Identity and the Couple Relationship: An Interpretative Phenomenological Analysis of Women's Experiences of Caring for a Partner with Dementia

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Abstract

Within an ageing population, the number of people with dementia is rapidly increasing. Dementia is considered a global health issue affecting 44 million people worldwide (Alzheimer's Research UK, 2015). Due to an increase in the prevalence of dementia, the number of informal caregivers is also rising, with life-partners most commonly taking on this role and facing the transition into a caregiving relationship (Balfour, 2014).

Historically, research has predominantly focused upon caregiver stress and burden and the biomedical model of dementia has prevailed (McGovern, 2011). Both of these approaches overlook relational and experiential lived experiences of dementia. This thesis aimed to understand the lived experience of caring for a partner with dementia, focusing on the impact upon the intimate relationship and identity of the person caring. Six women who were caring for their partner with dementia were interviewed and photographs were incorporated into the interview. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA) and three superordinate themes were developed: 'Loss and the Emergence of a New Present'; 'Navigating a New Reality' and 'Becoming Devoured for Caring'.

The findings revealed the gradual loss and decline of a familiar relationship and partner through which a new partner and relationship emerged. The women were simultaneously experiencing loss whilst attempting to adapt to a new reality, which was challenging to adjust to and resulted in a complex array of feelings. Relationship roles were destabilised resulting in a lack of reciprocity and the familiar intimacy of the past was disrupted with a particular loss of sexual intimacy. In order to cope with their confusing and complex experience the participants tended to engage in a number of strategies, for example blaming their partner for their new behaviour and underplaying their overwhelming emotions. The women experienced a conflict between attempting to maintain aspects of their previous identity and gradually becoming submerged by caring for their partner. Participants tended to feel obliged to take on the caring role and perceived caring their duty as a wife, often resulting in a consumed and isolated position where their own identities disappeared as much as their partners'.

A number of important clinical implications have arisen from this research. Firstly, it seems significant for professionals to provide a containing space for caregivers to understand their defences/coping mechanisms, acknowledge their complex emotions and process loss. The aim would be to provide a space where feelings can be explored, perhaps leading caregivers to feel less overwhelmed and more able to adapt to their significant change (Auclair, Epstein, & Mittleman, 2009).

The Dementia Grief Model (Blandin & Pepe, 2015) is a theoretical model of dementia grief which is significant for the findings of this research and provides a framework for professionals. It acknowledges dementia related grief as a unique experience and highlights particular therapeutic interventions that are specific to working with dementia grief, for example tolerating difficult feelings and behavioural adaptations (Blandin & Pepe, 2015) that are relevant for the findings of this research.

Furthermore, it seems pertinent for services to support couples to adjust to change and maintain a continued sense of relatedness, enabling significant relationships to continue (McGovern, 2015). Supporting couples to co-construct new ways of connecting/relating allows for a redefinition of dementia by nurturing what remains, as well as acknowledging what has been lost (McGovern, 2011). Additionally, it is crucial for professionals to support caregivers to maintain alternative identities outside of the caring role. It does not seem adequate to support partners solely in their role as 'carer' but to help them maintain a sense of self-identity in order to prevent the consumption and isolation that was highlighted in this research.

Finally, it is vital that Counselling Psychologists challenge the existing dominant discourses that exist within dementia care of decline, despair and burden to promote new understandings. Challenging dominant discourses could have significant impact upon how future dementia care services are implemented and the findings of this research contribute towards the argument for services and professionals to prioritise experiential and relational experiences of caregivers and couples living with dementia.

Table of Contents

List of Tables

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Chapter 1: Introduction

1.1 Preface

This research explores the lived experience of caring for a partner with dementia and aims to understand its impact upon the long-standing couple relationship and caregiver's identity. Participants were interviewed using a semi-structured approach incorporating a visual methodology, photo-elicitation. The participants' accounts were analysed using Interpretative Phenomenological Analysis (IPA). Due to recruitment challenges, as opposed to research design, only women were recruited. This is discussed further in Chapters 3 and 5. This Introduction contextualises the research by outlining a background in dementia caregiving and highlighting the relevance to Counselling Psychology.

1.2 Research Background

Dementia is primarily a syndrome of old age and therefore, within an ageing population, the number of people living with dementia is due to increase exponentially (Balfour, 2014). Approximately 850,000 people in the UK currently live with dementia and predictions indicate this will rise to over two million by 2051 (Alzheimer's Society, 2014). It is estimated that currently two thirds of people with dementia live in the community and there are over 670,000 people acting as their carers (Alzheimer's Society, 2014). The economic impact of dementia to the UK is estimated at over £20 billion a year (Department of Health [DoH], 2009) and, with life expectancy increasing, caring for an ageing population is likely to cost future economies considerably more (Partridge, 2009).

The implications of an increased prevalence of dementia are vast, this is particularly significant for spouses who provide the majority of care for adults with dementia (Feeney & Hohaus, 2001). There is a societal pressure for people with dementia to be cared for at home. Care is often provided unseen by a spouse, with many delivering more than 50 hours of care per week, highlighting the great quantity of care provided (Balfour, 2014). The impact of dementia on families and societies extends to physical, psychological and social difficulties and there is often a lack of awareness and understanding of living with dementia, resulting in stigmatization, inequalities and barriers to diagnosis and care (World Health Organisation [WHO], 2012).

The National Dementia Strategy (DoH, 2009) was designed to address public awareness, perception and expectations about living with dementia and aimed to reduce misconceptions and stigma, improve diagnosis and develop services. One of the objectives was focused upon implementing the ‘Carers Strategy’ for people with dementia, which outlined how this group of caregivers are exposed to the greatest degree of stress and burden across caregiver groups of any condition and are most vulnerable to experience psychological problems (Alzheimer’s Disease International, 2009). Furthermore, The Dementia Challenge (Alzheimer’s Society, 2012) is a UK Government initiative which aims to improve diagnosis and care, create dementia-friendly communities, increase public understanding and promote research.

Despite these advances, the significant numbers of people affected by dementia are still largely obliged to face living with dementia without adequate support. Given the preference for community care by older adults as well as by health and social care policy makers, there is a clear need to develop research and interventions for couples living with dementia (Balfour, 2014).

1.3 Relevance to Counselling Psychology

Due to the increasing number of adults with dementia, Counselling Psychologists will be seeing such individuals more frequently in their professional practice. However, the challenges of living with dementia are not experienced in isolation, particularly impacting the lives of partners (Baikie, 2002). A growing number of couples are facing the transition to a caregiving relationship when one spouse develops dementia; it affects the identity of both members of the couple and the relational bond between them (Hellstrom, Nolan & Lundh, 2007). Older adult services tend to focus upon the measurement of neurological decline in the person with dementia, overlooking emotional and relational experiences (Camic, Tischler, & Pearman, 2013). Greater understanding of personal and relational experiences is essential to ensure Counselling Psychologists and other professionals can provide improved care and effective therapeutic support for couples living with dementia (Whadham, Simpson, Rust, & Murray, 2015).

The dominant understanding of dementia currently exists within a biomedical framework; dementia is characterised by neurodegeneration and is widely constructed as a ‘disease of the brain’ (WHO, 1992). Dementia research has traditionally adopted an individualistic and biomedical perspective, separating caregiver from care-receiver and emphasising loss and decline (McGovern, 2010). This biomedical model of dementia takes a reductionist approach, neglecting personal, social and contextual factors (Cheston & Bender, 1999). In comparison, the complexity of dementia-affected relationships and the experiential lived experience of dementia caregiving remain largely unexplored (Hellstrom et al., 2007). It is therefore crucial to research them, in order to challenge dominant frameworks that currently exist and enable effective interventions to be developed.

Counselling Psychology is based upon existential-phenomenological psychology, where engagement with subjective experience and meaning is central (Woolfe, Strawbridge, Douglas, & Dryden, 2010) and qualitative research methods such as IPA are congruent with this approach. Therefore, this research aims to provide new understanding for Counselling Psychologists, enabling them to work more effectively with caregivers and dementia-affected couples, providing the opportunity to enhance knowledge and practise for the profession.

1.4 Reflexivity

Reflexivity is crucial in qualitative research to understand and explore the ways in which the researcher influences and shapes the research process, as they cannot be objectively separated from the topic they are researching (Finlay & Gough, 2003). It is particularly important in IPA, given its commitment to hermeneutics. There are two types of reflexivity; personal and epistemological (Willig, 2013). Personal reflexivity is considered in this section, whilst epistemological reflexivity is discussed in Chapter 5, where personal reflexivity is also re-visited. It is important to note that reflexivity was incorporated throughout the research process in various ways, for example by keeping a journal and reflexive notes, through supervision and discussions with peer-researchers.

Personal reflexivity considers how the researcher's gender, ethnicity, age, values and personal experience might shape the research and affect data collection and/or analysis and therefore the knowledge that is generated from the research (Willig, 2013). Initially, I considered some of the different positions I hold and how they might have influenced the research process:

- White British female
- Thirty year old

- Married
- Living in the South East of England
- Trainee Counselling Psychologist with an interest in psychodynamic approaches
- Having grandparents affected by dementia

These identities might have impacted upon what was or was not discussed in the interviews and may have also impacted upon the data analysis; these areas are reflected upon further in Chapter 5.

Throughout the research process, I was mindful of my personal knowledge of dementia stemming from both my clinical practice and personal experience. As a trainee Counselling Psychologist, I had contact with people who cared for a partner with dementia within a generic counselling service, where I felt very restricted in what I could offer, which led me to feel helpless. I became aware of the lack of psychological input for both the caregiver and the couple. Older adult services seemed focused mainly upon assessment and diagnosis of dementia.

I also had personal experience as my grandad had dementia and was cared for at home by my grandmother. During this research, my grandad was in his mid-late stages of dementia and sadly he passed away. This was a significant loss that was important for me to process in order to stay engaged with this research and to ‘bracket’ my own emotions during data analysis and write up. I was mindful that some of the issues the participants spoke about might trigger feelings about my own experiences, which I reflected upon in my reflexive notes (see Appendix F), supervision and personal therapy. It was important that I bracketed my own experiences during the interviews and analysis so that they did not influence how I approached my participants and the interview data.

Through my personal experiences, I became aware of how incredibly complex caregivers’ experiences were; they had to adapt to so much change which was rarely acknowledged. The focus was on practical support, with a lack of therapeutic input offered individually to caregivers or to couples to help with the emotional aspects of their role. They seemed to be a group that was neglected by society/psychology services and not understood, with emphasis placed upon the biomedical model, which motivated me to carry out this research.

1.5 Summary of Following Chapters

The next chapter provides a critical review of current literature, highlighting gaps and ending with a rationale for the research. Chapter 3 outlines the chosen methodology and rationale, alongside recruitment, ethics and data analysis procedure. Chapter 4 outlines a narrative account of the themes. The final chapter includes a summary of the analysis, clinical implications and limitations of the research.

Chapter 2: Literature Review

2.1 Introduction

This chapter begins by defining and conceptualising dementia and caring. Subsequent sections critique research and theory in dementia caregiving, beginning with broader topics such as stress and burden and then focusing on research specific to the couple relationship. A rationale for the current research and the research questions and aims conclude the chapter.

2.2 Defining and Conceptualising Dementia

Dementia is a set of symptoms including memory loss and difficulties with thinking, problem-solving or language and is caused when the brain is damaged by diseases such as Alzheimer's or a series of strokes (Alzheimer's Society, 2014). There are a number of different types of dementia, Alzheimer's disease being the most common, and the specific symptoms will depend on the part of the brain that is damaged. A person with dementia may also develop behavioural and psychological symptoms such as hallucinations, mood/personality changes and wandering, which can complicate care. The changes often start small, but there is normally a progressive decline that can become severe enough to affect daily functioning, requiring significant support from others.

The current construction of dementia is primarily that of a progressive, pathological, biomedical disease (Davis, 2004) and the DoH (2009) classify dementia within a biomedical conceptual framework. Although the application of the biomedical model to dementia may be a way of aiding shared understanding and enabling access to medication to manage neurocognitive deterioration, there is no medical cure for dementia (NHS choices, 2015) or justification for such dominance of the biomedical model (Wyatt & Midkiff, 2006). The biomedical model and evidence-based practice are influenced by political, economic, social and cultural factors and are based upon assumptions embedded in Western and positivist cultures (White, 2013). Much of the research associated with dementia remains focused on the aetiology of illness or on the pathology and physical symptomatology of disease.

The biomedical model has been condemned for being deficit-focused, often the social and psychological worlds of people with dementia are ignored, and difficulties are attributed solely to neurological decline (McGovern, 2011). Considering the person with dementia or their caregiver in isolation does not inform us about the dynamic inter-relationships that exist in dementia care (Hellstrom, Nolan, & Lundh, 2005). It has been suggested that family members supporting a person with dementia often accept the biomedical explanation, impacting upon the caregiving experience (Kitwood, 1987). The study of ‘personhood’ (Kitwood, 1997) attempted to move the focus away from this biological model of dementia and highlighted how the relationship between the person with dementia and those around them, is crucial in maintaining a sense of self. Hellstrom et al. (2005) proposed that the couple relationship in particular should be at the centre of dementia research.

Guidelines acknowledge the need to consider the psychosocial model of dementia alongside the biomedical model (National Dementia Strategy, 2009). Counselling Psychology has arisen from humanistic and existential traditions, which challenge the dominant influence of the medical and positivist models and acknowledge other models of health/illness and alternative research paradigms (Strawbridge & Woolfe, 2003). Therefore, further research is required to better understand dementia from perspectives that challenge the current biomedical framework.

2.3 Defining and Conceptualising Caring

An informal carer is broadly considered as someone who provides “unpaid care by looking after an ill, frail or disabled family member, friend or partner” (Whitman, 2010, p.17). Caring involves a range of tasks and the type and amount of input required varies with the level of impairment (Alzheimer’s Society, 2014). Ory, Yee, Tennstedt and Schulz (2000) define caregiving as a “dynamic process that unfolds and changes over time” and “evolves from pre-existing social expectations and obligations” (p.6).

The term ‘carer’ defines both those individuals providing informal care and professionals employed to provide formal care, it is therefore considered contentious due to misunderstandings and the possible professionalisation of informal carers (Molyneaux, Butchard, Simpson, & Murray, 2011). Molyneaux et al., (2011) found that identification with the term ‘carer’, a service-driven terminology, has been found to negatively impact the identities of the persons caring and being cared for and Dean and Thompson (1996) argue that service use of the term ‘carer’ has transformed the action of caring to a position of carer which can objectify and detach people from their traditional relationships. Furthermore, it is not considered a valid description of the relationship between caregiver and care-receiver; it implies burden and potentially polarises two individuals. Molyneaux et al. (2011) suggest abandoning the term ‘carer’ altogether, highlighting how “descriptions of the caring relationship that focus on the relationship from which it arose would be both more acceptable and useful” (p. 422).

Health and social policies are directed towards home treatment due to high financial costs of institutional care (DoH, 2009) and it is assumed that unpaid work by informal carers will enhance formal care provision. The normalisation of the informal carer as a way of reversing public expenditure has pressurised individuals towards the moral obligation to care at home without being offered appropriate support, isolating those who care (Balfour, 2014). It has been argued that the term ‘carer’ is a “socio-political construct” (Netto, 1998, p.223) which lacks focus upon, and understanding of, feelings and relationships. In Counselling Psychology, it therefore seems crucial to understand the affective and relational aspects of dementia caregiving.

2.4 Caregiver Stress and Burden

Research on living with dementia across several decades has focused on the experience of the informal carer, with an emphasis upon stress and burden (Van Der Lee, Bakker, Duivenvoorden, & Droes, 2014). The impact of the caregiving process on the caregiver has often been described in terms of ‘caregiver burden’, which has multiple and inconsistent definitions and measurements (DiBartolo, 2000; Harper & Lundh, 1990). The construct of caregiver burden is most frequently used to describe the enduring stress and frustration experienced by family members caring for individuals with dementia at home and includes the increased health risks, emotional disturbance and financial strain on caregivers (Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). Caregiver burden is associated with depression, illness and decreased quality of life (Cuijpers, 2005; Ferrara, Langiano, Di Brango, De Vito, Di Cioccio, & Bauco, 2008; Ferri et. al., 2005) and also poor outcomes for dementia patients such as early institutionalisation (Gaugler, Kane, Kane, & Newcomer, 2005; Yaffle et al., 2002). However, framing the caregiving experience solely in terms of stress and burden, prevents it from being understood from other perspectives (Cheston & Bender, 1999).

Over eighty percent of dementia caregivers say they frequently experience high levels of stress and almost half report they suffer from depression (Etters, Goodall, & Harrison, 2008). Factors affecting caregiver stress have been identified, such as caregiver gender and coping style, dementia severity and behavioural issues, duration of caregiving, quality of the caring relationship, and social networks (Donaldson, Tarrier, & Burns, 1997; Ford, Goode, Barrett, Harrell, & Haley, 1997; Kneebone & Martin, 2003; Teri, 1997; Whitlatch, Feinberg, & Stevens, 1999). Much of the research on caregiving burden regards caregivers as a homogenous group, assuming that all caregivers define their roles and experience caregiving in much the same way. However, it is essential to understand the experience of specific caregiving groups in order to provide effective support (Bedard, Pedlar, Martin, Malottt, & Stones, 2000).

Gender differences in dementia caregiver outcomes have been researched and women were found to experience more primary stress and secondary role strain due to caring responsibilities (Kramer & Kipnis, 1995; Merrill, 1997), as a result of the more intense care and larger quantity of personal care provided by women. However, there appear to be inconsistencies in the findings since contradictory research reports no differences linked to gender in caregiver outcomes (Kramer & Kipnis, 1995; Barusch & Spaid, 1996). Evidence outlining the impact of culture on caregiver burden is also ambiguous. Familism, the belief that family responsibilities and needs take precedence over individual needs, has been found to be a primary determinant of caregiver stress and burden (Merrill, 1997**).** However, whilst some research supports differences in caregiver burden based on culture (Connell & Gibson, 1997) other research disputes cultural differences (Burton et al., 1995). Research into stress and burden has provided contradictory and confusing findings. Rather than being influenced by one factor, it seems that the caregiving experience is influenced by a confluence of factors such as gender, age and culture (Montgomery & Williams, 2001).

The majority of research conducted on family caregiving in dementia has been premised on the Stress Process Model devised by Pearlin et al. (1990). This model provides a conceptual framework which consists of four domains: the background and context of stress; the stressors; mediators of stress and manifestations of stress. It views caregiver stress as a process resulting from a number of interrelated conditions including: socioeconomic status, the problematic behaviour of the adult with dementia, family conflict, self-esteem and mediators such as social support. A similar model has also been proposed by Lazarus and Folkman (1984). These generic models of the stress process have guided much of the research on caregivers, focusing upon identifying determinants of caregiver strain and developing interventions that might buffer that strain (Gottlieb & Johnson, 2000).

A parallel literature has found that caregiving can have positive outcomes and rewards such as role gain, satisfaction, gratification, mastery and growth (Andrén & Elmståhl, 2005; Kramer, 1997). A study by Sanders (2005) found that it is common for caregivers to experience feelings of both strains and gains, specifically that caregivers became more compassionate, forgiving, helpful, tolerant and loving. This highlights how the experience of caring for an adult with dementia is far more complex than only a positive or negative impact upon the caregiver.

The majority of research into stress and burden tends to be carried out within the dominant positivist paradigm which has been uni-dimensional, objectively orientated and conflicting in its findings (Upton & Reed, 2006). Much of the research uses quantitative methods to measure psychological constructs such as stress using standardised scales, for example, the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) or the Zarit Burden scale (Cooper, Katona, Orrell, & Livingston, 2008; Zarit, Reever, & Bach-Peterson, 1980) and predetermined models such as the Stress Process Model (Pearlin et al., 1990). Using scales which are limited by predetermined responses can prevent research from capturing the multi-dimensional depth, richness and complexity of psychological phenomena.

Dementia is multifaceted, characterised not only by deterioration but also an emergence of something new. For example, people with dementia may begin to remember things from the past, see or hear things that other people do not, or experience a change in personality but with specific parts remaining intact (Alzheimer's Society, 2014). This suggests that caring for a partner with dementia is likely to be a very intense and complex psychological experience. A preoccupation with typically narrow approaches has delayed the development of a more accurate understanding of the lived experience, therefore it is essential for Counselling Psychology to take a phenomenological approach to dementia and care research, to further understanding from other perspectives.

Furthermore, by focusing on stress and burden it has overshadowed the importance of the relationship between caregiver and care-receiver and it has been argued that research should take a broader view of caring, given that the stress-burden framework is not universally applicable (Montgomery & Williams, 2001). This framework tends to overlook the nature of the relationship between caregiver and care-recipient and couples are not considered as living-in-relationship but living-in-parallel (Baike, 2002). Moving beyond the stress-burden model suggests the need to re-contextualise the experience of dementia as an illness affecting relationships rather than individuals, which is the focus of this research.

2.5 The Couple Relationship in Dementia Caregiving

Dementia caregiving research has gradually shifted from a stress-burden framework, which focuses solely on the caregiver, towards understanding the relationship between the couple in dementia caregiving. Spouses caring for and living with the adult with dementia are likely to experience the most significant changes within their relationship. Although cognitive, functional and behavioural changes in the adult with dementia are stressful for all family members, it is their impact upon the spouse caregiver's primary, and sometimes exclusive, relationship that has been identified as a distinctive source of stress (Rankin, Haut, & Keefover, 2001).

2.5.1 Relationship Quality

Change in the quality of the martial relationship following the onset of dementia has been researched using, primarily, caregivers' reports and quantitative research methods. It shows a decline in the quality of the relationship specifically in the following areas: intimacy (Morris, Morris & Britton, 1988), reciprocity (Eloniemi-Sulkava et al., 2002; Murray, Schneider, Banjeree, & Mann, 1999) communication (De Vugt et al., 2003; Murray, Schneider, Banjeree, & Mann, 1999), happiness in the marriage (Eloniemi-Sulkava et. al., 2002) and overall perceived quality of the relationship (Knop, Bergman-Evans, & McCabe, 1998).

Research that focuses only upon a decline in the marital relationship from a positivist perspective can be misleading and prevents research from capturing the complexity of the couple relationship in dementia care. This is evidenced by contradictory research that some aspects of the marital relationship increase following the development of dementia, specifically; closeness (De Vugt et al., 2003), warmth (Eloniemi-Sulkava et al., 2002) and mutual affection (Murray et al., 1999). Braun et al. (2009) outline how both positive and negative relationship changes can co-exist, which underlines caregivers' complex experience.

Research into the impact of prior couple relationship factors upon the experience of dementia caregiving uses a wide range of quantitative measures to operationalise various relationship factors. It has found that prior relationship quality and current relationship quality are related (e.g. Knop et al., 1998). Caregivers who report lower relationship quality prior to the onset of their partner's dementia report greater depression and distress (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Knop et al., 1998; Kramer, 1993; Morris et al., 1988), greater burden (Robinson, 1990) and greater strain (Morris et al., 1988). Conversely, caregivers who report high relationship quality prior to dementia report greater reward and satisfaction (Kramer, 1993; Williamson & Shaffer, 2001) and higher quality of life (Kramer, 1993).

Following a review of predominantly quantitative research in the area of relationship quality, Ablitt, Jones, and Muers (2009) developed a theoretical framework outlining the interaction between the quality of the couple relationship and dementia. The model proposes that the couple's prior relationship quality impacts the maintenance of their relational bond following development of dementia. Any reduction in relationship quality then impacts both individuals' emotional wellbeing, resulting in a progressively negative experience, increasing the presentation of dementia thus creating a vicious circle of worsening the relationship as the cycle continues (Ablitt et al., 2009).

Whilst research which looks at the quality of the relationship in dementia begins to inform us about the impact of dementia upon the couple relationship and vice versa, it is mainly from a positivist position and does not capture the multi-dimensional depth, richness and complexity of personal meanings. Implications include substantive methodological changes; expanding research to include qualitative explorations of how couple meaning-making processes are affected by dementia is crucial (McGovern, 2011).

2.5.2 Loss and Grief

An important aspect of the psychological impact of developing dementia on both members of the couple can be the experience of loss. Anticipatory grief is grief that occurs prior to a loss and has been viewed as a potential coping mechanism associated with anticipated loss (e.g. Garner, 1997). It includes the caregiver's belief that the sufferer is, in some way, already dead and that death would come as a relief. This highlights how caring for an adult with dementia is a very complex and intense experience.

The partner of an individual with dementia can experience ongoing, multiple losses (Rankin et al., 2001) and research has highlighted how the process of loss is complex due to the changing nature of dementia and the sporadic reappearance of the 'former self'. Robinson et al. (2005) used IPA to explore couples psychological responses to receiving a diagnosis and found that couples were engaged in an ongoing process of "making sense of and adjusting to loss" (p.343). Their experiences suggested a cyclical process of denial, minimisation and gradual realisation as they began to accept that the changes were permanent.

When living and caring for their partner with dementia, caregivers have reported a number of specific losses including: a confidant, independence, shared experiences, affection and intimacy, social networks, memory, hopes for the future and previous roles and lifestyle (Beeson, 2003; Doka, 2010; Gillies, 2012; Robinson et al., 2005).

Research has also found that the caregiver role can result in loss of self by the caregiver. Skaff and Pearlin (1992) examined 'loss of self' in spouses and adult children who cared for someone with Alzheimer's disease which was defined as: "loss of identity that comes about as a result of engulfment in the caregiver role" (p.656) and is the compression and diminishment of self-image. They administered a number of quantitative measures and found that limited social contact and lack of social roles related to greater loss of self, which was associated with lower self-esteem and with greater depression symptoms. This highlights how dementia caregiving can significantly impact the identity of the person caring.

Todres and Galvin (2006) carried out a case study using a descriptive phenomenological approach to explore six phenomena that had been identified by previous research as important aspects of caring for a partner with Alzheimer’s disease. They identified three processes; drifting apart, reconnecting in a complex way and being effortlessly together. This suggests that, rather than holding onto old patterns of relating, the couple reconnected in a way that was better suited to their current relationship. Such research challenges the experience of dementia being solely about loss and decline and suggests that changes in the emotional relationship between couples can continue to support the relationship, despite neurological decline.

Focusing upon loss is compatible with the deficit and decline perspective that dominates the current societal perception of dementia and suggests a demise of quality of life for couples living with dementia (McGovern, 2015). Whilst dementia research has highlighted how loss is an important part of the psychological experience of living with dementia, the preoccupation with loss has delayed the development of a more accurate understanding of the lived experience of dementia (McGovern, 2010).

Viewing the lived experience of dementia from other perspectives challenges the core belief that the experience of dementia is solely about loss and thus universally devastating (McGovern, 2015). It opens up possibilities for alternative approaches to be developed wherein Counselling Psychologists can support couples to adapt and maintain their relationship.

2.5.3 Couplehood and Continuity

Research has highlighted that a gradual transition in the relationship between husband and wife occurs due to dementia. Couplehood is a concept that has emerged for describing how dementia impacts the couple relationship and the extent to which couples continue a sense of togetherness, including intimacy, trust and support within the relationship (Evans & Lee, 2014). One area of research has explored how couples make sense of their relationship following diagnosis, particularly how much of a sense of couplehood is maintained. Kaplan (2001) examined the impact of dementia on spousal relationships, using semi-structured interviews and quantitative measures, with sixty eight individuals whose partner lived in a care home. They explored whether spouse carers retained a sense of togetherness when their partner was diagnosed with dementia and classified couples along a continuum from "We" where there was a strong experience of couplehood, to "I" where spouses no longer considered themselves part of a couple.

Developing this, Hellstrom et al. (2007) recruited twenty couples who described having mainly 'positive' relationships prior to dementia and explored strategies they used to live positively with dementia. They conducted interviews with couples over a five year period and analysed the data using grounded theory to understand the main processes and how they changed over time. Their model proposed three broad phases: 'sustaining couplehood'; 'maintaining involvement'; and 'moving on'. Within the 'sustaining couplehood' phase, the caregiver appeared to try and maintain a sense of continuity both with the person with dementia and within their relationship. However, the narrow focus of this research upon strategies spouses use to live ‘positively’ with dementia prevents the understanding of more challenging aspects of adapting to relationship change.

Walters, Oyebode and Riley (2010) further explored relationship ‘continuity’ in female caregivers whose partners had dementia, they carried out interviews and used IPA to analyse the data. They found that continuity with the past meant that caregivers were better able to adapt to caregiving and continuity was significant for their overall experiences. Discontinuity was experienced when past and present experiences opposed one another. Finally, O’Shaughnessy et al. (2011) carried out phenomenological research looking at ‘changes’ in the couple relationship and found nothing is constant for the caregiver and there is a process of re-evaluation and re-positioning within the relationship. They reported that feelings of continuity and ‘connectedness’ were associated with a sense of ‘separateness’ between themselves and the person with dementia.

Whilst the concept of couplehood and research exploring relationship continuity has begun to inform us of the ways in the couple relationship might change due to dementia, it takes a broad view of the relationship rather than focusing on specific areas and tends to overlook the impact upon the identity of caregiver and/or person with dementia.

2.5.4 Identity and Intimacy

Self-identity is influenced by attitudes, beliefs and ideas that are created and maintained through an individual’s engagement with others (Berger, 1966) therefore caring for a partner with dementia can be a turning point in defining one’s self and the relationship (Calasanti & King, 2007). It has been suggested that intimacy plays an important role in the construction of self-identity and, the reciprocal expression of trust and emotional closeness, contributes to the validation of personal worth (Jourard, 1971). Hayes, Boylstein and Zimmerman (2009) and Boylstein and Hayes (2012) explored how caregivers reconstruct the meaning of closeness within their marriage. They used grounded theory to examine how dementia affects the identity of their spouse and the ways in which these changes influence caregiver identity and intimate relations. Twenty eight caregiving spouses were interviewed, including both men and women. They found that identity changes in the person with dementia impacted intimacy and most reported reduced intimacy due to dementia. Caregiver wives were more likely to report changes in their own identity due to the changes in their partner with dementia. Furthermore, they found that dementia impacted how caregivers viewed their marriage and their ability to re-establish a sense of marital closeness.

Without marital closeness caregivers may feel alone and isolated, leading to higher levels of depression (Boylstein & Hayes, 2012). By understanding ways in which intimacy changes when one partner has dementia, it may be possible to understand ways in which marital closeness can be maintained or re-constructed in meaningful ways. There is a lack of qualitative research exploring the ways in which caregivers experience and reconstruct intimacy within their relationship following the onset of dementia and the ways in which the identity of the person caring is affected, highlighting a need to explore these areas further from alternative perspectives (Boylstein & Hayes, 2012).

2.6 Interventions in Dementia Caregiving

The NICE-SCIE National Clinical Practice Guidelines for supporting dementia carers (British Psychological Society [BPS], 2006), highlight the importance of psychological therapy for people experiencing ‘psychological distress’ whilst caring for a person with dementia (National Institute for Health and Clinical Excellence, 2006). However, there is conflicting evidence about the effects of interventions on caregiver wellbeing, with some research suggesting no significant effects on caregiver burden (Acton & Kang, 2001) while other research suggests small to moderate effects upon psychological morbidity (Brodaty, Green, & Koschera, 2003) and burden, depression and subjective well-being (Pinquart & Sorensen, 2006). Interventions that target dementia caregivers tend to be divided into four main categories; psychoeducational-skill building, psychotherapy/counselling, multicomponent interventions and technology based interventions (Elvish, Lever, Johnstone, Cawley, & Keady, 2013).

The literature highlights how the majority of psychological interventions for caregivers of people with dementia focus on psychoeducational-skill building (e.g. Hepburn et al., 2005; Stern et al., 2008; Ulstein, Sandvik, Wyller, & Engedal, 2007). Most research examines the constructs of depression, burden, social support and well-being and recent evidence suggests that these interventions, at the least, help to maintain levels of well-being over time (Elvish et al., 2013). However, there are issues in providing an evidence-base for interventions for caregivers of people with dementia. Caregivers are a heterogeneous group and it is therefore problematic to measure interventions that address dementia caregivers as a whole, as the type of intervention required depends upon the relationship to the care-receiver. Furthermore, designing and measuring interventions for dementia caregivers socially positions caregiving as a disorder, which contradicts the values inherent in Counselling Psychology and suggests that further research is needed to develop innovative ways of working with dementia caregivers (Zarit & Femia, 2008).

To date, most interventions with individuals with dementia and their caregivers have focused solely on the caregiver and have attempted to teach caregivers how to assist with activities of daily living, manage problem behaviours and decrease sense of burden

(Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003; Hepburn, Tornatore, Center, & Ostwald, 2001). However, there is a small body of literature that suggests simultaneously engaging both caregivers and care-recipients in group interventions (Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004) and in-home interventions (Whitlatch, Judge, Karit, & Femia, 2006) results in positive outcomes.

The majority of psychoeducational-skill building interventions are based upon cognitive-behavioural theory and principles (Beck, Rush, Shaw, & Emery, 1979) and stress and coping theoretical models (Pearlin et al., 1990). Models such as these are reductionist and in line with the medical model, suggesting a set of symptoms are located within the caregiver that can be ‘fixed’ by applying manualised interventions, overlooking the unique individual subjective experience and complexity inherent within dementia caregiving. The preoccupation with interventions which focus upon education and stress reduction, enabling cargivers to remain in their role, are perhaps driven by policies aimed at home care as a way of reducing high financial public costs (Netto, 1998). Furthermore, these approaches polarise the experience between the person with dementia and the caregiver and a shift towards relationship-centred interventions is essential, where an understanding of the dementia experience focuses on the dynamics and multidimensional aspects of relationships (Morhardt & Spira, 2013).

Ng (2009) highlights how, despite the scale of dementia, “provision of psychological support to this group is diminutive in comparison with other illnesses” (p.202). As dementia tends to be viewed within a biomedical model, it is a neglected area for psychologists. Whilst dementia affects cognitive functioning, it does not mean a loss of emotional experience which can still be addressed by professionals (Ng, 2009). Nonetheless, it is noted that a few services offering psychological therapy for couples living with dementia have been established. For example, an initiative called “Living

Together with Dementia" launched in 2013 by The Tavistock Centre for Couple Relationships, is a two-year project offering therapy to couples where one partner has dementia. Auclair et al (2009) carried out preliminary research exploring relationship-centred therapy for couples affected by dementia and tracked the short and long-term effects of couples' counselling, which was shown to have lasting positive effects on the wellbeing of both partners. These novel approaches are influenced by psychodynamic theory where the aim is to provide a containing space where feelings can be openly explored; allowing emotions to be validated and attempting to preserve the integrity of the relationship (Auclair et al., 2009).

2.7 Rationale for the Current Research

Dementia has become acknowledged as a global issue in health and social care (Alzheimer's Disease International, 2010; WHO, 2012) and has moved to a more central position in the awareness of health and social care professionals, researchers, policy makers and society as a whole (Ablitt et al., 2009). Whilst the couple relationship can be an invaluable resource in providing care that is costly in institutional settings, protection of this resource depends upon understanding and addressing the emotional challenges they face (Balfour, 2014).

Evidence shows that when there is insufficient support, then often unnecessary residential placement may be the outcome (Moniz-Cook & Manthorpe, 2009). If these issues are not addressed by professionals, then it can be costly to emotional wellbeing (Wright, 1991, 1994) and promote unnecessary hospital or residential admission (Brodaty, Gresham, & Luscombe, 1997; Mittelman, Hayley, Clay, & Roth, 2006). Traditionally, services have focused upon the practical needs of couples with dementia, which prevents the relationship from being addressed and does not enable caregivers to address the emotional aspects of their role. Given that caregiving has been shown to break down as a result of caregiver strain, it is essential for services to address not only the practical but also the emotional needs of caregivers (Baike, 2002).

Whilst dementia is now central in political, social and media attention after prolonged neglect, there is a need for further research to understand and address the emotional and psychological aspects of the caregiving role and avoid the neglect of life-long significant relationships affected by dementia. A greater understanding of the caregiving process might be achieved, leading to better provision of emotional support for dementia-affected couples, by seeing the couple relationship facing major inter/intrapersonal stresses, rather than primarily as a medical disorder with behavioural consequences which require practical support (Baike, 2002).

2.8 Research Aims and Questions

The literature has indicated that, whilst there is a wealth of research on stress and burden from a positivist perspective, there is a need to explore in-depth phenomenological accounts of how caring is experienced within social, cultural and historical contexts. The study of the phenomenon of caring for a partner with dementia, which understands both the impact upon the relationship, in particular intimacy, and the identity of the caregiver, with a focus on subjective meaning, seems crucial. Introducing a visual methodology into this area of research is novel; it can help gain richer conceptualisations of experience and further inform us about how caregivers make sense of their experiences.

This realigns the current focus of dementia research from dominant discourses which focus on neurological decline, loss and burden towards emotional and relational perspectives. It is essential to consider different perspectives in order to inform theories and psychological interventions. This issue may be addressed by gaining descriptive knowledge where personally lived experiential understandings of the phenomenon can be interpreted for the advancement of Counselling Psychology practice. This thesis therefore aims to explore the following research questions:

- What is the lived experience of caring for a partner with dementia?
- How do caregivers make-sense of the ways in which caring for a partner with dementia can impact upon the long-standing couple relationship, particularly intimacy, and their own identity?
- How can these understandings help inform Counselling Psychology clinical practice?

The next chapter considers how IPA is the most appropriate methodology and how this was applied to answer the research questions.

Chapter 3: Method

3.1 Introduction

This chapter begins by outlining the epistemological position taken up in the current study and a justification for the methodological approach that has been adopted. Participant selection, reflexivity, data collection and the analytic procedure are then discussed.

3.2 Why Choose a Qualitative Methodology?

Qualitative research involves the search for meaning and is used to understand how individuals make sense of the world (Braun & Clarke, 2013). When attempting to understand individual experience and meaning making, open approaches, for example in-depth interviews, are used that allow researchers to recognise the importance of context and participants' frames of reference (Willig & Stainton-Rogers, 2008).

This research focuses upon meaning and the quality of experience, thus qualitative methods are more appropriate (Denzin & Lincoln, 2005). Qualitative research aims to explore an experience in great detail and focuses on personal experiences, rather than measuring an attribute in large numbers of people or making generalisations to large populations. Whilst a realist epistemological approach can be taken in qualitative research, qualitative epistemologies, for example phenomenology, tend to contrast with quantitative research which assumes the existence of a set of universal truths waiting to be discovered (Willig, 2013). The focus of this research is upon lived experience and meaning and is interested in complexity, rather than being concerned with the quantification of data (Langdridge, 2007), therefore the research questions at hand are better aligned to a qualitative methodology.

3.3 Epistemological Position

Epistemology is concerned with the theory of knowledge and methods of obtaining knowledge (Willig, 2008). Epistemological positions can be viewed as sitting along a continuum and much research does not fit neatly into one distinct position, but rather involves a range of positions and methods (Madill, Jordan, & Shirley, 2000). However, it is vital to communicate the basic underlying assumptions and values that are guiding the research in order to highlight the researcher's motivation for methodological approaches used (Hays & Wood, 2011).

At one end of the continuum sits positivism, which states that there is a real world we can learn about through the use of scientific methods, known as naive realism (Richardson, 2003). Positivism posits that a phenomenon itself directly determines our perception of it and that the external world determines absolutely the only correct view that can be taken of it (Denzin & Lincoln, 2005). At the other end of the continuum sits radical social constructionism, which suggests that pure experience or truth (relativism) do not exist and the aim of research is to identify ways in which cultural and discursive structures and resources construct reality (Willig, 2008; Braun & Clarke, 2013). There are a range of positions that sit between the positivist and social constructionist position, these include: phenomenological, hermeneutic and critical realist.

This research adopted a phenomenological position, as it is concerned with lived experience and ways of capturing it that are subjective and involved (Langdridge, 2007). Phenomenology relates to individuals' subjective experiences and is concerned with the quality and texture of experience (Willig, 2013; Langdridge, 2007). However, rather than a descriptive phenomenological approach, the position taken was influenced by hermeneutic versions of phenomenology, which are interpretative. Humans interpret and understand their world by formulating their own stories into a form that makes sense to them; therefore, the interpretation of participants' meaning-making activities were central to this phenomenological inquiry (Langdridge, 2007).

The experience of participants exists within a world of people, language, history and culture, and cannot be detached from it (Smith, Flowers, & Larkin, 2009), thus the position taken intends to understand participants' experience in relation to wider contexts. The interpretative and phenomenological position taken intended to generate knowledge about the quality of subjective experience of caring for a partner with dementia, as well as knowledge about its meaning and interpretation within a particular context.

3.4 Why IPA?

IPA is a qualitative approach to research which focuses upon lived experience and individual meaning, particularly when people are having major life experiences (Smith et al., 2009). Therefore, IPA is relevant to this area of research into in how spouses experience and make-sense of caring for a partner with dementia. The research questions are open and exploratory, focusing on meaning and individuals' understanding of their experiences, aligned with IPA's epistemological position (Smith et al., 2009). In IPA, concepts set the scene rather than provide any prescriptive framework. IPA is inductive and uses flexible techniques to allow unanticipated themes to emerge during analysis. In line with IPA, the research questions do not make predictions nor look for causality.

IPA has been informed by three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography. Phenomenology is a philosophical approach to the study of experience, specifically focusing on what "the experience of being human is *like"* (Smith et al., 2009, pg.11). Husserl, a phenomenological philosopher, was interested in how someone might come to know their experience of a given phenomenon in a way that allows them to identify the essential qualities of that experience (Smith et al., 2009).

The second main theoretical underpinning of IPA is hermeneutics, the "theory of interpretation" (Willig & Stainton-Rogers, 2008, p.180). Heidegger explains how our interpretations are founded upon 'fore-conception', prior experiences, understanding, assumptions and preconceptions and therefore new stimulus is viewed in the light of prior experience (Smith et al., 2009). The 'hermeneutic circle' is the most resounding concept in hermeneutic theory and is concerned with the dynamic relationship between the part and the whole; to understand a given part you look at the whole and to understand the whole you look to the part; thus interpretation is a dynamic, non-linear process (Smith et al., 2009). Within IPA, the process of analysis is iterative, therefore the researcher's relationship to the data shifts according to the hermeneutic circle.

IPA involves interpretation, and making sense of what has been said by research participants involves close interpretative engagement on the part of the researcher. A two-stage interpretation process, a 'double hermeneutic', is involved whereby the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osbourne, 2003). The researcher is unlikely to be aware of all their preconceptions, so reflective practice is required (Smith et al., 2009). The aims is to 'bracket' or suspend previous assumptions or understandings and remain open to the phenomenon as it appears. The researcher not only has access to the participant's experience through what they report, but is also seeing this through the researcher's own experientially-informed lens (Smith et al., 2009).

The third theoretical underpinning of IPA is idiography, which is interested in the particular rather than making claims about a group or population (Smith et. al., 2009). IPA involves understanding how experiential phenomena have been understood from the perspective of particular people in a particular context. Thus, IPA uses small, specific and carefully-situated samples.

In summary, IPA focuses on the “detailed examination of human lived experience” (Smith et al., 2009, p.32) and the meanings individuals impress upon it, which are the main foci of this research. IPA is particularly relevant when people are having fundamental life experiences, as the multidimensional, embodied, cognitive, affective and experiential aspects of their response to that experience emerge (Smith et. al., 2009).

3.5 Participants

3.5.1 Inclusion Criteria and Rationale

IPA research recruits purposeful samples of participants who share a particular lived experience and therefore it was important to outline a set of inclusion criteria. Participants are selected on the basis they can give access to a particular perspective on the phenomenon under study and therefore the criteria below were identified so a homogenous sample could be selected (Hefferon & Gil-Rodriguez, 2011).

This research aimed to recruit caregivers who lived with the adult they care for, as non-resident caregivers can have notably different experiences of the caring role (Bruce & Paterson, 2000). Specifically, this research aimed to recruit adults who were married to or in a long-term relationship with the person with dementia, where the relationship pre-dated the development of dementia. In order to understand how dementia caregiving might impact upon such a relationship, the research was particularly interested in relationships that were long-standing and where the partner had dementia for at least two years, ensuring that the participants had both significant experience of caring for their partner, and of dementia.

3.5.2 Recruitment

Participants were recruited through “opportunities” as a result of contacts and “snowballing” which is referral by participants (Smith et al., 2009, p.49). Recruitment proved challenging and, although many organisations were contacted, most were already involved in research and therefore declined. Some also stated that their caregivers seemed to be constantly surveyed and they were therefore reluctant to advertise this research. Furthermore, two participants dropped out of the research, one because they were unable to find time to attend the interview and another because their partner sadly passed away before the interview and chose not to be included.

Following an ethics application and authorisation from the Alzheimer’s Society, their local support services in London and the South East agreed to distribute my poster (see Appendix A). Five participants were recruited this way. One further participant was recruited by posting information about this research on the Alzheimer’s Society online forum. A few other caregivers’ support organisations agreed to distribute the poster and post information online. One organisation invited me to a social evening and support group to talk about this research, and one additional participant was recruited. The challenges of recruitment are reflected upon further in Chapter 5.

3.5.3 Participant Characteristics

Although seven participants were interviewed, only the six described below were included in the analysis. The rationale for excluding one participant from the analysis is outlined in section 3.7.3. All participants were white British women, aged between 63 and 75 years. The partners with dementia were aged between 64 and 80 years and had lived with dementia between 3 and 8 years. All participants had cared for their partner for a minimum of 3 years and all, apart from one participant, lived at home with their partner at the time of the interview and considered themselves full-time carers. One participant's partner moved to a care home 3 years prior to the interview. Five participants were retired and one worked part-time as a tour guide. All of the couples were heterosexual and had been married between 30 and 57 years. Whilst one couple had separated, they still considered themselves to be married. Three partners had Alzheimer's disease, two had Vascular dementia and one Frontotemporal dementia. All participants lived in South East England and were accessing support from a carers' organisation which may have impacted upon their experience and accounts, compared to those not accessing support or living elsewhere. This is discussed further in Chapter 5.

It was not a selection criteria for women only to be recruited and an equal balance of men and women was initially sought; however, only women volunteered to participate. This might have been because there are more female than male caregivers (Baike, 2002) or due to other factors such as gender stereotypes, where women are more likely to identify with the role of carer due to socio-cultural expectations to adopt nurturing roles (Montgomery & Williams 2001). This is reflected on further in Chapter 5. Whilst gender difference was not an intended aspect of the study, and therefore not a central focus of the analysis, it is acknowledged that gendered positioning of the participants inevitably impacted upon their experience. Table 1 provides a table outlining participant characteristics.

Table 1: Participant Characteristics

Name	Gender	Age	Ethnicity	Employment Status	Husband's Age	Years Married	Type of Dementia	Duration of Dementia
Sarah	Female	75	White British	Retired	78	57	Vascular Dementia	8 years
Debbie	Female	75	White British	Retired	80	55	Alzheimer's Disease	3 years
Jill	Female	66	White British	Part-time Tour Guide	78	30	Fronto-temporal Dementia	5 years
Gail	Female	74	White British	Retired	76	40	Alzheimer's Disease	7 years
Mary	Female	66	White British	Retired	78	45 (separated for 21 years)	Alzheimer's Disease	8 years (in care home for 3 years)
Louise	Female	63	White British	Retired	64	41	Vascular Dementia	7 years

3.6 Data Collection

3.6.1 Why Conduct Individual Semi-Structured Interviews?

Individual semi-structured interviews were chosen as they allow for a rich, detailed, first-person account of participants' experiences. Interviews are one of the best means of accessing such accounts, as interaction with the participant allows exploration of their lived experience, enabling the elicitation of stories, thoughts and feelings about the target phenomenon and an intimate focus on one person's experience (Smith et al., 2009).

A semi-structured interview format meant that a set of questions was developed (see Appendix B for interview schedule) to enable the researcher to think explicitly about the material to be covered relevant to the research questions. However, the interview schedule was used to guide, yet not dictate, the interview, allowing for new and unanticipated areas of inquiry to be followed as the interviewee is viewed as the experiential expert (Willig & Stainton-Rogers, 2008; Braun & Clarke, 2013).

3.6.2 Why Include a Visual Methodology?

A visual methodology, photo-elicitation, was incorporated into the research. Photo-elicitation is a technique whereby existing images are used in research interviews (Reavey, 2011). Photo-elicitation is advocated as images evoke deeper elements of human experiences and phenomenology than do words-alone interviews (Harper 2002). Visual methodologies can gain a richer conceptualisation of experience and gain access to meanings and emotions beyond those obtained just by talking (Reavey, 2011). Visual materials can also tell us more about the ways participants make sense of their experiences and can give participants agency over the research process (Willig, 2013). Introducing visual methodologies into qualitative research is consistent with the epistemological position and aims of this research.

Photo-elicitation methods are useful for exploring issues of change, process and life stage and were therefore appropriate for this research (Del Busso, 2011). Participants were asked to select existing photographs representing important aspects of their relationship and caring role to discuss at the interview. Questions about their photographs were incorporated into the interview schedule and photographs were used as a stimulus to gain a deeper understanding of the interviewee and their experience. The photographs were not analysed independently but were used to elicit verbal data for analysis using IPA (Willig, 2013).

3.6.3 Interview Schedule

A semi-structured interview format was used. Interview questions were open and non-directive, encouraging participants to talk at length, and were developed using the steps outlined by Smith et al., (2009):

1. Identify the broad area of interest and research questions.
2. Identify the range of topic areas to be covered by the interview.
3. Put the topics in the most appropriate sequence, using a “funnelling” technique (Smith et al., 2009, p.61) starting with broader questions and working towards more sensitive or specific topics.
4. Prepare appropriate, open questions for each topic area and possible prompts/probes, particularly for those more abstract questions.
5. Discuss the interview schedule and re-draft as appropriate.

The interview schedule was reviewed in supervision and amended following feedback. Due to recruitment challenges, it was not possible to carry out a pilot interview with a participant. Nonetheless, the schedule was practised in advance to ensure familiarity with the questions. It proved challenging to follow the schedule in a way that meant the interview questions were answered and also be led by the participants and hear their story and experiences; this is reflected upon further in Chapter 5.

3.6.4 Interview Process

Once potential participants had expressed an interest in the research, they were contacted to check that they met the inclusion criteria and answer any questions they might have. They were then given an invitation letter (see Appendix C) which further detailed the nature and purpose of the research, including their rights, and then given time to confirm their participation. All participants requested that the interview took place in their home.

At the start of the interview, participants were given time to ask any questions they might have. Participants were reminded of their right to withdraw at any time and that the interview would be audio-recorded. All participants then completed the consent form (see Appendix D). Before beginning, demographic information was collected, the interview process was discussed, and photograph availability confirmed. Participants were advised that the interviewer was interested in understanding their experiences and reassured there was no right or wrong answer (Smith et al., 2009). Interviews lasted between 56 and 126 minutes. A digital voice recorder was used to audio record all the interviews. At the end of the interview, participants were asked how they found the interview process and were given time to ask any further questions.

Most participants had selected four to six photographs they wanted to talk about. The photographs were discussed in the middle of the interview, once a rapport had been established, and various questions were asked, for example, what the photograph meant to them and how they felt looking at the photograph. The photographs seemed very meaningful to the participants and tended to represent various stages of their relationship. For some participants, looking at the photographs was very emotive and this had to be dealt with sensitively. The visual aspect of the data collection appeared to access particular emotions and meanings that were not elicited by talking alone and it was a valuable part of the research process. This is discussed further in Chapters 4 and Chapter 5.

3.7 Ethics

Ethical approval was granted by the University of East London's School of Psychology Research Ethics Committee (see Appendix E). The main ethical considerations for this research are outlined below.

3.7.1 Informed Consent

All participants were initially given an invitation letter which fully outlined the research, prior to agreeing to take part. Participants were given time to read this information and ask any questions they might have. Participants were advised that they were not obliged to take part in the research and had the right to withdraw from the study at any time without consequence. Participants were advised, that if they withdrew after the completion of the analysis, the researcher reserved the right to use the participant's anonymous data in the write-up of the research. Participants then gave their informed consent to take part by signing a consent form.

3.7.2 Confidentiality and Anonymity

Confidentiality was emphasised in the invitation letter. The interview was audio recorded and only heard by the researcher. Audio recordings were transferred from a password-protected Dictaphone to a password-protected computer on the day of the interview and then erased from the Dictaphone. All original material was saved on the password-protected computer or in a lockable cabinet and was not seen by anyone other than the researcher.

Participants’ identity was protected; all written and visual material was anonymous and all names and places mentioned were changed. Participants, or anyone they talked about, were not identifiable in the write up of the research. However, participants were advised that extracts from the transcript of the interview would be seen by the researcher’s supervisor and examiner(s). Participants were also advised in the invitation letter that contact details, audio recordings and anonymised transcripts will be kept securely by the researcher for up to 5 years to allow for the possibility of further analysis.

3.7.3 Potential Distress

It was understood that the research topic might have been a sensitive issue for the participants, so their safety and comfort were respected at all times. The interviews took place in a location that was comfortable, safe and private. They were advised that they could stop the interview, take a break at any time or not answer any particular question. It was checked frequently that they felt comfortable to continue throughout the interview. These issues were particularly relevant, as they had taken time out of a demanding role and, in all interviews apart from one, their partner was in the house at the time of the interview.

It was made clear in the participant invitation letter and subsequent communication that they were being asked for approximately one hour where they could be alone and preferably uninterrupted. It was therefore unexpected, although understandable, that three male partners with dementia were in the house and briefly entered the interview room, whilst another three were present during the whole interview, two of these apparently asleep. However, the person with dementia was never asked any questions by the researcher and did not attempt to participate in the interview. I was acutely aware of the ethical implications of these occurrences and, before proceeding, asked participants if they would prefer to reschedule the interview. The participants all stated a preference for proceeding, mentioning that arranging time alone would be very difficult. I was mindful of the fact that these discussions were taking place by virtue of the nature of the research being conducted.

Professional sensitivity was used to take into account the impact of the interview on both members of the couple when a male partner with dementia was present. At no time during the course of interviews where both parties were present did the partner with dementia show visible signs of distress. No assumptions were made that the person with dementia could not understand what was being said or that they could not potentially be affected by what was said, even if apparently asleep. When potentially sensitive subjects were being discussed, the interview was carefully conducted. This will have impacted upon the data generated and is reflected upon further in Chapter 5. At the end of each interview, time was given to reflect upon how the participants found the interview process, for them to ask any remaining questions and to offer details of local counselling organisations.

In one of the interviews where the partner was present, the participant frequently asked her husband questions by way of confirming what she had said. Inasmuch as he answered his wife's questions and thus effectively became a participant without having given his consent, this interview was deselected from the dataset for ethical reasons. No material from this interview was considered for the analysis.

3.8 Data Analysis

3.8.1 Transcription

All interviews were transcribed verbatim, following the principles set out by Smith et al. (2009), including a semantic record of the interview, so that all words spoken were transcribed. Words were spelt conventionally and notes of non-verbal utterances were taken. See Appendix G for transcription key.

3.8.2 Procedure for Data Analysis

Qualitative analysis is a complex process and the steps outlined by Smith et al. (2009) as a guide for IPA are not linear; the process is intended to be personal, creative and rewarding. The guidelines are a set of common principles and processes that should be applied openly according to the research task at hand. Analysis is an iterative and inductive cycle and the following stages were applied flexibly during my analysis:

Reading, re-reading and initial commenting: In order to immerse myself in the data, I read and re-read each transcript, initially whilst listening to the recording. Listening whilst reading enabled the tone of voice to be captured which helped to decipher some of the meanings behind the content. I noted initial thoughts or observations so that I could return to them at a later stage if necessary.

I then began commenting on the transcripts (see Appendix H), exploring different levels of the data: descriptive comments focusing on content (for example, sadness and loneliness due to changes in husband); linguistic comments focusing on use of language (for example, repetition of ‘loss’ emphasised feelings of loss) and conceptual comments moving to a more interpretative level and taking a more interrogative approach (for example, loss lead to a different kind of relationship that contradicted relationship norms).

Developing emergent themes and searching for connections across emergent themes: Potential themes were then noted, as patterns within the transcripts became apparent. I developed words or phrases that captured my comments, for example ‘loss’, ‘gradual change’, ‘loneliness’, ‘past versus present’, ‘denial of dementia’, ‘complex emotions’, ‘obliged’ and ‘consumed’. I considered discrete sections of transcript, whilst still holding in mind the overall interview. I was mindful that I was gradually moving further from the text and becoming more interpretative, whilst attempting to remain with the data. I found this challenging and reflect further on this in Chapter 5.

In order to draw together emergent themes and produce a structure that included salient elements of an interview, I wrote out my themes and placed together those with similar understandings and meanings (see Appendix I). They were rearranged until they were in a group, had been discarded or merged with other themes due to overlap.

Moving to the next case and looking for patterns across cases: I repeated the steps above for each transcript, bracketing ideas emerging from the analysis of the previous cases when analysing subsequent transcripts. However, the more transcripts analysed, the more challenging this became. Identifying patterns across cases was an iterative process where themes were revisited until a structure was formed. I ‘mapped’ emerging themes to order and cluster them into superordinate themes (see Appendix J).

Different combinations of themes and superordinate themes were trialled and themes with only a small number of participants or that were not relevant to the research questions were discarded. Verbatim quotes providing evidence for each theme were extracted from the transcripts and listed in a table. A story board was drawn up to create connections between the themes (see Appendix K), although this may not identically match the final analysis, which evolved during the writing up phase. A narrative account of the themes is presented in the next chapter.

Chapter 4: Analysis

4.1 Introduction

This chapter provides a narrative account of the three superordinate themes and ten subthemes that were developed, following analysis of the six transcripts. Supporting extracts are provided throughout and all names and places have been changed to ensure the anonymity of participants and their partners. Table 2 summarises the themes. The process of IPA involves engaging in a double hermeneutic, thus it is acknowledged that the themes presented are based upon the researcher's subjective interpretation of the participants making sense of their world; this is discussed further in Chapter 5.

The three superordinate themes offer an interpretative account of the participants' experience of caring for a partner with dementia and aim to capture the quality of the participants' lived experiences. The first theme reflects the ongoing loss and change which seemed to come about due to dementia and created a different experience of the person with dementia and the relationship. Superordinate Theme Two outlines some strategies the women appeared to adopt in response their confusing and overwhelming experience and how there seemed to be a struggle to adapt to their new relationship and partner. Finally, Superordinate Theme Three highlights how participants tended to become consumed and trapped within their caring role and found it challenging to maintain a sense of themselves outside of this position.

Table 2: Summary of Themes

Superordinate Theme	Subtheme
One: Loss and the Emergence of a New Present	One: The fading of someone familiar: "it's just a deterioration of a person that you've known"
	Two: The reduced man: "he's not the man I married"
	Three: The disrupted connection: "it's not as a marriage should be"
	Four: Destabilised relationship roles: "it's not like husband and wife"
Two: Navigating a New Reality	One: Blame and denial: "sometimes I don't know whether he is putting on these symptoms"
	Two: Dividing time and privileging the past: "that's my lovely husband as he was then"
	Three: Denying and underplaying complex emotions: "I mustn't think about it because then I'll get depressed"
Three: Becoming Devoured for Caring	One: A submerged self: "you're just absolutely consumed by it all"
	Two: Caring as obligation: "that's the duties of a wife"
	Three: Isolated and neglected: "you feel like you're the only one in the world"

4.2 Superordinate Theme One: Loss and the Emergence of a New Present

Theme 1 highlights how, due to the changing nature of dementia and the appearance of someone different, there was a sense of loss and a pressure for the women to adapt to a different partner and relationship. The loss tended to be experienced as a gradual decline of both the individual and the relationship through which new partner and relationship seemed to emerge.

4.2.1 Subtheme One: The fading of someone familiar: “it’s just a deterioration of a person that you’ve known”

Typically within the women’s accounts there was a sense of loss with the worsening of their husbands’ dementia and a deterioration of a person that was once familiar. When Debbie was asked what dementia meant to her and how she imagined the future, she described the loss of a person once known:

> Extract 1: Debbie
> It’s about loss. I’ve lost the person I knew. The family have lost their dad. So dementia to me is loss. The whole loss of it. They’ve lost their dad. They see him in another light. They see him, what he can do, what he can’t do, surprised at some of the things he can do, surprised at some of the, the way[s] he can answer a question that they’ve put to him or the way he responds. So it is about loss. Yes, it’s loss, just complete loss of all of it. (Lines 121-129)

The repetition of the words ‘loss’ or ‘lost’ nine times in this extract exemplified Debbie’s feelings and yet there seemed to be a contrast between a ‘complete loss’ and her children’s ‘surprise’ about some of the things that her husband could do. Therefore, whilst Debbie described a ‘complete’ and ‘whole’ loss, there also seemed to be a new experience of her husband which was perhaps unexpected and confusing. The way in which Debbie’s husband was viewed in ‘another light’ suggested there was a contrasting experience of him in the present and that he had been illuminated and made visible in a new way. It suggested that whilst there was a loss of the known, there seemed to be an emerging, different way of knowing for Debbie and her family. Debbie elaborated later in the interview:

> Extract 2: Debbie
> Well, from the day I knew he had the illness it was going to be a long bereavement. […] Yeah, very, very long one. It's just the deterioration of a person, a person that you've known. (Lines 1143-1147)

The way in which Debbie described her experience being like a 'long bereavement' and 'deterioration' suggested, in her experience, the perceived changes happen slowly and there is a gradual movement away from and crumbling of someone who was 'known' to someone very different. There was a sense that Debbie prepared herself for a loss from the beginning, which may have prevented her from relating to her experience in any other way.

When Gail explained some of the difficulties she experienced with her husband, specifically how he often did not want to get out of bed, she described the changes as being a 'deteriorat[ion]' of the person that he was. The following extract is part of a post Gail put on an online forum, which she read to me during the interview:

> Extract 3: Gail
> For the last three months, we've had more bad days than good days. On his black days, he doesn't want to get out of bed and literally will stay there all day. When he does get up, he will sleep in the chair. Encouragement on my part is just no good. It really just wears me out. So I let him be and leave him to sleep, but is this right? It is all so terribly sad that such a gentle and intelligent man has deteriorated in this way. (Lines 578-587)

As with Debbie, Gail also experienced the changes in her husband as a 'deteriorat[ion]' suggesting she experienced him as disintegrating and falling apart. There was sadness associated with the deterioration of Gail's husband and her use of the phrase 'black days' suggested darkness and heaviness. Like Debbie in Extract 1, she used a change in light to describe her new situation and the contrast between light and darkness perhaps represented the past versus the present, which seemed to have led to a different view of her husband, one where he cannot be seen. The way in which Gail positioned her husband as not ‘want[ing] to get out of bed’ suggested she perceived he was making a choice and was doing it purposefully. This implied an underlying feeling of blame and anger towards her husband, implicitly suggesting she viewed him as someone who could be almost controlling, as opposed to the ‘gentle’ husband that previously existed. As with Debbie’s husband, there appeared to be a movement from someone who was clearly defined to someone very different. There appeared to be an implied conflict between Gail and her husband, which led Gail to ‘let him be’ and ‘leave him’, suggesting she had moved away and given up on her husband. The way in which Gail questioned ‘is this right?’ suggested she was doubting her own judgement in how to deal with her husband’s new behaviour. Gail explained how it ‘wears me out’ which emphasised feelings of exhaustion and suggested Gail felt used beyond repair or effectiveness. Gail’s account suggested that all she could do was observe her husband deteriorate and that she had no control.

When explaining how her husband does not understand what is happening and gets frustrated, Mary described observing her husband disappear:

> Extract 4: Mary
> I sit on Mouse Hill station, you know, waiting for the train back to Luton High Road. And you just think, “Oh, this is so hard.” It is very hard to watch someone you love disappear. I suppose that’s the, that’s the only word I can use. They, they’ve disappeared, yeah. (Lines 118-123)

Mary’s description of ‘disappear’ being ‘the only word’ was evocative and suggested she felt empty; as if all her other words had vanished and she too was diminishing. The train station scene outlined by Mary perhaps symbolised the journey she was on and was evocative of the constant movement and change she experienced. The coming and going of trains could be metaphorical of her experience of disappearance: that she drew on the image of waiting for a train could have suggested her own identity was waning, along with her husband’s disappearance. Mary returned later to the idea her husband had disappeared:

> Extract 5: Mary
> Yes I mean, you know, he’s always been very interesting, he’s always been very, very political, always been very active in the Labour Party and things like […] so yes, yes, it’s a different, different relationship but, um, he’s still my husband and it’s just very sad watching a human being disintegrate, disappear. (Lines 561-575)

The idea that Mary’s husband had ‘disintegrate[d]’ suggested her husband had broken into pieces and that this was something Mary had observed but was out of her control. Mary’s description of ‘disintegrate, disappear’ seemed to represent the process she experienced; she witnessed her husband crumble but there were still elements of him left and then he faded until he was gone. The way Mary described her experience as ‘very hard’ (Extract 4) highlighted how challenging it was and, as with Gail, Mary highlighted her sadness. She described how he was ‘interesting’ and ‘political’ in the past compared to the present, where his disappearance created a ‘different relationship’.

Overall, participants’ descriptions suggested that, in their experience, there was a crumbling of their husband’s original identity into someone very different and unknown. Their accounts tended to highlight how this was a process that happened gradually over time and there was a continual ebbing and fading of a person they once knew.

4.2.2 Subtheme Two: The reduced man: “he’s not the man I married”

Within the women’s accounts, there appeared to be a focus upon the characteristics and attributes their husbands no longer possessed, which seemed to underpin and accentuate their sense of loss. For Sarah, the changes in her husband were so apparent, she was explicit that he was not the same person she married:

> Extract 6: Sarah
> Well, I am his wife, but it’s not [laughing]…. He’s not the man I married. (Lines 66-67)

Sarah laughed when speaking these words, which seemed to be one of her ways of coping when painful emotions were experienced during the interview. There was a feeling of frustration and sadness in this moment and Sarah’s laughter seemed to contradict the significance of what she was saying, perhaps masking her true feelings. Sarah quickly moved on and I wondered, if she hadn’t laughed in that moment, whether she might have broken down into tears. Sarah’s husband was asleep in the same room throughout the interview; this seemed poignant, as it suggested that she was constantly being reminded of how different he was.

The way in which Sarah denied her husband was the man she married symbolised how significantly she experienced the changes and, therefore, how difficult it was for Sarah to integrate her experience of him in the past with her experience of him in the present. Whilst he was no longer the man Sarah married, it was not clear who he had become, other than someone she cared for. The way in which Sarah’s husband was asleep seemed to represent how dormant and inactive he was, in contrast to Sarah, who seemed to be active and alert within the relationship.

Some participants compared their present husband with who they were in the past. For example, when talking about how retirement was not as she expected, Sarah spoke about the practical tasks her husband used to do:

> Extract 7: Sarah
> And I can’t say we enjoy our retirement. I don’t say I’m miserable; I’m more sad and lonely because I don’t like what’s happened to him. And there’s not…you can’t reverse it, you can’t do anything about it at all, you know. And he’s always been one, he’d climb roofs, he’d do everything for you. So that again I’ve missed a lot of, you know. (Lines 166-173)

Sarah described feeling sad and lonely due to her husband’s dementia. The way in which she spoke about herself as being unable to ‘do anything’ suggested that she felt impotent. There seemed to be a contrast between Sarah’s husband doing ‘everything’ for her in the past and Sarah who felt unable to ‘do anything’ in the present. Sarah positioned her husband almost as a hero in the past; this might have accentuated the change she experienced that could not be ‘reverse[d]’. The idea of Sarah’s husband climbing roofs, not just one roof but multiple, seemed to symbolise the great heights he would go to for her compared to Sarah who perhaps now felt fixed on the ground and powerless.

When looking at a picture of a family Christmas, Gail spoke about the practical tasks her husband was no longer able to do:

> Extract 8: Gail
> Well, again, it’s when he was well and when he was jolly. And he was quite the handyman in that he was very fastidious. Like he used to look on his house as though it was the ship and he used to have this little book and go around saying, “Oh, that needs doing,” or “That needs doing.” Well, now, it’s the complete opposite. (Lines 981-987)

This extract highlights how Gail focused upon what her husband was no longer able to do or the characteristics he no longer retained, particularly those things that might have affirmed his stereotypical masculine identity. In Extract 8, Gail used the metaphor of a ship suggesting her husband was once like a captain in control who held power over the course the ‘ship’ was sailing. The image of a ship seemed poignant and symbolised something sturdy that was capable of withstanding great storms. However, this was suddenly contrasted with ‘now it’s the complete opposite’ which suggested that her husband had lost control and the ship had floundered.

Like Gail, Louise also spoke about the practical tasks her husband could no longer do. When asked what it was like to see her husband feeling down, Louise described:

> Extract 9: Louise
> Horrible. Because he was always a bloke that could do anything. He was very good at his job. He was very good at being an electrician. He was…he loved his job at the Tower of Leeds. He could do plumbing; he put the central heat in this house. He would do anything. Plastering, wallpapering, painting, anything. New tap, Neil's your man, new bath, Neil's your man. […] he was so, so capable. […] So capable and it's just horrible to see that he can't…he can't do that stuff now. (Lines 360-372)

Again, Louise seemed to have an overtly masculinised view of her husband in the past as a 'bloke' who could do all the practical tasks around the house. The fact Louise mentioned her husband worked in a 'tower' perhaps emphasised how powerful and authoritative she perceived him in the past. Louise's husband seemed to be a reliable and consistent figure in the past, perhaps someone who provided her with stability.

There appeared to be a divide based on time between who their husband 'was' and who they were 'now', suggesting discontinuity. The way in which these women described their husbands in the past as 'capable', the 'handy man', someone who would 'do everything', suggested they were idealised which perhaps accentuated their perceived sense of change. Portraying their husbands as 'jolly', 'fastidious' and 'capable' in the past suggested there was a strong sense of who he was and a strong connection with him in the past, compared to the present. Gail and Louise's use of repetition and their fast pace in these extracts evoked feelings of excitement and images of their husbands as someone adored in the past, which was demolished by the end of the extracts and contrasted with the 'now', where they were so reduced.

The interview set-up was indicative of a very complex experience for the participants; in all interviews, except one, the participant's partner was present during at least part of the interview. This created a challenging dynamic at times for both the participants and interviewer; this has been reflected on further in Chapter 5. Therefore, whilst there was a loss and decline of who their husband was, the interview set-up suggested that the participants were constantly reminded of who their husband had become and he continued to have a strong presence in their lives.

4.2.3 Subtheme Three: The disrupted connection: "it's not as a marriage should be"

Generally, maintaining closeness and connection with their partner seemed important. As dementia disrupted the familiar past relationship, the women seemed to be faced with adapting intimacy, creating a different kind of relationship. When asked what intimacy meant to her and how it might have changed, Sarah described the lack of 'sex' with her husband:

> Extract 10: Sarah
> You know, there's no intimacy now. Only…oh, well kiss him and that [inaudible], but [sigh]…how to explain it? It's not as a marriage should be. That's all I can say. I can't, I can't describe it any other way. As I said, I more care for him and there's no real response. […] Oh, there's no sex at all now, at all. There used to be plenty, but there just isn't any more. That's the difference now. It's like I said, I'm more a carer in that respect than a wife. (Lines 1031-1073)

Sarah found it difficult to talk about her relationship at times which perhaps reflected her struggle to accept the level of change. Her description of 'that's all I can say' suggested she felt lost for words, which happened on numerous occasions during the interview. Whilst Sarah made attempts to maintain intimacy with her husband, it seemed to be one directional and there was 'no real response' suggesting she felt rejected. The way in which she seemed to be commanding herself to 'kiss him' or 'care for him' implied that she perhaps felt obliged to do these things due to marital convention, but was detached from her experience. The loss of a sexually intimate relationship seemed significant and there seemed to be a contrast between ‘plenty’ of ‘sex’ in the past to nothing in the present. Sarah described her relationship not being ‘as a marriage should’, which highlighted how it did not fulfil her expectations of a married relationship and suggested a different kind of relationship. Lack of sexual intimacy seemed to have led to a shift in how Sarah positioned herself within her relationship, also highlighted where she stated, ‘I’m more a carer […] than a wife’.

Gail also emphasised how her intimate relationship had significantly altered, suggesting it contradicted relationship expectations:

> Extract 11: Gail
> It’s changed tremendously. No, I…you know, at times, as I said, I don’t want to have a little boy. I want to have a normal…not necessarily sexual relationship, but I would like to have had a really loving relationship, to share things, to do things together that one enjoys, to laugh, to go out. (Lines 1174-1180)

The way in which Gail described ‘tremendous[ly]’ change, seemed to symbolise the enormity of her relationship transformation. Gail longed for a ‘normal’ intimate relationship, suggesting that her present relationship contradicted expectations and assumptions about how intimacy should exist within a marital relationship. This linked to Sarah’s description in Extract 10, suggesting a different kind of relationship which is challenging to adapt to. Mutuality seemed an important aspect of a relationship that was absent for Gail, suggesting distance and the loss of certain ideals. Gail’s husband was described as a ‘fastidious’ ‘handyman’ (see Extract 8) in the past but was now positioned as a ‘little boy’; this perceived regression seemed to be a barrier to intimacy. There was a denial and rejection of her husband in the present when Gail stated ‘I don’t want to have a little boy’. Gail elaborated below:

> Extract 12: Gail
> Well, you just haven't got that, that same…that's gone what you did cherish because the intimacy of how you are with each other because it's one-sided in that you've got to make the effort. (Lines 1216-1220)

In the extract above the idea that, what was cherished has 'gone' and that intimacy is not the 'same', highlighted the sense of loss and difference within Gail's relationship. Like Sara in Extract 10, the fact that it was now 'one sided' suggested the relationship had become unequal and Gail emphasised the energy she used in trying to maintaining her relationship.

Louise also highlighted how her ideas of how intimacy should be, no longer fitted with her current experience:

> Extract 13: Louise
> I think [pause], hard to put it all into words. When you're in a, when you're in like a loving relationship, you kind of like you might touch each other in a certain way or look at someone in a certain way and [pause], but I, I can't do that anymore. I can't, I can't…I don't very often. I do hug him, but I don't touch him or – I'm frightened he's going to hear. (Lines 1382-1388)

The way in which Louise explained how it's 'hard to put it all into words' highlighted how challenging it was for her to talk about intimacy. Despite finding it challenging to talk about, she acknowledged its importance, as she felt it was a crucial aspect of a relationship. Louise was concerned about her husband in the next room hearing and we therefore returned to this topic once he had gone into the garden.

It seemed that there were expectations about how intimacy and love are expressed within a relationship which did not fit with Louise's current experience. Although Louise might 'hug' her husband, it seemed that other types of intimacy were absent. Louise's statement that she 'can't' be intimate with her husband in particular ways, implied a rejection of particular types of intimacy in her relationship in the present, perhaps linked to the transformation of her husband. The repetition of ‘I can’t’ seemed to emphasise how challenging this was to accept. Ideals about how love should be expressed in a relationship which did not fit with Louise’s present experience, suggesting a different kind of relationship experience for Louise. Later in the interview, Louise elaborated further:

> Extract 14: Louise
> It’s my job to care and I know he’s changed and I know he’s not the man that I married, but it’s not my job also to make sure he’s happy in a sexual way. […] It’s hard and it’s actually quite hard to voice it because those things are quite private and it’s not easy to say those things that you don’t have an intimate relationship with your husband because that part of it is not natural. (Lines 1675-1684)

It seemed the significant changes in Louise’s husband were a barrier to maintaining a sexually intimate relationship and that sexual intimacy did not fit with the role of caregiver. Louise was the youngest participant, which perhaps meant that the absence of a sexual relationship with her husband was more challenging to accept and adapt to, emphasised by the idea that it was ‘not natural’, suggesting her present relationship was experienced as abnormal.

Some participants described how they maintained closeness within their relationship in alternative ways. Mary described how she made physical contact with her husband as a way of expressing love towards him:

> Extract 15: Mary
> I still very much touch him. So, for example, when we sit next to each other, on these little settees in the big sitting room, when they have a little service on Fridays. I always hold his hand. I always stroke his hand, or I just put my hand on his lap or something. So, and I always kiss him hello and I always kiss him goodbye. […] I think, well, even if he’s not bothered by it, I need to show that I still care. And that’s my outward sign I suppose of showing that I still love him. Yeah. I’ve met very different sort of love as well. Well, love always does change, you know. Love grows and recedes and does all sorts of things, doesn’t it? (Lines 1221-1237)

This extract emphasised how, for Mary, intimacy had evolved within her relationship. Mary had separated from her husband although she still considered herself married and was close to him. In being separated, Mary had perhaps already transitioned from expecting sexual intimacy with her husband. The way in which she described love as ‘grow[ing]’ and ‘reced[ing]’ suggested intimacy had changed as her husband’s dementia developed. It seemed that Mary’s understanding of how love can change, enabled her to experience intimacy in alternative ways. Mary highlighted how, whilst she was working to maintain connected to and express intimacy towards her husband, it was ‘different’ now compared to the past. Mary seemed to connect with her husband in different ways, taking into account her husband’s dementia. The way in which love and care was expressed outwardly, for example by holding or stroking his hand, suggested that there was perhaps a more tangible expression of intimacy within the relationship now. It seemed Mary maintained intimacy with her husband for her own need and did this, despite her husband being ‘not bothered’. This indicated that she was perhaps trying to preserve the relationship and maintain some normality.

Debbie highlighted how intimacy had got ‘stronger’ within her relationship:

> Extract 16: Debbie
> Well, in a way…no, it hasn’t changed at all. I think it’s gotten just that bit stronger. […] I suppose knowing how he was and how he is now, there’s more tenderness in the transact[ions] you know now, the way we are. But he likes to be cuddled and things like that. It means so much to him, so there’s more of that going on, you know, as he goes along, you know, day to day. […] It’s nice because then I have a communication with him then. You know, it’s all about communication with him, the intimacy part of it. (Lines 1049-1063)

The way in which Debbie described there being more ‘tenderness’ now suggested there was more affection and sensitivity in Debbie’s relationship in the present. In contrast to Mary’s experience, maintaining intimacy seemed to be important for both Debbie and her husband. Debbie seemed to maintain intimacy within her relationship by physically connecting with her husband, for example by cuddling him. As with Mary above, there appeared to be a willingness to experience difference and maintain intimacy in alternative ways. Connection and closeness tended to be crucial aspects of a marital relationship and dementia presented significant challenges for how this was maintained. For some women, the current relationship seemed to contradict relationship norms which, coupled with the absence of sexual intimacy, created a different relationship.

4.2.4 Subtheme Four: Destabilised relationship roles: "it's not like husband and wife"

Central to some of the women's accounts was how their relationship was no longer reciprocal and their husbands had become almost wholly dependent upon them. The women tended to gradually adopt the role of both husband and wife, destabilising accepted relationship conventions. The lack of reciprocity seemed to create a sense of loneliness for some of the women, also highlighted in Subtheme Three, which, together with the loss and distance between them, seemed deeply affecting.

When asked how her relationship had changed, Louise spoke about how she missed the 'reciprocal caring' and how her husband no longer did certain things:

> Extract 17: Louise
> I don't want to sound really horrible, it's not less meaningful but it's not a full married relationship. It's me caring for him and him not caring for me because he can't care for me. So I have to care for myself. In a proper marriage, your husband… you would have that cross-over, that caring for each other, wouldn't you? […] I miss that. I do miss the caring, the reciprocal caring. […] I will care for him because he's my husband. And I have to put into the back of my mind that it's not that he doesn't want to care for me. He can't care for me. He's lost that. He's lost that ability to care for me. […] It's nice to feel loved and cared for. It doesn't have to be great show of love and affection. Just the little things in life actually are just as meaningful. Knowing when your birthday is, buying you a bunch of flowers. Neil always used to buy me flowers every week. Every week. (Lines 759-794)

The way in which Louise stated ‘I don’t want to sound really horrible’ suggested she felt guilty about expressing her feelings and perhaps minimised her experience as a result. The lack of exchange and reciprocity was highlighted in Louise’s account where she talked about the absence of a ‘cross over’ in her relationship. The way in which Louise described her marriage as not being ‘a full married relationship’ or ‘proper marriage’ highlighted the sense of difference which appeared to be underpinned by constructions of a normative couple relationship, also outlined in Subtheme Three. Reciprocity and being cared for appeared important and the absence of these things meant that her relationship wasn’t ‘proper’. Louise’s relationship changes seemed to create conflict and confusion; Louise perhaps questioned whether her husband did not want to care for her, suggesting abandonment, a thought she seemed to supress, and the way in which she reminded herself ‘he can’t care for me, he’s lost the ability to’ suggested she was rationalising her complex experience.

There was a sense of loss linked to what was absent from Louise’s relationship, for example her husband buying her flowers every week. The repetition of ‘every week’ seemed to emphasise the consistency of how things were in the past, compared to the unpredictable present and also showed she was perhaps nostalgic for a time where her husband played a significant role in their relationship. Louise was the youngest participant (63 years old) and was more than 10 years younger than some of the other participants. Due to Louise’s age, it is possible that there was a greater sense of loss experienced which was more challenging to adapt to because her relationship was derailed earlier, compared to other participants.

When asked whether her relationship had changed, Debbie highlighted how she now had to make all the decisions in the relationship:

> Extract 18: Debbie
> I don’t like the constant, constant having to push him around, make decisions for him. When we make a decision together and it’s good, it’s lovely, really nice, but they're few and far between. (Lines 666-670)

This extract highlights the one directional nature of the relationship and, like Louise’s relationship, a lack of reciprocity. The way in which Debbie described not liking the constant ‘push[ing] him around’ indicated the struggle she experienced within her relationship and the perpetual effort she exerted. It appeared that there was a shift from sharing of responsibility and decision making in the past, to pressure and responsibility falling on Debbie in the present.

Sarah highlighted the disparity between her relationship now and how a ‘marriage should be’:

> Extract 19: Sarah
> Well, as a married couple you go out together […] So when he’d come to retirement, he was home, I was home, that’s when we thought, “Oh yeah, we can go here, there, and everywhere.” Instead of that, we can’t go nowhere now. We can’t even go on holiday now. He can’t stand. I can’t take the form of moving him from one place to the other with me. So, you know, it is like a separate life. (Lines 176-188)

And later

> It’s not like husband and wife where you decide together and you talk about things together. I’m the decider now. I have to make all the decisions for everything now, so. (Lines 493-496)

Sarah indicated how there were certain ideas and expectations of how a marriage should be experienced that did not fit with her current experience, also outlined in Extract 10 by Sarah. Sarah highlighted how they were unable to go anywhere, which suggested she felt restricted and stuck. As with Debbie, there seemed to be a lack of reciprocity and joint decision making. The way in which Sarah described being the ‘decider now’ suggested that she had adopted multiple roles within the relationship, with more pressure placed on her. It seemed that Sarah’s experience of having plenty in the past, contrasted with nothing in the present, highlighting the extent of her change and how the present felt empty.

When asked how her relationship might have changed, Gail also highlighted how there was now an unequal sharing of roles:

> Extract 20: Gail
> Over the years he's sort of more and more leaning on me that I've been sort of taking his role. And of course now with his illness, I'm doing the whole lot you know. (Lines 727-730)

The word 'leaning' emphasised how her husband had become more reliant upon her, suggesting there was more pressure and responsibility placed upon Gail within her relationship now, compared to the past, and less sharing of roles and responsibilities. This extract suggested that the process began before her husband's dementia, but worsened with his 'illness'. The way in which Gail described her husband leaning on her 'more and more' emphasised the increased weight and burden she was holding. Gail spoke about taking her husband's 'role' within the relationship and there was a sense that she was overwhelmed by having to adopt multiple roles and suggested that relationship roles underpinned the women's different experience of their relationship in the present.

In contrast to other participants, when asked whether her relationship had changed, Jill described:

> Extract 21: Jill
> No. Don't think it's changed. We see more of each other now. He is much more…he is dependent on me. No I mean, his life has changed hugely much more than mine. (Lines 195-198)

Initially, Jill was explicit that her relationship had not changed. However, she then elaborated how her husband was 'dependant' upon her, which seemed to be in line with a reduction in reciprocity and increase in pressure, outlined by other participants. In contrast to other participants, Jill stated her husband’s life had changed more than hers. Jill seemed adamant not to let her husband’s dementia change her life, this is elaborated on in Theme Three.

Summary: Theme One outlines the significant loss and change experienced in multiple areas. For many women, loss seemed to be experienced as a gradual disintegration of one way of knowing their partner, through which a new, different way of knowing seemed to emerge. There tended to be a disconnect between past and present experiences, related to an almost idealised sense of who their partner was before, compared to the present, where he was experienced as so much less. A complex range of emotions were experienced including sadness, loneliness and hopelessness, coupled with a perceived lack of control. Dementia seemed to cause vast upheaval to something previously constant for the women and there was a conflict between the stable past relationship and their different relationship in the present. Absence of a sexually intimate relationship and reciprocity seemed to contradict relationship conventions and adapting to a new kind of relationship appeared challenging.

4.3 Superordinate Theme Two: Navigating a New Reality

Participants appeared to find the transition difficult; moving from a familiar relationship, to a very different present, where they must cope with the emotions that are experienced. The women seemed to respond to, and make sense of, their experience in various ways such as: blaming their husband, privileging the past, and underplaying their emotions.

4.3.1 Subtheme One: Blame and denial: “sometimes I don’t know whether he is putting on these symptoms”

The confusion associated with the participants’ new experience appeared to be offset by some participants by blame. For example, Gail wondered whether her husband was ‘putting on’ his behaviour and symptoms:

> Extract 22: Gail
> Unless I specifically keep telling him “I think it’s time you had a shower or bath,” he wouldn't. He just has a wash. Why he can’t be bothered, I don’t know. Sometimes I don’t know whether [sighs]…whether he’s, you know, putting on these symptoms, you know. Alright, I mean I understand the forgetfulness, you know, things like that, but sometimes the behaviour, you know, it’s…whether he’s sort of trying to sort of, you know, obtain more attention out of me. You know, I feel emotionally absolutely exsanguinated. You know, it’s though he’s taking everything from me. […] I, you know, begin to wonder as to what is true and what isn’t true. But it’s…oh, it’s…it is such an incomprehensible illness that a lot of the behaviour that I don’t understand… (Lines 141-185)

Gail described her experience as ‘incomprehensible’, how she didn’t understand her husband’s behaviour and she questioned ‘what is true’ which highlighted how her experience was confusing. His ‘forgetfulness’ seemed understandable but other behaviour appeared more difficult to make sense of. The way Gail questioned whether her husband was ‘putting on’ his symptoms suggested denial, that she perhaps didn’t believe the changes in her husband were entirely associated with dementia. Gail positioned her husband as someone who had choice and agency over his behaviour and suggested that he used this as a way of manipulating her and gaining attention. Gail’s use of the word ‘exsanguinated’, the process of blood loss severe enough to cause death, was powerful and appeared symbolic of how drained she felt to the extent that it was killing her off. The way in which she described how her husband was ‘taking everything’ from her suggested she felt empty as if he had taken advantage of her and she had nothing left to give.

Jill spoke about how her husband's behaviour deteriorated when he went into respite. During the interview she turned to her husband and told him that if he were to 'work at it' he could change his behaviour:

> Extract 23: Jill
> It didn't do him much good. That is unfortunate but I don't regret…I don't feel guilty about it. I think if you were to work at it Peter, we could get back a bit more of what you used to be like, a few months ago. Are you listening? (Lines 235-239)

As with Gail, Jill's response to her husband's behaviour suggested that he had choice and control, with a sense of blame directed towards her husband. Jill's husband was present during the interview (mostly asleep) and Jill presented as angry about her experience; I wondered whether she wanted her husband to hear how difficult her own experience was. It was difficult at times during the interview to hear the intensity of Jill's feelings, I wanted to protect her husband and I also wondered whether my grandmother experienced similar feelings, as a result I had the urge to move the interview on and did not want to probe deeper. In comparison to other participants, it seemed that Jill and her husband had a difficult and distant relationship prior to his dementia, therefore I wondered if this compounded her feelings. Jill further alluded to the fact that her husband had choice over his behaviour in the extract below:

> Extract 24: Jill
> Well I think, you know, life's for living. Just because he's decided he's not going [out] or just happens he is no longer in any way living a meaningful life, I don't need to go that way. And so, you know, when things happen, well, I need to go out, I want to go out, I go out. (Lines 146-151)

The way in which Jill stated that her husband 'decided' he was not going to live a meaningful life suggested that he had actively chosen to behave in this way and there seemed to be a resistance to accepting her husband's dementia. Aged 66, Jill was younger than some of the other participants and was adamant that she was not going to give up meaningful activities. This is elaborated on further in Theme Three. Jill's repetition of 'I need', 'I want', 'I go' seemed powerful and emphasised how adamant she was about not giving up her freedom. She seemed to be rebelling against the restrictions and rules that her husband's new behaviour had imposed upon her life. This was in contrast to Sarah, where, in Extract 19 she spoke about not being able to 'go anywhere', highlighting a conflict between being free versus being constrained by dementia.

Such a strategy was also apparent in Louise's extract where she thought her husband used his behaviour as a 'bargaining tool':

> Extract 25: Louise
> Sometimes, he might use it as a bit of a…I don't know, to get me to do stuff and that…you know, I can't remember, can't do it. […] I can't…can't do that. Sometimes, I think, you know, "just push yourself a little bit" and he won't. […] A bit of a bargaining tool. Yeah. (Lines 54-63)

Louise's description of how her husband used his behaviour as a 'bargaining tool' positioned him as someone manipulative and controlling, similar to the understanding held by Gail. Louise highlighted how she wished her husband would 'push' himself but how he chose not to, again suggesting that she viewed him as having choice over his behaviour. There was a sense of anger and blame in this extract associated with her husband's behaviour.

Gail expressed some of the complex emotions she experienced:

> Extract 26: Gail
> Sometimes I don't love him. I hate him at times. You know, I…well that's a bit harsh to say that. Resent, you know, that he's taken our life away. You know, poor man, I know he can't help it, but you know. (Lines 313-318)

And later on

> But at times I don't. I don't want to be bothered with him. I, you know, if he wants to stay okay, great, that means it's giving me a break if he's in bed or

> whatever. I can get out or, you know, because otherwise…because when he's here, you know, he's trying to sort of get every emotion, every breath out of me. I do, I feel exsanguinated. There's just no…and you write these silly little notes like, you know, oh, I'm dancing, he'll say, "I've gone to bed," and he'll say, "Love you," such and such. I thought mate you don't know what the word love means, you know. But that's, that's childish because he's like a child. That's the way he's portraying it. (Lines 1227-1241)

Gail explicitly described resentment towards her husband for taking their life away, as if he had stolen it from her and she was powerless. The way in which she described feeling hatred towards her husband at times seemed to signify the intensity of her anger, however this was quickly minimised by Gail and she seemed to find it difficult to acknowledge the strength of her emotions. Furthermore, these extracts further suggested that Gail viewed her husband's behaviour as exhausting and that her husband was actively trying to drain her of all emotion and energy. The way in which Gail stated 'I don't want to be bothered with him' suggested that there was a rejection of her husband in the present. Viewing her husband as being 'like a child' possibly prevented her from relating to him as a partner and experiencing his behaviour in other ways.

Overall, there was a sense that the changes experienced resulted in a very confusing and foreign present. One strategy that some of the women used to make sense of the confusion was to blame their husband for their behaviour and position them as someone who had agency and control over the changes, rather than attributing them to dementia.

4.3.2 Subtheme Two: Dividing time and privileging the past: "that's my lovely husband as he was then"

The participants' various relationships to the photographs highlighted the dichotomy between who their husband was in the past and who he is in the present. As alluded to in Theme One, some participants seemed to find it difficult to integrate the past with the present. When exploring a picture of her wedding day, Sarah described how it represented her husband as he was ‘then’ which emphasised her different experience of the past compared to the present:

> Extract 27: Sarah
> That’s my lovely husband as he was then cutting our wedding cake. (Lines 913-914)

Moreover, when looking at a photograph of when she and her husband first moved into their current house, Gail explained:

> Extract 28: Gail
> We were very happy then. I think just generally I think that’s a really lovely photograph of him how he was. (Lines 1087-1089)

When Debbie was looking at a picture of a family day out, she described:

> Extract 29: Debbie
> Well, how he [husband] was [laughing]. How he was. What he was doing. How well he looked, you know. (Lines 847-848)

When looking at photographs, some participants used phrases such as ‘as he was then’ and ‘how he was’ to relate to their husband. This suggested that a disconnection was created between the past and present and that, in their experience, there was no continuity between who their husband was in the past and who they are now. Their husbands appeared to be experienced as two different people; one before the dementia began and one after they developed dementia.

The women tended to place importance upon the past; a photograph of Louise and her husband when they were just engaged, elicited the following:

> Extract 30: Louise
> it was a really happy day. You, you used to be able to get boats and row around [laughs] this Cannock Waters, but you can't now but you used to be able to do that. And I think that we'd been on a boat or something and it was a really happy nice day. But looking back at it, I just think, oh, he just looks so handsome. No wonder I love him and, you know, it's just like, how lucky was I? (Lines 1085-1091)

The idea of Louise being able 'to get [a] boat[s] and row round' perhaps symbolised her sense of freedom in the past, compared to the present. Louise's relationship to the photograph and her use of the past tense emphasised how she associated her feelings of love, happiness and luck to the past, rather than to the present. The past seemed to be idealised, in contrast to and separate from the present.

When looking at photographs of past holidays Gail described:

> Extract 31: Gail
> Well, because our relationships were strong. That's what I would say. We had a loving and a really good relationship in that one. There wasn't any resentment or any frustrations or anything like that. I mean alright, usual little niggles, but no. I mean we, we had a good marriage in those…in that, yeah. (Lines 1052-1058)

Furthermore, when looking at a picture of a house Mary's family used to live in, she stated:

> Extract 32: Mary
> I think, you know, we were all really happy there and the girls just look back on those years at that house as being, um, really liking it […] it was a nice place to bring up a family and we were very much part of the community. So it's, uh, happy times, those. Yeah. (Lines 916-940)

Within these extracts, representations of the past as being 'good', 'loving', 'strong' and 'happy' further emphasised how the past tended to be romanticised and associated with only positive emotions.

Some participants explicitly expressed a desire to return to a happy past. When asked why the photographs were important, Sarah described a longing to return to the past:

> Extract 33: Sarah
> Just that we were very happy, as I say, it was the best day of our life. And I suppose I'd like to be back in them days […] I wish he was more like that now, but it's gone hasn't it. There's nothing you can do about it. You just have to accept it and make the best of it, you know. I mean look, it's all he's doing, he's soundo [pointing to husband]. (Lines 968-994)

The extract above highlights a conflict between the past and the present. In Extract 33 Sarah made reference to her husband who was asleep in the interview room, highlighting how there were constant reminders of who her husband was in the present. The yearning for, and focus upon, the past contrasted with the constant reminders of the present seemed to create a conflict between the past and the present. The privileging of the past, which suggested that the present was perhaps not acceptable or experienced as valuable.

When Debbie was describing the changes in her relationship, she expressed a wish to return to how things were:

> Extract 34: Debbie
> I just wish that this illness never came upon him, that I could go back and be how we were, you know, him making lots of decisions that I just went along with. And yeah, I wish for that a lot, but I know it's just pie in the sky that sort of thing and, you know. (Lines 676-681)

This highlighted how Debbie longed for her relationship to return to how it was in the past, suggesting the past was privileged and the present was resisted. There seemed to be a desire to undo the changes that had occurred, which indicated a conflict between past and present. There was a longing for Debbie's husband to make decisions, perhaps fitting relationship norms as outlined in Theme One. The way in which Debbie described her wishes as being ‘pie in the sky’ suggested hopelessness, that they were an unattainable dream that could not be reached.

The significant changes experienced by the participants seemed to create a dichotomy, whereby the past was privileged and longed for, compared to the present which seemed to be challenging to transition into. It is important to acknowledge that the interviews were set up to explore the relationship between past and present and therefore would have contributed towards the construction of the narrative in this subtheme, as reflected on further in Chapter 5.

4.3.3 Subtheme Three: Denying and underplaying complex emotions: “I mustn’t think about it because then I’ll get depressed”

Another way in which some of the women coped with their experience was to deny and underplay their emotions. They tended to find it difficult to acknowledge their complex feelings associated with their experience and possibly perceived that the only way to deal with this was to ‘just get on’ with their caring role. When asked how she felt about the change she had experienced, Debbie responded by saying she ‘mustn’t think about it’:

> Extract 35: Debbie
> I don’t want to think about it too much. No [tearful] [pause]. No, I mustn’t. I mustn’t think about it because then I’ll get depressed or fed up. Not depressed because when you’re depressed it carries on. I get fed up, it goes. No, I mustn’t do that. (Lines 1156-1160)

This extract highlighted the struggle Debbie seemed to have with her emotions and how she perhaps coped with her emotional pain by inhibiting thoughts and emotions. Debbie became tearful during this part of the interview, however she quickly moved away from her emotions by stating ‘I mustn’t think about it’, which maybe represented the internal dialogue and battle she tended to have. The repetition of ‘I mustn’t’ seemed to represent the pressure she was imposing upon herself not to think about her situation through fear of becoming ‘depressed’. There seemed to be a dread of her emotions never ending as if they might consume and cripple her. Debbie also used humour as a way of coping with her experience:

> Extract 36: Debbie
> I can say, “Your dad’s out with the fairies,” you know and things like [laughing] you know. We try and humour it all. I have to. It’s so, so awful that I get through with a lot of humour, so does the family. (Lines 79-83)

Debbie explained how her family used humour as a way of coping with how ‘awful’ their experience was. In Extracts 35 and 36, there was a sense that Debbie could not allow herself to experience her emotions and that they were feared. Therefore, by using humour the painful emotions associated with her experience were possibly underplayed. It seemed there was an ongoing battle against the emotional pain that was brought about by the impact of her husband’s dementia.

When asked what it was like to experience the changes in her relationship, Louise responded by saying she ‘can’t think about it’:

> Extract 37: Louise
> I have to let it go. I can’t think about that, it’s there in my memory, so I know that it’s not always been like this. It’s… there has been, you know, those lovely times when, you know, we’ve had the children and, you know, good times. Good holidays. Good times. But you don’t…you don’t forget about them but [pause] your life has taken a different path. It’s veered off a bit. (Lines 799-805)

The idea that Louise’s relationship had taken a ‘different path’ and ‘veered off’ highlighted the diversion from a ‘good’ past. The difference within Louise’s relationship in the present was fuelled by memories of the past, which were associated with ‘good’ and ‘lovely’ times. One way in which Louise coped with this was to try and push her memories away and dissociate her memories of the past from the present. It seemed that the past was something to be forgotten, as it opposed Louise’s different experience of her relationship in the present. However, it did not seem possible for Louise to completely remove these memories from her awareness. By repressing memories from the past, Louise was perhaps attempting to avoid her painful emotions associated with the level of change she has experienced within her partner and relationship.

Gail described some of the feelings she experienced and highlighted how it was an ‘awful admission’ to disclose them:

> Extract 38: Gail
> At times I feel frustrated and resentful which is an awful admission to make and feel terribly guilty for doing so. I just find it so difficult trying to get my head around such an incomprehensible illness where one is incapable of evaluating one’s feelings. […] getting to know this illness more and more, it’s so incomprehensible that…well, one is absolutely, well, struck, dumbstruck really. I mean I…always with me, Andrea, if I have a problem, I will solve it and that’s what’s frustrating. I can’t solve this problem. (Lines 595-654)

This extract further highlighted some of the complex emotions that Gail experienced, including frustration and resentment. Gail described feeling ‘terribly guilty’ for expressing her emotions and the view that they were an ‘awful admission’, suggested that she should not experience them and they were in some way wrong. It seemed there was no allowance for these feelings and that they must be concealed and avoided. The interview dynamic also seemed to reflect this; we were shut away in a small room in the corner of her large house, away from her husband, reflecting how her emotions had also perhaps been shut away. There was a desire to ‘solve’ the ‘problem’ which suggested there was a longing to move away from the emotional pain and a yearning to fix her husband’s dementia, as if he were in some way broken. Not being able to ‘solve’ her problem suggested she felt out of control and powerless. However, Gail described being ‘dumstruck’ indicating how she was so astonished she was rendered speechless. On several occasions Gail defined dementia as being ‘incomprehensible’ which seemed to highlight the complexity of her experience. The way in which Gail explained how she found it challenging to understand an illness where ‘one is incapable of evaluating one’s feelings’ suggested her husband’s inability to understand and express his own emotions might have compounded Gail’s struggle with her own emotions. Gail’s use of the word ‘one’ indicated that she perceived her husband as detached from his emotions.

Another way in which some participant’s coped was to ‘just get on’ which again seemed to avoid their emotional experience and was perhaps the only way in which they could cope. When discussing what it was like caring for her husband Debbie responded:

> Extract 39: Debbie
> Sometimes, you know, I want to escape from it all, but that passes. You know, I think, “Well, this is it.” You know, you’ve, I’ve got to get on. You know, it’s no good moaning. [laughing] Get on with it. Just get on with it, yeah. (Lines 369-373)

Debbie highlighted how she would like to ‘escape’, which suggested that she would like to break free from her restricting or confining experience as if she felt imprisoned; the only way she could cope was to ‘just get on’. Debbie’s laughter in this extract seemed to mask her frustration and her repetition of ‘get on with it’ perhaps represented her internal dialogue and struggle with her experience.

Sarah described how hard it was to talk about her feelings:

> Extract 40: Sarah
> Well, I can’t explain it. It just winds me up. And I just think, you know. I can’t do anything about it. That’s probably what is the crux of it. Once it happens, I’ve got to accept it, but it’s hard to accept. But, you know, it’s not his fault and I don’t blame him for it, but…I don’t know. It’s hard to describe it, how you feel. […] It’s hard to accept what’s happened to us, but at the same time, I just get on with it. As I say, I think about it and get wound up now and again, but other than that, there’s nothing you can do about it so you might just as well get

> on with it and I usually do. […] Well, again I can't explain it. All I know is that, you know, it's not fair really. No, that's how I feel about it because [sigh] we've been through it once with our son [becomes tearful and leaves the room to take some painkillers for a headache]. (Lines 665-685)

It is clear that Sarah experienced complex and confusing emotions about her experience, possibly compounded by her previous experience of losing her son, who had physical disabilities, at an early age. When Sarah described how it is 'hard to explain' and 'hard to describe how you feel' it highlighted this complexity. There was a sense throughout the interview that Sarah was battling against her emotions and trying to prevent herself from becoming tearful to avoid her emotional pain. Sarah seemed to underplay how she truly felt about her experience, although she stated several times how her experience 'winds [her] up' which emphasised a sense of frustration and anger. There appeared to be a conflict between pressure to accept her situation but at the same time, her situation being difficult to accept. The way in which Sarah described that there is 'nothing you can do' and 'you can't alter it' emphasised a lack of control in her experience and therefore, her way of dealing with this was to 'get on'. Sarah had to leave the room shortly after this extract to take some pain killers for a headache, the very fact that she developed a headache could be taken to reflect the emotional intensity of her experience. I wondered if her leaving the room reflected the pain evoked by the interview, therefore I checked whether Sarah felt okay to continue. When Sarah returned to the room, she continued to talk about her experience and again became tearful:

> Extract 41: Sarah
> Well, I don't, talking about it like this, I just feel it's unfair [tearful]. I mean I thought it when it happened, but I don't usually talk about it like this and it don't usually worry me, but sitting, thinking like this, it's just thinking how unfair it is that we went through it once and we should've been enjoying our retirement. I just feel as though I've been cheated if you know what I mean. But again, as I said, there's nothing you can do about it. You just get on with it. […] So I've never really thought about this as deeply as now. […] And I don't like what's

> happened. There’s no doubt about that. But it’s happened and you really…you can’t alter it so you have to get on with it, you know. (Lines 707-743)

Sarah described not talking about her experience as ‘deeply as now’ and not talking about it ‘like this’ which highlighted how there tended to be no opportunity to talk about her feelings outside of the interview. It was clear that the conversation was eliciting some painful emotions which had to be dealt with sensitively during the interview; this is reflected on further in Chapter 5. There was a strong sense of sadness at this point of the interview; this related to the intensity of Sarah’s emotions and also perhaps triggered sadness about my own experiences. I had the urge to move the interview on but was able to notice this and remain with Sarah’s story. The way in which Sarah described her situation as ‘unfair’ also highlighted a sense of unjustness and feeling she had been ‘cheated’ suggested that she felt something had been taken away from her. However, Sarah quickly moved away from these feelings by stating she ‘can’t alter it’ and therefore, ‘you just have to get on with it’. There was a sense that the only way in which Sarah could cope with her experience was to deny and dismiss her emotional pain.

Summary: Theme two outlined various mechanisms the participants seemed to adopt as a way of coping with and attempting to make sense of their experience, something which appeared incredibly complex and almost impossible to accept straightforwardly. Moving from a familiar, stable past to a confusing and very different present appeared challenging for the women and the past appeared to be idealised and yearned for. At times there was a sense of anger directed towards the person with dementia, who tended to be positioned as someone who had choice over their behaviour and was therefore felt to be manipulative. The women tended to avoid and sometimes fear their own emotions and their only perceived way of coping was to ‘just get on with it’.

4.4 Superordinate Theme Three: Becoming Devoured for Caring

It appeared very challenging for the women to maintain a connection with meaningful parts of their life outside of caring for their husband. Their own identities tended to gradually fade in parallel with the disappearance of their partners' former selves. Taking on the role of carer appeared to be tied into marital obligation and the women became isolated with a lack of emotional support.

4.4.1 Subtheme One: A Submerged Self: "you're just absolutely consumed by it all"

Whilst some participants spoke about trying to maintain aspects of who they were in the past, this appeared challenging. There tended to be a conflict between maintaining their past identity and becoming consumed by dementia. Gail spoke about how her wellbeing had become consumed:

> Extract 42: Gail
> At times I do, I flip and I say, "If I have a stroke, don't you resuscitate me. Don't call 999. I don't want to be resuscitated. What for? What, to look after you?" And I'm 74 and my life is finished in that we can't go anywhere or do anything. Oh, yeah, I could put him in a car and we could go off for a weekend, but it's me again. I have got to do all the organising, all the planning. I'm exhausted, you know. And, as I said, to keep myself sane, at the moment, I can leave Ray in the evening because I go dancing. I line dance and that is my respite. It is wonderful. It is marvellous. I'd go mad if I haven't got it. And really, when you think about it, living under this sort of strain, you can't quite honestly, and I don't mind admitting it, I can see how murders are committed. (Lines 93-109)

In the extract above Gail highlighted how her 'life is finished' suggesting her entire existence had been taken over by caring for her husband and his dementia. Her life being finished was reminiscent of death and the way she comically spoke about not wanting emergency care or murders being committed had a serious undertone and suggested she felt as if she were being slowly killed by her husband's dementia. The harsh tone in which this extract was spoken suggested an undertone of anger and resentment towards her husband. Furthermore, the fast pace in which Gail sometimes spoke seemed to reflect how manic she felt at times, perhaps echoing her fear of ‘going mad’. Gail described the ‘strain’ she was living under which seemed to communicate the extreme pressure she felt and the way in which she described ‘flip[ping]’ suggested she had a sudden, quick and strong reaction to her husband. Gail outlined not being able to ‘go anywhere or do anything’, suggesting she felt trapped within a position that was both restrictive and exhausting. However, Gail attempted to maintain aspects of her life outside of her caring role by going ‘line dancing’ and described how ‘wonderful’ this was, signifying freedom from her caring role. Later in the interview, Gail elaborated about how consumed her wellbeing was:

> Extract 43: Gail
> I fear for the future. My whole wellbeing at the moment seems to be consumed by this awful illness that I cannot move on. It seems I have the diagnosis, not my husband. […] Well, that I’ve got the diagnosis, yes, because he hasn’t got the diagnosis in that he doesn’t know. He’s incapable. He can’t comprehend it. I mean poor man, he can’t help himself, you know, but I just find it so frustrating. So I’ve got the diagnosis. I know what is going to happen. […] But, oh, and you wake up some mornings and you think, “My God, here we go again and I don’t want to do this anymore.” You know you just feel you could pack a bag and go. But you know, you can’t…I can’t leave him… […] I’m just absolutely in sort of a whirl really. As I said, you're just absolutely consumed by it all. It’s the most terrible thing… (Lines 357-400)

The interview with Gail was very intense and overwhelming at times, perhaps reflecting the level of emotion she experienced and her desperate need to express this and be listened to. This extract embodied how consumed Gail was; the flow of words seemed to highlight this. Gail talked about having the diagnosis herself, which emphasised how consumed she felt by her husband’s dementia, compared to her husband who she described as not understanding his condition. Gail found it difficult to ‘move on’, suggesting she felt stuck in a ‘whirl’ where she was going round in circles without being able to move forward. The way in which Gail described her position as ‘frustrating’ and ‘terrible’ emphasised how challenging it was. Gail also suggested her position was relentless and repetitive and something that she would like to escape from and there was a sense of desperation. The change in pronoun from ‘you can’t’ to ‘I can’t leave him’ suggested she wanted someone else to stay with her husband, then realising the huge responsibility and obligation that she alone held towards her husband.

Louise spoke about how every Friday she met friends for lunch which made her feel ‘special’ and ‘freer’ and how she did her hair and make-up; when asked what it meant to maintain these things, she described:

> Extract 44: Louise
> Yeah. It means a lot to me to keep that going. I think um, if I was to let that go, I think a lot of…a lot of other stuff would go, it would be an end. I don’t know quite what of but it would be the end of me as a person if I really let myself go. […] Sometimes it’s a chore because it’s like fitting it all in… […] I think although it’s hard to work out, you know, can I get someone to look after Neil that evening, as long as I can leave after he’s had his dinner, there’s only that time between dinner and going to bed that he needs to be looked after, and you know, I’ve had an evening out. I might be shattered but I broadened my…there are other things that I can talk about other than dementia. I can talk about the play I went to see last week. I can talk about, oh, what colour have I got on my toe nails. At the moment, I can talk about other stuff. […] Because dementia and caring is all consuming. There’s actually, no two ways about it, it is all consuming. (Lines 851-899)

Louise described caring as ‘all consuming’ and the above extract highlighted how there was a conflict between becoming consumed by dementia and her caring role and attempting to maintain other interests and relationships in her life. The way in which Louise described this as a ‘chore’, ‘hard to work out’ and ‘shatter[ing]’ highlighted how challenging this was. However, for Louise it seemed important to be connected to aspects of herself outside of her caring role and she explained how, if she did not continue with those things, it would be the ‘end’ of her as a person, as her whole existence would be tied up in caring for her husband. Doing things which mean Louise had ‘other stuff’ to talk about seemed significant for her and meant she could sustain and express other parts of herself.

When describing how her retirement was not how she had hoped, Sarah also described how her life had become consumed by her caring role:

> Extract 45: Sarah
> So I haven’t got a life, do you know what I mean? We go down to the centre once a week and I’ll meet the other carers, ex-carers mostly. So that helps. Other than that, you know, there’s not a lot you can say really on it. (Lines 188-193)

The way in which Sarah described how she had ‘no life’ highlighted how her life had been taken over by caring for her husband. It seemed that Sarah had little contact with anything outside of the realm of dementia and, whilst it appeared helpful for Sarah to meet other carers, there was no connection with other meaningful aspects of her life. Sarah elaborated about how restricted she was:

> Extract 46: Sarah
> I’ve no regrets, just that it is hard and frustrating and we…you can’t just say, “Oh, I’ll pop out, I’m doing this and doing that”. There’s always that consideration. Yeah, like when…during the week, when he’s gone to the centre, I’ve got to be organised to get him ready for the transport and I’ve got to be here when he comes back so you’re pinned to time all the time. Do you know what I mean? (Lines 252-260)

And later

> That’s the only thing I feel, it’s that you’re, I suppose I’ll call it tied down (Lines 578-579)

Sarah’s husband had dementia for eight years and was in the later stages of dementia, this seemed to significantly impact how consumed and restricted Sarah was, compared to some of the other participants. There was a strong sense of frustration with her position and Sarah described how she was ‘pinned’ and ‘tied down’, highlighting how she felt fixed within a position that was unchangeable.

In contrast to some of the other participants, Jill described how she resisted identifying as a ‘carer’, as it would mean that her identity would become consumed:

> Extract 47: Jill
> I don’t care. I don’t care […] No…well, someone’s got to….Yes… I don’t think of myself as ‘a carer’. But I am well aware that there are things that need to be done. So, somebody’s got to wash him. Someone’s got to make sure that he’s had his bottom wiped. I mean, it’s just an extension of….You do it for babies; you do it for adults, if you have to. I do it but I don’t think of myself as ‘a carer’. […] I’ve got many more interest in life. If I were to describe myself as ‘a carer’, I think that puts everything else on hold. And I think life’s got a lot more going for me. […] Well, unless I was asked. ‘Who’s…who is your husband’s carer?’ I am. But, ‘What do you do?’ I do all sorts of things. (Lines 41-65)

This extract highlighted Jill’s rejection of the label ‘carer’. There was a sense of anger and resentment towards her husband and her position when she repeated ‘I don’t care’. The way in which Jill outlined how, ‘someone’s got to’ care, highlighted how she felt obliged or compelled to care, rather than it being something she wanted to do and suggested she felt detached from her husband. It seemed that Jill associated the things she did for her husband as tasks you would do for ‘babies’, highlighting how her husband was perhaps no longer perceived as an adult. Jill described how, if she positioned herself as a carer, it would ‘put everything else on hold’, emphasising the association between identifying as a carer and becoming consumed. In Jill’s view, she either became consumed or rejected the position of carer, there was no middle ground. It seemed that Jill was attempting to preserve and protect her sense of self and was fearful of losing her own identity. Jill explained how she had ‘many more interests in life’ and that ‘life’s got a lot more going for me’, accentuating her determination to maintain interests outside of caring for her husband. However, at the end of this extract Jill outlined how, if someone else asked who her husband’s carer was, then she would label herself as a carer, highlighting the complexity inherent within her position.

When looking at a photograph of other carers, Jill described how they care differently to her:

> Extract 48: Jill
> I don’t see myself as…as a victim. I see myself able to get things done, however much I have to. I’ve got the energy to…to sort things out. I don’t get walked over. I think some of these people, probably are being walked over. […] I won’t see myself as a victim. […] I have an afflicted husband. I am not afflicted myself. I am not afflicted by his affliction. These women are. (Lines 773-788)

This further highlights Jill’s resistance to becoming consumed by caring for her husband. Jill viewed other carers as ‘tired’, ‘walked over’ and ‘victims’ and there was a sense that if she were to recognise herself as a carer, that she would also become like them. Jill positioned her husband as someone who was ‘afflicted’, suggesting that he was suffering and troubled, but refused to also suffer because of her husband’s alleged pain. Jill seemed to reject the position of carer as a way of protecting herself from emotional harm. They way in which Jill described herself as ‘not afflicted’ seemed to contrast with Gail, who described ‘I have the diagnosis’ (Extract 43).

4.4.2 Subtheme Two: Caring as obligation: “that’s the duties of a wife”

Whilst participants described how their identity can become consumed by their caring role, some felt obligated to take the caring role and did not always label themselves as ‘carers’. When asked when she made the decision to become a full-time carer, Sarah described:

> Extract 49: Sarah
> I can’t say it was no choice, but I didn’t want nobody else looking after him. He’s my husband and I wanted the best for him. […] I’m not a person who can dump somebody and forget them. No way. So that is how I came to that decision. He’s my husband. He don’t deserve what’s happened to him. And, yeah, it’s the only way I can describe it. I feel as his wife anyway, I married him for better or worse, sickness and in health, so. […] Oh, from the start, nobody else was going to do it, yeah. No, I never had no qualms about it from the start.

> I'd just done what I had to do and that's it. (Lines 224-243)

There appeared to be a sense of loyalty felt towards her husband and this extract suggested she felt protective of him, not wanting anyone else to look after him, suggesting she felt obliged to take on the caring role. There seemed to be no doubt that she was the only person who was able to provide the 'best' for him, suggesting the pressure that she felt under. Her husband not 'deserv[ing]' dementia, suggested that he was perceived as a victim of something unjust. Reciting some of her marriage vows perhaps emphasised the commitment felt towards her husband and there appeared to be certain assumptions that being a wife meant that she automatically assumed the caring role. The idea that she did what she 'had to do' highlighted how it was unquestionable that she would care for her husband and the way in which Sarah suddenly ended with 'and that's it' suggested there was nothing more to say on this indisputable matter.

When asked whether it was a decision to care for her husband, Mary outlined:

> Extract 50: Mary
> Well, it wasn't even a decision I had to make. And it wasn't…it was never in question, never in question, no. No. (Lines 714-716)

The sense that it 'wasn't' a decision highlighted how Mary automatically assumed the caring role. Even though Mary had separated from her husband, this matter was 'never in question', emphasising the extent of her sense of responsibility and how there was no element of doubt she would care for her husband; her repetition of 'never in question' accentuated this.

When asked whether it was her decision to become a carer, Gail spoke about caring being bound up with the 'duties' of a wife:

> Extract 51: Gail
> Well, I mean, as I said that I didn't…I didn't sort of think that that is caring.

> That’s the duty of a wife. […] That’s the duties of a wife. You don’t think…you don’t label it as such that you are a carer. If somebody did ask, well, yeah, of course I care for Ray, I am the carer. […] So as regarding carer, I mean I wouldn't put myself down as that...that…that’s my duty, I’m looking after him, you know. He doesn’t need toileting and all this, that, and the other at the moment. I have to get clothes out for him and also put him in the right direction for this, that, and the other, but for me that’s the duties of a wife, you know. (Lines 413-467)

This extract highlighted the complexities inherent within the ‘carer’ identity. Gail talked about caring being the ‘duty of a wife’ which highlighted how some women perceived a lack of choice in taking on the caring role. The word ‘duty’ suggested that Gail felt obligated to take on the position of caring for her husband and it was not something that she had chosen but rather a role that she must take up as a woman and wife. This suggested that it was not necessarily a conscious decision to take the position of carer, but that her experience was perhaps embedded in social expectations about women’s roles and/or the role of a married partner. Gail did not view her role as caring, but rather the responsibility of a wife and, as such, did not always label herself as a ‘carer’. However, this extract suggested that if someone asked, Gail might feel compelled to identify herself a ‘carer’, emphasising the confusion inherent within Gail’s position. There seemed to be an association for Gail between physical care, such as ‘toileting’, which might then lead her to label herself as a ‘carer’. However, other types of caring, for example ‘get[ting] clothes out’, seem to be associated with the role of a wife.

When asked what being a full-time carer meant to Debbie, she explained:

> Extract 52: Debbie
> Well, it’s just what a marriage is I think, you know. I married a man. We’ve always done things together. We’re quite…very close and everything we ever did, we did it together. You know, I didn’t go off and he didn’t go off. And our interests were the same, so that’s what a carer is, you know. That’s what a wife and a carer is. I can’t see the difference actually. (Lines 360-367)

Debbie described how they have ‘always done things together’ which suggested a sense of loyalty felt towards her husband. Debbie began describing her relationship as ‘quite’ close and then corrected this to ‘very’ close, suggesting she was censoring herself and felt the need to portray her relationship as more positive in the past than it was. Debbie also explained how, in her experience, wife and carer were the same, suggesting that her current position was also perhaps underpinned by certain social expectations about what it means to be a wife.

4.4.3 Subtheme Three: Isolated and neglected: “you feel like you’re the only one in the world”

Participants spoke about feeling lonely within their caring role and a lack of support being available, which is likely to have kept them trapped within their consuming position. When asked about her experience of caring for her husband, Louise described it as being ‘very lonely’:

> Extract 53: Louise
> Very, very lonely. You feel like you’re the only one in the world that’s got this problem. And a complex problem. Nobody, nobody knows what it’s like. You go to the hospital and when we were first diagnosed, when Neil was first diagnosed I sort of said, “well, what do we do now?” They said, “well go home and sort your finances out.” Oh, I thought, you know, “sod the finances, what do I do for him? What…what do we do?” (Lines 639-647)

The way in which Louise described feeling like the ‘only one in the world’ highlighted how isolated and alone she felt. She described her experience as being a ‘complex problem’ which created the sense that she felt stuck in a complicated dilemma that required fixing. Louise felt ‘nobody knows that it’s like’ emphasising the lack of understanding from others, which reinforced her sense of isolation. When Louise’s husband was diagnosed, the medical professionals focused on the practical and financial aspects, neglecting her emotional and relational experience. They way in which Louise stated ‘what do I/we do’ highlighted her desperation and need for a different kind of support. Louise exclaimed ‘sod the finances’ which emphasised that practical implications were far less important to her than the emotional effects of her experience.

Gail, Debbie and Mary also spoke about the lack of available support and how they were left abandoned:

> Extract 54: Gail
> Well, let’s put it like this, what is available in the NHS is zero. They are not going to tell you anything about agencies or anything like that. You are on your own. And it’s up to you. You are the person that’s got to find out. (Lines 1347-1352)
>
> Extract 55: Debbie
> Oh, yeah. It was non-existent. It was only meeting the women in that King’s Hospital that I knew anything like that. I didn’t know a thing. I thought you just got on with it. You know, it was an illness that you went to the doctor, they gave you some pills, and, and that was it. (Lines 1274-1279)
>
> Extract 56: Mary
> I’d just like a day off to go somewhere and there’s nowhere, there’s no re– …there’s no respite for anybody. I mean, it’s, it’s really awful. (Lines 1588-1591)

In these extracts Debbie and Gail highlighted how the help that was provided was ‘non-existent’ and ‘zero’, emphasising the lack of support. Gail described how she had to find out what support was available and the way she described being ‘on your own’ emphasised how lonely and isolating her experience was. Debbie spoke about how she thought she ‘just got on with it’, a view held by most participants, suggesting an assumption that caregivers should continue in their position without support. Debbie viewed dementia as a medical illness and therefore, thought the only support available was medication. This indicated professionals placed emphasis on a medical approach, neglecting the emotional and relational aspects of dementia. When asked how she felt about her husband not being able to understand her, Gail talked about the need for a counsellor:

> Extract 57: Gail
> Well, terrible. It's exhausting, you know. It really is. And, as I said, I can't see any way out of it. And as I said, to keep me sane, before I commit murder, that's what I need, a counsellor […] this is what the Alzheimer's carer needs. She don't need anything else. She don't need anything else, but that's what she needs. She needs someone to lean their head on their shoulder who understands the illness. Okay, I know that there are counsellors around, but really you need somebody that is experienced in this awful illness, dementia. And unless you know about the dementia, you know, you know, you just can't comprehend it. If you lived her for 24 hours, you'd see what it's all about. (Lines 540-563)

This extract emphasised Gail's desperate need for support and the intensity of her experience. Gail described feeling exhausted by her role, and the way in which she spoke about needing a counsellor to 'keep me sane before I commit murder' suggested her situation was critical and, without emotional support, she might not be able to continue caring. Gail was unable to 'see any way out' which suggested that she felt trapped and lost. Her husband was no longer able to understand her feelings, indicating she needed this to be provided elsewhere, through a 'counsellor', to prevent her from reaching a crisis. The way Gail stated she needed 'someone to lean their head on their shoulder who understands', suggested emotional support was most important for Gail and emphasised how she needed someone else to share her burden. When Gail stated 'if you lived here for 24 hours you'd see what it's all about', emphasised that the only way to fully understand her experience was to live it. I was aware Gail would be left alone with her overwhelming experience after the interview and, in an effort to help, responded by offering her details of a counselling service.

Summary: Theme Three highlighted how all-consuming caring for a partner with dementia can be. There tended to be a conflict between maintaining a past identity and becoming consumed by caring as well as by dementia. There could also be a resistance to the 'carer' identity as it held negative associations. The participants' wellbeing seemed to become gradually submerged in their role and it was incredibly challenging to maintain other aspects of their lives; the consumption could be so severe that they themselves felt like they had the diagnosis. The women seemed to become trapped within a position that was exhausting and relentless.

Caring for their partner was not always a decision that the women made, rather they felt obliged to take on this role and did not always label themselves as ‘carers’. There tended to be a perceived lack of choice in taking on the caring role and there was a conflation of wife and carer. The position tended to be lonely and isolating for the women; a focus seemed to be placed upon practical and medical aspects of their experience, with their emotional needs severely neglected.

Overall summary: The narratives within the themes revealed the gradual loss and deterioration of a familiar partner and relationship. Through this decline, a new partner and relationship tended to emerge which seemingly contradicted relationship norms and was challenging and complex for the women to adapt to. Loss and change seemed to create a confusing and different present experience for the participants; past and present experiences tended to contradict one another, with the past idealised and separated from the different present. There tended to be a conflict between maintaining aspects of their lives outside of dementia and becoming consumed by caring for their partner. Some women felt obliged to take on the caring role and had a lack of emotional support available to them, resulting in a consumed and secluded position where perhaps the only perceived way of coping was to ‘just get on’. The women seemed to gradually become consumed by dementia, with their identities and relationships potentially disappearing as much as the person with dementia.

Chapter 5: Discussion and Conclusion

5.1 Introduction

This chapter begins by summarising the findings in relation to the research questions. The ways in which this research contributes to the literature and the field of Counselling Psychology are then considered, including a discussion about how the findings can inform clinical practice. For IPA research, it is not uncommon to discover unexpected themes during analysis that require the researcher to consider additional literature, therefore new literature is discussed where relevant (Smith et al., 2009). A critical review of the research then focuses upon the validity of the findings and methodological limitations of the current study. Finally, recommendations for future research are made.

5.2 Summary of Research Findings

Semi-structured interviews were conducted with women who cared for their male partner with dementia. This research aimed to address the following research questions:

- What is the lived experience of caring for a partner with dementia?
- How do caregivers make-sense of the ways in which caring for a partner with dementia can impact upon the long-standing couple relationship, particularly intimacy, and their own identity?
- How can these understandings help inform Counselling Psychology clinical practice?

Interviews incorporating a visual methodology were conducted and IPA was used to analyse the participants’ accounts. The analysis focused on subjective experience and meaning-making, whilst also understanding participants’ experience in relation to wider social, cultural and historical contexts. Initially, a number of subthemes were generated, from which three superordinate themes were then identified, to provide a picture of how women caregivers can experience caring for a male partner with dementia: ‘Loss and the Emergence of a New Present’; ‘Navigating a New Reality’ and ‘Becoming Devoured for Caring’. It is important to note that interpretations were based on the researcher’s own assumptions and prior experiences, reflected upon further in section 5.4.5.

The findings of this research are in line with previous literature which suggests that, central to dementia caregivers’ experience is loss: loss of a partner, loss of self and loss of a relationship as it once existed (Robinson et al., 2005). Participants’ experiences of loss can be associated with a grief process, including feelings of anger, sadness, helplessness, isolation and a desire to return to a happier past (Sanders, Ott, Kelber & Noonan, 2008). The results of this research highlight how caregivers can experience a wide range of complex emotions, challenging the universally adopted stress-burden model which has historically dominated.

Theme One highlighted how the women tended to experience continual and gradual loss of the person they married. This agrees with previous research demonstrating how, as dementia progresses, the individual’s personality, communication and role function can alter (Harris, 2009; Sanders & Power, 2009; Walters et al., 2010) and how caregivers are engaged in a continual process of adjusting to loss (Robinson et al., 2005). For participants analysed in this thesis, loss tended to be experienced as a decline and deterioration of someone known, through which a different way of experiencing their partner emerged. Furthermore, some women in this research experienced a particular loss of someone who was masculinised and perceived as a hero in the past, which perhaps accentuated their experience of loss and meant their husband was experienced as so much less in the present.

The analogy with bereavement and the idea that there was a fading of something familiar demonstrates the complexity in dealing with the changes at a psychological level. Whilst the experience of loss is well documented as part of the experience of living with dementia, how individuals cope and feel as a result of loss appears under-documented (Street & Mercer, 2014). Within psychodynamic theory, defence mechanisms are understood as unconscious coping techniques to deny or distort reality in order to reduce anxiety and unacceptable or unpleasant feelings and impulses (Jacobs, 2009). It could be argued that some of the strategies outlined in Theme Two, for example denial and underplaying emotions, acted as defence mechanisms and may be understood as a way of warding off bewilderment and the painful emotions associated with their experience. This has also been considered in other research (e.g. Auclair et al., 2009). Balfour (2006) highlighted how it is common to deny something so agonising; this may explain in part why some participants engaged in certain strategies as a way of coping with their experience. These understandings of how caregivers experience caring for a partner with dementia move from the dominant stress-burden framework towards alternative conceptualisations.

Kneebone and Martin (2003) critically reviewed quantitative research based on Lazarus and Folkman’s (1984) stress-coping model, which proposed that adaptation to stress is mediated by different coping strategies employed by individuals. This model proposed two main types of coping mechanism: emotion-focused, which included avoidance, minimisation and distancing, and problem-focused denoted by practical problem-solving. Kneebone and Martin (2003) concluded that a problem-solving style of coping is likely to be “advantageous to caregivers” (p.1) and one which clinicians should encourage, since it can result in reduced depression and burden. However, they warned that, despite these findings, the ability of current research to inform clinicians is significantly limited and a substantial revision of methodology is required to produce findings that can influence practice (Kneebone & Martin, 2003). Conversely, the strategies outlined in Theme Two in this thesis seemed to reflect some of the emotion-focused coping mechanisms and suggest that spouse caregivers tended to struggle most with their intense and complex emotional experience, thus requiring more than just practical support. Therefore, it seems helpful for professionals to also support caregivers to understand their emotional experience, instead of focusing solely on problem-solving strategies in line with the stress-burden discourse that has dominated historically. Clinical implications linked to this are outlined in section 5.3.

The findings of this research also challenge the perception of caregivers' experience being solely about loss, as the participants spoke about their struggles with adapting to change and maintaining a relationship with their partner. A recent review of qualitative research by Evans and Lee (2014), exploring the impact of dementia on marriage, highlighted how transition and loss are inter-related; each change resulted in loss and each loss created another change in the relationship; the results of this thesis resonate with this idea.

Participants tended to experience multiple changes in their relationship. In line with research by Boylstein and Hayes (2012), some women experienced reduced intimacy in their relationship and found it challenging to maintain this aspect of their relationship. Specifically, the absence of a sexually intimate relationship and the lack of reciprocity experienced by participants in this research seemed particularly challenging. As previously documented, the person with dementia became less able to perform their normal roles, the caregiver therefore increasingly taking over roles previously undertaken by the person with dementia (Hellstrom et al., 2007). Awareness of change was evident in the ways in which past and present experiences of the person with dementia and the relationship contradicted one another, which was particularly apparent during the exploration of the photographs; this links to the idea of discontinuity outlined by Walters et al., (2010).

The multiple losses and changes identified in this thesis resulted in a very different relationship for the participants, which tended to contradict relationship norms. The struggle with transition and change demonstrated in this research, particularly outlined in Themes One and Two, contradicts previous literature by Hellstom et al. (2007) who proposed an iterative model of ‘sustaining couplehood’, ‘maintaining involvement’ and ‘moving on’, strategies that spouses use to live positively with dementia. Whilst attempts were made to continue their relationship with their partner, generally participants struggled to adapt to and accept the different person and relationship that dementia had created.

Adapting to changes in identity has been previously found to be one of the most difficult challenges and this thesis highlights how the women’s identity and needs tended to become subsumed by their caring role, supporting previous research (e.g. Skaff & Pearlin, 1992; Robinson et al., 2005). Furthermore, the women in this thesis tended to become trapped within an exhausting position and the consumption could be so intense that they themselves felt as if they had the diagnosis of dementia.

As revealed in Theme Three, there appeared to be underlying assumptions, based on relationship conventions and the role of a wife, which assumed their availability for the caring role. Some women felt obliged to care for their husband, viewing it as the role of a wife, and thus did not always label themselves as carers. This linked to research by Eriksson, Sandberg and Hellstrom (2013) who explored the gendered aspects of long-term caregiving for women caring for a spouse with dementia. Their results found that women might prioritise their caregiving role over looking after themselves and highlighted the importance of recognising when women downplay the need for support. The women in this thesis highlighted how professionals tended to focus upon practical and/or medical support, in line with the dominant stress-coping and biomedical frameworks that have historically dominated. The lack of emotional support available to caregivers to help them process and adjust to the significant consequences imposed by dementia was apparent, which seemed to further reinforce the participants' sense of isolation (Lockeridge & Simpson, 2012; O'Shaughnessy et al., 2011).

5.3 Clinical Implications

A number of important clinical implications have arisen from this research which will be considered in four sections; psychodynamic approaches; processing loss; maintaining balance and wellbeing and adapting to relationship change

5.3.1 Psychodynamic Approaches

The findings of this research illuminate how psychodynamic concepts can inform clinical practice when working with dementia-affected couples. This research demonstrates how caregivers experienced a complex range of emotions and perhaps engaged in unconscious defences, such as denial and suppression, in order to avert acceptance of their distressing experiences (Jacobs, 2009).

Splitting is a defence that describes the unconscious process of polarising good and bad feelings, love and hate, towards an attachment object, as a way of protecting against intense negative emotions (Frosh, 2012). The main function of splitting is to cope with negative feelings which threaten to damage a relationship and it is the inability to bring together positive and negative qualities and emotions into a cohesive whole (Jacobs, 2009). The sense of discontinuity some participants seemed to experience between their past and present relationship and partner, and their idealisation of the past, could be understood as the defence mechanism of splitting; separating past attachment to and love towards their spouse from potential negative feelings triggered by dementia changes in the present (Walters et al., 2010). However, the protection that may be provided by splitting and other defences, is likely to be only temporary, as the emotions that are split off or denied are unlikely to be completely removed from consciousness, potentially causing more distress in the long-term (Walters et al., 2010; Jacobs, 2009).

Attachment theory offers an understanding of behaviour in close relationships and began with the dynamics of relationships between children and parents, but now covers the lifespan (Howe, 2005). Contemporary psychoanalytic understandings of relationships that are embedded within attachment theory (Bowlby, 1980) can contribute towards professionals' understanding of relationships in dementia; close or romantic relationships can be viewed as a secure base and a means by which the attached person regulates their internal security (Bowlby, 1997). This research highlighted how dementia appeared to unsettle the stable and familiar relationship that once existed, creating a very different relationship in the present; this could be understood as disrupting the long-standing attachment bond which serves as a secure base. There tended to be the loss of a strong, masculinised figure, perhaps representing a secure attachment figure that existed in the past. The actual or perceived disappearance or loss of an attachment figure evokes intense distress and is the normative response to loss of a significant source of security (Perren, Schmid, Herrmann, & Wettstein, 2007). When a partner is not available or responsive, the attached person can become anxious, leading to defensive strategies to avoid the pain of abandonment and rejection (Shaver, Hazan & Bradshaw, 1988). This may in part explain why participants in this research engaged in a number of behaviours, such as seeking blame and denial, distancing or suppression. Adaptation to the loss of a secure base often requires the reorganisation of attachment and the transfer of the secure base, at least partly, to a new relationship (Bowlby, 1980).

Containment is the need for feelings to be absorbed and understood throughout an individual’s life, to enable secure attachment to others (Bion, 1962). Participants in this research highlighted how responsibility and pressure tended to shift to them and there was a lack of reciprocity. The mutuality of the relationship tended to fade and the person with dementia became increasingly dependent upon the caregiver, leading them to feel overwhelmed. Some participants spoke about how their partner found it difficult to understand and/or express emotions due to their dementia, the caregiver thus becoming the sole container in the relationship.

Therefore, it seems pertinent for professionals to offer a secure base through the therapeutic relationship, providing a containing and validating space for caregivers to understand their defences, acknowledge their complex and conflicting emotions and process their loss (Gomez, 1997). The results of this research highlight the significance for caregivers to be able to talk to a non-judgemental professional and have another take in their feelings (Balfour, 2014). The clinician’s role would be to communicate that expressing feelings such as anger and sadness can be helpful and might increase their resilience (Auclair et al., 2009). However, caregivers might be from a generation who are not used to psychotherapy and therefore this would need to be undertaken in a sensitive way.

The therapist’s aim would be to provide a holding and containing space where feelings can be openly explored (Winnicott, 1971); by allowing complex emotions to be acknowledged and validated, caregivers may feel less overwhelmed and be more able to adapt to their significant change (Auclair et al., 2009). Where appropriate, this could also be undertaken with the couple together and these approaches would be aligned with exploratory, open and supportive therapeutic spaces, as opposed to approaches that might be more solution-focused, such as cognitive-behavioural therapy (Jacobs, 2009).

5.3.2 Processing Loss

The findings highlight how loss was a significant aspect of the participants' experience and tended to be experienced as a gradual disappearance of one way of knowing their partner and relationship, through which a new and very different way of knowing them emerged. Participants were faced with coming to terms with multiple losses whilst concurrently attempting to adapt to a new and unfamiliar partner and relationship, resulting in a challenging experience. Participants experienced a complex range of emotions including sadness, loneliness, anger and hopelessness which they tended to find difficult to acknowledge. The loss experienced by the women in relation to dementia was unique and complex, it is therefore crucial for professionals to support caregivers and couples to understand and process their loss.

The Dementia Grief Model (Blandin & Pepe, 2015) is a theoretical model of dementia grief which acknowledges it as a unique grief experience and holds relevance for the findings of this research. The model incorporates an overarching framework of grief which identifies specific mechanisms for moving through patterns of loss over time. It highlights how grief cycles through three states: separation, liminality and re-emergence, each state is characterised by a particular psychological experience and has a dynamic mechanism that drives movement through the grief processs (Blandin & Pepe, 2015).

The first state, separation, highlights how an individual is in a state of separation when they experience significant losses (Blandin & Pepe, 2015). For dementia, each loss results in a state of separation from relationships, a past life and an anticipated future. The dynamic mechanism of this state is acknowledgement of loss which can be inhibited through a lack of recognition/acknowledgement, resistance and denial, some of which were evident in this research. The model highlights how achieving resolution of multiple, compounded losses can be complex and challenging, especially given the fact that loss is often linked to a gradual loss years before actual physical death (Blandin & Pepe, 2015).

The next stage in the model is liminality which is “the state of being in-between a previous situation and an emerging situation” (Blandin & Pepe, 2015; p.7). This stage is characterised by ambiguity and the dynamic mechanism is being able to tolerate difficult feelings. Caregivers move through ambiguous loss where there is a disappearance of someone known which precedes physical death, this stage is linked to a state of transition which potentially leads to ambiguity and instability (Blandin & Pepe, 2015). The grief process can be stalled if painful feelings are avoided or suppressed which might result in unhelpful behaviours such as compulsive behaviours, angry outbursts or distracting behaviours. Complex feelings were experienced by participants in this research and some of the behaviours above were demonstrated by them. The model highlights how tolerating painful emotions can enable the grief process to move towards clarity and the possibility of adaptation to the new, emerging situation (Blandin & Pepe, 2015).

The final state, re-emergence, is defined by acceptance and the associated dynamic mechanism is adaptation (Blandin & Pepe, 2015). The model outlines how tolerating and acknowledging difficult emotions can lead to a state of clarity where losses are acknowledged, accepted and their consequences understood. Adaptation is indicated by behaviours such as taking on new responsibilities and communicating or being intimate in a new ways (Blandin & Pepe, 2015). As highlighted by this research, participants not only experienced loss but also the emergence of a new present which they found it challenging to adapt to, which is relevant to this stage. The model highlights that adaptation suggests that the caregiver has been able to recognise and accept the loss and the new reality has been moved into, providing aspects of stability (Blandin & Pepe, 2015). However, it is likely the cycle is repeatedly enacted until physical death occurs.

The Dementia Grief Model is significant for the findings of this research and provides a framework for professionals. It highlights particular therapeutic interventions that are specific to working with dementia grief, for example acknowledging loss, tolerating difficult feelings and behavioural adaptations. The model characterises dementia grief as a normal grief process with unique properties; it is based upon the distinct characteristics of dementia grief and identifies mechanisms unique to the dementia grief process that might facilitate or hinder caregivers in moving through loss (Blandin & Pepe, 2015).

5.3.3 Adapting to Relationship Change

Given the significant change participants in this research seemed to experience and the challenges this presented to them, it seems pertinent for professionals to support couples to adapt to this change and maintain a continued sense of relatedness. Whilst a significant body of research emphasises negative aspects of dementia, with a dominant discourse surrounding neurological decline, it appears important to challenge this with an approach that embraces difference and enables significant relationships to continue, if this is what is wanted (McGovern, 2015). Many older adult services currently focus upon the assessment of deficits and losses, in line with the biomedical model. However, the findings of this research suggest that, where appropriate, practices based on reconstruction and adaptation may help with the process of adjustment (Camic et al., 2013).

Counselling Psychologists could consider using a family-systems model when working with couples affected by dementia. This perspective outlines how relationships and roles evolve over time and renewed meaning-making between intimately connected people is possible (Blumer, 1986). It stipulates how meaning is co-constructed by family members through the repeated interactions between them; thus meaning-making can be “removed from the cognitive realm, and relocated in engaged dynamics” (McGovern, 2010, p.180). This approach seems significant for the results of this research, as it means relationships can be sustained. Individuals affected by dementia can be positioned as continued contributors to meaning-making within their relationships and continue a sense of relatedness despite the losses implicit within dementia (McGovern, 2010).

Heidegger (1996) and Merleau-Ponty (2002) outline how meaning-making and communication do not just occur through verbal exchange, but can include sense-based perceptions and physical interaction; therefore, meaning-making can be determined by embodied communication. This seems significant for some participants in this thesis who found it challenging to experience continued connection with their partner, as it means that professionals can support dementia-affected couples to co-construct alternative ways of connecting through eye-contact, physical affection and smiling (McGovern, 2011). Replacing words with physical touch, affection and other non-verbal communication, as evident in some of the participant accounts, and encouraging couples to connect and express themselves in alternative ways, can enable a continued sense of connection (Ryan, Nolan, Reid, & Enderby, 2008). Focusing on difference and a new type of intimacy can enable relationships to continue in the present, improving wellbeing of both the people with dementia and their caregivers (McGovern, 2010).

Approaches such as these are in line with the Strengths Perspective (Saleebey, 2013) and Positive Psychology (Lopez & Snyder, 2009) allowing a redefinition of dementia and caregiving by nurturing what remains, as well as acknowledging what has been lost. Positive Psychology is based on the idea that all individuals hold strengths and focusing upon them can enhance self-value and lead to growth and experiencing a more fulfilling life (Lopez & Snyder, 2009). Employing these approaches goes against the dominant paradigm in dementia, where people with dementia are seen in an almost wholly pathological light (McGovern, 2015). Taking a strengths-based and positive psychology perspective to support couples to understand and build upon what remains allows potential for growth (Whitlatch, 2008).

In comparison to other participants, Jill’s relationship with her husband prior to dementia seemed to be difficult and distant. As highlighted in Chapter 4, this appeared to impact upon her experience, she presented as angry and seemingly struggled more to accept and adapt to the changes in her partner/relationship and distanced herself further from her husband. This finding is consistent with research by Knop et al (1998) which, as outlined in Chapter 2, suggests that relationship quality prior to dementia and current relationship quality are related; lower relationship quality prior to the onset of dementia is linked to greater depression and distress. This also links to Ablitt et al’s (2009) theoretical model which suggests that prior relationship quality impacts the maintenance of the relationship following the development of dementia. Therefore, this highlights the importance for professionals to understand a couple’s relationship quality prior to dementia and be aware this might impact upon their experience as dementia progresses, potentially leading to difficulties in adapting to dementia and maintaining their relationship.

Research has highlighted the positive impact of maintaining connectedness in dementia-affected relationships (Hellstrom et al., 2005; Todres & Galvin, 2006). However, as described in this thesis, couples often find it difficult to adapt to their different relationship and maintain their relationship in alternative ways. This section has described a number of suggestions for how couples can be supported by professionals and has emphasised the significant need for services that help couples to achieve this is significant.

5.3.4 Maintaining Balance and Wellbeing

This research highlighted how women might unquestionably assume the caring role becoming consumed and isolated within their position. Assumptions that women and partners will take on the caring role might prevent the needs of caregivers from being addressed. Counselling Psychologists need to challenge the historical assumptions in relation to women's propensity to provide uncompensated care to ensure that they are not trapped within an oppressive institution that limits options for equality in older adult life (Montgomery & Williams, 2001).

Current health and social policies are focused upon home care due to high economic costs of care-homes (DoH, 2009). This wider social and cultural context is likely to have impacted participants' experiences, causing pressure for women/men to care for their partner at home and, therefore, potentially preventing them from choosing for the person with dementia to be cared for in a care-home. It is probable that this wider context compounded the feeling of being consumed that tended to be experienced by participants in this research and potentially prevented them from getting their needs met, increasing pressure, burden, and isolation.

Self-identity or self-concept is the collection of beliefs someone holds about themselves and includes aspects such as sexuality, gender roles and racial identity. It is used to describe the idiosyncratic things that make a person unique and includes qualities, beliefs, and social roles (Baumeister, 1999; Schwartz, 2001). Self-identity is fluid and dynamic and can be understood as a joint production between self and other, this research highlights that a transformation occurs over time in the identity of both members of the couple due to dementia and the marital relationship is reconstructed due to shifting identities (Karner & Bobbitt-Zeher, 2005). This research indicates that consumption can occur, resulting in caregivers' self-identity being reduced due to the decrease in outside interests, social relationships, and other roles, and also by lack of exchange, intimacy and reciprocity within their relationship (Skaff & Pearlin, 1992).

It seems essential for services and Counselling Psychologists to work with female partners to help maintain alternative identities outside of their caring role and to attend to their emotional wellbeing. This could be achieved through individual therapy and also through consultation with services to improve available support. Further suggestions around how to challenge more widely the assumptions of uncompensated care are outlined in section 5.3.4. The results of this research highlight how it is not adequate for Counselling Psychologists to support partners only in their role as 'carer', but to help them sustain balance and maintain a sense of self-identity in order to try to prevent the consumption and isolation that was evident.

5.3.5 Contributions to the Literature and Relevance to Counselling Psychology

This research contributes to the literature in several ways. Most significantly, it highlights how important it is for Counselling Psychology to embrace and apply a relational and psychological model for couples living with dementia. Taking this approach helps move the dominant understanding from a stress-burden, decline and biomedical framework towards an experiential and relationship-based conceptualisation of dementia.

Although the focus of this research was upon individual experience and the couple relationship, implications for practice are wider and it seems important for Counselling Psychologists to consider some of the social, cultural and historical contexts that impact upon the experience of caregivers and couples living with dementia. Societal expectations about what it means to be a woman and/or married, seemed to influence participants' experience, assuming their availability for the caring role and thus potentially limiting the amount of support that was sought, offered or received. This tended to lead caregivers to become consumed and isolated.

It seems vital to consider how the term 'carer' is used by professionals, and society more widely, as participants in this research did not always identify with the term; where it is used unthinkingly it might prevent the partner of someone with dementia accessing support and result in the professionlisation of marriage partners, with consequent neglect of their needs (Lewis, 1998). However, the 'carer' identity is complex; partners may be unintentionally forced to accept the 'carer' identity in order to access particular support, for example respite or Attendance Allowance, which might indirectly lead them to become further trapped in a carer identity discourse (Baike, 2002). It would be crucial therefore for professionals to sensitively consider when and how the term ‘carer’ is used, to ensure partners are receiving the help they need in order to reduce their isolation and consumption. A more accessible term may increase uptake of support services (Molyneaux et. al., 2011). Redefining the role as one that enables emotional support and maintains social connections and a personal identity, might help improve wellbeing and potentially avoid the consumption and isolation of long-term caring (Boylstein & Hayes, 2012).

For some participants in this research, their relationship influenced by dementia seemed to contradict norms and conventions associated with married relationships. Therefore, in order to support couples to adapt to dementia, it seems important for Counselling Psychologists to challenge ideas about normative relationships. Considering alternative conceptualisations of marital relationships, where roles and intimacy can be experienced and expressed in alternative ways, may help couples to adapt to the impact of dementia.

The construction of dementia based on the dominant theory of decline and despair which is promoted by the biomedical model can result in limited options for couples with dementia. This research helps challenge the understanding of dementia as a progressive, neurodegenerative disease and contributes towards an alternative conceptualisation that considers interpersonal relationships, identity and emotional experience. By adopting this approach, Counselling Psychologists can begin to challenge the widespread cultural belief that dementia is solely about decline in the brain, which suggests hopelessness for couples living with dementia (McGovern, 2010).

It is important that Counselling Psychologists challenge currently existing dominant discourses, to promote new understandings which take an emotional and relational understanding of the experience. Through this paradigm shift, a new discourse of dementia and care can be made possible, enabling a more optimistic perspective, meaning couples living with dementia are more likely to be offered and access support (McGovern, 2015). Challenging dominant discourses could have significant implications for how future dementia care services are implemented and how dementia is thought about by professionals and society and is particularly relevant for Counselling Psychology as it "places a commitment to understanding social context and socio-political processes at the heart of its mission" (Rafalin, 2010, p.49). It might be achieved through consultation with older adult services and carer/dementia organisations/networks, attendance at conferences in order to disseminate research findings and through education, training and supervision of staff.

5.4 Critical Review

Different frameworks have been developed for assessing quality in qualitative research, including Yardley's (2000) criteria, advocated by Smith et al. (2009) as an approach to evaluating IPA. Yardley's main principles are: sensitivity to context, commitment and rigour, transparency and coherence, impact and importance. Each of these areas will be considered below.

5.4.1 Sensitivity to Context

Sensitivity and awareness of epistemological and methodological issues in the wider literature were demonstrated via the literature review and the research findings were also grounded in relevant literature in the Conclusion and Discussion. Sensitivity was given to the socio-cultural milieu in which the study is situated, particularly relevant given the rapidly increasing number of couples living with dementia. Choosing IPA as a methodology demonstrated sensitivity to context through close engagement with the idiographic and the particular (Smith et al., 2009).

Sensitivity to context was demonstrated by facilitating sustained engagement with important gate-keepers to access participants. This was achieved in various ways, including establishing rapport with carers' organisations by attending staff meetings, carers' forums and social events to talk with staff and caregivers. Feedback from carer organisations about ways to improve recruitment were also implemented. Permission was sought from online forum managers before posting anything about my research and an application was submitted through the ethics committee of the Alzheimer's Society, the UK's leading dementia support and research charity, in order to recruit through their local services.

Sensitivity to context was also demonstrated through an awareness of the interactional nature of data collection within the interview situation. In order to produce good data for analysis, I attempted to put participants at ease, demonstrating empathy and recognising any interactional difficulties. This was achieved through verbal and non-verbal interpersonal skills, for example by using minimal encouragers, making eye contact and nodding. I also reassured participants that they did not have to answer any questions if they felt uncomfortable and that there were no right or wrong answers.

I was mindful that the participants were caregivers and that the majority of their partners were present in the house and therefore I asked on several occasions throughout the interview if they needed to take a break or stop completely. Sensitivity to context was complex due to the interview setting; I managed this by pausing, suggesting that we went into another room, not probing further on sensitive areas or moving onto another question. For example, when discussing intimacy, Louise was concerned that her husband, who was in another room, could hear what she was saying. Therefore, we came back to that question later in the interview when she felt more comfortable.

Sensitivity to context was also demonstrated through immersive attention to the data, in an attempt to interpret how participants were making sense of their experience. Smith et al. (2009) highlight that data is the strongest context to which IPA will be sensitive, therefore attention was given to the raw material by ensuring a considerable number of verbatim extracts were provided in the analysis to support my analytic narrative. Interpretations were provided as possible readings and claims were presented cautiously.

5.4.2 Commitment and Rigour

Commitment was required during the recruitment process in order to overcome significant challenges. A high volume of emails was sent to different organisations to increase likelihood of recruitment. It was crucial that consistent contact was made with key organisations that expressed interest and willingness to attend staff meetings and support groups was pertinent. Once initial contact had been made with potential participants, flexibility was required in order to ensure that a suitable time and location were organised for the interviews.

Commitment was also required during data collection in attending closely to each participant. During Sarah’s interview my commitment was demonstrated through empathic attention to her meta-communication. Sarah’s restlessness and desire to leave the room to take painkillers, revealed how she does not normally think about her emotions, possibly highlighting a neglect of emotional needs. On several occasions I offered to stop the interview, but Sarah chose to continue. Commitment and rigour were demonstrated by probing deeper when noticing important cues from the participant, enabling idiographic understanding.

Rigour was demonstrated through thoroughness of the research, for example the appropriateness of the sample, which was selected in order to address the research questions and ensure sufficient homogeneity. Rigour was also demonstrated through systematic and thorough analysis; in-depth reading of the data was carried out, ensuring an understanding of each data set before moving onto the next. I attempted to provide an interpretative analysis, rather than just providing a description of the data, whilst ensuring that my interpretations were still grounded in the data. I attempted to select appropriate extracts for each theme that included a range of participants. However, some participants were represented more than others which I mention in my reflexive comments.

5.4.3 Transparency and Coherence

Transparency was established in various ways, particularly through outlining how participants were selected and the steps used during analysis. Diagrams have been included in the Appendices to detail elements of the analytic process, demonstrating examples of emergent themes from initial notes and how superordinate themes developed from emergent themes. The interview guide and ethical documentation have also been included in the Appendices to further enhance transparency. In order to ensure the research presented a coherent argument, the themes linked together logically and ambiguities were dealt with clearly, considerable drafting and redrafting was essential and themes were discussed in supervision.

The thesis aimed to demonstrate coherence with the underlying principles of IPA through phenomenological and hermeneutic sensitivity throughout. There is an experiential focus and close attendance to the phenomena under study, whilst also attempting to demonstrate awareness of IPA as an interpretative activity. I attempted to demonstrate a commitment to the double hermeneutic in reflexive sections throughout the thesis.

5.4.4 Impact and Importance

The research aimed to address an interesting and important topic that is relevant to Counselling Psychology, other professions and, more widely, society. This research offers insight into the experience of caring for a partner with dementia and holds significant clinical implications for Counselling Psychologists and could help initiate changes in health and social care policies.

5.4.5 Personal Change and Reflexivity

Throughout the research process a lot of change occurred in my personal life, in particular the progression of my grandad’s dementia and the final loss of my grandad when he passed away. Through the experience of my grandad’s dementia, I was aware of how much my own relationship with my him changed, he was no longer the person I had known and I was experiencing loss whilst also attempting to adjust to someone new. He was a changed person and I had to take a different role in our relationship, compared to the past; I had to support him practically/emotionally and take more responsibility in our relationship, whilst he gradually became more dependent on those around him. I also witnessed my grandmother’s relationship with him change, over time she was doing more and more for him and taking on multiple roles in their relationship, as she became engulfed by caring. I experienced complex emotions about my experience: anger, sadness and confusion which were hard to acknowledge at times. The interviews sometimes brought these emotions and experiences to the fore.

Hearing the participants’ experiences was sometimes very challenging and triggered feelings and memories about my own experiences. My grandmother was not very open about how she felt and so hearing the participants’ feelings/thoughts and intimate experiences sometimes made me wonder whether she had similar experiences. Throughout the research process I continued to process my emotions through personal therapy and I kept a reflexive journal. This helped me to remain mindful of my emotions/experiences and how they might impact the research process, in attempt to remain led by the participants during the interviews and remain open to other interpretations of the data during analysis. For example, there were times during the interviews where it was hard to hear about strong feelings of anger and I had the urge to move the interview away from these powerful emotions, being aware of this was important so that I could remain led by the participants and probe deeper where appropriate. Moreover, I was aware that I was more likely to be drawn to aspects of the data that were in line with my own personal experiences; for example being more sensitive to aspects of the data that reflected a reduction in reciprocity within the relationship. Again, being mindful of this helped me to remain open to other aspects of the data and alternative interpretations.

When my grandad passed away it was a significant loss and important that I took time away from the research in order to process my own emotions through personal therapy. I was grieving but it felt complex as, due to the impact of dementia, I had already started to grieve his loss before he passed away. This loss felt different to others I had experienced and in some ways felt more complicated to make sense of. Once I had taken time to process my loss I felt less overwhelmed, I was more mindful of my feelings and felt able to re-engage with the research process. I had completed the interviews at this point and was carrying out my analysis, I continued to attend personal therapy and keep a reflexive journal to be mindful of my emotions/experiences and how they might have been impacting upon the research process.

5.4.6 Personal and Epistemological Reflexivity

This section explores how I might have shaped and influenced the research and how the research impacted upon me. I attempted to remain reflexive throughout the research process through discussions in supervision/with peer-researchers and by writing a reflexive diary after each interview to note my initial impressions, thoughts and feelings.

In the interviews, I attempted to bracket my theoretical knowledge and tried to adopt a phenomenological stance by closely attending to participants' accounts. I was saddened by the participants' accounts and often felt very heavy and tired after the interviews. I found it difficult to hear some of the participants' experiences and how isolated and helpless they were. As a trainee Counselling Psychologist, my natural instinct was to want to help the participants, to formulate their difficulties from different perspectives and possibly challenge some of their unhelpful patterns of relating and it was important for me to bracket this. I remained mindful that my role was a researcher rather than a therapist, although it was difficult to step out of the therapist role at times.

Trying to balance asking probing questions to ensure the interview covered material needed to answer my research questions, whilst also being led by the participants in order to hear their experiences, proved challenging. I noticed that this skill improved with each interview. Listening back to the interviews straight after and reflecting upon this in supervision was also helpful. All of this I reflected on throughout my research in reflexive notes, supervision and personal therapy. I felt very privileged to meet with the participants and was struck by their openness and honesty. After hearing how they often do not talk about their experiences, particularly their emotions, I felt immense duty to do them justice by ensuring their voices were heard through this research.

It was important to reflect upon the interview set-up, such as what participants were told the interview would be about and what it would be for (Potter & Hepburn, 2005). Not only does this raise important ethical dilemmas such as informed consent, it was also important to acknowledge what influence this had on the story they presented. For example, did they want to show they were doing a good job? Were they using this as an opportunity to seek guidance from someone whose role was to help people? One participant (Sarah) told me she was worried she was 'being criticised' for how she was caring for her partner. This concern also applied to me as the interviewer, and this will therefore have impacted upon the story that she told and it is likely that she would have only shared aspects of her experience that might suggest she was doing a 'good job'.

The questions, and the way they were posed, would have also shaped the interview process and the analytic narrative that was constructed. For example, in some ways the interview explored the relationship between past and present, particularly by the use of photographs, which would have contributed towards particular narratives, particularly in Themes One and Two. Therefore, I have outlined the interview questions in the narrative where possible, in an attempt to be transparent.

In researching dementia, it is also important to reflect upon the presence or absence of the person with dementia during the interview process. In most interviews the person with dementia was present during at least part of the interview. This was challenging and created a difficult dynamic at times, influencing the particular topics that I did or did not ask, and also impacting upon the participants' response. The presence of both partners may have prevented free expression, and if interviewed alone, caregivers may have been more direct about their experiences (Molyneaux et. al., 2011). Conversely, as outlined in the analysis, some participants spoke in a harsh way that may have been aimed at communicating some of their emotional pain.

There is also the question of what it meant for the participant to have their spouse at the interview. For example, did it emphasise how consumed the participants were and how difficult it was for them to take time out of their caring role? This highlights how the third person in this area of research cannot be bracketed and potentially held significance for the interpretation of the data. Additionally, being with the participants in their homes where they cared for their partner on a daily basis potentially gave me insight into their experience from a different perspective, compared to holding the interview in a neutral setting. I reflected upon these dilemmas in self-reflexive notes and considered them when analysing my data. This information goes beyond the spoken interview itself and highlights the importance of reflexivity to further enhance the interpretative element of IPA (Brocki & Wearden, 2006; Smith, 2004).

Having owned my position, it is essential to consider how this might have influenced the data/research, for example, if it hindered or facilitated whether participants shared certain information. It may have been that my position as a trainee or young female affected power dynamics. The participants were considerably older than me and this might have hindered the information they shared on certain topics, particularly in relation to intimacy. Alternatively, my experience and training in therapeutic practice, and viewing the participants as experiential experts, hopefully enabled a safe and validating environment in which to share their experiences. This might have encouraged them to express their personal experience rather than coming from the biomedical perspective expected in conversations with other professionals.

My fore-understandings would have influenced my analysis; for example, my attention would have been drawn to certain aspects of the data based on my lived experiences and prior knowledge. This was conflicting, as I sought to use my knowledge to inform the design of the research but equally did not want my beliefs to distort or restrict rich data and/or findings. For example, based on my past experience, I was aware of the lack of psychological input for couples living with dementia and therefore I might have been drawn towards aspects of the data that demonstrated this. I was also aware of my personal preference in clinical practice for understanding difficulties from a psychodynamic perspective. I questioned whether this led me to conclude that the participants' coping strategies acted as defence mechanisms, rather than potentially understanding them from different perspectives. I also wondered if this sometimes led me towards a more suspicious interpretation of the data which moved me too far away from a phenomenological perspective; I have reflected on this further below. I remained open to alternative perspectives and ensured my interpretations were grounded in the data throughout the analysis.

Throughout the research process, I was constantly questioning how much to interpret and found it difficult to balance between the descriptive (empathic interpretation) and interpretative (suspicious interpretation). Remaining close to the accounts, whilst also being able to step outside of them to make significant interpretations, was a tension I managed throughout the analysis. For researchers using IPA, which incorporates both interpretative and phenomenological positions, encapsulating these principles in practise is not straight-forward. As a novice of IPA, I constantly questioned how interpretative my position was; for example, did I acknowledge my own theoretical standpoint and prior assumptions whilst remaining open to the subjective experience of the participant? Did my beliefs impact upon data collection and analysis? Were my interpretations grounded in the data? Could the wider context of the interview tell me more about the phenomena? Such questions highlight the importance of these issues; reflexivity and supervision were crucial to this process (Smith et al., 2009). For example, during an early analysis draft, I interpreted how participants' focus upon loss prevented acceptance of the present. However, on reflection, I realised this interpretation was not sufficiently grounded in the data, but was perhaps based upon my assumptions.

5.4.7 Methodological Limitations and Recommendations for Future Research

There are a number of limitations of IPA. One of the main critiques of IPA is that phenomenological research is interested in the essence of experience itself and using interview data relies upon the representational validity of language. It can be argued that language does not provide the means of expressing subjective experience, but instead prescribes what we think and feel; thus language can never simply give expression to an experience (Willig, 2013). IPA has therefore been criticised for not engaging sufficiently with its constitutive role. There is a tension between IPA's assumptions about the representational validity of language, which I attempted to overcome in my analysis by focusing upon subjective experience with a consideration of the role of wider social and cultural influences upon experience.

Another criticism of IPA relates to the suitability of participant accounts and descriptions of their experience for phenomenological analysis. Phenomenology is interested in the essence of experience and it is important to consider how successfully participants were able to communicate the rich texture of this to the researcher using language (Willig, 2013). A visual methodology was incorporated into the research to mitigate this limitation of IPA. The photographs enabled participants to represent their experiences in a different way, enriching the holistic understanding of participants' experiences. The photographs meant that the interview was an embodied and affective experience; as participants interacted with them, they triggered different experiences for the participants, for example, feelings of loss or sadness. It can be argued that, when confronted with photographs, participants imagine their emotions or embodied states, creating a more complex narrative (Reavey, 2011).

All participants in this research were White British residents in the South East of England; therefore social context may have impacted upon the participants’ experience. All participants were accessing support from a carers’ support organisation, which might also have impacted upon their experience and accounts, and therefore the findings. Future studies might consider carrying out similar research with caregivers from other parts of the UK, from different cultural and ethnic backgrounds or with caregivers who are not accessing support from a carers’ organisation. Participants were required to self-select, which may have resulted in the recruitment of participants who were more confident and open in discussing this topic and therefore less restricted in their meaning-making.

It is important to acknowledge that one participant’s husband had moved to a care home, therefore they were providing a more retrospective account. However, they still had significant experience of caring for their husband, which continued even after he moved into a care home. Therefore, their experience was still considered relevant to the research question.

One risk of not including the person with dementia is that they could be positioned as a passive agent with nothing to contribute to the knowledge base. Therefore, future research could consider carrying out similar research and formally including both partners as active research participants in the interview process, which could be considered particularly useful where the research aim is to focus on the relationship. Although, as outlined in section 5.4.5, there are pros and cons of interviewing both members of the couple, some research has done this (e.g. Hellstrom et al., 2007) and yielded positive results.

The sample size was deemed sufficient for the purpose of the research to enable a significant level of analysis to ensure idiosyncratic and convergent meanings were elicited (Smith et al., 2009). The intention of using a sample size of seven was to enable a deeper level of understanding, which was prioritised over generalising the findings, in order to develop descriptive and interpretative knowledge that could enrich understanding. Three participants had a partner with Alzheimer’s disease, which is the most common type of dementia. Different types of dementia result in different symptoms and therefore this might impact upon the caregiving experience (Alzheimer’s Society, 2014). Future research might consider whether there are differences in how the changes in relationship are experienced by couples living with different types of dementia.

The individuals with dementia were at different stages, with diagnoses ranging from 3 to 8 years. This is likely to have impacted on the experiences presented. Whilst it can be difficult to measure, future research might consider carrying out similar studies with caregivers whose partners are at a similar stage in their dementia. There was also variability in the ages of the caregivers (between 63 and 75) and care-receivers (between 64 and 80) which is likely to have impacted upon their experience and was taken into account during analysis. Future research might consider carrying out similar studies with caregivers or care-receivers experiencing early-onset dementia.

Despite the fact that no restrictions were imposed upon the gender of the participants and an equal balance of males and females was initially sought, only females volunteered. This may have been because, traditionally, caregiving is considered to be a female role and males have less societal expectation to provide care (Hirsch, 1996). Therefore, males may be less likely to identify with the position of caregiver, preventing them from volunteering to take part in this type of research. Men tend to have a shorter lifespan and therefore women with dementia are more likely to survive alone, whereas males with dementia tend to be cared for at home by their wives (Baike, 2002); overall, there are more female than male caregivers (Carers Trust, 2015). Future research might consider carrying out similar studies with male caregivers as their experience may differ from females. It could also be important to carry out similar research looking at the experience of same sex couples.

Future research could explore the effectiveness of applying particular clinical implications outlined in this research to further inform clinical guidelines and understand practitioner and patient experiences. It could also focus on specific themes identified in this research to explore them further, for example, coping strategies adopted by caregivers as a way of dealing with their complex experience.

5.5 Final Remarks

The number of people living with dementia and their caregivers is continuing to rise significantly, and whilst the potential for a cure remains in the future, the need for care exists now. Given the complex challenges of living with dementia, research which provides insights into this experience and can help inform clinical practice and social policy is crucial (McGovern, 2011). The findings of this research hold important implications for practice and highlight the need for professionals to support caregivers and couples to adapt to the challenges that dementia presents. Reconceptualising dementia as a condition that affects relationships, rather than individuals alone, offers hope compared to the historical focus on cognitive decline.

Although the biomedical, individualised model of dementia continues to prevail, this research views dementia from a different angle and adds further support to arguments to refocus dementia care on relationships and therapeutic input (Whadham et al., 2015). It is imperative that the psychological needs of caregivers are considered and the relationship between couples living with dementia is supported (McGovern, 2011). Moving beyond the biomedical model highlights a need to redefine the experience of dementia as an illness that affects relationships and, where emotional and psychological experience are prioritised, developing improved policy and practice.

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Appendices

Appendix A: Poster

Caring for your partner with dementia?

Seeking volunteers who are caring for their partner to take part in a one off interview for 60-90 minutes.

This important research is exploring the experience of caring for a partner with dementia.

****

If you think you might be interested in taking part and would like further information please contact:

Andrea Degutis, School of Psychology,
University of East London
07830 484 274 / u1129292@uel.ac.uk

I look forward to hearing from you

I am a doctoral student at the University of East London and the research has been fully approved by the University's ethics committee

Appendix B: Interview Schedule

Start:

Thank you for your time.

Do you have any questions at all?

Just before we start I would just like to gather a few details:

- Age of participant and person with dementia
- Ethnicity of participant and person with dementia
- Married or not
- How long been in relationship
- Living with partner or not
- How long lived together
- How long has your partner had dementia/type of dementia
- How long have you been caring for your partner
- Do you care for them full-time or part-time
- Where else does their care come from (if not the only carer)
- Working
- What kind of work to/used to do
- How long stopped working for
- Highest education
- Any children

Thank you for that, let’s start our chat. I do have some questions which I will look at from time to time.

1. Do you identify what is going on with your partner as dementia or is there something else you use?
   If something else, why is that something else preferable? Or if dementia why use that term?
   Is that similar or different to how your partner likes to be referred as? How do you manage/overcome the differences?
   Do you identify yourself as a carer or is there something else you use?
   If something else, why is that something else preferable? Or if carer why that term?
2. In a general sense what does caring mean to you? (in any context)
3. If a full-time carer for your partner, when and why did you make that decision?
   What did becoming a full-time carer mean for you?
   If a part-time carer does that work for you? Do you see it changing in the future?
   If it did change what do you think that might mean for you?
4. What is your experience of caring for your partner with dementia?

5. Can you describe how your relationship with your partner may have changed since you have become their carer? (if at all)
6. Can you describe how you personally may have changed since becoming a carer? (if at all)
7. PICTURES- Can you tell me about the pictures and what they mean to you and your relationship/caring role?
   How do you see yourself in that picture?
   Why is this picture important to you? What does it mean to you?
   When looking at this picture what are you thinking?
8. What does intimacy in a relationship mean to you?
9. How is intimacy experienced in your relationship with your partner now? And how has it changed?
10. How does intimacy get experienced in your home?
11. How do you imagine your relationship in the future? And how do you see yourself in it as a carer?
12. What is your experience of seeking help since caring for your partner?

Thank you, anything not spoken about that is important?

What was it like having this chat?

Prompts:

Can you tell me more about……

Can you give me an example of……

What does that mean to you?

Can you tell me what you mean by that?

How does that feel?

Appendix C: Invitation Letter

UNIVERSITY OF EAST LONDON

Stratford Campus

Water Lane

London

E15 4NO

Dear Participant,

In keeping with the School of Psychology's ethics procedures, the purpose of this letter is to provide you with information about my research study so that you can make an informed choice about participating in it.

I am a third year Professional Doctorate in Counselling Psychology student at the University of East London and am conducting research as part of my doctorate thesis.

My research is about the experience of caring for a partner with dementia. You will be asked to talk about your experiences of caring for your partner with dementia, the changing nature of your relationship with your partner and how caring might have impacted upon you.

During the interview you will also be invited to show and talk about some existing photographs (approximately 4-6) that you may have of yourself and your relationship with your partner. Having some photographs ready before the interview that are meaningful to you and represent important aspects of your relationship and caring role now and over time would be appreciated. You may be asked for a copy of the photographs that you talk about but you are not obliged to do this.

It is acknowledged that this may be a sensitive issue for you and your safety and comfort will be respected at all times.

If you choose to participate it is anticipated that the interview will take approximately 60-90 minutes. It will be like having an informal chat with me and you will have the right to not answer a question(s) if you choose not to and you will be able to stop the interview at any time without consequence to yourself.

The interviews will take place in a location that is comfortable, safe and private. It would be preferable for the interview to take place in your home, however if this is not convenient a neutral location can be organised. The interview will take place between you and the researcher only and it is important the interview takes place at a time when you are free from disruptions.

All personal information will be saved on the researcher's password protected computer and lockable cabinet and will not be seen by anyone else. The interview will be audio recorded and the recording will be transcribed into written format. The recording will only be heard by the researcher who will also transcribe the interview. While you are being asked to provide your name for the purposes of consent your identity will be protected. Extracts from the transcript of your interview and photographs that you may provide will also be seen by the study's supervisor and its examiner(s). Any written and visual material taken from your interview will be anonymous and you, or anyone you may talk about, will not be identifiable in the write up of the study or in any consequent presentation of the research. All names and places mentioned will be changed.

Once the research has come to an end contact details, audio recordings, anonymised transcripts and photographs that you may provide will be securely kept by the researcher for up to 5 years to allow for the possibility of further analysis. Your contact details will be stored separately from the other material so that you cannot be identified. Only the researcher will have access to the secure storage of your contact details and data, none of which will be stored on a computer after completion of the study.

If you agree to participate you have the right to withdraw from the study at any time without explanation or consequence. You are not obliged to take part in the study. Should you withdraw after the completion of the analysis and beyond, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

Please feel free to ask any questions. If you are happy to continue you will be asked to sign a consent form prior to the interview.

Please retain this invitation letter for reference.

Thank you in anticipation of your participation in the study.

Andrea Degutis

Please feel free to ask me any questions, I can be contacted on:
Email: u1129292@uel.ac.uk
Telephone: 07830484274

Project supervisor: Dr Mark Finn. School of Psychology, University of East London.
Email: m.finn@uel.ac.uk
Phone: 0208 223 4493

Appendix D: Consent Form

Consent to participate in a research study

An Interpretive Phenomenological Analysis (IPA) of caring for a partner with dementia: impact upon the relationship and carer's help-seeking.

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw after the completion of the analysis and beyond, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………………………….

Participant's Signature

……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

……………………………………………………………………………………..

Researcher's Signature

………………………………………………………………………………………

Date: ……………………..…….

Appendix E: UEL Ethical Approval

School of Psychology
ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Mark Finn **ASSESSOR:** Richard Ralley

STUDENT: Andrea Degutis **DATE (sent to assessor):** 11/07/2013

Proposed research topic: An Interpretive Phenomenological Analysis (IPA) of caring for a partner with dementia:_impact upon the relationship and carer's help-seeking.

Course: Professional Doctorate in Counselling Psychology

1. Will free and informed consent of participants be obtained? YES
2. If there is any deception is it justified? N/A
3. Will information obtained remain confidential? YES
4. Will participants be made aware of their right to withdraw at any time? YES
5. Will participants be adequately debriefed? YES
6. If this study involves observation does it respect participants' privacy? NA
7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? NA
8. Is procedure that might cause distress to participants ethical? NA
9. If there are inducements to take part in the project is this ethical? NA
10. If there are any other ethical issues involved, are they a problem? NA

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: RR Date: 25 July 13

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Mark Finn **ASSESSOR:** Richard Ralley

STUDENT: Andrea Degutis **DATE (sent to assessor):** 11/07/2013

Proposed research topic: An Interpretive Phenomenological Analysis (IPA) of caring for a partner with dementia: impact upon the relationship and carer's help-seeking.

Course: Professional Doctorate in Counselling Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

1	Emotional	YES
2.	Physical	NO
3.	Other (e.g. health & safety issues)	NO

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: LOW

APPROVED

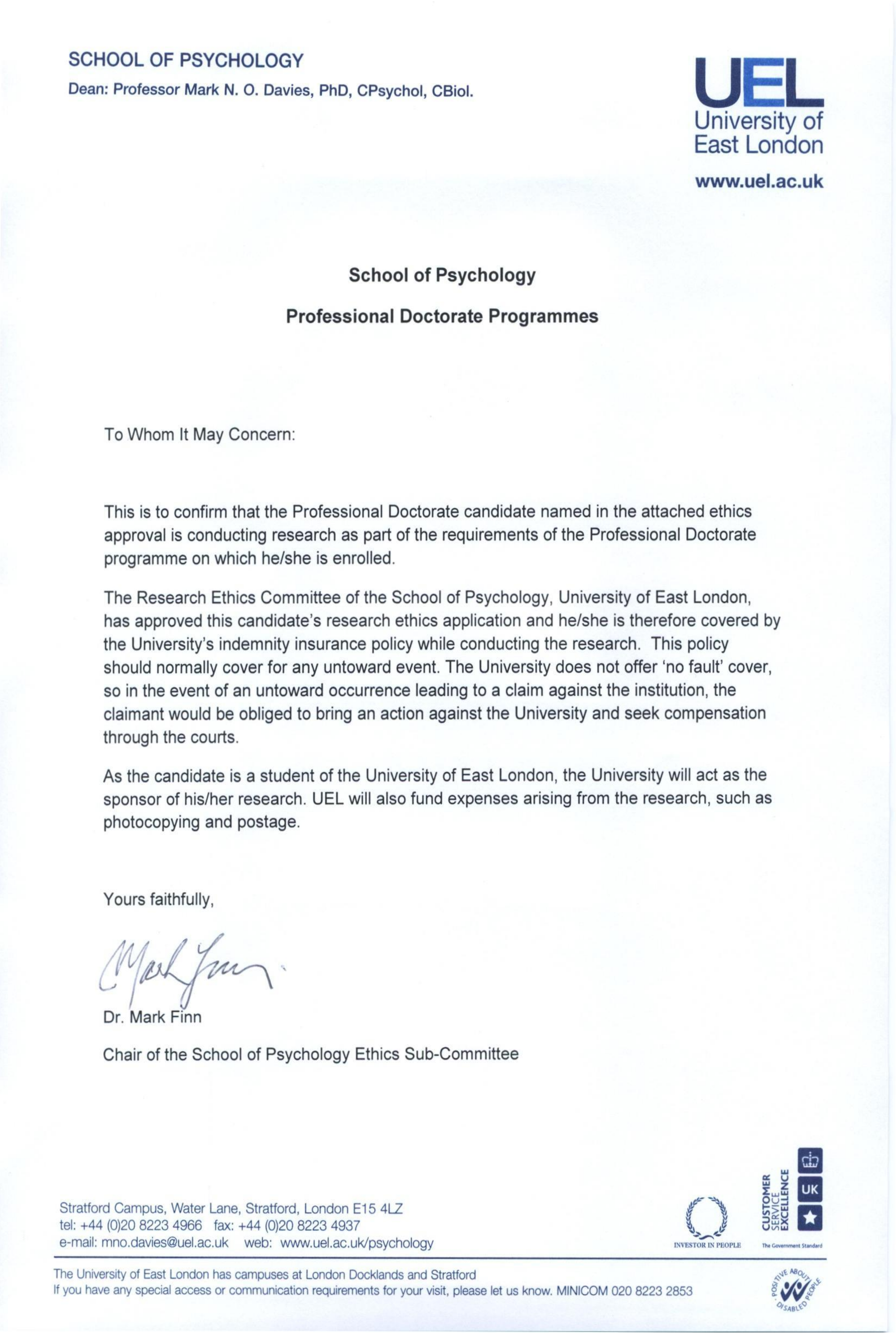
YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **RR** Date: 25 July 13

For the attention of the assessor: Please return the completed checklists by e-mail to ethics.applications@uel.ac.uk within 1 week.



SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Mark Finn

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

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If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853

POSITIVE ABOUT DISABLED PEOPLE

Appendix F: Extract from Reflective Diary

Sarah’s husband was asleep throughout the entire interview and he didn’t make a sound. It seemed very poignant that he was present throughout the interview and suggested that she was constantly being reminded of how much he has changed. It also felt that Sarah had to be near her husband at all times, even during the interview and there was a sense that her husband was always there in the background, dormant and inactive.

Sarah’s physical environment had clearly been impacted by her husband’s dementia and there were a lot of changes that had had to be made due to her husband mobility problems. It was clear that dementia had significantly impacted her life in many ways, including the space she lived in and it felt very busy/chaotic.

I felt a huge sense of sadness during Sarah’s interview when hearing about her experiences and felt very tired afterwards. At times I wondered if some of the sadness I was feeling reflected some of the feelings that Sarah seemed to find it hard to express. Sarah spoke about how she tended not to think about her experiences as deeply as during the interview. I felt conflicted at times; I was mindful that I didn’t want Sarah to talk about things she didn’t feel comfortable to but it was also important to ask questions in order to try and gather meaningful data. This was a tricky balance to achieve at some points during the interview and Sarah’s wellbeing was always the priority. She became very emotional at one point and had to leave to take some aspirin for a headache, I wondered if her headache reflected the intensity of her emotional pain. I offered to stop the interview but she chose to continue.

Sarah laughed on several occasions which seemed to be one of her ways of coping when painful emotions were experienced and seemed to minimise her experience. There was a sense throughout the interview that Sarah was battling against her emotions and trying to prevent herself from becoming tearful.

Sarah told me at the end of the interview that she worries other people might criticise her and that this applied to me during the interview. I reassured Sarah that I wasn’t there to criticize her in any way but was interested in hearing what her experience is like. However, I wondered if this impacted the story that she told me and meant she only shared certain parts of her experience to prove she was doing a ‘good job’. I also wondered if this is why she sometimes found it difficult to express how she was truly feeling and whether she viewed me as a ‘professional’ in a position of authority rather than someone who was genuinely interested in hearing her story.

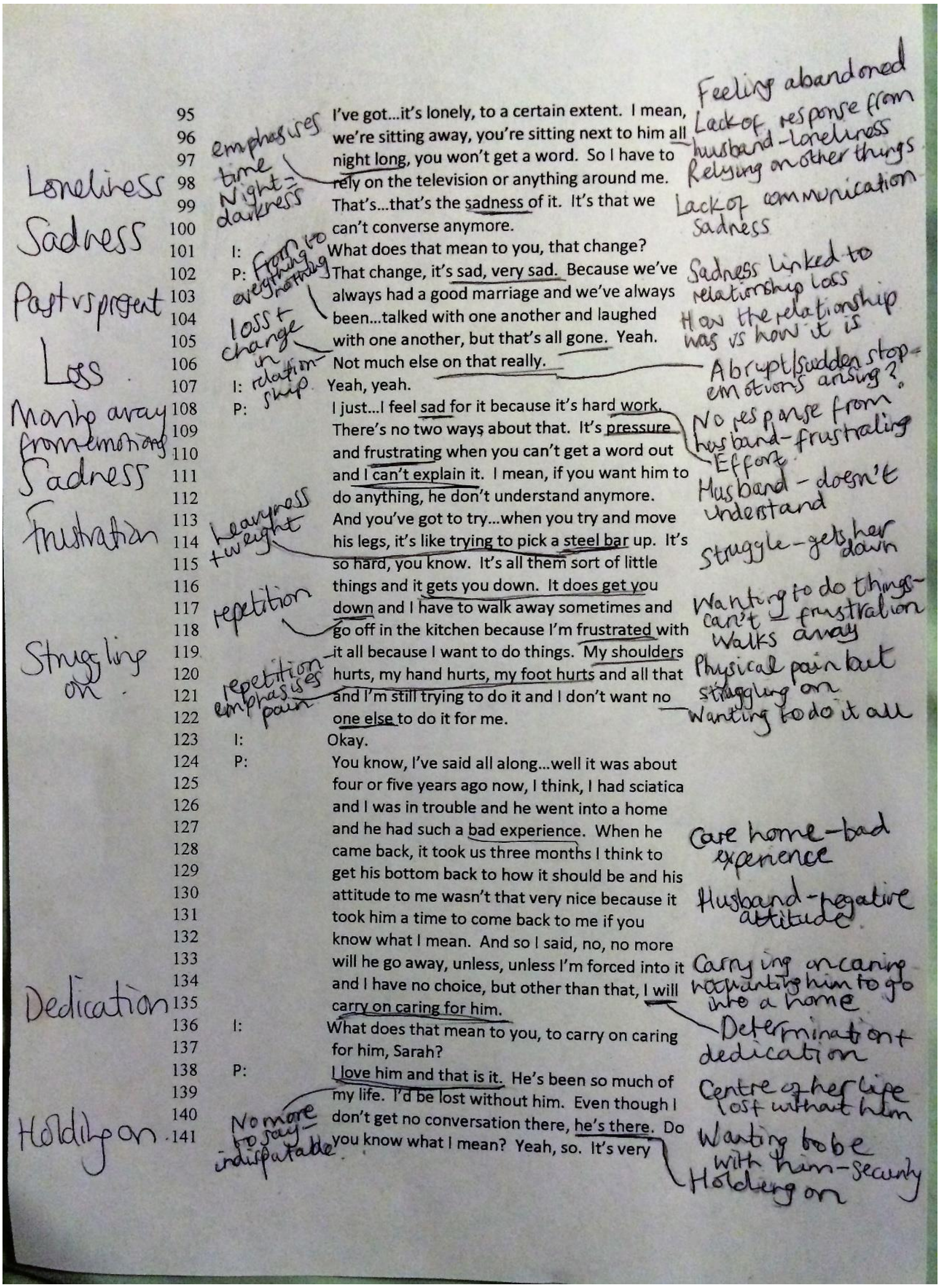
I was mindful that Sarah appeared to have built up defences against her emotional pain and that she seemed to struggle to accept the significant change that dementia had imposed upon her and her husband. I was aware that it was important to bracket this information for future interviews so that it didn’t impact on what I did/did not ask and the narrative that was constructed, in order to remain open to hearing each participant’s unique story.

I also got the sense that Sarah was very lonely and I felt a strong urge to want to help her. Her whole world seemed to be dominated by her husband's dementia. I had to remind myself of my role as a researcher rather than a therapist. However, giving her the number for local counselling services at the end of the interview provided me with some reassurance that she was aware of where she could access further support if she wanted/needed to.

Appendix G: Transcription Key

[pause]	Denotes pause for longer than 2 seconds
[non-verbal]	Denotes non-verbal utterances or actions such as laughter
[inaudible]	Denotes inaudible section of interview
[…]	Denotes words that have been cut out to ensure that extracts are concise and clear. However, the researcher has been mindful not to alter participants’ intended meaning.

Appendix H: Annotated Transcript



I've got...it's lonely, to a certain extent. I mean, we're sitting away, you're sitting next to him all night long, you won't get a word. So I have to rely on the television or anything around me. That's...that's the sadness of it. It's that we can't converse anymore.

I: What does that mean to you, that change?

P: That change, it's sad, very sad. Because we've always had a good marriage and we've always been...talked with one another and laughed with one another, but that's all gone. Yeah. Not much else on that really.

I: Yeah, yeah.

P: I just...I feel sad for it because it's hard work. There's no two ways about that. It's pressure and frustrating when you can't get a word out and I can't explain it. I mean, if you want him to do anything, he don't understand anymore. And you've got to try...when you try and move his legs, it's like trying to pick a steel bar up. It's so hard, you know. It's all them sort of little things and it gets you down. It does get you down and I have to walk away sometimes and go off in the kitchen because I'm frustrated with it all because I want to do things. My shoulders hurts, my hand hurts, my foot hurts and all that and I'm still trying to do it and I don't want no one else to do it for me.

I: Okay.

P: You know, I've said all along...well it was about four or five years ago now, I think, I had sciatica and I was in trouble and he went into a home and he had such a bad experience. When he came back, it took us three months I think to get his bottom back to how it should be and his attitude to me wasn't that very nice because it took him a time to come back to me if you know what I mean. And so I said, no, no more will he go away, unless, unless I'm forced into it and I have no choice, but other than that, I will carry on caring for him.

I: What does that mean to you, to carry on caring for him, Sarah?

P: I love him and that is it. He's been so much of my life. I'd be lost without him. Even though I don't get no conversation there, he's there. Do you know what I mean? Yeah, so. It's very

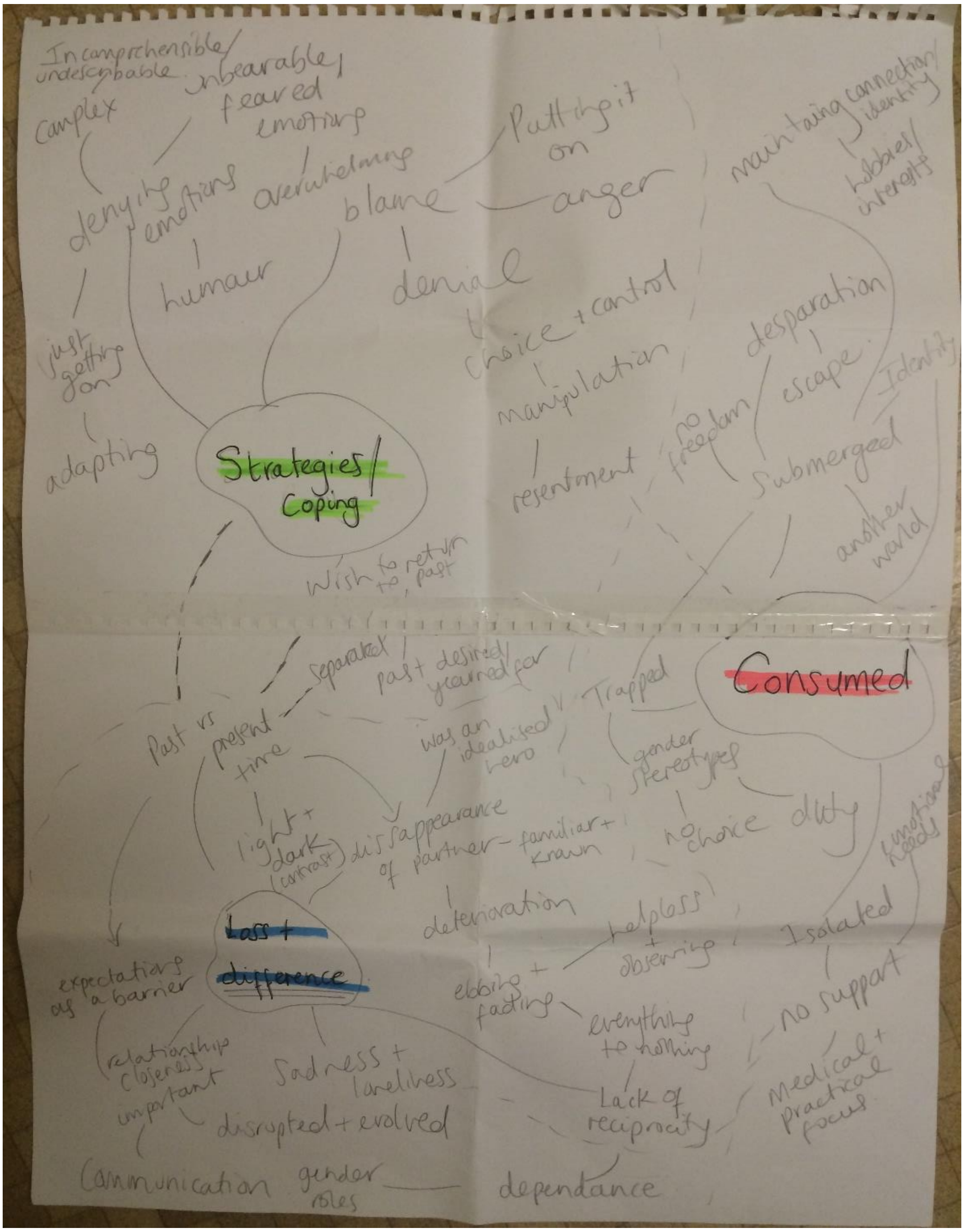
Loneliness
Sadness
Past vs present
Loss
Moving away from emotions
Sadness
Frustration
Struggling on
Dedication
Holding on

emphasises time
Night = darkness
From everything to nothing
loss + change in relationship
heaviness + weight
repetition
repetition emphasises pain
No more to say - indisputable

Feeling abandoned
Lack of response from husband - loneliness
Relying on other things
Lack of communication
Sadness
Sadness linked to relationship loss
How the relationship was vs how it is
Abrupt/sudden stop - emotions arising?
No response from husband - frustrating
Effort
Husband - doesn't understand
Struggle - gets her down
Wanting to do things - can't = frustration
Walks away
Physical pain but struggling on
Wanting to do it all
Care home - bad experience
Husband - negative attitude
Carrying on caring not wanting him to go into a home
Determination + dedication
Centre of her life lost without him
Wanting to be with him - security
Holding on

Appendix I: Connections between Emergent Themes

Appendix J: Mind-Map Clustering Emergent Themes across Participants



Appendix K: Story Board Creating Connections between Themes