 9076200

Date:

Dear

After your recent appointment at the memory clinic at the Sheila Gibson Unit, you agreed to be contacted with regard to some research. Please find enclosed an information sheet detailing this research.

If you decide that you would like to take part in the research then please return the attached tear off slip below, and return to me in the enclosed stamped addressed envelope within 7-10 days.

Contact details have been included in the information so if you have any questions then please contact me.

Yours sincerely

Lindsay Flatman  
Trainee Clinical Psychologist

-✂-----✂-----✂-----✂-----✂-----  
✂-

**I agree to be contacted further with a view to taking part in the research ‘The experience of adjusting to a diagnosis of Alzheimer's in couples’**

Signed:.....

## **PARTICIPANT INFORMATION SHEET**

### **(Individual with Alzheimer's disease)**

The experience of adjusting to a diagnosis of Alzheimer's in couples

Investigators:  
Lindsay Flatman  
Dr Shirley Thomas  
Dr David Connelly

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

**Part 1** tells you the purpose of the study and what happens if you take part.

**Part 2** gives you more detailed information about how the study will be conducted.

Please take time to read the following information carefully and ask if there is anything that is not clear, or if you would like more information.

Thank you for reading this.

### **PART 1**

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

The purpose of the study is to explore how couples adjust when one of them has received a diagnosis of Alzheimer's type dementia. It is a piece of research which aims to increase our understanding of how couples cope over time. This is so that we can contribute towards helping dementia services provide support which is useful and relevant.

#### **Why have I been invited to participate?**

You have received a diagnosis of Alzheimer's type dementia from the Sheila Gibson Unit, Nottingham.

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

It is up to you to decide. If you do decide to take part then you will keep this information sheet and be asked to return the tear off slip at the bottom of your invitation letter.

### **What will happen to me if I choose to proceed?**

The researcher will arrange to come and visit you and your partner to explain the study so that you can ask any further questions about the research and give your written consent if you decided to proceed.

You and your partner will then be interviewed together.

The researcher will interview you and your partner together at your house, and the interviews will last between 60 and 90 minutes. It is recognised that the interviews can be tiring for some individuals and so if needed it is possible that the interviews can be:

- a) Split into two sessions with a break in between
- b) Split over two separate days

This is flexible and can be discussed with the researcher on your initial meeting. You can also request to stop the interview at any time.

All interviews will be audio taped, so that the interviews can be transcribed.

The interviewer will ask you some questions about your life (e.g. age, gender, marital status, living environment, past occupations, and whether you have children), and broad questions around your experience as a couple of living with dementia.

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

Both you **and** your partner will need to give consent if you agree to take part in the study. If you decide to take part then you will need to complete the tear off slip at the bottom of your invitation letter and return it the envelope provided within 7-10 days. You will then be contacted to arrange the first interview. All you have to then do is take part in two **joint** interviews with your partner.

### **What if I decide not to take part?**

If you or your partner decides not to take part your treatment will not be affected in any way.

### **What are the possible disadvantages and risks of taking part?**

It is possible that you may find it upsetting or uncomfortable to discuss your current problems. You do not have to answer questions, and you are free to withdraw at any time. Every effort will be made to ensure that emotional discomfort or distress is minimal. If you feel further support is needed then you can contact Dr David Connelly at The Sheila Gibson Unit.

### **What are the possible benefits of taking part?**

Taking part in the study will be of no direct benefit to you. However, the information we get from this study will help us to understand the experience of couples who have received an Alzheimer's diagnosis. It is hoped that this information can then be used to improve the treatment available to these individuals.

## **PART 2**

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

If you have any complaints regarding your experience of the study then you can contact the Patient Advice and Liaison Service (PALS) by telephone on: **0800 015 3367**.

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

You are free to withdraw up until your data has been anonymised and transcribed. If you withdraw prior to that point then any existing data will be destroyed and proof provided of this if you require it. This will not affect your treatment in any way.

### **Will my taking part in the study be kept confidential?**

Limited information will be gathered from you/your partner's medical notes at the memory clinic for the purpose of this study. You will not be identified in any part of the study. The information you provide will be confidential and your names along with any other identifying information will not be used. Quotes may be used when reporting the study, but these will also be anonymous and you will not be identifiable from them. Tape recordings and information from the interviews will be stored securely at the university. The tapes from the interviews will be destroyed, and the anonymous paper copies stored securely for 7 years.

### **Involvement of the General Practitioner/Family Doctor**

The GP responsible for the care of the individual with Alzheimer's will be informed that you are taking part in the research. They will be asked to contact the researcher if they think that you may find the research distressing.

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

The research will be published, and this will take approximately 3 years from the start of the study. You will not be identified in any part of the study, and a copy of the summarised results will be available to you at the end of the study on request.

### **Who is Organising and Funding the Research?**

The research is being funded through the University of Lincoln as part of a Doctorate in Clinical Psychology thesis.

### **For further information please contact:**

Lindsay Flatman – Trainee Clinical Psychologist  
C/o David Connelly – Clinical Psychologist  
Broxtowe Integrated Mental Health Team for Older People  
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## **PARTICIPANT INFORMATION SHEET**

**(Partner of individual with Alzheimer's disease)**

The experience of adjusting to a diagnosis of Alzheimer's in couples

Investigators:

Lindsay Flatman

Dr Shirley Thomas

Dr David Connelly

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

**Part 1** tells you the purpose of the study and what happens if you take part.

**Part 2** gives you more detailed information about how the study will be conducted.

Please take time to read the following information carefully and ask if there is anything that is not clear, or if you would like more information.

Thank you for reading this.

### **PART 1**

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

The purpose of the study is to explore how couples adjust when one of them has received a diagnosis of Alzheimer's type dementia. It is a piece of research which aims to increase our understanding of how couples cope over time. This is so that we can contribute towards helping dementia services provide support which is useful and relevant.

#### **Why have I been invited to participate?**

Your partner has received a diagnosis of Alzheimer's type dementia from the Sheila Gibson Unit, Nottingham.

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

It is up to you to decide. If you do decide to take part then you will keep this information sheet and be asked to return the tear off slip at the bottom of your invitation letter.

#### **What will happen to me if I choose to proceed?**

"The researcher will arrange to come and visit you and your partner to explain the study so that you can ask any further questions about the research and give your written consent if you decide to proceed." You and your partner will then be interviewed together.

The researcher will interview you and your partner together at your house, and the interviews will last between 60 and 90 minutes. It is recognised that the interviews can be tiring for some individuals and so if needed it is possible that the interviews can be:

- a) Split into two sessions with a break in between
- b) Split over two separate days

This is flexible and can be discussed with the researcher on your initial meeting. You can also request to stop the interview at any time.

All interviews will be audio taped, so that the interviews can be transcribed.

The interviewer will ask you some questions about your life (e.g. age, gender, marital status, living environment, past occupations, and whether you have children), and broad questions around your experience as a couple of living with dementia..

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

Both you **and** your partner will need to give consent if you agree to take part in the study. If you decide to take part then you will need to complete the tear off slip at the bottom of your invitation letter and return it the envelope provided within 7-10 days. You will then be contacted to arrange the first interview. All you have to then do is take part in two **joint** interviews with your partner.

### **What if I decide not to take part?**

If you or your partner decides not to take part, your partner's treatment will not be affected in any way.

### **What are the possible disadvantages and risks of taking part?**

It is possible that you may find it upsetting or uncomfortable to discuss your current problems. You do not have to answer questions, and you are free to withdraw at any time. Every effort will be made to ensure that emotional discomfort or distress is minimal. If you feel further support is needed then you can contact Dr David Connelly at The Sheila Gibson Unit.

### **What are the possible benefits of taking part?**

Taking part in the study will be of no direct benefit to you. However, the information we get from this study will help us to understand the experience of couples who have received an Alzheimer's diagnosis. It is hoped that this information can then be used to improve the treatment available to these individuals.

## **PART 2**

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

If you have any complaints regarding your experience of the study then you can contact the Patient Advice and Liaison Service (PALS) by telephone on: **0800 015 3367**.

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

You are free to withdraw from the study up until your data has been anonymised and transcribed. If you withdraw prior to that point then any existing data will be destroyed and proof provided of this if you require it. This will not affect your partner's treatment in any way.

**Will my taking part in the study be kept confidential?**

Limited information will be gathered from you/your partner's medical notes at the memory clinic for the purpose of this study. You will not be identified in any part of the study. The information you provide will be confidential and your names along with any other identifying information will not be used. Quotes may be used when reporting the study, but these will also be anonymous and you will not be identifiable from them. Tape recordings and information from the interviews will be stored securely at the university. The tapes from the interviews will be destroyed, and the anonymous paper copies stored securely for 7 years.

**Involvement of the General Practitioner/Family Doctor**

The GP responsible for the care of the individual with Alzheimer's will be informed that you and your partner are taking part in the research. They will be asked to contact the researcher if they think that your partner may find the research distressing.

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

The research will be published, and this will take approximately 3 years from the start of the study. You will not be identified in any part of the study, and a copy of the summarised results will be available to you at the end of the study on request.

**Who is Organising and Funding the Research?**

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**For further information please contact:**

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Brayford Pool  
Lincoln  
LN6 7TS  
01522 837336  
01522 886029 (course administrator)  
shtomas@lincoln.ac.uk

Study Number:

Participant Identification Number:

**CONSENT FORM****(Individual with Alzheimer's disease)****Title of Study:****The experience of adjusting to a diagnosis of Alzheimer's in couples.**

Name of Researchers: Lindsay Flatman, Trainee Clinical Psychologist.  
 Dr Shirley Thomas, Research Tutor  
 Dr David Connelly, Clinical Psychologist

Please tick each box

- |   |  |                          |
|---|--|--------------------------|
| 1 | I confirm that I have read and understood the information sheet for Individuals with Alzheimer's disease, dated December 2007(version 2) for the above study. I have had the opportunity to consider the information, ask questions and have these answered. | <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.  | <input type="checkbox"/> |
| 3 | I understand that the researcher may look at sections of my medical notes, where it is relevant to my taking part in the research. I give permission for the researcher to have access to my records.  | <input type="checkbox"/> |
| 4 | I agree to my GP being informed of my participation in the study.  | <input type="checkbox"/> |
| 5 | I understand that the interviews will be tape recorded, and that quotes from these will be used in the study.  | <input type="checkbox"/> |
| 6 | I understand that I will be interviewed together with my partner as part of a couple.  | <input type="checkbox"/> |
| 7 | I agree to take part in the above study.   | <input type="checkbox"/> |

-----  
Name of Participant

Date

-----  
Signature-----  
Name of Researcher

Date

-----  
Signature

1 copy for participant; 1 for researcher, 1 to be kept with medical notes.

Study Number:  
 Participant Identification Number:

**CONSENT FORM**  
**(Partner of individual with Alzheimer’s disease)**

**Title of Study:**

**The experience of adjusting to a diagnosis of Alzheimer’s in couples.**

Name of Researchers: Lindsay Flatman, Trainee Clinical Psychologist.  
 Dr Shirley Thomas, Research Tutor  
 Dr David Connelly, Clinical Psychologist

Please tick each box

- |   |  |                          |
|---|--|--------------------------|
| 1 | I confirm that I have read and understood the information sheet for partners of individuals with Alzheimer’s disease, dated December 2007(version 2) for the above study. I have had the opportunity to consider the information, ask questions and have these answered. | <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.  | <input type="checkbox"/> |
| 3 | I understand that the researcher may look at sections of my medical notes, where it is relevant to my taking part in the research. I give permission for the researcher to have access to my records.  | <input type="checkbox"/> |
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| 6 | I agree to take part in the above study.   | <input type="checkbox"/> |

-----  
 Name of Participant                      Date                      Signature

-----  
 Name of Researcher                      Date                      Signature

1 copy for participant; 1 for researcher, 1 to be kept with medical notes.

## Appendix F

## Interview schedule

1. Can you tell me something about your understanding of what Alzheimer's disease means?

*P: what changes are likely to occur in your life?*

*P: what is your understanding of the typical pattern Alzheimer's' follows*

2. Can you cast your mind back as a couple, to a time when Alzheimer's was not part of your life? Can you describe to me what your relationship was like?

*P: Who did what?*

*P: did you do things together?*

3. You have given me a really good feel for what your relationship was like. Can you see any changes which have occurred in your relationship *since*.....

*P: when I was thinking about ..... I imagined that there would be things that you would find more difficult now. How do the two of you experience this?*

4. We have talked about the difficult aspects the.....has on your relationship. Have you noticed any positive changes in your relationship?

5. Today we have talked about what your relationship was like before ....., and what it is like now. How do you see things in the future?

6. Finally is there anything about your relationship that I have not covered in my questions and which you think is important for me to know about?

P = prompt

## Appendix G

### Extended results of analysis

Table G.1 Overview of themes

Theme	Sub theme
1.Relating to AD	i. Understanding AD disease ii. AD as a disruption iii. Being swept along by the Alzheimer's
2.Living and Relating	i. Relating to each other ii. Relating to others
3.Facing the future	
4.You, me and "it"	i. Two's company ii. Threes a crowd

### **Relating to AD**

In this theme, participants described a range of experiences and thoughts around their understanding of Alzheimer's, Alzheimer's as a disruption, and being swept along by the Alzheimer's.

#### 1. (i) *Understanding the Alzheimer's*

This subtheme looked at how couples understood the disease. How the illness was described was an important factor in determining how the couples understood the disease. Some couples chose to actively find out more information about the disease, however in some cases they actively chose to avoid finding this out.

*"is it a degeneration of the cells or the brain cells or something of that sort?"*

*Keith, (12-13)*

*"it's progressive loss of memory I guess."(11)... "we prefer not to know the pattern it follows" (42)*

*Sandra.*

Both Sandra and Keith are vague in their descriptions, and conveyed a sense of reluctance in wanting to know more about the disease,

1. (ii). *AD as a disruption*

Within this subtheme some couples demonstrated a complete rejection of the AD and described it as unmentionable. Michael states:

*“it’s a damned nuisance, not easy to live with”*

*Michael (7-9)*

Michael and Sandra communicate that Alzheimer's is an annoyance and doesn't sit alongside their current lifestyle. They also seem to place Alzheimer's as a separate entity in so far as it is not incorporated into the psyche of Michael who has the disease. He states he lives 'with it' almost as if it is not a part of him.

David and Joan address the Alzheimer's as a nuisance which does nothing but create problems for them.

*“it creates problems”*

*David, (79)*

1. (iii). *‘being swept along by the Alzheimer’s*

Many of the couples discussed their views on medication. Focusing on this appeared to lessen the feelings of helplessness and increase the feelings of hopefulness. Thus allowing the couples to grasp onto something which makes them feel less 'swept along' may make living with the disease slightly easier.

*“it may be that ... there seems to be some hope that this medication will ... obviously it’s not going to cure anything but it will probably, hopefully, slow down some of it”*

*John, (768-772)*

*“I think its made things perhaps a little bit better for you”*

*Todd, (878-888)*

The above quotes imply that the couples are relying purely upon the medication and are tentatively hoping that the medication will make a difference. In this sense, medication can be seen as playing an important part in the development of hope.

In contrast to this, Keith and Margaret take ownership and responsibility for getting better, and can be seen to be using and identifying their own methods to help alleviate the Alzheimer’s. They state;

*“We are trying to self heal ourselves with the magnets and a combination of everything”*

*Margaret, (1094-1096)*

### **Living and relating**

Within this theme two subthemes emerged which focused upon relating to each other and to others.

#### *2. (i) relating to each other*

This subthemes encompasses the couples feelings about their relationship in general, along with changes in the individual with Alzheimer’s, changes in the partner, changes in roles and responsibilities, conflict and coping with the Alzheimer’s.

When asked about their relationships, the responses from the couples varied despite none of these being negative. It was interesting to include this within the results as it was felt it set the context for gaining insight into what the relationships were like.

Joan and David described their relationship as;

*“fantastic, always has been right from the word go” Joan, (174-175)*

*..“more like mates than anything, total reliance on each other” David.(177-178)*

Two couples described their relationship as “normal”, whilst Mary and John stated:

*“our relationship is different as we’ve both been married before. Probably never going to be as intense as your first love, your first marriage”*

*John, (211-219)*

Many of the couples described having individual lives as well as being part of a couple. However, a strong concept of togetherness appeared to be a more prominent feature for the couples interviewed.

*“we never go anywhere without one another, always been together”*

*Sandra, (66-68)*

*“We have always done lots together haven’t we?”*

*Margaret, (111-112)*

*“it was always together anyway, we still are”*

*Joan, (219-220)*

This appeared to be a positive thing for the couples. In this way the Alzheimer’s was mostly viewed positively as they had always relied upon each other anyway and so

the fact that they now spent a lot of time having to do things together, such as the shopping, going out into town etc was not too much of a change for them. Some couples did not explicitly mention the idea of togetherness as a change, but made it clear this aspect of the relationship was different since the diagnosis. By contrast, Rosemary and Todd indicate that they now do more things together whereas before they were more independent.

*“Now we keep together more, we don’t have the separate life that we used to have.” Todd, 9147-148)*

Change in the personality of the individual with Alzheimer’s was seen as a major factor which contributed to overall change within the relationship. This was identified by quotes from partners of spouses with Alzheimer’s and those with Alzheimer’s themselves.

*“He tries to well just be the old Michael you know, not ... people wouldn’t know really that he ... and then the next day he has a bad day when he’s put on a brave face. The next day he’s all to pieces. So I dread people coming sometimes”*

*Sandra, (384-389)*

Sandra’s quote conveys a feeling of sadness as she reflects upon him trying to be his old self. Inherently this implies that he is no longer who he was, and this is difficult to accept. It also feels as though Sandra has to weigh up the benefits and costs of having visitors because of the impact this can have on them the next day.

Within Mary and John’s relationship, both partners separately discuss these changes:

*“The second worry to me is the fact that the changes I’ve noticed in Mary is this absolute falling or lowering of confidence and self-worth and everything, that’s you know, really horrible. From someone who I knew was a teacher, confident, could get on and make decisions, ‘yeah, we’ll do this, do that’. Now, you just ... it’s all gone, you know and it’s horrible, that’s all I can say really”.*

*John, (472-476)*

*“I just forget. I start on something and you know, then I forget. And then I go back to something else and that’s really the worst thing.”*

*Mary, (427-431)*

The change in Mary seems very difficult for John to accept. John cannot help but compare Mary to what she used to be like, and in doing so it feels like he is grieving for the loss of the old Mary.

Many of the individuals with Alzheimer’s were aware of the impact of their illness on their partners.

*“the wife has to suffer I’m afraid”*

*Michael, (703)*

*“it worries me I’m upsetting Todd all the time”*

*Rosemary, (936-37)*

*“I don't want to upset people or anything like that”*

*Mary, (698-699)*

The individual's making these utterances seemed apologetic for the impact they were having on their partners. Despite this there appeared to be an element of helplessness, as the individuals were resigned to the fact that they would be (and were) having a bigger impact on their partner, yet they had little control over this. This seemed to be a difficult challenge for them to assimilate.

Throughout the interviews many other changes were noticed in relation to roles and responsibilities, particularly with the partner of the individual with Alzheimer's disease taking on a larger portion of this. This will be discussed further on, however, in some interviews it was noted that the Alzheimer's disease had also had an impact upon changing the way in which the person without the Alzheimer's behaved within the relationship.

*“I try and be quite diplomatic”*

*Margaret, (354-355)*

*“I should be more patient perhaps”*

*David, (456)*

Both Margaret and David demonstrate an awareness of how they feel they should behave around their partner, and in the case of David he appears quite hard on himself. In contrast to this, John also explains that he tries to be aware of the situation however, John is less hard on himself, and recognises that sometimes this is not possible, giving himself permission that it's ok not to always be perfect.

*“now I know what the situation is you know, I try to be aware of it.*

*I don't always succeed you know.*

*I mean I'm only human, I get frustrated, I get angry, I get annoyed  
sometimes.”*

*John, (670-674)*

In the case of Mary and John, Mary also noticed that John's behaviour had changed.

*Mary; I think you aren't as hard about people because ...*

*John; Well no, I'm probably not because for one reason, I now know what the  
situation is... (643-647)*

This quote implies that John is now more tolerating of the changes in Mary as he now understands why these are occurring. In turn, this has led Mary to feel that John is less hard towards her and more accepting of when things aren't how they used to be.

Many of the couples described very traditional gendered domestic roles in their relationship before Alzheimer's had become a part of their life. For example, the women would cook and do the housework, while the men went out to work and did jobs in the garden and around the house. When asked about these in their relationship, David and Joan summed this up by saying:

*“very old fashioned, you cook it, I'll eat it”*

*(David, 201-202)*

The couples also described that although they had separate roles these were flexible when they needed to be. For example;

*“we worked it out between us to fit the pattern of life as it was then”*

*John, (299-300)*

*“I used to cook if rosemary was ill and things like that and deal with things*

*Todd, (289-293)*

When asked how these roles had changed, the majority of couples stated that the partner without the Alzheimer's took more of a leading role in everyday life. This is illustrated in the following quotes by Sandra and Margaret.

*“I'm leading the major role now”*

*Sandra, (707-708)*

*“I was the organiser. (I always have been), the planner. And I suppose I still am now, probably more so now.”*

*Margaret, (155-158)*

Couples also explained that they had begun to have increased levels of responsibility. Sandra expresses this in terms of responsibility to look after Michael and wanting to try and reduce his distress as much as possible.

*“When I'm sitting consoling you and trying to sort things out for you. That's when I say it's a bad day”*

*Sandra, (349-351)*

John describes his increased responsibility in terms of dependence and Mary's dependence upon him in comparison to how it used to be. This quote highlights a

level of worry and fear for John that for some reason he may not be able to fulfil that responsibility.

*“the biggest thing I’ve noticed is (pause), and a very worrying thing from my point of view, is how much more dependent Mary’s become on me. I mean in times past you were totally independent and now the dependency level to me is very high. And I find that very worrying because you know, fortunately I think I’m in good health but one never knows”*

*John , (436-446)*

Along this idea, many of the partners of those with Alzheimer’s discussed a responsibility they felt they had to keep themselves as healthy as possible so that they could care for their partners as well as possible.

*“I find it very worrying, fortunately I’m in good health but one never knows”*

*John, (444-446)*

*“if Keith’s got a slight problem I’d best keep myself healthy as well”*

*Margaret, 9541-542)*

*“I’ve got to be able to look after you so I’ve got to stay as healthy as I can”*

*Michael, (743-744)*

In the case of Todd and Rosemary, Todd stated that he too was experiencing health problems and this was a major concern for him as he felt that if he became ill then Rosemary would not be able to cope:

*“if something goes wrong anymore than it is now, it’s going to be difficult I think You know, if one of us really ... well say catches the flu or even*

*something as simple as that, I think it's going to be a problem that something could go wrong maybe."*

*Todd, (664-671)*

Margaret, David and Todd describe a more general sense of the responsibility that they feel to check up on what their partner has said they have done. In the following quotes, the partners appear almost apologetic for having to do this, yet they recognise that this is something which is now a part of their life.

*"I've probably taken on myself more responsibilities like I am aware that Keith's memory isn't quite so good, so I am more concerned like that the fire's off before I go to bed and the doors are locked ... you know, I'm checking up on things."*

*Margaret, (298-303)*

*"I have to double check everything pretty well, bless her, because you just can't ... well you..."*

*David, (191-193)*

*"I'm constantly having to follow her and check that things have been done, which is worse than doing it in the first place a lot of the time, but I don't see any way round it really."*

*Todd, (362-366)*

In the next quote it can be seen that Todd is having to now take on responsibilities and think about things which before the Alzheimer's he wouldn't have given a second thought about.

*“I don’t like leaving rosemary which before I wouldn’t have thought anything about” Todd, (419-421)*

Many of the couples also described not being comfortable with their partners going out on their own anymore and as such it felt that they had become more protective and felt a greater sense of responsibility for them.

Within this subtheme, it was felt important to incorporate ideas which reflected some of the possible consequences of all the above concepts upon the couple’s relationship. One of the main concepts within this was that of conflict. Much of the conflict seemed to arise out of the individual with Alzheimer’s forgetting or losing items and reflected feelings of frustration by both parties. Some couples were open about the conflict and this was reflected in their narrative. In particular couples addressed the ideas of conflict by comparing it to how things used to be or how things had changed since the Alzheimer's had been a part of their life.

*“it causes some quite bad arguments really”*

*John, (104-105)*

*“well we do argue a little bit more don’t we?”*

*Sandra, (162)*

*“I must admit we get on each other’s nerves far more than we did”*

*Rosemary, (423-424)*

Rosemary offers insight into how she feels her forgetfulness is impacting upon Todd.

*“I think he gets a little bit short with me sometimes. Especially when ... I mean I realise this when I’m asking him a question and half an hour afterwards I’m asking another question and he’ll come back and say ‘Well*

*you've already asked me that'. And of course I've forgotten the answer you see, so I haven't achieved anything by it.*

*Rosemary, (338-344)*

Rosemary almost feels as though her gradual loss of memory makes asking futile as all she is doing is creating tension, and she is not achieving anything as she cannot remember anyway. For Rosemary this seems like a difficult position to be in. On the one hand she does not want the Alzheimer's to be impacting on her to this extent, yet on the other hand by trying to carry on as normal she is aware that this upsets Todd and is frustrating for him

An alternative perspective to this is proposed by David:

*"your upset doesn't last as long as mine you see. But I use ... try and use that, knowing that Joan will forget something and if I get screwed up about what she's not done or has done, I try and stay calm because I know Joan will have forgotten about it. So it's no good me jumping up and down because Joan would wonder what I'm jumping up and down about it. Because you'll have forgotten won't you?"*

*David, (475-485)*

David portrays himself as being very aware of how he is affected by Joan's memory loss. Despite this, he makes a concerted effort to rationalise why he should not get upset about things Joan has forgotten and is sensitive towards the impact he could have on Joan. Again, the concept of futility seems to arise from this statement, as David recognises that conflict will not achieve anything because of the impact the AD has i.e. Joan won't remember.

Another concept within this subtheme appears to be that of 'getting by'. The couples seemed to switch between needing to 'be normal' on the one hand, and sometimes demonstrating varying degrees of acceptance of the Alzheimer's on the other hand. When placing importance upon 'being normal' couples tended to use strategies of humour and minimisation. However, when accepting the Alzheimer's, couples demonstrated varying levels of insight and adaptation.

In relation to being normal, often the couples would relate their difficulties to age. Although this was a relevant argument, it was felt that at times it was easier to give their age more weight and responsibility for the difficulties they were facing, than the Alzheimer's disease.

*"any problems we have are likely to be due to our age. I get quite forgetful too and he can remember what I've forgotten.*

*Sandra, (285-289)*

Many of the couples discussed their difficulties throughout the interviews, but then would make comments about being normal. It was felt that this served to help them cope as they were not ready to accept the changes which had happened and which were likely to happen. Examples of these quotes were:

*It's a normal life at the moment"*

*Sandra (712-713)*

*Life goes on pretty well as normal"*

*David, (496-497)*

Many of the couples appeared reluctant to talk about how the Alzheimer's may affect them later on. Casual language was often used to state that the Alzheimer's might get worse. However, this seemed to feel like a scary prospect for many of the couples and it was easier for them to cope with everyday life if they in some way ignored the inevitability of the disease. By doing this, it allowed the couples to cling onto some hope that things just might not get that bad.

*"You just don't want anything to change and get worse"*

*David, (741-742)*

Many of the individuals with Alzheimer's made comments during the interviews about 'not being that bad'.

*"(ive) not got that bad"*

*Joan, (95)*

*"I'm not bad all the time"*

*Mary, (577)*

*"but I'm still able to do it, even if it takes me twice as long"*

*Rosemary, (648-650)*

These quotes seemed to indicate a general feeling of 'I'm not dead yet'. There appeared to be a general sense of wanting to hang onto normality and if that meant taking twice as long to do everyday tasks, then this did not matter as it was important for their self esteem and mental wellbeing.

The concept of humour arose frequently within the interview process. Couples appeared to use humour to soften the blow of the symptoms of the Alzheimer's, e.g. the forgetfulness.

*“And I say ‘well there’s nobody here only me’ and the one-eyed bloke we call it now. We say now when things go awry or things go missing, ‘oh it’s the one-eyed bloke’s been again’. And we pass it off like that, we have to joke about it. You have to laugh or else you cry”*

*Sandra, (182-189)*

This next extract between Joan and David arose when David was discussing purchasing identity cards for them both, and it addresses the reality that Joan may wander off. They turn this into a joke and by doing this David is able to make a very serious point, but in a way which does not make Joan feel guilty. This can be seen as an example of keeping things light-hearted (which he mentions above).

*D “say if ever you ran away and left me, you know what I mean ...*

*J Don’t think I’d do that.*

*D Shot off to the pub and never told me or something like that ...*

*J Oh aye.”*

Alternatively couples also used humour to joke about their partners increased responsibility, often attributing this to their wife/ husband’s personality rather than it resulting from their illness. Both Keith and Michael give examples of this.

*“she’s a perfectionist and I’m not”*

*Michael, (565)*

*“(on Margaret) professional whittler”*

*Keith, (395)*

Not many of the couples described acceptance of the Alzheimer's, although Michael and Sandra discussed how the diagnosis of the Alzheimer's affected them.

*M      "because we know it's an illness, you've got to accept something haven't you?"*

*S      Yeah, I didn't accept it for a while did I? No, I didn't, I didn't accept it, not for a long while.*

*M      Because she'd had me so many years and I'd just do anything wouldn't I?*

*S      Yeah. Yeah, maybe it was me at the start who was awkward you know, I used to blame him really you know. But we've had to accept it now, so that's it".*

From this extract of dialogue, Sandra is honest about her feelings towards the Alzheimer's. She is able to recognise and understand her own reactions to the diagnosis and has now accepted it into her life.

During the interviews with Mary and John, Mary appeared to be more accepting of the Alzheimer's than John and stated:

*"but you know, that's the way it is"*

*Mary, (483)*

The interviews highlighted that when couples demonstrated acceptance of the Alzheimer's they were often insightful which in turn led to adaptations in behaviours. A couple of examples of this relate to being attuned to the Alzheimer's and adapting their behaviours towards one another to suit their needs:

*“I don’t tell him now until we are about ready to go out because it annoys me that he can’t remember”*

*Sandra, (303-305)*

*“if I’ve had a decent night, well then I feel like doing something. But if I’ve had a bit of a restless night or something’s worrying me, well then I don’t do it”*

*Rosemary, (966-971)*

## 2. (ii) *Relating to others*

This subtheme looks at how the Alzheimer’s disease has impacted upon the couple’s relationships with their friends, family and outside interests. Within this subtheme the concepts of change and loss are ever present.

The experience of ‘being alone’ came across strongly in some of the interviews. This was focused around couples being afraid of what would happen if they could no longer care for their partner, and also feeling isolated from friends.

For some of the couples, the family played a strong part in helping to alleviate the fear that they would no longer be able to look after their partner. David and Joan discussed how their daughter now comes and cleans for them which is a great help.

In these instances, family was important as it provided a sense of security, and sometimes helped the couples to forget about their problems for a while. An example of this is a quote by Margaret who states:

*“the children are very protective, but they inject life into us”*

*Margaret, (780-794)*

Margaret sees the family as an important factor in helping to keep herself and Keith young and active, and distracts them from always thinking about the difficulties within their own life.

In some couples there appeared to be a lack of regular family input, and this served to increase the partners worries about caring for their other half. John sums this anxiety up when he states (in relation to his family):

*“now obviously they’ve got their own lives and such like... I do find that worrying in the quieter moments”*

*John, 462-463)*

John then goes on to say:

*“It’s something we have talked about and not quite sure how to solve that one yet. I think that’s one major area of worry”.*

*John, (467-471)*

Rosemary and Todd go on to describe how they had experienced a sense of isolation from speaking with their friends and a general sense that people now treat them as a couple differently.

*T “And one thing we find, that other people are ... if Rosemary mentions Alzheimer’s, you don’t get a very good reaction, it’s almost as if you’ve got the Plague or something.*

*R Yeah, it is really, yes.*

*T Or you know, you've got some infectious disease or something, you can see people visibly step backwards from you, which is not what you would expect quite honestly, but it seems to be ...*

*R Well they probably just think ... I mean they hear about these outbursts and all that sort of thing and they probably think that that's all the time.*

*But it's not, I mean there's so many different things and different ways that it affects you."*

Todd describes feeling shocked by the behaviour of their friends, as this feels like they are being excluded. Their mention of it being like an infectious disease, seems to leave them feeling that their friends think if they stay in contact with Rosemary and Todd then they may catch something. Rosemary is able to rationalise that they are maybe uncertain of how to react or how she may react towards them, but the reader still gets a sense that this is painful for Rosemary too. Later on in the interview, Todd states;

*"There's definitely a different feel with people. That you know they're suspicious and they talk in whispers a little bit."*

*Todd, (269-272)*

This again seems to highlight Rosemary and Todd's isolation as they feel unable to talk openly about the Alzheimer's which is a large part of their life. Todd's use of the word suspicious implies that their friends almost think that they are untrustworthy and that the Alzheimer's is unmentionable.

Many of the couples' experiences were similar in that they described a general sense of loss over their social life. Although this was at times attributed to external factors such as their friends getting older, or passing away, this loss was usually attributed to the affects of their age and the Alzheimer's.

*"I mean Rosemary used to go out; she stopped doing it before me, but I mean with my other problems, health problems, I've stopped going out"*

*Todd, (152-155)*

*" the only thing we don't have much of is a social life isn't it?"*

*David, (535-536)*

Keith and Margaret described that they never did have much of a social life, but each of them saw their friends one night a week and this was important to them. They also continued to be as active as possible and continued with their hobbies around the house and garden. Keith and Margaret are avid football fans, and felt that going to watch games was a good thing to do together.

*"Just being one of the crowd for once isn't it? And nobody feels old or young or disabled or whatever there do they?"*

*Margaret, (1164-1166)*

This quote implies that attending football matches was a great way of maintaining normality and escaping from the Alzheimer's.

## **Facing the future**

This theme captures the couple's experience of facing their future. Many of the accounts could be identified as sitting on a continuum whereby at one end the future was described positively, and at the other end there was seen to be no future.

Sandra and Michael sat somewhere in the middle of the continuum and stated that they were actively not thinking about the future. This idea was reflected in their views on AD in general and the progression that it would follow.

*"We'll take it as it comes, rather than have it in your mind, you know"*

*Michael, (601-602)*

For Sandra and Michael life was easier if they just took each day at a time because they then wouldn't spend time worrying about what may or may not happen.

Mary and John and Joan and David sat somewhere different along the continuum. They all expressed that they did not know what the future held, and to some extent it was unknown'

*"really we don't know whether anything is going to happen"*

*David, (809-810)*

*"Its going to be conditioned as to what the future holds for Mary"*

*John, 763-765)*

These quotes seemed to illustrate that the couples felt they had a complete lack of control over their future. The unpredictable nature of how the AD would affect their partners seemed to completely define their future.

Many of the couples described that they lived their life by taking one day at a time.

*“we just poddle along”*

*Sandra, (245)*

*“we limp on from day to day”*

*Todd, (1058)*

Both of these quotes seem to indicate that the couples try and exist as best they can, but their lives have been slowed down and changed.

In some couples living their life took the form of needing to just accept what was happening;

*“this is life, get on with it in the best way you can”*

*John, (932-933)*

Whilst in others, for example Sandra and Michael, there appeared to be an element of denial in thinking about what was happening.

*“the only way we can carry on is not to think about it”*

*Michael, (48-49)*

### **You, me and ‘it’**

#### 4. (ii) *Threes a crowd*

In this subtheme, there were three main patterns of interaction which emerged.

Firstly, many of the couples externalised the AD so that it was not part of their relationship. These responses ranged from a complete rejection of the illness:

*“we don’t like to use the A word”*

*Margaret*

Through to some acknowledgement of the illness, yet not wanting anymore to do with it.

*“and that’s why I don’t want to go to any Alzheimer’s meetings or anything like that, I don’t want to see what...”*

*Sandra, 593-595*

One couple showed some extreme distancing from the AD by referring to it as a completely separate entity:

*“Well people do these sort of things, you have to watch people with..”*

*Todd, 436-437.*

Secondly, the Alzheimer’s was seen as part of the individual who had the diagnosis. In such instances, the problem was referred to as occurring within the individual. Thirdly, the partner without the AD was unable to assimilate their partner with the AD. Through analysis of the transcripts these quotes were named ‘unmentionables’ as they were felt to encapsulate the partners inability to assimilate (out loud) their partner having AD.

An example of this comes from Sandra who states:

*“He tries to just be the old Michael you know, not...people wouldn’t know really that he... and then the next day..”*

*Sandra, 384-3866*

Throughout this quote Sandra avoids openly naming what Michael now is and what is wrong with him.

In a similar vein Todd states:

*“well its taking her all her time to manage to do... isn’t it, to cope with..*

*Todd, 645-646*

This quote illustrates Todd’s inability to say out loud what Rosemary has to cope with as it is just painful.

## **Appendix H**

### **Extended discussion**

The study has identified several themes which capture the lived experience of couples living with Alzheimer's. It can be seen from the results that not all of these experiences are the same, and this is to be expected given the interpretative nature of the methodology.

Many changes were identified within the results and appeared in some form or another across all themes.

Many of the couples described a change in roles, as more and more the partner of the individual with Alzheimer's took on increased responsibilities. Role changes from spouse to carer have been identified in other studies. Duke, (1998) found that the role of the spouse was juxtaposed with that of a carer, and this fits with the account of John who discussed the difficulties in being a carer and also a loving husband. Paun (2003) studied women caring for spouses within their home and identified that many of the women acknowledged a change in roles. Many of the partners within the study also described having to spend time checking up on what their partner had done or said they had done. Many of the couples appeared to accept this as part of the process of Alzheimer's, and in other studies this has been described as caregivers experiencing a permanent state of vigilance (Parsons, 1997). Alongside this, many of the couples reported not letting their partners go out alone with the view that forgetfulness may make them liable to create danger for themselves and others (Gillies, 2000).

The analysis of the results also demonstrates the use of a range of coping responses used by the couples. Self protective strategies such as minimizing the problem (Clare, 2002; Pearce, Clare & Pistrang, 2002), maintaining hope (Clare,

2002), normalisation (Gillies, 2000; Clare, 2002) and the use of humour (Burgener & Dickerson-Putman, 1999) were all present to varying degrees. These strategies have been identified as being important in helping to protect the individual's identity and to maintain normality and continuity in line with their identity before the dementia (Steeman, et al., 2006; Clare, 2002). Alongside this, couples also demonstrated the use of integrative strategies which allow for the development and adjustment of the self concept (Clare, 2002). In this study these strategies included engaging in holistic practices and spiritual activities (Margaret and Keith strongly believed in the use of magnets and homeopathic remedies), attending support groups (David had attended an 8 week group), finding out more about dementia, and taking a proactive stance. This fits with research which states individuals with Alzheimer's struggle to hold onto their identity, yet at the same time try to adjust to the changes which are occurring (Dierckx de Casterlé et al., 2005).

It has been identified that individuals with Alzheimer's are likely to be sensitive to the quality of their interactions with family members and others (Pearlin, Harrington, Powell Lawton, Montgomery & Zarit, 2001). In the case of Mary and John, Mary frequently made reference to John being 'hard on her' and seemed very sensitive to this often taking it very personally. Despite this, there was a sense that the diagnosis of the Alzheimer's had enabled the couple to make sense of what was happening to them. In this case, John was more aware of his interaction with Mary as he was able to attribute some of the difficulties within the relationship to the illness (Baikie, 2002) and Mary agreed that this had had an impact. Some of the couples identified having regular contact with their children and this was identified as positive. In particular, Keith and Margaret discussed how this helped them to feel young. Research has highlighted the importance of social interaction particularly in

relation to feeling supported, and being understood, accepted and valued as an individual (Burgener & Dickerson-Putman, 1999; Pratt & Wilkinson, 2003)

The concept of cohesion has been identified by Carter and Carter, (1994) who when studying marital adjustment and effects of illness, found exceptionally tight bonding and high levels of cohesion between the spouses. They proposed that such levels of bonding could in themselves 'facilitate coping with an illness through increase support, empathy and improved care giving' (p.323). This fits in with the idea of congruence proposed by Whitlach (2001). It can be seen from this study that many of the couples were felt to be cohesive within their accounts and views on the Alzheimer's disease. When they discussed certain topics, it was genuinely felt that this was a cohesive understanding and that they shared a similar perspective on this. However it is acknowledged that at times the notion of "we" within the couples may not always have been seen as congruence, but may have been indicative of domination from one partner. This was taken into account when analysing the data and consideration was given to whether this was a power play dynamic within the couple and whether one couple was subjugating their own needs. Care was taken when interviewing the couples that neither one of them felt marginalised, although the difficulty in ascertaining this was recognised throughout.

Within Hellström, Nolan and Lundh's (2007) account of couplehood in couples with dementia, they identified three main phases which couples progressed through. These included sustaining couplehood, maintaining involvement and moving on. Within this study, couples were felt mainly to be within the first phase whereby their interactions sought to sustain their couplehood. Particularly in this study, the main strategies involved by the couples involved making the best of things and keeping the peace. Making the best of things involved searching for positives,

and in particular living for today. Some couples engaged in the strategy of 'keeping the peace', whereby the partner of the individual with Alzheimer's demonstrated an awareness of how their partner may react to certain situations. Examples of this within the study included partners being aware of when it was a 'good' or 'bad' day, and also not responding to their partner if they had an angry or emotional outburst. It may be hypothesised that maybe the other phases of couplehood were not found to be as prominent as this was not a longitudinal study but captured the participants at one time point. Many of the participants within this study had relatively mild symptoms of the Alzheimer's and this may have been indicative of the stage of the disease the participants were at.

Some couples described a reduction in their social life and in some senses isolation from those around them. Husband (2000) and Robinson et al., (2005) hypothesised that this may have led to decreased access to a valued social identity which in turn may lead to increased feelings of hopelessness about their situation. This appeared to be the case for Rosemary and Todd who felt increasingly isolated from their friends once they had discussed the Alzheimer's diagnosis with them. Rosemary highlighted the impact of negative stereotypes upon their reactions, and this has been identified as a factor which may lead to people with dementia becoming secretive about their diagnosis or hiding it (Clare 2002; Clare et al., 2005) this could also be seen in the case of Rosemary as it led her to use more casual language when describing the Alzheimer's and 'dropping' it into conversation in a casual manner. This also fits in with Kitwood's (1997) element of stigmatisation which contributes towards malignant social psychology through whereby people are treated as if they are disease, an alien or an outcast.

The parent to child dynamic that was observed within Rosemary and Todd could be described in terms of infantilisation, whereby carer's actions can be seen as patronising, like an insensitive parent may treat a young child. This interaction was very powerful at times, although it was felt that this was not a conscious and deliberate act in Todd's case. Within the interviews Todd came across as quite fearful and overwhelmed by the Alzheimer's, and it was felt he had been thrown into this world which he didn't really know how to cope best with. In light of this, the dynamic could be seen as an example of the regression individuals with Alzheimer's make as their illness progresses. As such maybe this dynamic is to be expected, yet in the context of this study and the apparent incongruence between this dynamic and the reality of Rosemary's difficulties this contrast was stark.

Yalom (2008) in relation to Alzheimer's states "there are few ordeals more nightmarish than witnessing the gradual but relentless crumbling of the mind of a life partner" (pp.38), yet an area which was noticeable due to its absence was the discussion of death. This could have been due to several reasons including, couples wanting to focus on living from day to day, cultural barriers to discussing death, or their concern around existential angst. This would be a topic which would be interesting to explore in further research.

Kübler- Ross (1973) identified five stages of grief; denial, anger, bargaining, depression and acceptance. Although models of grief were not the focus of this research, some couples could be seen to be in the acceptance and the bargaining stage. Of noticeable interest, Margaret and Keith both talked of their hope in homeopathic remedies, having a positive attitude and wearing magnets. In some ways this was felt as a bargaining tool that if they did of all these things to help

themselves then maybe Keith's Alzheimer's won't get any worse, although this was not explicitly mentioned.

It is important to highlight that although interpretations have been made about couples' experiences of Alzheimer's, we don't know what their relationship was like before the Alzheimer's was a part of their life. This is difficult information to obtain and can often only be obtained through retrospective accounts.

### *Strengths, weaknesses and clinical implications*

This study explored the lived experience of couples living with dementia. The use of a phenomenological approach encouraged a 'non expert' position within the interviews.

The study highlighted the different strategies used by the couples at this time to cope with the Alzheimer's. The results indicate that couples were still mainly adopting a self maintaining stance and using self protective strategies. Although some couples were starting to use a self adjusting stance and use integrative strategies, it would be interesting to follow up all the couples to see whether the balance of strategies used begins to shift as the disease progresses. Research has indicated that individuals will continually shift between these responses due to the progressive nature of the Alzheimer's (Clare, 2002).

Due to the study only examining couples experiences at one point in time, further longitudinal research would be helpful to increase our insight into the different stages couples enter and at what point this happens.

The research highlighted the systemic considerations within the field of Alzheimer's. Due to the aims of this study it only focused upon the individual with Alzheimer's immediate relationship with their spouse. However, it was apparent that

as the illness progresses, the individual with Alzheimer's and their partner were having to interact with other wider systems such as the medical profession, social support groups and those interested in research. It could therefore be seen as important to consider this systemic perspective in further research.

The dynamics and positionality highlighted within the final theme could be interpreted using IPA, although it was felt that other qualitative approaches may compliment this methodology. For example, the use of discourse analysis may be helpful as this focuses on the way in which pre existing discourses are used within an interaction to accomplish particular aims. This approach could examine the discourses people with dementia use to discuss their situation (Clare, 2003). It could be argued that such language based approaches may only be appropriate within the early stages of dementia, given that language difficulties are likely to occur as the symptoms progress. Forbat (2003) disputes this claim and states that discourse analysis is compatible with Kitwood's work and other literature which highlights the importance of maintaining personhood. In line with this is research by Sabat and Harré (1992) which proposes it is possible to identify the maintenance of personhood through the use of personal pronouns such as me, myself and I. It may be that the combination of IPA and discourse analysis may provide a comprehensive account which takes into account not only the lived experience and meaning the couples give to living with the AD, but also gives insight into the ways in which they construct and position themselves within 'talk'.

When considering further research within this area, it may be useful to add a quantitative element to this. This could look at several areas. On a service level, surveys could be completed around the provision of information for couples and also the type and appropriateness of support offered.

On a relationship level, it may be interesting to consider aspects such as intimacy and how this is affected as the Alzheimer's progresses. For example on a continuum running from day to day intimacy e.g. holding hands etc through to 1:1 intimacy such as sex.

All participants within the study were of white British origin. It may be useful to explore the experience of living with Alzheimer's within other groups and cultures, to see if there are any differences. In line with this, none of the couples talked about death throughout the interviews. This may have been due to several factors, for example existential angst, denial, culture, and as such expanding the sample to include different cultures may elicit different experiences of this.

Due to the changing role of the clinical psychologists within the NHS, psychologists are increasingly required to not only provide individual therapy, but also to act as consultants and deliver teaching to other professionals. In relation to clinical implications, the study has highlighted the importance of increasing awareness and education around Alzheimer's disease and its impact upon the individual, their partner and their relationship. Psychologists can aid this through the development of teaching and training packages particularly for nurses who often have frequent contact with individuals assigned to memory clinics.

### *Critical reflection*

IPA identifies that the researcher is trying to get close to the participants personal world and gain an insider's perspective. The IPA methodology used within this study is derived from phenomenological approaches.

Phenomenology is concerned with the world and how it presents itself to us humans, in other words, "the phenomena that appear in our consciousness as we engage with

the world around us” (Willig, 2001, pp.51). The aims of phenomenological research are to study participant’s perspectives of their own world. Alongside this, research attempts to describe these perspectives in detail and then explicate their essential meanings. Within phenomenological research, the participants account becomes the phenomenon with which the researcher attempts to engage. Phenomenology is one of many branches of qualitative methodology. Qualitative methodologies however all share a similar concern and this is with extracting meaning. Qualitative approaches are concerned with quality and texture of experience which is different from quantitative methods which are positivist and aim to test hypotheses to gain an absolute truth. In such cases, the position of the researcher is detached and objective and does not engage subjectively with the material being researched. Alongside this, quantitative methods are data driven and strive to prove relationships between cause and effect.

It was felt that IPA was an appropriate methodology for the research question being posed as the aim was to explore and try to understand couple’s lived experiences of living with Alzheimer’s.

When designing the research, the ethics around interviewing a couple together were raised and, care was taken to ensure no member of the couple felt marginalised, and as such they interviews worked well. As mentioned previously, the dynamics between the couple were an interesting observation and as such analysis of the same data using a different method of interpretation would be interesting.

Such exploration of experience is important particularly within the field of dementia as it enables us to gain insight into individual’s psychological worlds. The topic of dementia is currently under the media spotlight due to the increasing

numbers of individuals it is affecting, and the predictions around how many individuals in the future will be affected. It is only through the continuation of research that we can ensure appropriate and effective psychological strategies and help are provided, to those who need it, and at the time they are needed the most.

### *Personal reflection and interaction with results*

A key component of the research process was maintaining a reflective research diary. Throughout the research, I had an image of Alzheimer's which kept cropping up, and helped me to conceptualise the experiences of the participants.

The images created by this analysis focused on Alzheimer's disease as a visitor to the couple's houses. In some cases I had an image of the AD knocking on the door of the couples house and them turning it away, except that they couldn't shut the door as the AD had it's foot in it and wouldn't leave. In another image, the couple had let the AD into the house and lived alongside it, yet they completely ignored it and carried on with their own lives. The final and most striking image was of the AD being allowed into the house, and it gradually taking over all the rooms up until the point the couple were confined to one room with it being inevitable that shortly they would be evicted. On reflection I wonder if the ideal situation is to let the AD in and to live and interact with it as if it were a part of the couple.

## Appendix I

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