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DEMENTIA: CONSTRUCTING A RELATIONAL PERSPECTIVE

Section A: The Experience of Dementia in the Context of Couple

Relationships: A Review of the Literature

Word Count: 5,458

Section B: Couples Constructing Dementia:

The Construction of and Processes Involved in Couples' Experiences

Word Count: 7,997

Section C: Critical Appraisal

Word Count: 1,944

Overall Word Count: 15,399

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

JULY 2012

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

Firstly, I would like to thank the seven couples who participated in this study for giving up their time and for sharing their experiences with me. I was moved by their openness and honesty and by their determination to live life as fully as possible, despite their experiences of dementia. Their stories were inspirational and I hope that by sharing them, other couples, as well as professionals who work in the field of dementia care will also be moved.

I would like to thank my supervisors, Paul Camic and Margaret O'Shaughnessy, for the time and consideration that they gave to this project. Their advice, guidance and input at all stages was invaluable.

I would like to thank Linda Riley, who gave up her time to help me at various stages of this project, by generously sharing with me some of her experience of dementia and offering advice at various stages.

Thank you to my friend and colleague, Clare, who provided me with emotional and practical support with this project whenever I needed it. And thank you to my partner, Tim, for all of his support over the past three years.

Summary of the Portfolio

Section A is a review of literature which has explored the experience of dementia in the context of couple relationships. Four key themes thought to be central to this experience were identified and highlight the impact of dementia upon couple relationships, and how aspects of relationships may influence the experience of dementia. Limitations and gaps in our understanding are highlighted. Most significantly, the existent literature focuses upon care partners' perceptions and excludes people with dementia. Therefore, it is argued that a relational understanding of the experience of dementia, in the context of couple relationships, remains unknown. The review concludes with a rationale for why further research is needed and how people with dementia could be included.

Section B describes a qualitative study, using interpretative phenomenological analysis, to investigate couples' experiences of dementia. Seven couples were interviewed and five master themes emerged from analysis of the data. These themes offer an understanding of the experience of dementia from a relational perspective and depict the ways in which couples construct their experience in order to make sense of dementia, and the processes that they adopt in order to adjust to dementia. The findings of this study are supported by existing empirical and theoretical literature and have implications for future research and clinical practice.

Section C is a critical appraisal of the qualitative study. The process of undertaking the study is reflected upon, as is what has been learnt. Research skills that have been learnt and developed over the course of the study are identified and discussed, including: establishing relationships, specific skills relating to research with people with dementia, and interviewing

skills. Aspects of the research that could have been approached differently are considered, including: the use of observational data and working with the wider research community. The ways in which my clinical work has changed as a consequence of carrying out this research are discussed, including: consideration of the importance and influence of relationships, and the use of solution-focused approaches. Possibilities for further research in this area are considered, including: investigation of mentalizing abilities among people with dementia and the impact of this on relationships, and exploration of the impact of dementia on other significant relationships.

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SECTION A

The Experience of Dementia in the Context of Couple Relationships:

A Review of the Literature

Abstract

This review examines existing literature which has explored the experience of dementia in the context of couple relationships. A definition of dementia and an outline of different theoretical perspectives is provided, including how understanding of the experience of dementia has shifted from the medical model to one that takes account of psychosocial factors and interpersonal relationships. The importance of developing a relational understanding, in particular in the context of spousal or couple relationships, is considered. Following which the existing literature in this area is reviewed. Four key themes thought to be central to the experience of dementia in the context of couple relationships are identified: ‘intimacy’, ‘loss’, ‘in sickness and in health’, and ‘retaining couple identity’. Literature relating to each theme is described and critiqued and a number of limitations and gaps in our understanding are highlighted. This review concludes with a rationale for why further research is needed and suggestions are made regarding the nature, type and focus of this research.

Introduction

There are currently 750,000 people with dementia (PWD) in the UK, at an annual cost of £17 billion (Alzheimer's Society, 2011). This figure is expected to rise to 1.4 million by 2038, at a cost of over £50 billion (Department of Health, 2009). As such, there is a growing need to address the wellbeing of this population and those that care for them, usually spouse partners. In order to support this population, an understanding of the personal experience of PWD and their partners is needed. This review will examine the existing empirical and theoretical literature which has explored the experience of dementia in the context of couple relationships.

What is Dementia?

Dementia is an umbrella term used to describe disorders resulting in cognitive difficulties and progressive loss of functioning. The most common form of dementia is Alzheimer's disease (AD). Symptoms include short-term memory, orientation and language difficulties, which become more problematic as the disorder progresses and individuals become increasingly confused. The second most common form is vascular dementia (VD). Symptoms depend upon the area of the brain affected and progression usually occurs in a 'step-wise' fashion, remaining at a constant level for a period followed by a sudden deterioration. There are many other forms of dementia, including dementia with Lewy bodies and frontal temporal dementia (FTD). A limited number of treatments aimed at improving symptoms and slowing down disease progression are available, but there are currently no cures (Alzheimer's Society, 2012).

Models of Dementia

Different theoretical perspectives on dementia exist, influencing how PWD and those who care for them are supported.

Medical model. According to this model, dementia is understood solely in terms of biological processes and symptoms are directly attributed to brain disease and neurological impairment. This model has dominated thinking for much of the twentieth century however it has been criticised for reinforcing the view that ageing inevitably leads to deterioration and disease (Estes and Binney, 1989), for positioning PWD as passive victims and neglecting subjective experience (Bender & Cheston, 1997; Kitwood, 1997), and for neglecting psychological and social factors (Downs, Clare & Mackenzie, 2006).

Holistic model. Kitwood (1990; 1997) challenged the medical model by proposing that dementia was best understood as the result of neurological impairment, psychological factors and the social context. Central to his thinking was the notion of ‘personhood’ (1997; p.8); he proposed that maintaining each individual’s personhood, by acknowledging their unique biological, psychological and social circumstances, was paramount. Kitwood suggested that PWD could be stripped of their personhood by the attitudes and actions of those around them, including interpersonal processes of infantilisation, disempowerment and invalidation, which he argued led PWD to experience accelerated decline. He suggested that in positive social environments, in which personhood is promoted, deterioration may decelerate. Kitwood’s holistic perspective contributed to the development of person-centred approaches to dementia care which now underpin many current policies, including the Department of Health’s National Service Framework for Older People (2001), National Dementia Strategy (2009) and the Nuffield Council of Bioethics Report on Dementia (2009).

Relational approaches. There has been growing interest and awareness of the importance of the relationship between PWD and those who care for them. However, most of this interest has focused upon caregivers' experiences, in particular, stress and burden. This has led to the development of policies, such as the Department of Health's National Carers Strategy (2010) and services aimed at meeting carers' needs, such as respite.

Whilst this has been incredibly valuable, Prakke (2011) has argued, in her recent review of literature exploring couple relationships when one partner has early cognitive problems (e.g. mild cognitive impairment), that a better understanding of the relationship between the person being cared for and their partner as 'a whole and complex matter' (p.201) is needed. Disease and chronic illnesses are known to have a potentially devastating impact upon couples who need to meet the challenge of maintaining their relationship, whilst also taking the roles of patient and caregiver (Rolland, 1994). Conditions involving cognitive difficulties are thought to be especially difficult (Borden, 1991).

Rationale for Review

The development of a perspective on dementia which takes account of relationships is needed if the wellbeing of PWD and those that care for them is to be addressed effectively (Nolan, Grant, Keady & Lundh., 2003) and the importance of this has been reflected within recent policies, including the National Institute for Health and Clinical Excellence Guidelines on Dementia (NICE, 2006), which state that good dementia care requires an understanding of 'the importance of relationships and interactions with others to the person with dementia' (p.6). The most significant of these relationships is usually the couple relationship, as most PWD, particularly in the early to mid stages of the disease, are cared for by their partner. This relationship also tends to gather more salience as other roles and relationships, such as those with friends and work colleagues, weaken (Bender, 2002).

However, despite this, there has been a tendency to ‘forget that there is a real living couple behind the disease’ (Daniels, Lamson & Hodgson, 2007; p. 162) and little attention has been paid to the experience of couples affected by dementia, including the impact that dementia may have upon relationships and how the nature of relationships may affect the lived experience of dementia. This review aims to examine the current empirical and theoretical literature that has explored this, and identify key themes upon which a greater understanding of the experience of dementia may be developed.

Throughout this review the term ‘partner’ is used, rather than ‘spouse’, to include people in an established couple relationship but who may not be married. Similarly, the term ‘care partner’, rather than ‘spouse carer’, is used to include unmarried couples.

Results

In total 19 publications were reviewed: 14 empirical and five review or discussion papers (see Appendix A for a description of search methodology and Appendix B for a list of results). Additional publications have been referenced where relevant. Four key themes were identified: ‘intimacy’; ‘loss’; ‘in sickness and in health’; and ‘retaining couple identity’. An overview of the literature relating to each theme is provided, followed by a summary and a critique, in which limitations within the literature and gaps in our understanding are highlighted. Suggestions regarding further research are then proposed.

Intimacy

Intimacy refers to the feeling of being in a close, familiar, and loving relationship and is considered of central importance to couple relationships (Moss & Schwebel, 1993). There are many forms of intimacy: emotional, social, physical, sexual, spiritual and intellectual (Renshaw, 1984). Intimacy was explored in six publications (Baikie, 2002; Duffy, 1995;

Eloniemi-Sulkava et al., 2002; Hayes, Boylstein & Zimmerman, 2009; Wright, 1991, 1998), each of which used surveys and/or interviews to explore perceptions of intimacy within couple relationships and how intimacy had been impacted by dementia.

Sexual intimacy. In face-to-face surveys with 38 care partners in the USA, Duffy (1995) found that 79% reported a significant change in their sexual relationship since the onset of their partner's dementia. Care partners tended to feel less sexually attracted to their partner, think that sex was less important to their partner and found that their partner was less able to attend to their sexual feelings. In interviews in the UK, Baikie (2002) found that the majority of care partners reported that their sexual relationship had ceased altogether. In a longitudinal study in the USA, comparing 17 couples where neither had AD with 30 couples where one person had AD, 82% of well couples reported regular sexual intimacy versus only 27% of AD couples (Wright, 1991). Two years later this had declined to 62.5% of well couples versus 19% of AD couples (Wright, 1998). The results of this study suggest that decline in sexual intimacy is associated with the experience of AD itself, rather than just older age.

Drawing upon the idea of symbolic interaction (Blumer, 1969), it may be that decline in sexual intimacy is related to changes in how partners perceive their role and that of the person with dementia. For example in both Duffy and Baikie's studies, and in a study by Hayes, Boylstein and Zimmerman (2009) in which 28 care partners (13 male and 15 female) were interviewed, female care partners described how their role shifted from that of a wife to that of caregiver/mother and how this left them feeling that sexual activity was inappropriate.

The results of a telephone-based interview study with 42 care partners, which took place in Finland, were less conclusive. The researchers, Eloniemi-Sulkava et al., (2002) found that 46 % of couples continued to practise sexual intercourse three years after the onset

of dementia, 41% after five years and 28% after seven years. They also found that 10% of care partners experienced positive sexual changes.

These results suggest that dementia often has a negative impact upon sexual intimacy, although in some cases this aspect of couples' relationships may be preserved. Further exploration of the factors which may determine this is needed.

The studies described all focus upon care partners' perceptions and the experiences of PWD are absent; only Wright (1991, 1998) interviewed PWD but discounted much of this data on the basis that it was not considered reliable. A further limitation of this research is that the majority of participants were female and therefore findings may not reflect the views of male care partners.

Readers are directed to Davies, Zeiss and Tinklenberg (1992) and Davies, Zeiss, Shea and Tinklenberg (1998) for further information on sexual intimacy which falls outside the remit of this review.

Physical intimacy. Both Wright (1998) and Baikie (2002) found that physical intimacy declined following the onset of dementia. Additionally, Hayes et al., (2009) found that care partners reported that affection and affectionate acts, including hugging, sitting close, kissing and touching, declined. Like sexual intimacy, decline in physical intimacy may be related to care partners' perceptions of changes to their roles and identity and that of their partner.

However, the results of the study by Eloniemi-Sulkava et al. (2002) were again less conclusive: 33% of partners reported increases in expressions of tenderness by the person with dementia, 26% reported no changes, 31% reported a decrease and 10% reported a total loss. These results suggest that physical intimacy does not necessarily decline for all couples and that aspects of intimacy may be preserved or even increase. Eloniemi-Sulkava et al,

proposed that intimacy helps couples to retain their couple identity and motivates partners to continue providing care. Further research to determine the factors which might help to maintain intimacy may be beneficial.

Emotional and social intimacy. Wright (1991) found that care partners reported lower levels of companionship and feelings of closeness compared to well couples and Hayes et al. (2009) found that care partners reported a decline in emotional and social intimacy, as their partner became unable to reciprocate during conversation. Reciprocity generally refers to the practice of give and take and in this context refers to the mutual exchange of information between people in a relationship (Simmel, 1950). Intimacy is based upon reciprocity, so as the disease progresses and PWD are unable to continue reciprocal interactions, intimacy may be threatened (Hayes et al., 2009).

Few studies have considered how dementia impacts social and emotional intimacy and reciprocity. What research there is has focused upon care partners' perceptions and the experiences of PWD are absent. The current literature is also limited by difficulties operationalising and measuring abstract concepts, such as intimacy, which makes consolidating the results and drawing conclusions difficult.

Loss

Loss emerged as a major theme in O'Shaughnessy, Lee and Lintern's (2010) interpretative phenomenological analysis (IPA) study, in which seven care partners were interviewed and Robinson, Clare and Evans' (2005) IPA study in which nine couples were interviewed, both of which took place in the UK. Loss also emerged as a theme in discussion papers by Baikie (2002) and LoboPrabhu, Molinari, Arlinghaus, Barr and Lomax (2005).

Baikie (2002) described how care partners experience multiple losses within their couple relationship, including loss of emotional and practical support and joint decision making. Additionally, O'Shaughnessy et al. (2010) found that care partners reported loss of shared activities and understanding and reported losing a sense of their partners' personality as well as a sense of their own personal and social identities.

Robinson et al., (2005) found that couples described a cyclical process of noticing changes in the person with dementia, including memory, mood and temperament, and changes in the relationship, as partners became carers; taking on more responsibility for practical tasks and managing the increased dependence of the person with dementia. Couples in this study described how they adjusted by acknowledging difficulties and losses, whilst also recognising resilience and developing ways of coping.

Social death and anticipatory grief. To understand the experience of caregivers researchers have drawn upon the concept of 'social death', which is said to occur when an individual is described as 'for all practical purposes dead or non-existent' (Kalish, 1968, p.254), and 'anticipatory grief', which has been defined as 'any grief occurring prior to a loss' (Aldrich, 1974, p.4). For example, in interviews with 100 caregivers, Gilhooly, Sweeting, Whittick and McKee (1994) and Sweeting and Gilhooly (1997) reported that many caregivers believed that their relative was in some ways already dead. Using content analysis, Almberg, Grafstrom and Winblad (2000) also found that many caregivers (21 out of 30 that they interviewed), expressed grief before their relative died. These studies suggest that bereavement may begin long before the final loss of the person with dementia.

It has been suggested that perceiving their partner as socially dead may help care partners to accept or come to terms with their death. In the study by Gilhooly et al., (1994) some caregivers reported that death would come as a blessing and in their review paper,

LoboPrabhu et al. (2005) suggested that care partners experience anticipatory grief as changes and losses highlight the need for them to separate psychologically and physically from their partner and consider their lives without them.

Research which has explored the phenomenon of social death and anticipatory grief among care partners is limited and further consideration needs to be given to why caregivers may perceive their partners in this way and the impact and implications of this. Furthermore, there has been no research which has explored PWD's experience of these phenomena and their relevance to understanding couples' joint experiences.

Dual-process models of grief. These models describe people as oscillating between the positions of looking back and experiencing the pain associated with loss, and looking forward and moving on (Stroebe & Schut, 1999). This model resonates with the findings of O'Shaughnessy et al. (2010), who found that care partners oscillated between positions of connectedness and separateness with their partner as they adjusted to changes and losses in their relationship, and the findings of Robinson et al. (2005), who found that couples oscillated between acknowledging losses and holding on to what remained for each person and the couple. Robinson et al. proposed that this oscillating process helped couples to make sense of dementia and adjust.

This literature suggests that dual-process models of grief may be helpful in understanding the experience of loss for couples affected by dementia and Robinson et al. should be credited for including PWD and conducting joint interviews which captured couples' shared experiences. However, more research is needed to assess whether this theoretical model is relevant to other couples.

In Sickness and In Health

As well as considering how dementia impacts upon relationships there is also a body of literature which considers how aspects of relationships, such as the quality and history of relationships and values associated with established relationships, may influence the lived experience of dementia.

Quality and history. In a discussion paper Davies and Gregory (2007) proposed that the quality and history of the marital relationship influences how dementia is encountered and lived. They suggested that a positive ‘marriage biography’ may act as a protective factor, whilst a poor quality pre-morbid relationship may put couples at risk.

This is supported by a case study by Daniels, Lamson and Hodgson (2007) who found that a couple constructed their story of living with AD around positive reflections of their life together. This is also supported by the findings of a large questionnaire study, which took place in Canada, by O’Rourke, Claxton, Kupferschmidt, Smith and Beattie (2011).

Questionnaires relating to marital idealisation, burden and satisfaction were completed by 90 care partners and researchers found that those who idealized their partner and relationship, experienced lower levels of distress and higher levels of life satisfaction.

Conversely poor quality pre-morbid relationships have been found to impact upon care partners’ adaptation to the caring role, the quality of care provided, (Williamson & Shafer, 2001), caregiver depression, quality of life, satisfaction, (Kramer, 1993) and caregiver burden (Teusink & Mahler, 1984; Heru, Ryan & Iqbal, 2004).

This literature supports the idea that the quality and history of the couple relationship influences the experience of dementia, either positively or negatively. However, more research is needed and as the majority of research has focused upon the perspective of care partners, future research should aim to include PWD.

Values and commitment. Duffy (1995) noted that the current cohort of older people ‘vowed to love, honour, and cherish, in sickness and in health, till death do us part’ and suggested that the low divorce rate among this group demonstrates their commitment to these vows. However, it is also probable that economic factors played a large role in determining the low divorce rate, as women of this cohort are likely to have depended heavily upon their husbands financially, which may have affected their decision to remain or leave their marriage. Nevertheless, in their review of this area LoboPrabhu et al., (2005) proposed that commitment provides a strong foundation upon which partners feel that they can face the experience of dementia.

This has been demonstrated by Daniels et al. (2007), who in their case study reported that lifelong commitment to each other was central to the couples experience of living with AD. A recent mixed methods study by Davies (2011), in which six couples living in Canada were interviewed and completed questionnaires relating to commitment and life satisfaction, also lends support to this idea. Using narrative analysis four themes were identified: ‘partnership for life’, ‘reciprocity’, ‘resilience’ and ‘forgiveness’, which reflected the couples’ commitment to each other and according to Davies, preserved the couples’ ‘us identity’.

It is a credit to these researchers that PWD were included in their studies and that partners were interviewed together. However, more research is now needed to assess whether these findings extend to other couples.

Equity and investment. Baikie (2002), LoboPrabhu et al. (2005) and Braun et al. (2009) have considered why partners take on the role of caregiver. In interviews, Baikie found that care partners reported thinking about what their partner had done for them in the past and wanting to repay them. Similarly, LoboPrabhu et al. suggested that partners were

likely to provide care for the person with dementia if they felt that they owed it to them because they had cared for them in the past. They suggested that *quid pro quo*, the idea of an equal exchange between two parties, may be important in holding couples together.

In their review of this area Braun et al. (2009) drew upon the investment model (Rusbult, 1983), which proposes that individuals stay in relationships whilst the rewards outweigh the costs. Although rewards and costs may not always be in balance they are usually made equitable over time. If one partner invested in the other in the past, for example by supporting their career, or raising their family, then the other partner is likely to want to equal this investment by caring for them later in life.

Little research has attempted to consider how notions of equity and investment may impact upon couples' experiences of dementia. However it seems that care partners do reflect upon aspects of their pre-morbid relationship and that this is likely to influence their choice to, and experience of, caring for their partner. For instance, if the pre-morbid relationship was positive, partners may be more likely to invest in the relationship by providing care. Further exploration of these ideas, their potential impact and implications, is required. It would also be interesting to include the perspective of PWD in relation to the influence of these values.

Retaining Couple Identity

As described above, many aspects of the couple relationship may change and may be lost when one partner has dementia (e.g. sexual, physical and emotional intimacy, support, joint decision making, shared activities, etc). This has implications for the identity of the person with dementia, their partner and for the couple dyad (Baikie, 2002; Hayes et al., 2009; O'Shaughnessy et al., 2010). Several studies have described how couples attempt to retain their couple identity or 'couplehood' and from these two subthemes emerged: 'working to maintain involvement' and creating a 'nurturative relational context'.

Working to maintain involvement. In interviews with 11 couples in the UK, which were analysed using grounded theory, Keady (1999) found that participants described ‘working’ to maintain the involvement of the person with dementia. Couples tended to work in four ways: alone, when one or other partner worked in isolation; separately, when both partners were actively engaged in parallel but separate processes; together, when both partners opened up and worked jointly; and apart, when it was not possible to agree a way forward.

Sanders and Power (2009) interviewed 17 husbands caring for their wives with dementia in the USA. The men described how they worked to maintain their wives’ self-esteem, dignity and personhood. The researchers proposed that these husbands were motivated to maintain a sense of normalcy in their married lives and retain their couple identity. O’Shaughnessy et al. (2010) also found that care partners worked to maintain their partners’ self-esteem and sense of self and sought out evidence of continuity in their relationships in order to hold on to a sense of their couple identity. Furthermore, experiences which reminded caregivers of the couples’ shared identity reinforced their commitment to the caring role.

These studies suggest that couple identity is very important and that care partner and PWD (when able) actively work to try to maintain it. More research which aims to explore why and how couples do this is needed. Research of this kind would contribute to our understanding of couples’ experiences of dementia and may help to inform the development of services and interventions based upon couples’ experiences and needs. For example, simple, creative interventions such as the use of calendars, pillboxes and written reminders, may help to maintain the involvement of PWD and help the couple to retain a sense of couple identity. Relationship-focused counselling may also help to strengthen couple identity.

Nurturative relational context. Hellstrom, Nolan and Lundh (2005; 2007)

elaborated upon Keady's work and described how couples created a 'nurturative relational context' (p.10) in which they actively managed their experience of living with dementia and sustained their sense of couplehood. In a single case study, Hellstrom et al. (2005) illustrated how a couple did this by doing things together; describing their roles as reciprocal and complementary. In a study published in 2007, in which 20 couples in Sweden were interviewed over a period of five years and data was analysed using grounded theory, the same researchers found that couples used a variety of strategies in order to sustain their couplehood including: talking things through, being appreciative, making the best of things, and keeping the peace.

This research explored how couples try to retain their couple identity through the creation of a nurturative context and the strategies outlined above. The researchers should be credited for including PWD and for the longitudinal nature of their study, which provides rich data about the personal experience of dementia over time. However, further research is needed to assess whether the notion of a nurturative relational context, and the strategies used to create it, is applicable to other couples.

Summary

Research suggests that several dimensions of intimacy decline following the onset of dementia. This is thought to be associated with changes to the perception of roles and identity of both partners and a declining ability of PWD to reciprocate. However, this is not the case for all couples. The preservation of intimacy within couple relationships could be supported by services and clinicians and may help couples to retain a sense of their couple identity.

Care partners experience multiple losses and research suggests that bereavement begins long before the final loss of the person with dementia. This has been understood in the

context of social death and anticipatory grief. Dual-process models of grief may be helpful in understanding how couples try to make sense of and adjust to changes and losses, however further research is needed.

Couples' marriage biographies are thought to influence their experience of dementia; relationships of high pre-morbid quality may have a positive influence, whilst those of poor quality may have a negative one. In addition, ideas of commitment, equity and investment are thought to be central to couples' experiences, holding couples together and motivating partners to provide care. Exploration of couples' biographies may help to identify those who may be at risk.

Retaining a sense of couple identity appears important to couples. Research has highlighted how care partners in particular work to maintain the person with dementia's involvement, self-esteem and personhood, in turn sustaining a sense of couplehood. Some research has explored PWD's contribution to this and highlighted how couples adopt a range of strategies to create a nurturative relational context, in which a sense of couplehood can be retained. Interventions aimed at supporting couples to retain a sense of couple identity could be helpful. However, further research is first needed.

Limitations

The existing literature is characterised by a number of limitations; some conceptual, such as the tendency to focus upon care partner's perspectives, and some methodological, such as generalisability. These limitations restrict the degree to which it is possible to develop a full and complex relational understanding of the experience of dementia in the context of couple relationships.

Most of the existing literature focuses upon caregivers' perceptions, contributing to our understanding of their experiences and potential needs. However, the perspective of PWD

is largely absent and it can be argued that the development of a relational understanding is unapproachable when one member of the couple relationship is neglected or excluded (Braun et al., 2009).

In addition, focusing upon caregivers' perceptions subjugates PWD 'to an entity to be studied rather than someone who can directly contribute to an understanding of the illness and its course' (Cotrell and Schulz, 1993, p.205). Too often PWD have been situated as passive agents with no value and little to contribute (O'Shaughnessy et al., 2010). This view of PWD is problematic and unlikely to be accurate. Work by some dedicated researchers and the publication of several first-hand accounts (e.g. Davis, 1998; Friel-McGowin, 1993), has helped to challenge unhelpful assumptions and led to an increased awareness of the personal experience of PWD (Woods, 2001). However, more research of this kind is needed.

With regards to methodological limitations, it is difficult to generalise the results of the existing literature to the wider population, as in most cases participants were white, middle class and female and therefore not representative of the general population. It is particularly unclear whether findings can be applied to male care partners, especially as research suggests that there may be differences in relation to how men and women adapt to caregiving (Gilhooly et al., 1994).

There are many factors related to couple relationships that the literature does not consider in any depth, including the length of the relationship and whether the relationship is a first, second or other marriage. There are also factors related to dementia that are neglected, such as how different types of dementia may impact upon relationships. For instance, FTD, which is characterised by personality changes, including lack of empathy and disinhibition, might be predicted to have a greater impact upon intimacy than AD. A greater consideration of such factors would make the transferability of findings easier. Most of the existing literature also neglects to consider how dementia is experienced by couples at different stages

of the disease or as the disease progresses. Exceptions to this are Wright (1991; 1998) and Hellstrom et al. (2007) who conducted longitudinal studies.

Rationale and Considerations for Future Research

Despite the increasing number of PWD and the fact that most, at least in the early to mid-stages, are cared for by their partner, few researchers have attempted to study the couple relationship; how it is impacted by dementia and vice versa. An understanding of the experience of dementia in the context of couple relationships, including what it means to be a care partner and a person with dementia in a couple relationship, is fundamental to the development of services and interventions aimed at effectively supporting this population.

The existing literature is characterised by several limitations which restrict the degree to which a relational approach can be developed. Further research which aims to explore, examine and understand couples' experiences of dementia whilst addressing these limitations is needed. In particular, it has been argued that a relational approach cannot be developed solely on the basis of care partners' perceptions and that in order to understand the dyadic couple experience, both partners should be included in research and the views of PWD be considered whenever possible.

Cotrell and Schulz (1993) have suggested that research with PWD should: consist of small sample sizes; take place in people's homes, where they may feel more comfortable and less threatened; and allow PWD to set the timing of interviews, enhancing feelings of control.

A qualitative methodology, such as interpretative phenomenological analysis (IPA: Smith, Osborn & Jarman, 1999), which aims specifically to investigate the essence of subjective experience, appears complimentary. This type of study would enable researchers to gather the views of PWD and their care partners to acquire an understanding of how dementia is personally experienced in the context of couple relationships.

Braun et al., (2009) proposed that by interviewing couples together observational data relating to the subtleties of the relationship could be collected, helping to generate an insight into the dyadic interplay. Furthermore, for some couples joint interviews may facilitate the sharing of important information, which may have a therapeutic effect. However, one disadvantage of this approach is that the nature of the interpersonal relationship will undoubtedly influence what each partner feels able and willing to speak about in front of the other (Clare & Shakespeare, 2004; Robinson, Clare & Evans, 2005) and this should be borne in mind when planning research of this kind.

In addition, as PWD are one of the most excluded, marginalised and disempowered groups in society, facing both ageism and stigma, it is important that researchers bear in mind that power inequalities can be reflected in the researcher/researched dynamic (Wilkinson, 2002). IPA may be particularly well-suited to this task, as although it does not seek to re-address power inequalities, it does explicitly acknowledge that participants' views are elicited through a dynamic and interactive process with the researcher, which will inherently involve a power dynamic.

Additional suggestions for future research include further investigation of the theoretical ideas highlighted within the existing literature (e.g., dual-process models of loss, quality of the pre-morbid relationship, equity and investment, and nurturative relational context). Mixed methods, such as the use of interviews alongside questionnaires or surveys, would be well-suited to this task. Alternatively, as many of the studies reviewed consist of small, unrepresentative samples, which limit the generalisability of results, larger scale studies, including controlled studies, could be used to determine whether current findings extend to other couples. Future research could also consider how couples' experience of dementia is influenced by variables such as gender, sexual orientation, culture, socio-

economic status, education and age, relationship factors, such as length of relationship and variables related to dementia, such as type and stage of progression.

Conclusions

This review set out to investigate how dementia is experienced in the context of couple relationships. Four key themes were identified: ‘intimacy’, ‘loss’, ‘in sickness and in health’, and ‘retaining couple identity’, which highlight the ways in which dementia appears to impact upon couple relationships, and how relationships influence the experience of dementia. However, the current research is characterised by several limitations, most significantly, the absence of the perspective of PWD. Therefore, the degree to which an understanding of the experience of dementia in the context of couple relationships can be developed is restricted, leaving a gap in our understanding of dementia. In order to develop an understanding of how couples experience dementia, researchers need to take both partners into consideration. Qualitative methodologies or mixed-methods studies may be most suitable to this task.

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SECTION B

Couples Constructing Dementia:

The construction of and processes involved in couples' experiences of dementia

Abstract

There is a growing need to develop a relational understanding of the experience of dementia and in particular the ways in which dementia impacts upon couple relationships and vice versa. In this study seven couples affected by dementia were interviewed about their experiences. Using interpretative phenomenological analysis, five master themes were found to emerge from the data: 'foundations', 'altered structures', 'self-restoration', 'flexible scaffolding' and 'reflective capacity'. These themes reflect the ways in which couples construct their experience of dementia, in order to make sense of it, and the processes that they adopt, in order to adjust to dementia. These themes are supported by existing empirical and theoretical literature and contribute to the development of a comprehensive and complex relational perspective of the experience of dementia, upon which much needed services and interventions for couples could be developed.

Keywords: couples, dementia, relationships, qualitative research

Planned journal submission: Dementia - The International Journal of Social Research and Practice

Introduction

Dementia is undoubtedly one of the major public health issues of our time and presents a huge challenge to society. There are currently 800,000 people with dementia (PWD) in the UK (Alzheimer's Society, 2012) and as the aging population increases this figure will rise considerably. As such, there is a growing need to address the wellbeing of this population and those that care for them.

Recent plans for improvements to dementia care and research, set out in the Prime Minister's Challenge on Dementia (Department of Health [DoH], 2012), suggest that emphasis should be placed upon the relationship between PWD and those that care for them. The majority of PWD are cared for by their spouse or partner and therefore this relationship is particularly worthy of interest. To-date most interest has focused upon care partners' experiences, particularly in relation to stress, burden and wellbeing. However, recently interest has widened to consider other aspects of couples' experiences and a limited number of studies have sought to explore this. An overview of this literature follows.

The Literature on Couples' Experiences of Dementia

A number of studies have explored the impact of dementia on the couple relationship, mostly from the perspective of care partners. In questionnaire and interview based studies care partners have reported that sexual, (Wright, 1991; 1998; Duffy, 1995; Eloniemi-Sulkava et al., 2002) physical, (Wright, 1998; Baikie, 2002; Hayes, Boylstein & Zimmerman, 2009) emotional and social intimacy (Wright, 1991; Hayes et al, 2009) decline following the onset of their partner's dementia. This is thought to be related to how care partners perceive their role and that of the person with dementia.

In interviews care partners have also described experiencing a number of losses, including loss of emotional and practical support (Baikie, 2002), shared understanding, and

loss of a sense of their partner's identity as well as their own (O'Shaughnessy, Lee & Lintern, 2010). Robinson, Clare and Evans (2005) used interpretative phenomenological analysis to analyse data from joint interviews with nine PWD and their partners. They found that couples adjusted to loss through a process of looking back and experiencing the pain associated with losses and looking forward to find ways of coping. The researchers likened this to the dual process model of grief (Stroebe & Schut, 1999) however further research is needed to assess whether this model may be helpful in understanding other couples' experiences.

A small body of literature has explored how the couple relationship may impact on dementia. In a case study Daniels, Lamson and Hodgson (2007) found that a couple's sense of commitment to each other and positive reflections of their life influenced their experience. In a study in which six couples were interviewed and completed questionnaires, Davies (2011) also found that commitment was important and helped couples to maintain their couple identity. Further research is needed to assess whether commitment is important to other couples.

Using questionnaires, O'Rourke, Claxton, Kupferschmidt, Smith and Beattie (2011) found that individuals who idealized their partner and relationship experienced lower levels of distress. Conversely, poor quality pre-morbid relationships have been found to impact negatively upon partners' adaptation to caregiving (Teusink & Mahler, 1984; Kramer, 1993; Heru, Ryan & Iqbal, 2004; Williamson & Shafer, 2001). These findings have been linked with ideas of equity and investment (Baikie, 2002; LoboPrabhu et al., 2005; & Braun et al., 2009), in that caring is thought to be provided in return for care previously received. A limitation of this research is that it focuses only upon the perspective of care partners.

Keady (1999) and Hellstrom, Nolan and Lundh, (2005, 2007) found that couples affected by dementia worked to promote the 'personhood' of the person with dementia. 'Personhood' is a term Kitwood (1997) used to refer to the attributes that a human being

possesses that makes them a person. Kitwood advocated for person-centred approaches to dementia care that promote and maintain the personhood of PWD. This has become a key principle underpinning current policies, including the Department of Health's National Service Framework for Older People (2001) and National Dementia Strategy (2009).

Using grounded theory methodology to analyse interviews with 11 couples, Keady (1999) found that couples 'worked' to promote the personhood of the partner with dementia by maintaining their involvement and creating ways of sustaining their sense of agency and self. Keady identified four ways in which couples worked: alone, separately, together and apart. He hypothesised that as dementia progressed, PWD would rely more heavily upon the efforts of their partner to maintain their involvement.

Hellstrom et al., (2005; 2007) built upon Keady's findings in a case study and grounded theory study with 20 couples. They found that initially both partners worked to maintain the involvement of the person with dementia, but as dementia progressed, care partners found themselves increasingly working alone. As well as working to maintain the person with dementia's personhood, couples also worked to sustain their sense of couple relationship, or 'couplehood'. This involved: talking things through, being appreciative and affectionate, making the best of things, and keeping the peace. Again, as dementia progressed, care partners took the lead in this task. Further research is required to assess whether these findings extend to other couples.

Each of these studies has contributed to our understanding of couples' experiences of dementia however, the degree to which it is possible to develop a full and complex relational understanding of the experience of dementia is limited and more research which considers 'the relationship as a whole and complex matter' (Prakke, 2011 p.201) is needed.

Much of the existing literature focuses upon care partners' perspectives. Braun et al., (2009) have argued that there is an urgent need to integrate the perspective of PWD, in order

to improve understanding and inform the development of services and interventions.

Similarly, in a review of literature exploring relationships where one partner has early cognitive problems (e.g. mild cognitive impairment), Prakke (2011) has argued that both parts of the dyad should participate in relationship-focused research. The inclusion of PWD in research is supported by the *Prime Minister's Challenge on Dementia* (DoH, 2012).

Further research which explores the impact of dementia upon aspects of couple relationships, such as intimacy, and how couples adjust to losses is worthwhile. Research which explores: how aspects of the couple relationship influence the experience of dementia, how couples work to promote the personhood of the person with dementia, and how a sense of couplehood is sustained would be particularly valuable. Such research may help us understand why and how many couples stay together despite the experience of dementia and why some couples find that they are not able to accommodate and adjust to changes and losses. Most importantly, future research should include PWD.

The Present Study

This study aimed to enrich understanding of the experience of dementia, from a relational perspective, in the context of couple relationships. The study aimed to explore both the impact of dementia upon relationships and the impact of relationships upon the experience of dementia. As previous research has tended to exclude PWD, an additional aim was to develop an understanding of what it means to be a person with dementia and in particular a person with dementia in a couple relationship.

Interpretative Phenomenological Analysis

To explore this human experience, a qualitative approach was considered most appropriate (Smith, Flowers & Larkin, 2009). Interpretative phenomenological analysis (IPA:

Smith, Jarman & Osborn, 1999) was chosen because it explores participants' views and experiences in rich detail and depth and is considered 'particularly useful where issues relating to identity, the self and sense-making are important' (Smith & Osborn, 2007, p.520). In addition IPA seeks to consider findings within the context of existing theory, which complemented the study's aim of enriching understanding.

IPA also complemented the epistemological position of the researcher, which was based upon social constructionism and underpinned this study. In particular, as an aim was to give voice to PWD, it felt important to select an approach that would directly allow for this, but also acknowledged that research is constructed and informed by the researcher's own beliefs and assumptions. IPA considers research to involve a 'double hermeneutic', in that as participants are making sense of their experience, the researcher is making sense of the participant's sense making (Smith, 2004).

Method

Participants

A purposive sample was recruited through branches of the Alzheimer's Society. Contact was made with branch managers, who identified couples who might be interested in participating. With their agreement, these couples were sent written information about the study (see Appendix C). Ten couples contacted the researcher. Couples were considered eligible for inclusion if one partner had a diagnosis of dementia and if both partners were able and willing to consent. Three couples did not meet these criteria, as the person with dementia was considered unable to contribute due to communication difficulties and/or lack of ability to consent.

A total of fourteen participants, comprising of seven couples (five men and two women with dementia and their heterosexual partners, referred to as 'care partners')

completed the study. The mean age of PWD was 77.57 years (range 65-87) and the mean age of care partners was 74.42 years (range 63-83). Four participants had a diagnosis of Alzheimer's disease (AD), one had a diagnosis of frontal temporal dementia, one had a diagnosis of vascular dementia and one had vascular dementia and AD (see Appendix D).

Procedure

To gain a relational perspective, PWD and their partners were interviewed together. A semi-structured interview schedule (Appendix E) was developed in consultation with a Salomons Advisory Group Expert, and covered: the experience and impact of living with dementia as a couple, and responses to this, including making sense of and adjusting to dementia. Participants chose to be interviewed within their homes. Each interview lasted between 45 and 75 minutes and was audio recorded, transcribed verbatim by the researcher and anonymised.

Ethical Issues

Ethical approval was attained from the Canterbury Christ Church University Research Ethics Committee (Appendix F). Particular consideration was given to: consent, disclosure of diagnosis and distress.

Consent. A consent pathway, based upon Dewing's (2007) process method of consent, was developed by the researcher (Appendix G). This method provides an alternative to the gold standard of informed consent, which, because it is based upon cognitive competence, often means that PWD are excluded from research. In contrast, the process method is person-centred and inclusionary. It comprises five elements: background and preparation; establishing the basis for consent; initial consent; ongoing consent monitoring;

and feedback and support. The process relies heavily upon being able to engage with PWD, those around them and upon critical reflection.

Disclosure. PWD do not always hold their diagnosis in conscious awareness, so it was important that the researcher did not disclose this during the study. Therefore, participants were initially asked about their understanding of their memory difficulties (at which point most shared their diagnosis).

Distress. Participants were informed that interviews may evoke strong emotions and advised not to answer questions that made them feel uncomfortable and that they could withdraw at any time. At the end of each interview the researcher checked-in with participants about their experience and the impact of participating. Where appropriate information leaflets and signposting to relevant supportive services was offered.

Data Analysis

Interview transcripts were analysed according to the method of IPA described by Smith, Flowers and Larkin (2009) (see Appendix H for sample transcript). Each transcript was examined in detail, which involved reading, re-reading and making initial notes through a process of free association. The next stage involved looking for emergent themes. Connections between themes were then mapped, by writing all of the emergent themes into a list, eyeballing the list and arranging themes to form clusters of related superordinate themes. Once this process was completed, patterns were sought that occurred across cases, generating master themes (see Appendix I for photographs).

Quality Assurance

When undertaking qualitative research it is important that researchers identify their ‘vested interests, personal experience, cultural factors, assumptions, and hunches’ that could

influence how they view data and set these aside or ‘bracket’ them as much as is possible (Fischer, 2009, p. 583). To facilitate this, the researcher engaged in a number of reflexive practices, including being interviewed by a colleague (see Appendix K), keeping a diary (see Appendix L) and regular supervision.

During analysis of the data, the original transcripts were referred to repeatedly to ensure that developing themes were grounded in and relevant to participants’ experiences. In addition, two transcripts (28.57% of the data) were reviewed by supervisors to ensure that the themes produced were credible and warranted (Lincoln & Guba, 1985). The quality of this research was also assessed against Yardley’s criteria (2000) and an independent audit (Yin, 1989) was completed by a colleague not involved in the study. It was concluded that there was a clear, logical sequence leading to the development of themes and that the use of IPA and appreciation of the interactional nature of data collection demonstrated sensitivity to context. Furthermore, the care with which interviews and analysis was conducted demonstrated commitment and rigour. As final check of quality and trustworthiness, the researcher sought respondent validation from a care partner who had expressed interest in the analytic procedure. She reported that the themes captured her experience and that of others with similar experiences.

Results

This study aimed to explore the experience of dementia in the context of couple relationships. Eighteen superordinate themes emerged from analysis of the data, these were subsumed within five master themes: ‘foundations’, ‘altered structures’, ‘self-restoration’, ‘flexible scaffolding’, and ‘reflective capacity’. Each master theme is described and illustrated with quotes. Table I lists the superordinate themes subsumed under each of the master themes.

Table I. Superordinate themes relating to each master theme.

Master theme	Superordinate themes
Foundations	Commitment Togetherness History and quality of the relationship
Altered Structures	Changes to roles Oscillating reciprocity Determination for continuity Bonding over the problem
Self-Restoration	Loss of self Holding on to self Acceptance Focus on the present Humour
Flexible Scaffolding	Supporting partner's memory Maintaining partner's identity Recognising partner's remaining abilities Loss of partner
Reflective Capacity	Self awareness Awareness for other

Theme 1. Foundations

All of the couples spoke about the foundations upon which their relationships were built, encapsulating three superordinate themes: 'commitment', 'togetherness' and 'history and quality of the relationship'.

Couples spoke about their commitment to one another, as captured by Sue¹, who had been married to Mark for 45 years and Cyril, who had been married to Betty for 61 years:

I married Mark, in sickness and in health and now he's really sick, but it's for life. (Sue)

¹ All names given are pseudonyms

The most important thing..² is the love between us. I worship Betty and I know she worships me. (Cyril)

Betty's commitment to Cyril was based upon their friendship, mutual respect for each other and frequent communication. She saw being in love as something more transient and fluid:

The beauty of this is because we're friends. It isn't being in love because love changes. As the years go on your love goes in a different phase, each decade and ours we still respect each other, so we still chat like mad, don't we.

On the basis of their commitment to one another participants had developed a strong and seemingly unshakeable sense of togetherness, which provided them with a secure base, or foundation, upon which they were able to face multiple life experiences; including positive experiences, such as having children, but also times of adversity, including the experience of dementia. Betty said:

It is WE that is going through this. It isn't him-me.

Many couples in this study talked about the development of their relationship and recalled the story of when they first met. Despite their memory difficulties, PWD were often able to recall this or at least the emotional content related to it. The quality of the couples' relationship was also important, although this seemed to hold more significance for care partners than for PWD. Among all couples in this study the pre-morbid relationship was described as generally of high quality and care partners used this as justification for why they looked after their partner. For instance they spoke of owing it to their partner, as they had earned it by being a good provider or carer earlier in their marriage. For example Paul spoke about repaying his wife Lucy, for the care that she provided in the past:

She had a rough time with me, I had a serious accident..., so it's my turn to look after her.

² ...elision in quotation removed for clarity

Yes you were very poorly weren't you. (Lucy)

Well you looked after me so this is what it's all about isn't it. (Paul)

Kath reflected on a conversation with her son:

my son says to me, "remember, David has looked after you for twenty five years, now it's your turn to" and he says to me "don't be so impatient with him".

Unlike the other couples, Jim and Susan's relationship developed after Jim's memory difficulties began. Their relationship was based upon the same values as the other couples, which provided a foundation to enable them to face and manage the experience together. In fact Jim felt that their togetherness played an important role in identifying his difficulties:

lots of funny things happen and unless you've got someone close, like what Susan and I've got, close liaison, then you wouldn't pick it up.

Theme 2. Altered Structures

All participating couples reflected on how the structure and organisation of their relationship had altered and how some aspects of their relationships had weakened, whilst others were preserved or strengthened. Four superordinate themes: 'changes to roles', 'oscillating reciprocity', 'determination for continuity' and 'bonding over the problem', are subsumed within this master theme.

Couples spoke about how their roles had changed. This involved care partners taking up new roles and responsibilities, whilst PWD gave up certain roles. The two male care partners had taken on roles which they considered traditionally to be female. For example, Tom had taken responsibility for cooking, a role that had previously belonged to his wife:

We've changed complete roles. (Tom)

Yeah. I used to be the one that was in charge. Doing everything. (June)

June used to do all the cooking. Now I do all the cooking. (Tom)

Female care partners described how their role shifted from that of wife, to that of carer.

Lyn described the impact that this had upon her as a woman:

I'm still of the old fashioned type. I still like being a woman. Having doors opened for me and of course I don't get it any more. Where Bob always was very courteous and polite and always did.

Aspects of Lyn's marital relationship with Bob had been lost. The same was true for Kath who missed the security and support that her relationship with David had provided, leaving her feeling vulnerable:

I used to feel quite secure. But I don't any more. It's all in on me now. And I'm 80 you see, I'm getting on and sometimes I feel when things crop up, difficulties, problems, I just can't cope. And that's a horrible feeling.

Generally couples were reluctant to consider the aspects of their relationships that may have weakened, perhaps because to do so would threaten their sense of couplehood and be incompatible with their efforts to manage the impact of dementia. However, there was a sense that the degree of reciprocity had changed within couples' relationships. For example, Sue was determined not to let Mark's diagnosis of AD impact upon their relationship, but one aspect that had weakened was a sense of shared understanding and reciprocal conversation:

Have the memory difficulties had any impact upon your relationship? (R³)
Not on the relationship because I don't let it. But the bit that really gets me down is when we've had a bit of a laugh,... what gets to me is the fact of something will happen and then we have a laugh over it and then like ten minutes later I try and carry on the joke or conversation and he can't remember the conversation.

³ (R) represents the researcher's words

Kath shared this experience:

We just don't talk much now. I think the best talks we have are when we go to Marks and Spencer's cafe and have a cappuccino and then we sit facing one another and we chat. But mmm...not the same as we used to.

In this moment it seemed Kath's husband, David, was able to reciprocate and the couple connected through their sadness for the loss of this aspect of their relationship:

I don't have a solution to that really. I mean I wish there were but.

What's that like? (R)

Depressing really. (David)

Yeah. I feel that I've lost parts of him. (Kath)

Despite the ways in which their relationships had changed couples appeared determined for things to continue, as much as possible, as normal. As a result, certain aspects of their relationships appeared to be preserved or even strengthened. For example, Bob and Lyn spoke about bonding through the experience of dementia:

It's brought us closer together. (Bob)

Yes I think that it's brought us closer together. (Lyn)

I mean, in a natural husband and wife way. (Bob)

It seemed that as couples in this study found themselves faced with changes and losses, one way in which they managed was to become closer, to bond over the problem and to unite as a force against dementia.

Mark described how following his diagnosis, one thing that had altered for him and his wife, Sue, was talking together more:

I think we talk more. We discuss things and talk about things. Rather than try and bottle them up...our emotions, all this sort of thing. We talk more about it now because as I say we're getting older and you know if you don't talk about

your fears and what you see for the future, a serious one, then you have to
carry on, don't you...

It seemed that by sharing his existential anxieties, Mark felt closer to his wife at an emotional and psychological level, which further strengthened their relationship.

This theme describes how couples' relationships altered in several ways, including changes to roles and reciprocity, despite a determination for things to continue as they always had. There was also a sense of couples feeling closer and talking more.

Theme 3. Self-Restoration

This theme captures how PWD reflected upon their sense of self and how this had changed. They spoke about the aspects of themselves that had been lost, but also described a process of self-restoration, during which they managed the loss of aspects of their old self and tried to establish a new sense of self, which integrated their experience of dementia. Five superordinate themes: 'loss of self', 'holding on to self', 'acceptance', 'focus on the present', and 'humour' are subsumed within this theme.

In relation to loss of self, PWD spoke about their sense of agency and the positions of status and authority they had once held, describing what it was like to have lost these aspects of themselves. For example, David spoke of how the loss of his professional and social status left him feeling directionless:

I was in the Air Force for a long time. My time after I left the Air Force was very much the same kind of a life because...I had all these Air Force *connections. They are less and less tenuous these days. They're still there but not to the same strength. So I think the err, I'm more rudderless. I mean I knew which way I was going. Now I don't know where anything is.*

June described what it was like to lose her status, authority and ultimately, agency:

I get cross in the fact that I can't..., I want to do the things that I've always done, but he does for me now, but I want to do it...I mean really if you let yourself, you could let yourself go mmm..., you know as a person. I always used to be in charge of what we was doing and everything...and people used to come and ask me what they had to do. And I found it rather difficult to find that I couldn't do it now. Really you know, I thought it's terrible. You could get yourself quite sad really, just thinking what you used to be and what you can't be.

Some PWD feared that their entire identity would be lost to dementia. This was captured by Mark:

I always did have this err...nightmare, shall we say, umm that I would forgot who I was, where I was and you know, if I went out on my own, I got this paranoia about you know, forgetting. Suddenly, suddenly like you've turned the lights out.

In all cases, in this study PWD appeared to acknowledge, and to a degree, accept that they had lost aspects of their sense of self. They appeared to manage this experience by actively engaging in a process of restoring their sense of personhood. This process was based upon a powerful determination to hold on to what remained of their sense of self, whilst also integrating their experience of dementia. David spoke about his experience of coming to accept his losses:

I think it's difficult for me to accept the fact that I don't have the err...the facilities I had before. I mean I don't find life as easy... And that annoys me in one way and I accept it in another. It's err...it's difficult...The fact is I have to make allowances for it.

At a multi-agency meeting about dementia, Jim was able to hold on to his sense of self and demonstrate his agency by speaking out, whilst also being able to integrate his experience of AD:

No-one was saying a word, but I was quite prepared to stand up andI was thinking no-one's doing anything here...*they're not saying anything. And I* stood up and said something which I thought was quite admirable. [laughs].
But I did. A change that I could answer back.

In this study PWD tended to focus on the present and use humour to aid this process of self-restoration. Lucy who appeared the most cognitively impaired of all the participants, relied heavily on both of these strategies to preserve her sense of self:

well I just live for today...I just think, well you know we can put it right, *tomorrow's another day, so that's my...that's how I live...As I say I only know today at the moment. I don't know what's going to happen tomorrow. I haven't a clue...I don't get down about it... I don't worry about it. I just think, well...laugh it off...I can laugh at anything and anybody. And mmm I think that's my saviour actually, cos otherwise I'd perhaps worry...*

Theme 4. Flexible Scaffolding

Care partners in this study provided a supportive framework within which PWD were supported through the process of self-restoration and helped to hold on to a sense of their self. This has been conceptualised by the researcher as 'flexible scaffolding', as care partners adapted the level and nature of the support they provided, to reflect the fluctuating abilities and deteriorating functioning of the person with dementia. Four superordinate themes: 'supporting partner's memory', 'maintaining partners' identity', 'recognising partners' remaining abilities' and 'loss of partner', are subsumed within this theme.

Betty described how she provided scaffolding to support Cyril's memory:

I'm kind of a teacher now,...if he forgets a name or forgets something, I go to him remember your vowels, A-E-I-O-U or remember your alphabet. So I'll probably give Cyril a clue. He'll go is it B? And I'll go no, it's the end of the alphabet. Then he'll try that. I'll say no try the middle. So in a way, I'm making him remember...

When supporting Cyril with personal care, Betty aimed to promote his dignity, independence and self-esteem; working in a way that maintained Cyril's identity and personhood:

he's becoming slightly incontinent now, and I want him to keep his dignity, so I had a bidet put in upstairs...What I do with Cyril now, because I don't want him to lose his dignity, because I'm not giving in to it (dementia), I lay his things out on the bed, so when he's had the shower he goes upstairs, so there's his socks with his underpants on top, then his shirt, then his trousers, then his belt and then his pullover. That's it. I leave him...I think that's good for his brain and for his dignity.

Maintaining the identity of the person with dementia was a primary concern for care partners. Susan described how she supported Jim to adjust to the loss of his identity as a tailor and a driver whilst also protecting his self-esteem by keeping objects, such as his cloth, sewing machine and car, as concrete reminders of his identity:

I think it took a long time for him to realise that he wasn't going to do it (work) anymore. In fact he's still got a lot of cloth in there, still got his machine...They're big heavy things...and they are still there. You can see the car is still outside, yeah?you can't just say "that's it its finished" because you've got to have like a straw to hang on to, to say "well I might be alright, I

might do it, I might drive again or....” And I think it would be very cruel to take everything away,... So..m.mm...we sort of ease in to it slowly...

Tom described how he maintained June’s identity and self-esteem by sustaining her physical appearance:

I have to get all her bling out, when she’s going anywhere and tell her what day it is. She goes to the hairdressers every Friday. I take her down the hairdressers...

Care partners tended to recognise and promote PWD’s remaining abilities, enabling their continued involvement in couple life. For example, with some scaffolding, in the form of written prompts, Mark described how he was able to contribute to the running of their household:

She puts it (laundry) in piles and writes on a bit of paper the number I’ve got to set the washing machine on and I do it. And when it’s done I put it in the tumble dryer with the tissues and ...so long as she gives me a clue and I’ll do it. I couldn’t do it without getting the information.

Similarly, Susan recognised Jim’s remaining abilities and the importance of maintaining his involvement, even if he made a mess.

but you still do it (directed to Jim). I think that’s the most important thing. If, he will say “shall I make you a cup of tea?”, now I know if I go out there there’ll probably be tea spilt... in front of the washing machine or wherever. It doesn’t matter, because it’s just tea...I get up early in the morning and I’ll just clean it. What does it matter?

Susan’s flexibility meant that she provided Jim with the support that was most helpful for him at the time that he needed it.

There was a sense that care partners felt that they were losing the person with dementia and that without their support the person with dementia would be very vulnerable and might fall apart:

Luckily enough he's got me behind him. I dread to think what some people, who haven't got a me behind him or her, how they get on with all these things, cos it is really difficult. (Sue)

I keep him going. (Kath)

I couldn't bear to think of him on his own. (Susan)

Care partners promoted the personhood of PWD by supporting their memory, protecting their self-esteem, recognising their remaining abilities and maintaining their involvement. This supported PWD to adjust to the losses they experienced and helped care partners to manage their experience of losing their partner, whilst also sustaining a sense of their relationship, or couplehood.

Theme 5. Reflective Capacity

Two superordinate themes: 'self awareness' and 'awareness for other' are encapsulated by this master theme which describes how the PWD who participated in this study demonstrated a capacity to reflect upon their personal experience and that of their partner.

Mark spoke about his experience of short term memory difficulties, what this meant for him and how he tried to cope:

There's no rule of thumb, what actually happens, with the memory. Sometimes you can, it's all ok, and then other times I can walk from here to there and forgot what's happened. Usually when I go back to the beginning I remember what I went in there for... It's very frustrating. Very frustrating...It's like being

like Jekyll and Hyde. There's two of me. The good one and the bad one. But sometimes the bad one don't always come out, you know as good as he should be...it is worrying sometimes. Because the more you think about it the worse it gets. So I try not to think about it.

His description of himself as *'like Jekyll and Hyde'* illustrates his struggle with his identity; Mark experiences himself as either good (without AD) or bad (with AD). He seems to be grappling with the process of establishing a new identity which integrates AD. Although he is clearly able to reflect upon this, thinking about it is so anxiety provoking that he prefers not to.

David also described his grapple with adjusting his identity to integrate the experience of dementia. Throughout his life David had held positions of authority, status and power, and so when he was diagnosed with dementia and positioned as a patient or sufferer he found that this did not correspond with his own sense of himself:

I find it very difficult, not to...I mean, I can sympathise with them, that's fine. But err....I don't want their sympathy. I don't know how to do...how to handle that. It's foreign to me that.

This was substantiated by his wife's description of him as *'a fish out of water'*.

The finding that PWD were able to reflect upon their personal experience is an important one, as it challenges assumptions and preconceptions. However, the extent to which individuals had this capacity varied and in some instances appeared to fluctuate during the interview. Usually this related to PWD's perceptions of their remaining abilities. For example Bob claimed to: *'still do a lot a gardening'*, however, his wife, Lyn said: *'Oh darling you might think you do, but you don't really.'* It seemed that Lyn had exposed Bob's deficits, leaving him feeling embarrassed and ashamed, which led to him momentarily leaving the room. In the interviews it was often unclear whether the person with dementia

could not remember how their skills had changed or whether they were actively trying to portray a picture of themselves as more able than they knew they were, possibly to preserve self-esteem.

In most cases PWD demonstrated an ability to reflect upon and empathise with their partners' experience. June, who had been diagnosed with AD nine years ago, was able to imagine something of her husband's experience at a psychological and emotional level, and empathise and offer him reassurance:

He, he looks after me and I think sometimes it's a bit sad for him...

Well, really I think that sometimes he gets a bit worried and if he gets worried about things I'll say "yeah that's fine, fine", just so that he doesn't worry about me so much.

This captures, how despite nine years with AD, June has the capacity to 'mentalize'; she was able to think about others' feelings and envisage mental states in others (Allen, Fonagy & Bateman, 2008). This ability meant that June was able to respond sensitively to Tom's needs, which left him feeling supported and cared for:

She looks out for me...If I'm feeling a bit funny she'll come and give me a cuddle... (Tom)

David also demonstrated some capacity to mentalize; he was able to reflect upon his own mental state and envisage the mental state of his wife:

This is intensely irritating to Kath, as you can imagine, because she knows that I've done something, but I've forgotten I've done it...I imagine that it err, annoys Kath intensely. I, I, I don't remember some of the simple things that have just happened. It's crazy...It must annoy her.

On many occasions throughout the interviews PWD let their care partners know that they were doing a good job. When Tom said:

“June has a job doing her hair and I try to do it sometimes, which *I can't, I'm* hopeless at it”

June stated:

“I like him doing my hair...*You know cos it's something [gestures brushing her hair] and he's holding me*”

Similarly, when Susan doubted her ability as a care partner, Jim reassured her that she was doing a good job:

Sometimes I say “I can't get inside your head at the moment”, cos I can't work out what it is he's trying to explain to me. Mmm...(Susan)

But you know my problem and you can talk, it clicks to you quickly, so you can...you know. (Jim)

When Lucy's husband, Paul, briefly left the room she said:

I must just say, while he's not here, that he is absolutely fantastic...Absolutely. Anything that needs doing, anything...We never get upset or anything like that and he's really, he really is a marvellous person.

Discussion

These five master themes are connected and depict the experience of dementia as constructed from a relational perspective, involving both PWD and their care partners. In particular, the themes describe the conditions and processes that enable couples to adjust to the experience of dementia. Findings are supported and illuminated by existing research and theoretical literature.

Central to couples' experiences were their reflections on the foundations upon which their relationships had been built, in particular, their commitment to one another. This is supported by the findings of Daniels et al., (2007) and Davies (2011) and seems to link with

Bowlby's (1969) concept of a 'secure base'. Bowlby proposed that early infant-parent attachment relationships provided a secure base from which infants could explore the world and when necessary (e.g. when threatened and in need of protection) retreat to. Similarly, the couple relationship provided a secure base, from which couples could face the experience of dementia together and also retreat to when their existence as a couple was threatened.

The quality of the relationship also influenced couples' experiences of dementia. Participants' perceptions of their relationship were generally positive and appeared to have a positive influence on adjustment. When care partners felt that the person with dementia had previously invested in them in some way, there was a sense that they wanted to repay them. This has previously been linked to models of equity and investment and to the notion of *quid pro quo* (Baikie, 2002; LoboPrabhu et al., 2005; Braun, 2009) but this experience is unlikely to be the case for all couples.

With the exception of the theme 'foundations', all other themes are underpinned by a sense of movement, or oscillation, between different positions. Most notably, participants moved between the position of acknowledging and letting go of what had been lost and the position of recognising and holding on to what remained, both for the person with dementia and for the couple. This resonates closely with the work of Robinson et al., (2005), who drew parallels between these oscillating processes and dual process models of loss, in which people adjust to loss by moving between loss-orientated positions and restoration-orientated positions (Stroebe & Schut, 1999).

This experience was captured by the theme 'self-restoration', which describes how PWD oscillated between the position of reflecting upon what aspects of themselves they had lost and holding on to what remained. Through this process they were able to come to terms with and accept losses and integrate dementia into their sense of self, whilst also maintaining their sense of self-esteem and 'personhood' (Kitwood, 1997).

The same oscillating processes occurred in relation to the couple relationship. The theme 'altered structures' describes how couples moved between acknowledging what had been lost, and focusing upon what had remained the same, or had strengthened within their relationship. This process enabled them to adjust to losses whilst also holding on to their sense of couple identity, or 'couplehood' (Hellstrom et al., 2005).

The theme 'flexible scaffolding' describes the support that care partners provided throughout the ongoing process of adjustment. This theme is also underpinned by a sense of movement or oscillation, as the level and nature of the support provided varied depending upon the fluctuating ability and functioning of the person with dementia. At whatever level it was provided, the purpose of the scaffolding was to promote the self-esteem of person with dementia, maintain their involvement and sustain their sense of personhood, as well as the couple's sense of couplehood. This theme relates directly to the work of Keady (1999) and Hellstrom et al., (2005; 2007) who found that care partners were motivated to promote the sense of personhood of the person with dementia and sustain their sense of couplehood. In the present study, couples appeared on the surface to be sharing this task; however, on several occasions care partners indicated that they were increasingly working alone, but did not want to discuss this in front of their partner.

The title of the theme, 'flexible scaffolding', draws directly from theories of learning and the concept of 'zone of proximal development' (ZPD), which Vygotsky (1978) defined as 'the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult supervision or in collaboration with more capable peers' (p.86). The idea that an individual could achieve more when collaborating with others was applied on a daily basis by care partners who identified what their partners' potential could be with their support, rather than dwelling upon their partners' limitations and deficits. Sabat (2001)

proposed that by attending to and supporting remaining abilities, care partners decrease the likelihood of engaging in forms of ‘malignant social psychology’ (Kitwood, 1997, p.46).

The theme, ‘reflective capacity’, has not emerged within previous studies of couples’ experiences and so can be described as a new finding in this context. Not only were PWD able to reflect upon their own personal experience and provide an account of what it means to be a person with dementia, but in many cases PWD were also able to reflect upon their partners’ experience, demonstrating an ability to ‘mentalize’ (Allen, Fonagy & Bateman, 2008). This finding is supported by Sabat (2001) who found, through case studies, that some PWD demonstrated concern for the needs of others, which he described as a highly valued and highly complex form of cognitive ability. Such findings challenge assumptions about PWD and as such are worthy of further investigation.

Critique of the Study

To explore the experience of dementia in the context of couple relationships, from a dyadic perspective, PWD and care partners were interviewed together. This allowed for a relational understanding as co-constructed by the couple to be developed. However, a disadvantage of this methodology is that the dynamics of couples’ interpersonal relationships were likely to have influenced what each partner felt able to talk about in front of the other.

The relationship between the couple and the researcher may have also influenced what was talked about. For example, although intimacy, including sexual and physical intimacy, has emerged as a theme in the existing literature, this was something couples did not talk about. This may have been because it is by nature a difficult and personal thing to talk about, especially in the context of a research project.

Another limitation of the study is that the sample could be considered biased. Couples who felt that they were coping well with the experience of dementia may have been more

likely to volunteer to participate in this study than couples who felt they were struggling. Also, couples who perceived their relationship to be of good quality might have been more likely to participate than couples who perceived problems in their relationship. Couples may have also felt a pressure to position themselves in a certain way, for example as coping well, and this will have influenced the data.

Whilst IPA does not aim for generalisability, it does aim for some degree of transferability (Lincoln & Guba, 1985). In this study, any transferability of findings may be limited since the participants were all white British and their experiences may differ from those of people from other ethnic and cultural groups. Similarly, participants were all heterosexual and with the exception of one couple, married, and therefore their experiences may differ from people in different couple relationships (e.g. same sex or unmarried). These factors need to be considered in future research. Further consideration could also be given to diagnosis and stage of dementia.

Clinical Implications

The findings of this study do not suggest a need for radical changes to service provision. However, they do highlight a number of ways in which health and social care services and those provided by the charitable sector, could be altered to better meet the needs of couples affected by dementia. Importantly no extra cost would be required, but instead a change of orientation, focus and values across services.

Firstly, the findings highlight a need for clinicians and others in the field of dementia care, such as support workers, to consider the importance and influence of the couple relationship. The tendency to ‘forget that there is a real living couple behind the disease’ (Daniels, Lamson & Hodgson, 2007; p. 162) needs to be addressed.

Given the importance of the foundations of couples' relationships and the potential for these to influence the experience of dementia, services may want to explore this with couples throughout the process of diagnosis and beyond, perhaps assessing for risk factors (e.g. negative experience of pre-morbid relationship) but also for protective factors. Services could possibly consider interventions that focus upon the attachment relationship and promote feelings of closeness, bonding and reciprocity.

Secondly, the findings suggest that the process of adjustment for couples affected by dementia involves oscillation between loss-orientated and restoration-orientated positions. This is worthy of further consideration as many older people's services tend to focus upon the assessment and identification of deficits, limitations and losses and rarely enquire about remaining strengths, abilities or even potential gains. By being entirely loss-orientated, services risk engaging in forms of malignant social psychology, stripping a person with dementia of their personhood and increasing excess disability.

The findings of this study suggest that, when appropriate, restoration-orientated practices would be welcomed and conducive to the ongoing process of adjustment. Interventions, such as solution-focused approaches and those that focus upon fostering resilience, may help couples to maintain the involvement of the person with dementia, sustain their sense of personhood and the couples' sense of couplehood.

Conclusion

This study aimed to explore the experience of dementia in the context of couple relationships and to do so from a relational perspective. This study also aimed to give voice to PWD in order to readdress the dominance of care partners' perspectives in the literature. Five master themes emerged from couples' accounts of their experiences. These themes describe the ways in which couples construct their experiences of dementia and in particular

the processes involved in adjusting to this experience. The results of this study complement some of the existing literature in this area, particularly that which has suggested that dual process models of loss may be helpful in understanding the experience of dementia, and literature which has identified ways in which couples seek to maintain involvement of the person with dementia, sustain their sense of personhood and the couple's sense of couplehood. A new and important finding was the recognition that PWD were able to reflect upon their personal experience and that of their partner, demonstrating an ability to mentalize. This appeared to play a role in sustaining the couple relationship and is worthy of further investigation.

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SECTION C

Critical Appraisal

In this section the study described above is critically appraised and the process of having carried out the study and what has been learnt from this is reflected upon.

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

The skills that have been most important, and determined the success of this project, relate to my ability to develop positive relationships with Alzheimer's Society branch managers. It was through these individuals that I made contact with people with dementia (PWD) and their care partners. Cresswell (1998) discusses this in terms of 'gatekeepers' who provide an 'entrance to the research site'. As I was reliant upon these gatekeepers' co-operation, I put a lot of effort into establishing relationships with them. I remained in regular contact, either over the telephone or via email, and attended numerous events, including various support and activity groups. Attending these events also gave me opportunity to interact with PWD and their care partners, or adult children, which was invaluable.

Many of the gatekeepers I contacted felt protective of the people that they worked with and I felt that it was down to me to demonstrate my trustworthiness and genuineness. One way in which I did this was to share with them my commitment to developing a better understanding of the experience of dementia and the value I placed on the hearing the perspective of PWD and their families.

Throughout the process of carrying out this project I learnt a lot about interacting and developing relationships with PWD, and in particular specific skills relating to research with PWD. I learnt that it was important to be sensitive and to actively listen and think about the

intention behind what was being said by PWD. I also needed to be patient and to try to mirror the pace of the person with dementia. I would like to develop these skills further, in order to be able to carry out more research with people who are often excluded, due to communication difficulties.

Although I have previously been involved in interviewing individuals, I had never interviewed couples together before. Doing so presented a number of challenges, such as ensuring that one person did not take over, or subjugate the other, and I also had to be aware of the impact of what one person was saying on the other. I would like to develop my interviewing skills further, in particular in relation to interviewing dyads, or small groups.

In addition to building relationships with gatekeepers and research participants, the success of this project also depended upon my ability to establish relationships with supervisors and trainee psychologist colleagues. One of the things that I have sometimes struggled with is a lack of confidence in my ability to express myself coherently. However, carrying out this study provided me with plenty of opportunities to practice this skill and as a result I feel more confident about my ability to communicate effectively with others.

If you were able to do this project again, what would you do differently and why?

I chose to use interpretative phenomenological analysis (IPA: Smith, Jarman & Osborn, 1999) to analyse interview data. Whilst this method does not aim for generalisability, it does aim for some degree of transferability (Lincoln & Guba, 1985). However, the transferability of the study's findings is likely to be limited, due to the characteristics of the sample, in particular the gender and ethnicity of participants. Therefore if I was to do this study again, I would consider ways of improving transferability, perhaps by recruiting a larger number of participants, with an equal number of men and women with dementia. I also

believe that the transferability of findings would be improved if I had focused upon just one type of dementia, such as Alzheimer's disease, which is the most common form.

If I was to do this project again, I would consider having an additional meeting with couples prior to conducting the interviews, in order to re-introduce myself and the purpose and nature of my research. In most cases my initial meeting with potential participants took place within the context of a larger group and often many weeks or even months before interviews took place, therefore PWD tended to forget who I was by the time I met with them to conduct the interview and it took a while to re-establish the connections I had initially made. If I had met with couples an additional time, they may have felt more familiar and comfortable with me, which may have impacted upon the richness of the data.

I would also consider adapting the methodology of the study to include the addition of observational data. Nygard (2006) has suggested that the combination of interviews and observations is a particularly effective method for studying the experience of PWD. Furthermore, in this study, the use of observational methods would have helped to capture the dyadic interaction and communication patterns between PWD and their care partners (Braun et al., 2009).

If I was to do this study again I would consider video recording the couple throughout the interview and integrating my observations with the data obtained via the interview. Alternatively, I would perhaps consider employing an approach similar to that adopted by Clare and Shakespeare (2004), who used voice-relational analytic methods, to investigate conversational interactions between people with early-stage dementia and their spouses. The voice-relational method was developed by Brown and Gilligan (1993) to provide a means through which the voice of people they described as 'not represented as full human beings within the dominant system' (p.17) may be heard. This complements the current study's aim

to give voice to PWD, who are often accorded 'less-than-full membership' status (Clare & Shakespeare, 2004, p.213).

Finally, if I was to do this project again I would consider how I could link up with the wider research community and possibly collaborate with others. Given that funding for research in the field of dementia has recently doubled (Department of Health, 2012), there are a number of larger scale research projects currently ongoing, including pharmacological trials. Whilst this is of course positive, I do believe that this made it difficult to recruit participants to my study, as many of the gatekeepers I contacted reported that they were helping to recruit to these larger studies, which they felt had more value and potential for impact.

Clinically, as a consequence of doing this study, would you do anything differently and why?

My approach to my clinical work has been influenced enormously by doing this study. Firstly, I give more consideration to relationships; no matter what client group I am working with, I enquire about the importance of different relationships to clients and how the presenting problem may impact upon relationships, but also how relationships may influence the presenting problem.

Secondly, I have noticed how the dominant discourse in the field of mental health, particularly older people's mental health and dementia, is often focused upon the presenting problem and associated deficits, limitations and losses. The findings of my study suggest that this may not always be most helpful and may not be the approach preferred by clients.

Although the couples who participated in my study reflected upon the problem and the losses they experienced, they did not dwell, ruminate or become fixated upon their difficulties rather they tended to accept them and actively try to find ways of managing and

develop coping strategies. For me this highlighted the role and necessity of both ‘loss-orientated’ and ‘restoration-orientated’ processes in relation to adjustment and coping (Stroebe, Schut & Stroebe, 1998). Therefore, in addition to talking to clients about their presenting problems and difficulties, I also enquire about the things that may be going well for them, their strengths and abilities, and seek to promote each individual’s sense of ‘personhood’ (Kitwood, 1997), or if I am working with a couple, their sense of ‘couplehood’ (Hellstrom, Nolan & Lundh, 2005; 2007) or if I am working with a family, their family identity.

As a consequence of what I have learnt from carrying out this study, I also aim for the clinical work that I undertake to help foster people’s sense of resilience. During my study I was struck by both PWD and care partners’ abilities to withstand and rebound from the major challenges that dementia presented and by their strength and resourcefulness. Subsequently, I have found it useful to draw upon the work of John Rolland (1994), to help me think about how I can facilitate the development of resilience in individuals, couples and families. One approach that Rolland advocates is networking with others who are in a similar position, or participating in multi-family discussion groups. I often discuss these approaches with clients and in my current clinical work, with families with children with moderate to severe learning disabilities, I have facilitated families to join networks and support groups.

I believe that the focus, with which I now approach my clinical work, is well-matched to systemic approaches and in particular narrative and solution-focused ways of working. I am also interested in community approaches and in particular how the community can be a resource for people facing difficulties, particularly chronic illness and disability.

If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

I would like to continue researching this area and expand upon relational approaches to understanding the experience of dementia. Initially, I would like to explore whether the findings of the current study relate to the experience of other couples and would seek to do this through a mixed methods study, using both interviews and questionnaires.

In particular, I would like to investigate whether the finding that PWD demonstrated an ability to ‘mentalize’ (Allen, Fonagy & Bateman, 2008) extends to other PWD and the impact of this upon couple relationships. Questionnaires which aim to measure mentalizing capacity, such as measures of awareness, empathy and reflective functioning could be used and data from these correlated with data from questionnaires relating to aspects of couple relationships, such as intimacy and quality. However, it is likely that some PWD may struggle to complete questionnaires. It is also likely that the ability to mentalize will depend on the type and severity of dementia, which is something that could be explored in future research projects.

I would also be interested in exploring the ways in which dementia impacts other significant relationships and vice versa, including the parent and child relationship. A specific area of interest I would like to explore would be the impact of young onset dementia upon families, specifically children. Young onset dementia can affect people as young as their forties and presents individuals and families with a number of challenges and difficulties that are different to those faced by older people. For example, a younger person with dementia may have dependent children, be in work at the time of the diagnosis, have heavy financial commitments (like a mortgage), may have a rarer form of dementia and may find it difficult to access appropriate support (Alzheimer’s Society, 2012). As far as I am aware there is no

current research in this area and therefore I would initially take an exploratory approach, similar to that of this study (i.e. interpretative phenomenological analysis).

Ultimately, I would like any further research that I do, to lead to the development of better services and useful interventions and would enjoy the opportunity to carry out service evaluation or improvement projects, or to evaluate the effectiveness of interventions as they are developed in the future.

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Section C: Critical Appraisal

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Appendix A: Literature Search Methodology

Three electronic databases (PsycINFO, OvidMEDLINE and Web of Science) were systematically searched for articles that explore the experience of dementia in the context of couple relationships.

The term ‘dementia’ and related terms, such as ‘Alzheimer’s Disease’ and ‘cognitive impairment’ were searched for and combined with the terms ‘couple relationship’, ‘marital relationship’, ‘spousal relationship’, and other related terms, including ‘couples’ and ‘dyads’. The search strategy included both the mapping and exploding of terms.

The reference lists of each relevant search result were examined in order to identify any literature that was not located in the first step of the search.

In addition the researcher arranged to receive regular notification of newly published articles in order to keep up-to-date with the literature.

Articles were included in this review if they were considered relevant to its scope and were written in English. No other specific exclusion criteria were used.

Additional publications, including empirical papers, review papers and book chapters were used to gather background information and information relating to theoretical frameworks and are referenced where relevant.

Appendix B: Literature Search Results

	Author	Participants	Method	Focus of article
1	Hayes, Boylstein & Zimmerman (2009)	Spousal caregivers	Interviews with 28 spousal caregivers	Caregivers' perceptions of changes in the identity of their spouse and themselves and the influence of this upon intimate relations
2	Wright (1991)	Spousal dyads	30 spousal dyads affected by Alzheimer's Disease were compared to 17 "healthy" spousal dyads on a range of measures	Spousal dyads perceptions of marital quality and of coping
3	Wright (1998)	Spousal dyads	As above	Spousal dyads experiences of affection and sexuality in relation to the trajectory of Alzheimer' Disease
4	Elonieme-Sulkava, Notkola, Hamalainen et al. (2002)	Spousal caregivers	Semi-structured telephone interviews with 42 spousal caregivers	Caregivers' perceptions of changes to their marital relationship, particularly quality and sexuality
5	Duffy (1995)	Spousal caregivers	Interviews with 38 spousal caregivers	Caregivers' perceptions of changes in sexual behaviour
6	Baikie (2002)	-	Discussion paper	The impact of dementia upon marital relationships
7	O'Shaughnessy, Lee & Lintern (2010)	Spousal caregivers	Interviews with 7 spousal caregivers	Caregivers' experiences of changes in the couple relationship
8	Robinson, Clare & Evans (2005)	Spousal dyads	Interviews with 9 spousal dyads	Spousal dyads psychological reactions to receiving a diagnosis of dementia
9	LoboPrabhu, Molinari, Arlinghaus et al. (2005)	-	Literature review	Aspects of spousal caregiving and value systems that enable spouses to care give
10	O'Rouke, Claxton, Kuperschmidt et al. (2010)	Spousal caregivers	90 spousal caregivers completed a range of measures	Marital idealization among spousal caregivers
11	Hellstrom, Nolan & Lundh (2005)	Spousal dyad	Single case study	Illustration of one couples experience of dementia

12	Hellstrom, Nolan & Lundh (2007)	Spousal dyads	Interviews with 20 spousal dyads	Strategies that couples use in order to live positively with dementia
13	Sanders & Power (2009)	Spousal caregivers - husbands	Interviews with 17 husbands caring for their wives with dementia and other chronic conditions	Spousal caregivers perceptions of changes to their roles, responsibilities and relationships
14	Daniels, Lamson & Hodgson (2007)	Spousal dyad	Single case study	Exploration of one couples' marital relationship
15	Davies & Gregory (2007)	-	Discussion paper	Marriage biographies in the context of dementia
16	Prakke (2011)	-	Literature review	Couples experiences when one person has early cognitive problems
17	Davies (2011)	Spousal dyads	Mixed-methods: 6 couples were interviewed and completed	Spousal dyads experiences of the meaning of commitment in the context of dementia measures
18	Keady (1999)	Spousal caregivers and spousal dyads	Interviews with spousal caregivers and 11 couples	Experience of dementia from both the caregiver's and PWD's perspective
19	Braun, Scholz, Bailey, Perren, Hornung & Martin (2009)	-	Literature review	How the dyadic perspective is taken into account and how dementia effects both parts of the dyad

Appendix C: Participant Information Sheet and Consent Form

Information Sheet

What are couples' experiences of memory difficulties? How do memory difficulties impact upon couple relationships?

Thank you for taking the time to consider participating in this research. Before you decide whether or not to take part it is important that you understand why the research is being done and what it would involve. Please take time to read the following information and feel free to discuss it with your family or friends. Please contact me if you have any questions or would like any further information. You can contact me by writing to Kim Merrick, Trainee Clinical Psychologist, Salomons Campus, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG; phoning me on 07737757883, or emailing me at k.r.merrick11@canterbury.ac.uk

1. What is the purpose of this research?

My name is Kim Merrick and I am a Trainee Clinical Psychologist. I am completing this research project as part of my Doctorate at Canterbury Christ Church University. The research aims to investigate couples' experiences, when one person in the couple has memory difficulties. The research also aims to investigate how memory difficulties impact upon people's personal relationships. It is hoped that the findings of this research will give services a greater understanding of the experiences of couples and be useful in planning services and support for couples.

2. What does the research involve?

If you and your partner decide to take part, the research involves meeting with me together for a one time interview. The interview will take place somewhere that is convenient for you, and can be at your home if you'd prefer. I will ask you and your partner questions about your experiences and of how memory difficulties have impacted upon your relationship. The length of the interview will depend upon you, but is likely to be between 60 and 90 minutes. I will audio record the interview.

3. Do you have to take part in this research?

No, it is your choice whether or not to take part in this research and your choice will be fully respected. You can withdraw from the research at any time, without giving a reason. Your decision will in no way affect the services that you and your partner receive now or in the future.

4. If you want to take part what do you do?

If you and your partner decide to take part please complete the enclosed Consent Form and return it to me, either in person, or by using the stamped addressed envelope enclosed. I will then contact you by telephone to arrange to meet with and interview you and your partner.

5. What happens to the information that you give?

All the information that you give during this research will be kept confidential. The audio recordings of the interviews will be stored securely and will be destroyed once the research is finished.

I will write a report as part of my training. This report may be published in a journal and disseminated to services that support people with memory difficulties. Your name will not be used in the report and I will remove any other information that may identify you and your partner. If you would like me to, I will share the findings of the research with you.

If you decide to withdraw from the study, any information that you have provided will be destroyed.

6. How might taking part in this study affect you?

For some people talking about how memory difficulties have impacted upon their relationship may be difficult and upsetting. At any time during the interview you can take a break and at the end of the interview I may discuss with you whether you have found it difficult and upsetting. I may talk to you about services which may be able to offer you and your partner support, such as the Alzheimer's Society and I may give you some information leaflets if you or your partner request this.

7. How do you contact the researcher?

If you have any further questions or would like more information, you can contact me by writing, phoning or emailing, using the details below. Alternatively, you can complete and return the reply slip below, using the stamped addressed envelope and I will contact you.

Thank you for taking the time to read this information.

Kim Merrick,
Trainee Clinical Psychologist,
Salomons Campus,
Canterbury Christ Church University,
Broomhill Road,
Tunbridge Wells,
Kent, TN3 0TG
07737757883
k.r.merrick11@canterbury.ac.uk

.....please tear off.....

What are couples' experiences of memory difficulties?

Titles: Mr/Mrs/Ms/Other.....(please deleted as appropriate)

Names:.....

We are interested in your research and would like some more information.
Please telephone us. Our contact telephone number is:.....

Consent Form

What are couples' experiences of memory difficulties? How do memory difficulties impact upon couple relationships?

Please read the statements below and if you are in agreement with them, please put a tick in each box. Then print your name and provide your signature and a contact telephone number overleaf. Each person within the couple should complete this form.

1. I have read, or have been read, the information sheet dated 23/02/2011 regarding the above study. I have had opportunity to consider the information, ask questions and have these answered satisfactorily by the researcher.

2. I understand that I am being asked to take part in an interview together with my partner and that the interview will be audio recorded.

3. I understand that my participation is voluntary and that I am free to withdraw from this study at any time, without giving a reason.

4. I understand that whatever my decision about taking part in this study, the services that either I or my partner receive now or in the future will not be affected in anyway.

5. I understand that the results from this research will be part of a formal submission to Canterbury Christ Church University for the researcher's doctorate degree and may also be included in a published article. Extracts from the interview will be included in these reports, however no information that could possibly identify me or my partner will be included in either report.

6. I give my consent to take part in the above study and to be contacted by the researcher.

Appendix D: Participant Information

Couple (PWD indicated *)	Tom & June*	Jim* & Susan	David* & Kath	Betty & Cyril*	Lucy* & Paul	Bob* & Lyn	Mark* & Sue
Ages	72 & 74	80 & 69	87 & 80	83 & 84	77 & 77	76 & 77	65 & 63
Diagnosis	AD	AD	Mixed – AD and vascular dementia	Fronto-temporal dementia	AD	Vascular dementia	AD
Approx time since diagnosis	9 years	5 years	2 years	4 years	4 years	Unknown	3 years
Details about relationship	Married for 53 years	Together for 5 years – not married	Married for 26 years – second marriage for both	Married for 61 years	Married for 56 years	Married for 52 years	Married for 45 years

Appendix E: Interview Schedule

Introduction

Outline that the purpose of meeting is for me to hear their experiences
Remind the couple that they do not have to answer any questions that they do not want to and that they can withdraw at anytime
Let the couple know that the length of the interview is up to them, although it is anticipated that it will last between 45-75 minutes and they can take breaks as and when needed
Invite the couple to ask any questions that they may have

Background Information

*Can I ask you both your date of birth?
And how long have you been together as a couple for?*

Diagnosis

I understand that one of you has some difficulties with things like memory. Is that right? Who?

What do you understand about these memory difficulties?

Prompts:

What have you both been told about these memory difficulties?

Have you been given a diagnosis?

What do you both understand about this diagnosis?

When did you first notice these memory difficulties? When did you receive this diagnosis?

Experience

Can you tell me about your experiences of living with these memory difficulties?

Prompts:

What is living with these memory difficulties like for you?

What it has been like for you as a couple since these memory difficulties began?

Impact

What impact, if any, has these memory difficulties had upon your relationship?

How have these experiences affected you as a couple?

Prompts:

Have you noticed any changes in your relationship? What have you noticed?

What are these changes like for you?

Have the things that you do as a couple changed? Can you tell me about that?

*Have there been any changes in the way that you communicate with each other? What is this like for you?
Has your relationship become closer/or perhaps more distant in any way? For example, do you spend more/less time together? Can you tell me about that and what this has been like for you?*

Making sense and responding

I would be interested in hearing a little bit about how you have managed these experiences.

Prompts:

*Can you describe how you may have done this as a couple?
Can you describe any adjustments that you might have made as a couple in response to your experiences?
What, if anything, has helped you to deal with your experiences?
Do you have particular ways of coping?*

Support

Can you tell me about your experiences of getting support as a couple?

Prompts:

*Do you have any support from family, friends, the Alzheimer's Society, or the NHS? What has this support been like?
In your experience, what support has been most/least helpful?
What additional support, if any, do you think would help you as a couple?
How/why would this be helpful?*

Ending and debrief

Let the couple know that's all of the questions I had.

Ask them if there anything else that I haven't asked about that they would like to tell me about?

Turn off the recording device.

Debrief the couple by checking in with them and asking about how they have found the process.

Let them know that I understand that it can be difficult and painful for people to talk about these very personal experiences, both individually and as a couple. Ask the couple how they have found talking about this.

Ask the couple if they have talked about anything today that they haven't shared before.

Ask the couple if the interview has raised any thoughts that they may find themselves worrying about.

If appropriate offer information leaflets and signpost to relevant services.

Thank the couple for taking part.

Appendix F: Ethics Approval

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Appendix G: Process Consent Pathway

Based upon Dewing's (2007) Process Method of Consent.

1. Background and preparation

- Seek permission to access the person with dementia from staff, relatives, or another named person
- Be transparent about my intentions to achieve process consent by including others who are of significance to the person with dementia
- Find something out about the biography of the person with dementia from others, such as how and when the person may be best approached

2. Establishing the basis for consent

- Speak to the person with dementia and others to establish the person's usual self-presentation; usual level of wellbeing; how a decrease in wellbeing can be recognised, for example verbal and non-verbal signs, are they able to tell me, what changes in body language would be observed; how the person usually consents/objects to other activities within their day-to-day life.

3. Initial consent

- Using written information, which may be adapted and simplified, or pictures and prompts (e.g. audio recording device)
- Make notes on the location, time, information given, questions and answers
- Critically reflect upon process

4. Ongoing consent monitoring

- Revisit consent by checking in with the person with dementia and their partner regularly during the interview
- Look for signs of wellbeing or any decrease in wellbeing (established during stage 2)
- If wellbeing decreases, ask the couple if they would like to have a break/stop the interview
- Discuss with couple whether the interview may be causing distress and harm, and if necessary end the interview

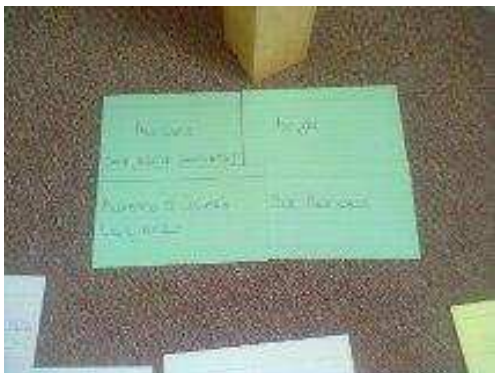
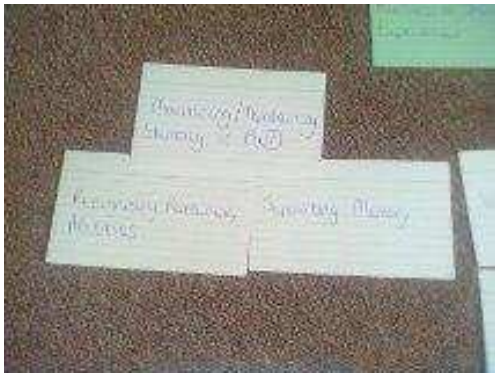
5. Feedback and support

- Debrief (as outlined in interview schedule)
- Critically reflect during the consent and interview process: Is this person consenting? Does this person have (informed) appreciation of their consent? Is any lack of objection genuine?"
- Use supervision as a forum to reflect upon my ability to engage with couples and consider decisions relating to consent. Analyse my decision making.

Appendix H: Example Interview Transcript

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Appendix I: Example Photographs of Analytic Process



Appendix J: Example of Quotes Relating to Master and Super-Ordinate Themes

Master Theme	Super-ordinate Themes	Example Quotes
Self-Restoration	Loss of self	<p data-bbox="1015 488 1385 633"><i>I'm more rudderless. I mean I knew which way I was going. Now I don't know where anything is. David</i></p> <p data-bbox="1015 674 1394 1032">I always did have this err...nightmare, shall we say, umm that I would forgot who I was, where I was and you know, if I went out on my own, I got this paranoia about you know, forgetting. Suddenly, suddenly like <i>you've turned the lights out.</i> Mark</p> <p data-bbox="1015 1077 1394 1659">I mean really if you let yourself, you could let yourself go mmm...[pause], you know as a person. I always used to be in charge of what we was doing and everything...and people used to come and ask me what they had to do. And I found it rather difficult to find that I <i>couldn't do it now. Really you know, I thought it's terrible. You could get yourself quite sad really, just thinking what you used to be and what you can't be.</i> June</p> <p data-bbox="1015 1704 1385 1839">It is very frightening though, <i>when you think you can't do things, when you've always done them.</i> June</p> <p data-bbox="1015 1883 1369 2024">when it goes <i>you're just stumbling for a second and your completely blank and it's gone.</i> Jim</p>

I said I did want to give it up.
Lucy

I was very glad that I'd finished when all this started to happen, because I wouldn't have been able to work, because I was a teacher. I couldn't do it.
Lucy

We don't surf now. I used to love surfing. Lucy

I've had to give up driving.
Bob

It's like being like Jekyll and Hyde. There's two of me. The good one and the bad one. But sometimes the bad one don't always come out. You know as good as he should be. But yeah...it is worrying sometimes. Because the more you think about it the worse it gets. So I try not to think about it. Mark

Holding on to self

I am the same. David

I try to get involved in those things which counteract reduced memory. Cyril

It was no great brain bashing to try to write anything and I can still do it. Cyril

I stood up and said something which I thought was quite admirable. [laughs]. But I did. A change that I could answer back. Jim

I like doing things. I like doing the garden. I like going out and I like going to where we go. Support groups. And I

talk to everybody and its fine.
Lucy

I make the bread. Lucy

I still do a lot a gardening.
Bob

I do all the lifting and
pushing and shoving and she
does all the...over there.
Mark

Acceptance

*I think it's difficult for me to
accept the fact that I don't
have the err...the facilities I
had before. I mean I don't
find life as easy. And Kath
has a lot more responsibility
then she did. And that annoys
me in one way and I accept it
in another. It's err...it's
difficult. David*

The fact is I have to make
allowances for it. David

I sort of got used to it. It
becomes part of you. Mark

When I first realised in
myself mmm... I did get
depressed and I did have a
bout where I used to burst
into tears for no reason, no
*reason at all. Mmm...that's
past now, that's gone.*
Mmm..., you know we all
have good days and we all
*bad days, but when you're
suffering with an illness it's
worse because, that illness is
stopping you doing what you
want to do. It hasn't really
stopped us doing what we
want to do. Mark*

I think because of my
condition it's acceptable.

Because now I've got to rely on Lyn for so much and err one way or another its...it doesn't hurt me mmm, but, I can't even put it into words really...Bob

Focus of the present

Well I just live for today, I *don't remember.* Lucy

I just think, well you know we *can put it right, tomorrow's another day, so that's my...that's how I live.* Lucy

As I say I only know today at *the moment. I don't know what's going to happen tomorrow. I haven't a clue.* Even if Paul told me. And I forget what happened the day before. So I only have today to really...laugh. Lucy

One day at a time. Mark

Humour

Oh we do have a laugh. We do have a good time. June

Because I can laugh you see. Lucy

But I don't get down about it. I don't worry about it. I just think, well...laugh it off. Lucy

I can laugh at anything and anybody. And mmm I think *that's my savour actually, cos otherwise I'd perhaps worry, I don't know. Even if it goes wrong I laugh.* June

Please note this list is not exhaustive and only a sample of quotes have been provided as way of an example

Appendix K: Example of Excerpts from Interview with Researcher

Some of my assumptions and how they might impact on my research:

I think that more women will volunteer to take part in my research, so it might be that there are more women care partners and men with dementia than the other way around.

Perhaps people with dementia may not be consciously aware of their diagnosis and I don't want to disclose someone's diagnosis to them. I think I'll ask people what they've been told about their memory difficulties. Or if they tell me their diagnosis I'll ask them what they know about that. I want to find out what they were told, or what they've read.

'Memory difficulties' are one symptom that really characterise what dementia is, although there are many others. Memory difficulties would be the symptom that most people would relate to.

I think that most people who participate will have Alzheimer's, because it's the most common form of dementia. I don't think that people with less common forms of dementia often get the right diagnosis. They are often misdiagnosed as having Alzheimer's. So Alzheimer's is often wrongly used as an umbrella term, or synonymously with dementia.

I was thinking that partners might be the first to notice difficulties. And that perhaps the person with dementia would be less aware.

I'm expecting to find that the couple relationship changes, from a relationship between a husband and wife, to carer and cared for. But I don't know what people will say this is like. I'm expecting intimacy to change and I'm expecting power and authority within the relationship to alter. New dynamics. But perhaps couples won't feel this way. I'll try and ask questions in an open way, for example, 'what changes, if any..'

I wonder if maybe there will be an impact on how the couple relate to others, such as friends, family, work colleagues and just members of the public.

Some of my experiences and how they might have influenced my decision to do this research:

I've been influenced by media portrayals of dementia, and I've heard people saying that it's worse than cancer. It's a disease characterised by lots of loss. Loss of memory, loss of skills, loss of the person. But I want to be open to other experiences, that might not be focused upon losses.

I think that the lens through which we view the experience of dementia will impact upon the way in which we interact with and support people with dementia.

I think I'd be worried about getting dementia, or family members having dementia.

I worked in a residential home for people with dementia for a few years. It was a very emotionally draining place to work. It was physically draining. It was really, really hard. I witnessed lots of practises which de-personalised people with dementia. So I guess I want to address this. I want to empower people with dementia and give them a voice.

Appendix L: Example of Excerpts from Research Diary

Spring 2010

Preliminary ideas

I've been thinking back to the research fair and in particular about Chris Gage who came to speak about The Ladder To The Moon, a theatre-based intervention which seeks to improve the quality of life for people with dementia (PWD) living in care homes, by modelling person-centred relationships and through training. Chris is looking for people to help with on-going research projects to evidence the effectiveness of the intervention. His presentation made me think back to when I worked in a care home for PWD and some of the practises that I witnessed which were anything but person-centred.

Meeting with others who are interested in research projects in dementia

A number of other trainee clinical psychologists are also interested in projects around dementia. So we met to think about our ideas. I am particularly interested in the relationship between PWD and those that care for them.

We heard that a different organisation has been commissioned to work with Chris Gage on The Ladder To The Moon project. I'm disappointed, as I was excited about the possibility of working as part of a larger research team and evaluating the effectiveness of this inspirational intervention. Nevertheless, I've decided to continue to pursue my interest in dementia and in particular to explore the relationships PWD have with others.

I met with a Clinical Psychologist, who works with older people, to discuss my initial ideas. Most PWD are cared for by their husband or wife. It's difficult to imagine what this must be like for both the person with dementia and their spouse. This Clinical Psychologist agreed to supervise me and directed me to some recent research completed by ex-trainees at Salomons.

Recent related research

I read a research project completed by Fiona Pipon-Young. Fiona carefully considered ethical issues related to research with PWD and used a process method of consent. I will look into this further, as I feel that it would be important to include PWD in my research.

Margaret O'Shaughnessy's research explores what it is like for spouses who are caring for PWD. Her research is very interesting and draws upon many theoretical models to understand the experience of spouse carers, but I am left wondering about the person with dementia, and how couples make sense of their experience of dementia jointly, as a couple. I've contacted Margaret and discussed my ideas for building upon her research. She agreed to supervise me.

Summer 2010

Reading about dementia

I've been looking in more depth at some the literature around dementia and in particular models of dementia, such as the biopsychosocial models, proposed by Kitwood (1007) and Sabat (2001). I am interested in how individuals can be positioned by others and how

expectations about an individual can impact upon their behaviour, skills and abilities, perhaps leading to excess disability. This makes me think about how I position PWD and how I want to interact with potential research participants.

I've come across a number of things to consider, or tips for interviewing PWD, including:

- Admitting if I don't understand what they are saying and working cooperatively.
- Inquiring about their intention, by rephrasing what I thought they said and asking if I got it right
- Speaking at a pace that mimics the pace of the person
- Having a non-anxious presence

I have also looked at some of the existing literature around the relationship between PWD and their partners. Very little of this includes PWD, so I've decided that my research should.

Meeting with a service user consultant

At Salomons we are lucky enough to have opportunity to meet with members of a Service User and Carer Group, who are willing to share some of their experiences and liaise with us about aspects of our training and work. I contacted Linda Riley, as I am aware that she is interested in and has some experience of dementia and we arranged to meet.

Linda shared with me her experience of when her mother got older and had dementia, although this was never formally diagnosed. I found this very useful and Linda helped me to think about some of the potential challenges that I may face during the course of my research. Linda has kindly said that she would be willing to meet with me again and consult with me about the development of written information relating to the project and my interview schedule.

Liaising with the Alzheimer's Society

I contacted local branches of the Alzheimer's Society to ask them whether they think my project is worthwhile and plausible. I'm concerned that it may be difficult to recruit people to participate in a research project which focuses upon relationships, as this is such a sensitive area. Of the five branches that I contacted three replied with a positive response, stating that they felt that my area of interest was important and that they knew of people who would be willing to take part.

Autumn 2010

Reading about methodologies

I've looked into different methodologies. I'm interested in phenomenology and interpretative phenomenological analysis (IPA), but I'm concerned about some of the potential limitations of this approach. For instance, it's reliance upon language as the means by which participants communicate their experiences, which is something the PWD may struggle with. I'm going to do some further reading regarding the suitability of this methodology.

Visits to the Alzheimer's Society

This Saturday I went to an Alzheimer's Society event, where about 40 people, mostly couples, were meeting for lunch. I spent time mingling and gave a short talk on my research. 6 couples approached me to say that they would be interested in taking part. I was really struck by what a good time everybody seemed to be having and how difficult it was to tell those with dementia apart from those without dementia.

On Monday evening I went to another Alzheimer's Society event. This time there were only 3 couples, plus one man and his daughter and a woman who came on her own (her husband had moved that day into residential care). It was interesting to observe the couples interacting. One woman kept moving her husband's teacup (he had dementia) without saying anything to him. Then when he went to find it where he had put it down it wasn't there. This must have been annoying and confusing for him. Another woman appeared very protective of her husband (he had dementia) and when I went to talk to him she told him to stay close to her and pulled him back. He later asked me to dance with him, which I did. His wife said that she was embarrassed of him. I thought that this was really sad. I realised that for some couples talking about their relationship might be very difficult and I will need to be very sensitive to this.

Winter 2010

Finalising the design of my project

Following supervision I have decided that I will interview couples together, as this will enable me to contribute to existing literature by offering a relational, dyadic perspective, and as I am interested in couples' experiences I have decided that IPA suits the aims of my project.

Reading on related empirical and theoretical literature

The reading that I have done has highlighted a number of theories that might provide a useful framework for understanding couples' experiences, including:

- Theories of loss, in particular dual process models and latent grief
- Theories relating to social context and identity in social contexts e.g. social identity theory
- Relationship dynamics in dementia, in particular Keady's (1999) model
- Attachment theory

Seeking ethical approval

I've applied for ethical approval for the project. Before this is granted in full the ethics committee have asked me to make some amendments, including revising the information sheet so that it clearly indicates the type of questions that will be asked. I feel that the ethics board's comments are fair and will set about making the necessary changes immediately, as I imagine that recruitment might be a lengthy process and would therefore like to start this as soon as possible.

Spring 2011

Setting up an IPA group

I decided to contact other trainee clinical psychologists who are using IPA and we arranged to meet regularly to discuss issues relating to this approach. It's been great sharing ideas with others and has helped me to feel less alone with my research, which has often felt the way when I've been working independently on my project. One of our ideas is to interview each other about some of the assumptions we hold and experiences that we have had that may influence our research.

Recruitment

I've started to make contact with branch managers and support workers at local branches of the Alzheimer's Society to ask them if they know of couples who might consider participating in my research. I haven't heard back from many of them, so have decided to make contact with branches further afield.

I've been in touch with 10 couples. However not all of these couples met my inclusion criteria, as in three cases the person with dementia was unable to consent. I talked with each of the couples about the process method of consent and couples appeared happy with this. Each of these couples appeared enthusiastic about my research and expressed a desire to help raise awareness of some of the issues that they face.

Summer 2011

Interviews

I'm due to meet with two couples tomorrow who agreed and consented to take part. I'm feeling a bit apprehensive and as if I could have done with more time to prepare.

I've just met with my first research participants. I thought that the interview went well and the couple said that they felt this way too. They said they felt comfortable and relaxed. Tom (a care partner) gave me a memory stick and said that he had written some more of his thoughts down for me to read. I thanked him, and explained that although I was very interested in what he had written, that I wouldn't use this as data. I was struck by their closeness as a couple and the strength of their couple identity.

Today I met with another couple. They were motivated to take part in my research because they felt it was important to raise awareness and increase understanding of dementia. They became emotional during the interview and seemed to manage this by changing the topic of conversation. I acknowledged that this was a very difficult thing to talk about and checked in with them about whether they were ok and whether they wanted to continue, which they did. It seemed that taking part in the interview allowed this couple to have a conversation and share information that they hadn't before. The person with dementia reflected upon how the interview had made him more aware of his partner's experiences. This was very moving.

Winter 2011 – Spring 2012

Starting my placement in an older adults psychology service

I've started my placement in an older peoples psychology service, as part of this placement I provide input into a memory service, assessing people with memory problems. I've noticed that the service tends to be loss-orientated, in that assessments focus upon what the person with dementia is no longer able to do, rarely have I heard professionals ask the person with dementia about the things that they are still able to do. The relationship between PWD and those that care for them is rarely discussed. I'm planning on doing some training with the team, during which I hope to facilitate some discussion around this.

The team I'm on placement within are very interested in my research and have asked me to present my initial findings and my experiences of doing the research during a team meeting. I'm really pleased that my project has captured their interest and hope that sharing my findings with them may influence their practice in some way.

Appendix M: Declaration of End of Study

Dear Ethics Committee,

I am writing to inform you that my study has now been completed and to share with you my progress and the outcome. Please see attached the summary I provided for participants.

My study aimed to explore the experience of dementia in the context of couple relationships. In total seven couples affected by dementia (i.e. when one person within the couple had a diagnosis of dementia) were interviewed about their experience. Using interpretative phenomenological analysis, five master themes which reflected the ways in which couples' constructed their experience of dementia, and the processes that they adopted in order to adjust to dementia, were found to emerge from the data. These themes were given the titles of: 'foundations', 'altered structures', 'self-restoration', 'flexible scaffolding' and 'reflective capacity'. Throughout the process of my research no ethical issues arose.

My findings are supported by existing empirical and theoretical literature and contribute to the development of a comprehensive and complex relational understanding of the experience of dementia, upon which much needed services and interventions for couples can be developed. I therefore plan to submit a manuscript to *Dementia – The International Journal of Social Research and Practice*, which I hope will be accepted. I also plan to disseminate my findings among relevant professionals via a newsletter published by the Alzheimer's Society and via presentation at a forthcoming PSIGE (British Psychological Society, Division of Clinical Psychology, Faculty for Old Age Psychology) event.

Yours sincerely,

Kim Merrick

Trainee Clinical Psychologist

Appendix N: Summary of Study for Participants

Dear.....

Some months ago now you both volunteered to take part in my research project about couples' experiences when one person, within the couple, has memory difficulties. You kindly agreed to meet with me and I interviewed you both at your home. I am writing to you to let you know how my project has been going and to share with you some my findings.

What did I do?

I interviewed 7 couples about their experiences of memory difficulties. I recorded and transcribed these interviews. I read over the transcripts a number of times and looked for themes.

What did I find?

I found five main themes. This is a brief summary of them.

- 'Foundations' - couples talked to me about the foundations upon which their relationships were built. People used words such as "love", "partnership", "in sickness and in health".
- 'Altered structures' - couples spoke about the things that they used to do, relating to the running of their household and their relationship. Couples told me that their roles within their relationship had changed and that sometimes their partner was not able to understand them. Couples also told me that they had become closer since one person had memory difficulties. For example couples said that they: "depend upon each other", "look after each other" and "balance each other out".
- 'Self-restoration' – people who had a diagnosis of dementia told me about the things that they were no longer able to do, but also about the things that they could still do. This seemed very important and helped people to feel confident about themselves and their sense of self worth.
- 'Flexible scaffolding' - care partners worked hard to support the person with memory difficulties to do as much as they could and live as active and full life as possible. For example, one wife said to me: "I keep him going". Care partners focused upon promoting their partner's sense of self-esteem, self-worth and their dignity. The support that care partners provided was flexible, so that the right level of support was provided at the right time.
- 'Reflective capacity' – both partners were able to reflect upon their own experience and that of their partner, demonstrating empathy for each other.

What next?

As I have been completing this research project as part of my Doctorate in Clinical Psychology at Canterbury Christ Church University, I will produce a report, upon which I will be examined. Following this, I will try to get my report published in a journal that is read by healthcare professionals involved in supporting people with memory difficulties. I will also send a copy to the Alzheimer's Society to include in their newsletter. I hope that my findings will provide services with a greater understanding of the experiences of couples and be used to make positive changes to the ways in which couples affected by memory difficulties are supported.

What can you do?

If you have any comments or queries please get in touch. I am particularly interested to hear about what taking part in this project was like for you. If you want to get in touch, you can email, phone or write to me and I enclosed a pre-paid envelope.

Thank you for taking the time to be part of this research and for sharing some of your experiences with me.

Kind regards,

Kim Merrick
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Appendix O: Manuscript Submission Requirements

Taken from

<http://www.uk.sagepub.com/journals/Journal201266#tabview=manuscriptSubmission>

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.
3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.
4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.
5. Your typescript (written in English) needs to be typed using double spacing on one side only of white A or US standard size paper, with generous left and right-hand margins (at least .cms) but without justification.
6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.
7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.
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.
9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.
10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

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.

Multi-authored articles: in the text, when the work has two authors, always cite both names every time. When there are more than two authors and less than six, cite all authors the first time and after that, just the surname of the first author and et al. The names of all authors should be given in the reference list.

14. *Language and terminology*. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

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.

16. The corresponding author will receive page proofs for checking. Twenty-five free offprints will be sent to the corresponding author, and each of the co-authors will receive a free copy of the journal.

18. *Typescripts*. Authors should retain a copy of their typescript and send an identical electronic version as a Microsoft Word document, together with all figures and tables and a separate covering letter, via email attachment to:

John Keady
Professor of Mental Health Nursing and Older People,
School of Nursing, Midwifery & Social Work,
University of Manchester,
University Place (Room 6.321),
Oxford Road,
Manchester,
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