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**University of Southampton**

Faculty of Social Sciences

Gerontology

**Couplehood, Cognitive Stimulation Therapy and Dementia: An Interpretative  
Phenomenological Analysis**

by

**Sara Elizabeth Johnson**

Thesis for the degree of Doctor of Philosophy

April 2019



# University of Southampton

## Abstract

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Couplehood, Cognitive Stimulation Therapy and Dementia: An Interpretative

Phenomenological Analysis

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Research into the lived experience of couples, where one spouse is affected by dementia has revealed that the type and quality of spousal relationships are integral to this experience. It is therefore important that we understand how couples relate to each other as they navigate the disruption to their relationship associated with the disease. Dementia impacts on both members of the couple, and can be burdensome, however it can also be an opportunity for growth and increased closeness. Traditionally, research has focused on the experience of spousal care partners rather than on the individual with dementia themselves and there is a lack of knowledge of the view of individuals and their spouse on their joint perspective of the impact of dementia on sense of couplehood. This study aims to address this gap by exploring couples lived experience of dementia and couplehood and the ways in which psychosocial interventions such as Cognitive Stimulation Therapy impacts on the couples' sense of couplehood.

This is a qualitative study which was underpinned by the theoretical and methodological framework of Interpretative Phenomenological Analysis. Face to face semi-structured interviews were conducted with four couples, where one of the partners from each couple had a diagnosis of dementia. In order to gain rich and open dialogue, each partner was interviewed separately. Four master themes were identified; Navigating Disruption, Re-appraisal, Mindfulness, and Living the New Normal. Results from the data analysis demonstrated that living with and adjusting to dementia is an ever changing process but that couples were determined to get on with their lives and saw dementia as an illness to be faced with together. Even as dementia worsened couples actively worked together to maintain a sense of togetherness. Cognitive Stimulation Therapy was seen as beneficial and aided couples in their efforts to preserve couplehood.



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# Research Thesis: Declaration of Authorship

Print name:	Sara Elizabeth Johnson
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Title of thesis:	Couplehood, Cognitive Stimulation Therapy and Dementia: An Interpretative Phenomenological Analysis
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I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature:		Date:	
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And to the participant couples who without their courage, honesty and generosity of time this thesis would not have been possible. I hope I have done justice to their stories.



## **Definitions and Abbreviations**

SWD – Spouse with Dementia

CP – Care partner

AD – Alzheimer’s disease

VaD – Vascular Dementia

LBD – Lewy Body Dementia

BPSD – Behavioural and Psychosocial Symptoms of dementia

MCI – Mild Cognitive Impairment



# Chapter 1 Introduction

## 1.1 Overview of the chapter

This study adds to and expands the existing body of knowledge in research on marriage and dementia by interviewing four couples in which both spouses were included equally in the research. The study is timely and relevant as the number of people with dementia is estimated to be 50 million people worldwide, a figure which is rising (Alzheimer's Disease International, 2018). The World Health Organisation (WHO) (Prince et al., 2016) have emphasised that dementia is a growing health concern. The number of people with dementia is predicted to double by 2030 and more than treble by 2050 (Prince et al., 2016). The annual economic cost of caring for individuals with dementia to the UK is estimated to be £26.3 billion (Prince et al., 2014) and this economic burden is likely to rise as the condition's prevalence increases (World Health Organisation, 2012). These stark figures are significant as dementia does not affect individuals in isolation, but rather impacts on and changes the lives of carers and family members, most crucially those of spouses caring for a partner with dementia. The aim of this introductory chapter is to provide the rationale, background and context for this thesis on couplehood, cognitive stimulation therapy (CST) and dementia.

The chapter begins with a definition of key terms, including the notion of couplehood and the importance of adopting a relational approach in research for couples where one spouse has a diagnosis of dementia. The chapter then discusses the difficulties and challenges faced by couples where one spouse has a deteriorating illness, dementia.

Section 1.3 provides an overview of the definition of dementia, while section 1.4

discusses prevalence of dementia in the UK. The symptoms and impact of dementia are discussed in sections 1.5 and 1.6. Leading on from this, section 1.7 examines treatment for dementia, both from a medical and a psychosocial perspective. The chapter then moves on to provide an overview of CST for dementia and discusses the evidence base for this intervention. The chapter ends with an overview of the structure of the thesis, research aims and justification for this study.

## **1.2 Definition of key terms**

The next three sections introduce the reader to key terms used throughout the thesis.

The aim of these sections is to give an overview of why applying appropriate terminology is important for couples and why the term 'care partner' rather than 'carer' has been chosen and this is discussed in Section 1.2.1. Section 1.2.2 then defines the notion of couplehood and section 1.2.3 provides a synopsis of what a psychosocial intervention is.

### **1.2.1 Carer versus care partner**

Traditionally, the term 'carer' has been assigned to any individual, either a family member or a paid helper who regularly looks after an individual who, due to illness or disability cannot cope without their support (Carers Trust, 2015). However, research on identity theory (Stets and Burke, 2000) suggests that when applying the term 'carer' to couples, this may imply burden and could even devalue the individual who is being cared for (Molyneaux et al., 2011c). This is because spouses perceive their help giving and help receiving activities to be a normal and expected aspect of their relationship (Hughes et al., 2013). Nolan (2001) and Molyneaux et al. (2011c) further purport that

under these situations, factors such as the giving and receiving of support which characterise marital relationships may be over-looked and conclude that a focus on the care relationship itself would be a more appropriate framework.

Research also suggests that the ways in which individuals perceive themselves is often a shifting variable with some spousal carer partners being unable to identify with the term 'carer' at all (O'Connor et al., 2007).

In keeping with the changing terminology within dementia research, throughout this thesis, the term 'carer' is used to describe an individual or family member who provides formal or informal care to another individual. The term 'care partner' or 'spousal care partner' is used to describe a partner or spouse who is in a married or a co-habiting relationship with the individual for whom they provide care, specifically informal (unpaid) care. This is in order to reflect a more recent shift in terminology which acknowledges the importance of pre-existing relationships of individuals who support and need the support of a spouse (Molyneaux et al., 2011b; Hellström et al., 2007; Merrick et al., 2016).

### **1.2.2 Couplehood**

For the purpose of this thesis, the notion of couplehood is understood as a harmonious match between two partners who are in a romantic relationship with each other and are committed to a shared future through marriage or co-habiting. Indeed, adopting the notion of couplehood from Horowitz (1999), couplehood is understood as a social process of negotiation between two individuals towards a sense of partnership which is characterised by shared goals and aims. The transformation from being a single

individual towards couplehood is characterised by respect, mutuality, commitment and reciprocity (Horowitz, 1999; Kaplan, 2001). Consequently, the couple establish a definition of couplehood which is accompanied by negotiated responsibilities and behaviours which in turn determine individual actions and reactions to life events. To further draw on the definition offered by Kaplan (2001), couplehood is defined as the extent to which couples identify as a 'we' in their relationship as compared to an 'I'. A sense of 'we-ness' has been identified as a fundamental dynamic of successful, resilient and satisfying relationships (Skerrett, 2003).

Research into the quality of life and wellbeing of healthy married couples (Horwitz et al., 1996) offers strong evidence of a positive association between the quality of marital relationships and wellbeing. Research also suggests that caregiving can negatively affect the quality of relationships between spouses and has significant clinical implications (Shields, 2000). For example, Fauth et al. (2012) demonstrated that loss of perceived closeness between care partner and spouse with dementia is associated with poorer mental health and wellbeing of both spouses than those who perceive that the closeness in their relationship has remained unchanged. Loss of closeness in the relationship also impacts negatively on care partner spouse's who report high levels of depression and decreased morale (Fauth et al., 2012). Additionally, Baike (2002) highlighted the impact of dementia on aspects of the marital relationship such as a decrease in shared activities, loss of emotional support and reduced quality of communication between spouses. These changes result in an overall loss of relationship quality, leading to increased stress and burden, particularly for care partner. Additionally, highly stressed care partners often do not realise that their ability to cope

has been compromised (McConaghy and Caltabiano, 2005), resulting in resentment and bitterness, guilt, deteriorating physical health and increased risk of developing dementia themselves (Christian, 2015). This is significant as a care partners ability to cope impacts on the support they can provide and can result in possible emotional and physical abuse and early admission to institutional care of the spouse with dementia (Moniz-Cook et al., 1998).

The notion of couplehood in dementia (Molyneaux et al., 2011b) provides a novel way of reflecting on how cognitive impairment may impact on and alter the relationship between a spouse with dementia and their partner (Ingersoll-Dayton et al., 2014; Hellström et al., 2005). Couplehood therefore is an important theoretical lens through which to view the impact of dementia from an inter-relational perspective. By adopting a more inter-relational standpoint to understand couples lived experiences acknowledges that spouses are themselves positioned within a network of giving and receiving and further recognises the manner in which couples are connected and how they impact on and affect one another (Hellström et al., 2005; Merrick et al., 2016). Whilst the majority of research on dementia caregiving relationships has tended to focus separately on either care partner or spouse with dementia, adopting a relational approach, which addresses notions of couplehood ensures that both spouses are included equally. That is, a relational approach provides a perspective which examines the ways in which an individual's relationship with their spouse can shape their daily experiences and can help identify the patterns that appear in the thoughts and feelings they may have towards themselves and their spouse (McGovern, 2011). By only investigating the perspective of one spouse has led to research which has a heavy bias

on the biomedical model of dementia (McGovern, 2011) (see section 1.6.2 for discussion the medical model). Historically, research exploring dementia has predominately focused on issues such as caregiving burden (Etters et al., 2008; Burns and Rabins, 2000; Vitaliono, 2015), stress and strain (Brodaty and Donkin, 2009) and depression (Mitrani et al., 2006) but has tended to ignore the complicity of the relationship dynamic. The impact of dementia on the spousal relationship can not be fully understood without the inclusion of both spouses (Braun et al., 2009; Hellström et al., 2005). The concept of couplehood therefore provides a more nuanced understanding of how couples construct and maintain their relationship in light of a deteriorating illness. Additionally, Hellström et al. (2005) contend that without adopting a relational approach, the very personhood of an individual can be undermined as notions of personhood are often shaped within the context of a relationship with a significant other.

However, despite an extensive literature search, defining the term couplehood within dementia research has proved elusive and challenging. Most papers that use the term couplehood, either make no attempt at definition or at best allude to couplehood as a 'relational process' which is affected by dementia (Forsund et al., 2014: p122). Indeed as Forsund et al. (2014) points out, the variety of terms used to describe different aspects of the spousal caregiving/care receiving relationship include partnership and companionship (Evans and Lee, 2013), connectedness/separateness (O'Shaughnessy et al., 2010) and continuity/discontinuity (Walters et al., 2010). Hellström et al. (2005) propose that the concept of couplehood (the couple and their relationship as primary focus) resembles the notion of personhood (the individual as primary focus) and

provides a means of understanding the ways in which spouses 'do things together' (Hellström et al., 2005: p19).

In a seminal study of the impact of dementia on couplehood typology, Kaplan (2001) identifies five stages or threats to sense of couplehood ('Til Death do us part' 'We but', 'husbandless wives/wifeless husbands', 'becoming an I' and 'unmarried marrieds'). Asked to rate perceptions of couplehood on a continuum ranging from 'I' (no sense of couplehood) to 'we' (strong sense of couplehood), Kaplan (2001) suggests that couplehood can be understood as the extent to which individuals perceive feelings of 'we-ness' rather than being an 'I'. Feelings of belonging, closeness and reciprocity are highly correlated to perceptions of couplehood even for spouses who were still married but lived separately due to the individual with dementia being in institutional care.

The notion of couplehood has been expanded by research by Forsund et al. (2014) whose study explored the experience of losing a sense of couplehood with an institutionalised spouse. In contrast to Kaplan's study (Kaplan, 2001), Forsund et al. (2014) reported that rather than being a static concept, one's sense of couplehood oscillates along the 'I' – 'We' continuum. Moreover, Forsund et al. (2014) highlighted that it was the care partner spouses who actively worked to maintain feelings of belonging by utilizing strategies such as frequently visiting their institutionalised spouse or encouraging shared memories and reminiscence. Although only concerned with the views of the care partner spouses, these studies are relevant as they provide insight into how notions of couplehood are interwoven with a sense of belonging and continued commitment even for separated spouses. This is verified by research by Chesla et al. (1994) who also suggest that feelings of closeness and continuity of relationships can be

maintained even with individuals in the later stages of cognitive decline. Despite this, the study by Kaplan (2001) only elicited the views of the non-institutionalised spouse and in this way the research tended to follow the dominant biomedical model of dementia (see section 1.6.2 for discussion on the medical model of dementia). The study may have benefited from discussion with or about the institutionalised spouse. One factor which was not addressed but which may have strengthened the discussion could have been the notion of 'enduring couplehood' (McGovern, 2011). Enduring couplehood refers to the ways in which theoretical assumptions about how couples derive meaning in dementia should include attention to the wellbeing of both members of the couple. Indeed Chesla et al. (1994) also introduce the notion of relationship continuity throughout every stage of the dementia journey.

These studies all conclude that those seeking to capture the experience of dementia and couplehood should include the voice of the person living with dementia alongside that of their care partner (Forbat, 2003). Research exploring couplehood and dementia strengthens the view that to consider the person with dementia in isolation does not tell the whole story and it is important to embrace the notion that their being is 'constructed through being in relation to others' (O'Connor et al., 2007: p122). Despite a growing body of literature on marriage and couples, the majority of studies tend to rely on the perspective of only one member of the couple which leads to only partial understanding of the relationship. Studies involving both members of the couple as equal participants provide a more holistic picture of the nuanced nature of relationships and shared couple experiences (Daniels et al., 2007; Molyneaux et al., 2011b; Wadham et al., 2015; Hellström et al., 2007). This current study aims to build on and expand

previous research by revealing the shared story of couplehood from the perspective of both members of the couple.

Keady and Nolan (2003a) suggest that a relational approach to care is important in order to provide services which are effective and appropriate for couples. This has been further reflected in a number of health and social care policies (NICE -SCIE, 2007).

However, despite these recommendations, there remains a tendency to 'forget the couple behind the disease' (Daniels et al., 2007: p162). Svanstrom and Dahlberg (2004) also highlight that the views of spouses with dementia are often overlooked and 'indeed persons with dementia have been most often observed or described by relatives and staff' (Svanstrom and Dahlberg, 2004: p672). NICE guidelines also highlight 'the importance of relationships and interactions with others to the person with dementia' (NICE, 2006: p6). This is significant given that statistics show that most care is provided by informal care givers, most significantly spouses; however, despite this, there is a paucity of literature on the impact of couplehood and relationship change which includes the individual with dementia.

Having discussed the importance and complexity of notions of couplehood, the next section provides an overview of what a psychosocial intervention is.

### **1.2.3 Psychosocial interventions**

Psychosocial interventions for dementia is a broad term used to describe different psychological and social strategies of support for individuals with dementia and their families in order to live well following diagnosis (Guss et al., 2014). Psychosocial interventions do not involve medication and are designed to support people to maintain

optimal mental health by introducing interventions to reduce stress, maintain social life and relationships, preserve independence and quality of life, come to terms with diagnosis and aid cognitive functioning (Guss et al., 2014). Deciding on the right psychosocial intervention will be dependent on an individual's needs. Psychosocial interventions for dementia that aim to improve and maintain cognitive function include Cognitive Rehabilitation (learning strategies to manage memory problems and tackling everyday tasks), CST (a 14 week course aimed to actively stimulate and engage people with dementia) (See section 1.8), Cognitive Training (training specific aspects of memory and other thinking skills) and Reminiscence (usually a group format designed to focus on an individual's preserved memories such focusing on familiar times and shared common experiences) (Guss et al., 2014).

Having discussed the notion of couplehood and the importance of a relational approach and having introduced the reader to what a psychosocial intervention is, the next three sections now present an overview of dementia including definition, prevalence and symptoms. This is followed by a discussion of the relational, psychosocial and economic impact of dementia.

### **1.3 Definition of dementia**

The World Health Organization, in their recently updated international classification of diseases for mortality and morbidity statistics (ICD-11) offers the following definition of dementia:

*Dementia is an acquired brain syndrome characterized by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such*

*as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuo-perceptual or visuospatial abilities). The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living. Based on available evidence, the cognitive impairment is attributed or assumed to be attributable to a neurological or medical condition that affects the brain, trauma, nutritional deficiency, chronic use of specific substances or medications, or exposure to heavy metals or other toxins (World Health Organisation, 2018)*

<https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/546689346>

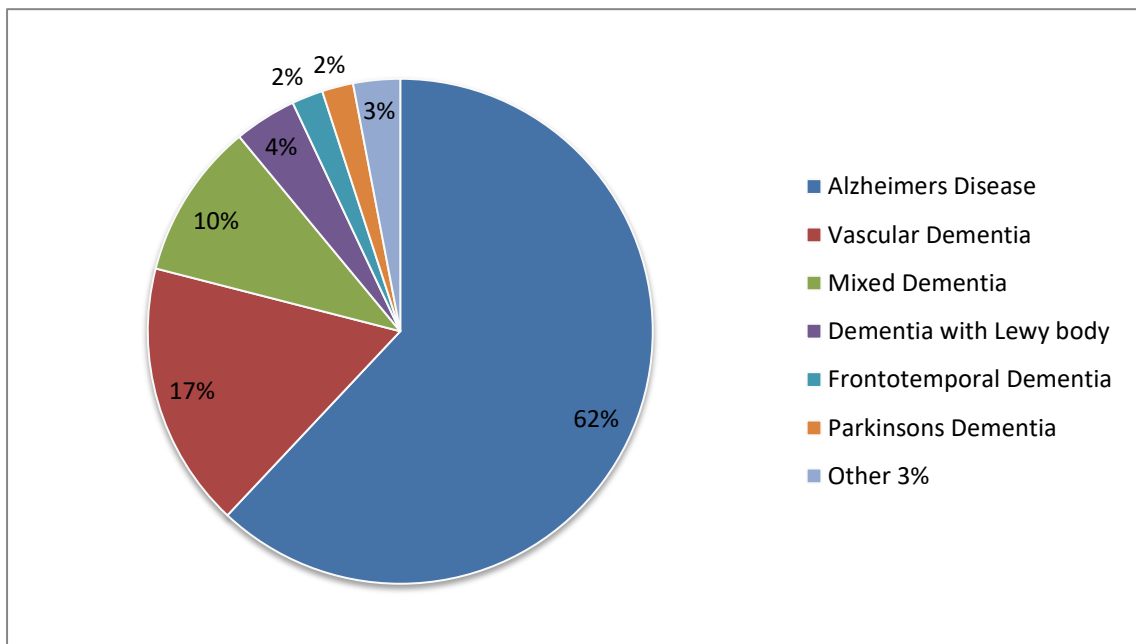
As the above definition suggests, dementia is an umbrella term, used to describe a group of symptoms that includes memory loss as well as difficulties with thinking, problem solving and language. These deficits result in substantial impairment in occupational or social functioning, leading to increased dependence on others. As dementia progresses, individuals with the condition have increasing levels of care needs. The majority of these needs tend to be met by informal or family caregivers. A recent report on the impact of dementia on family carers in the UK estimated that 36% of carers spend more than 100 hours per week caring for a family member with dementia (Alzheimer's Research UK, 2018).

## **1.4 Types and prevalence of dementia**

The most prevalent type of dementia is Alzheimer's disease (AD), which accounts for around 62% of cases of dementia in the UK (Prince et al., 2014). AD is characterised by proteins which build up in the brain to form plaques and tangles, resulting in the loss of connections between nerve cells. These plaques can ultimately result in the death of

nerve cells and brain tissue. Vascular dementia (VaD) is the second most common type and accounts for approximately 17% of the UK's population who are living with dementia (Prince et al., 2014). While clinically similar to AD, VaD is caused by stroke or small vessel changes which affect the flow of oxygen to the brain. VaD affects people in different ways and can cause stroke-like symptoms and confusion. A common presentation is VaD and AD together. This is known as mixed dementia and comprises approximately 10% of dementia cases. Lewy body dementia (LBD) represents approximately 4% of the causes of dementia and is characterised by fluctuations in cognitive symptoms alongside recurring visual hallucinations and movement disorder (Parkinsonism). Less common types of degenerative dementia also include Frontotemporal Dementia (FTD), Creutzfeldt-Jakob disease and Korsakoff's syndrome. Figure 1, below, illustrates the different subtypes of dementia by proportion.

Figure 1: Proportions of subtypes of dementia



(Prince et al., 2014)

The prevalence of dementia is of worldwide concern and is estimated to be a growing global challenge. In 2018, Alzheimer's Disease International (ADI) reported that worldwide, 50 million people currently live with dementia and estimate that this will increase to 131.5 million people by 2050 (Alzheimer's Disease International, 2018). The prevalence of people living with dementia in the UK is estimated to be 850,000 (1.1% of the population), which is set to rise to one million by 2025 and more than two million people by 2051 (Alzheimer's Disease International, 2018). The former UK Prime Minister David Cameron had called dementia one of the biggest health challenges for the nation (Department of Health, 2012). In the UK approximately two thirds of people with dementia live in the community in their own homes whilst one third live in a care home (Alzheimer's Research UK, 2018). Of those who live in the community, about one third live on their own and are cared for with formal and informal support (Miranda-Castillo et al., 2010). However, the majority of individuals with dementia are cared for at home by a family member and a high proportion of whom are spouses (Van Mierlo et al., 2012). A study by Davies and Gregory (2007) highlighted the increasing numbers of care partners and identified that up to 80% of dementia care is provided at home by spousal care partners. As the number of individuals with dementia rises, it is increasingly important to understand the lived experience of the disease in order to support individuals and their care partners in coping with the condition.

The experience of living with dementia is therefore not just loss of memory but covers a wide range of physical and emotional symptoms (Sanford, 2001), which are discussed in the next section.

## 1.5 Symptoms of dementia

Whilst a change to short term memory is often the first indicator of dementia, it is not the defining feature of the disease. Indeed, some variants of dementia may not result in cognitive impairment in the first instance and are characterised by disinhibited behaviour and personality changes. The symptoms of dementia are generally mild initially, gradually worsening over time until they interfere with activities of daily living. While there are varying differences between symptoms and type of dementia, symptoms commonly comprise memory impairment including damage to episodic memory (autobiographical events such as who, what, when, where and associated emotions), visuospatial processing (the 'whereness' of oneself in relation to objects and environment) and semantic memory (recall of general facts and meanings about the world) (Folquitto et al., 2011). In cases where only memory difficulties are present, the individual may be diagnosed with a Mild Cognitive Impairment (MCI) (Petersen, 2004). A diagnosis of MCI is a separate condition, although there is a 15% possibility that an individual with MCI will go on to develop dementia (World Health Organisation, 1992). Diagnosis of dementia can only be made following a comprehensive assessment of an individual (NICE, 2018). Within a clinical setting, distinguishing the numerous subtypes of dementia can be challenging (Paraskevaidi et al., 2018). This is because diagnostic methods are in constant development in attempts to tackle the disease and as yet there is no universally conclusive guide which incorporates wider techniques for diagnosing the different subtypes of dementia (Paraskevaidi et al., 2018).

Table 1 below summarises the four most common subtypes of dementia on various domains, including history of presentation, physical signs and symptoms as well as

pathology. The different subtypes of dementia can impact in discretely distinctive ways on individuals, which can complicate both the care and support that they need as well as the intensity of support needed by their care partner.

Table 1: Subtype of dementia by domain

	<b>AD</b>	<b>VaD</b>	<b>LBD</b>	<b>FTD</b>
<b>History</b>	Gradual onset and progression	Abrupt or gradual onset Stepwise or gradual progression	Insidious onset Progression with fluctuations	Early, insidious onset Rapid progression
<b>Physical Signs and Symptoms</b>	Normal gait, normal neurological exam in the early to mid-stages	Gait abnormalities, signs of vascular disease and focal neurological signs	Shuffled gait, increased tone, tremors, slow moving	At the late stage, patients develop gait abnormalities along with primitive reflexes
<b>Other Signs and Symptoms</b>	Memory loss, language deficits, mood swings and personality changes	Memory loss, language deficits, dysarthria, emotional lability, decreased concentration	Depression, hallucinations, variable in terms of day to day symptoms	Poor judgement, social withdrawal and socially inappropriate behaviour
<b>Imaging</b>	Generalised atrophy with noted medial temporal lobe atrophy	Strokes, lacunar infarcts, white matter lesions are noted	Generalised atrophy throughout	Frontal and temporal lobes are atrophied
<b>Pathology</b>	Beta amyloid plaques and neurofibrillary tangles	Cerebrovascular disease due to common cerebrovascular risk factors	Lewy bodies are present in both the cortex and the midbrain areas	Absence of plaques and tangles, pick cells and bodies are present in the cortex

(Dugue M et al., 2003)

For each sub-type of dementia and their associated symptoms, listed above, there is a need for support for both the individual with dementia and their care partner. However, this can present a major challenge since all forms of support require the physical and

psychological energy of care partners. The Dementia UK report suggests that the type and range of dementia services requires significant improvement in order to ensure that they are meeting the needs of people with dementia and their carers (Prince et al., 2014). A study of caregivers of people with dementia by Beerl et al. (2002) highlighted that the management of Behavioural and Psychological Symptoms of Dementia (BPSD) is cited as the most distressing manifestation of the disease. These symptoms include unpredictable agitation, anxiety, elation, irritability, delusion, hallucination, depression, apathy and disinhibition, alongside changes to sleep and/or appetite. It is estimated that up to 90% of all individuals with dementia will experience some degree of these symptoms (Cerejeira et al., 2012). These symptoms are distressing for individuals and their caregivers, and can lead to considerable social and economic costs. These behavioural and psychological symptoms are the single biggest factor that prompt caregivers to place individuals with dementia into long term care (Armstrong, 2000). Amongst all of the BPSD symptoms of dementia, apathy, loss of motivation and reduced communication are highly correlated to spousal frustration and can have a negative effect on the quality on spousal relationship (Massimo et al., 2013; Williams, 2005). These symptoms are also cited by carers as one of the most challenging features of dementia (Brodsky, 2012; Philippe et al., 2002; Zarit et al., 1980). However, the ways in which dementia manifests itself can be unique to the individual, and whilst everyone with dementia will display some form of BPSD, the intensity of these symptoms will vary from individual to individual, posing additional challenges for care partners and the individual with dementia themselves in anticipating and adjusting to changes.

The impact of dementia on individuals, carers and wider society is considerable and touches the lives of millions of people. In order to ensure that care is appropriate, research on dementia is increasingly arguing for the importance of including the views and experiences of individuals with dementia alongside that of their care partners (Merrick et al., 2016). This current study therefore is timely and appropriate as understanding the experiences of those affected by dementia and their care partners will help build services which are relevant and needs-led (Knapp and Prince, 2007).

## **1.6 Relational, psychosocial and financial impact of dementia**

Consistently, research suggests that the experience of being diagnosed with dementia is often characterised by feelings of shock and vulnerability (Vernooij-Dassen et al., 2006; Aminzadeh et al., 2007). Diagnosis can represent a time of intensified emotions and fear which can be as debilitating as the illness itself (Robinson et al., 2011). The period between seeking help for memory problems and receiving a formal diagnosis can be ‘a long emotional journey’ (Samsi et al., 2014: p29) marked by uncertainty, anxiety and frustration with the assessment process. However, consistent with research on chronic illness, these heightened emotions fade over time as individuals adjust to the diagnosis (Wolverson et al., 2010).

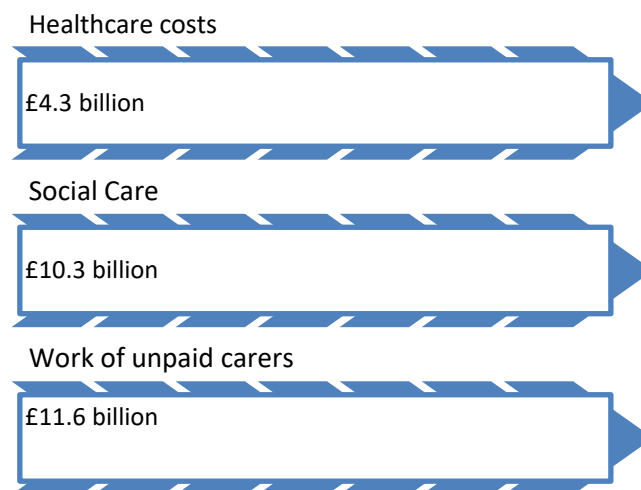
Dementia impacts on an individual’s capacity for independent living. Qui et al. (2007) suggest that two-thirds of all older people with dementia experience some loss of independence. Dementia is the leading cause of disability among older people and significantly affects health systems around the world, resulting in considerable societal costs (Wimo et al., 2000). As a consequence, meeting the multiple needs of those who experience dementia as well as their carers has become a significant global issue.

Dementia impacts on all levels of society including financial, psychosocial and relational factors and these are discussed in the subsections below.

### 1.6.1 Financial impact

Based on the most recent evidence, the total economic cost of dementia to society in the UK in 2014 was £26.3 billion, with an average cost of £32,250 per person (Prince et al., 2014). Figure 2 indicates the estimated annual cost of dementia to the UK.

Figure 2: Estimated annual cost of dementia



(Prince et al., 2014)

As can be seen, the financial cost of dementia to the UK is significant. However, the emotional and psychological impact on people with dementia and their families is more difficult to quantify, despite results from multiple studies highlighting the emotional and psychological challenges of caring for a person with dementia (Fauth et al., 2012; Høgsnes et al., 2014; Wawrziczny et al., 2014; Gaugler et al., 2003; Schreiner et al., 2006).

### **1.6.2 The psychosocial impact of dementia**

As discussed above, dementia is one of the most prevalent geriatric disorders and a major public health concern which impacts not only on the affected individual but also on wider networks including relatives and spouses (Prince et al., 2014). The majority of research on dementia has focused on the biomedical (organic) model of disease and has tended to focus on the neuropathology and biochemical explanations of dementia (Spector and Orrell, 2010). It has been argued that the medical model and emphasis on the pathology of dementia has ignored the individual with dementia themselves and the social world in which they live (Bond, 1992). This singular view of dementia was challenged by the pioneering work of Kitwood (1997), who highlighted that dementia not only involves organic changes in brain function but also impacts on the social and psychological environment of the individual, including changes to their social networks and relationships. This psychosocial framework purports that to understand the emotions and behaviours of the individual with dementia one must place them within the context of their social circumstances and biography. Within this social perspective, Kitwood upheld the notion of 'personhood', which is generally used to describe the essence and attributes of being a person (Dewing, 2008). According to Kitwood (1997), personhood is:

“a standing or status which is bestowed upon one human being, by others, in the context of relationship and social being, implying recognition, respect and trust”

(Kitwood, 1997: p8)

Kitwood argued for a more holistic view of dementia as encompassing both organic perspectives alongside that of the social and psychological view of the individual.

Through recognition, respect, trust and validation of their private experiences, the personhood of the individual is strengthened alongside their wellbeing. The opposite of this, Kitwood argued, would lead to what he termed 'malignant social psychology' (Kitwood, 1997: p225) in that the wellbeing of the individual is undermined. Kitwood theorised that there are psychological needs in all individuals but that these needs are heightened for individuals with dementia who are vulnerable to poor social interactions and inappropriate care processes, such as treating individuals like children or withholding choice and empowerment. Malignant social psychology occurs when systems and services fail to take account of an individual's life history and reduce an individual's self-efficacy, which can lead to further deterioration.

A psychosocial perspective is increasingly seen as integral to the experience of dementia, with a recognition that many individuals with dementia are living within a relationship with a significant other. However, despite this recognition, few studies have considered the perspectives of individuals who are part of a couple. Kitwood's work (1997) has been expanded to include the concept of 'relationship-centred care' (Nolan et al., 2004 ), which proposes that dementia care is provided within a binary relationship; that of giving and receiving care. Additionally, including the views of spouses with dementia alongside their care partners would enable a deeper understanding of the experience of dementia. Furthermore, there is a growing recognition that the concept of personhood cannot be maintained without acknowledging that the relationship between the individual with dementia and their care partner is key to maintaining a sense of self (Hellström et al., 2005).

### **1.6.3 The relational impact of dementia**

A growing body of research into the interpersonal relationships of people with dementia and their carers consistently suggests that the interaction between spouses is a meaningful determinant in the dynamics of dementia care (Braun et al., 2009; Brodaty and Donkin, 2009; Hellström et al., 2007; Baikie, 2002). This is because, as stated, 'dementia is not experienced in isolation' (Robinson et al., 2005: p337) but affects the systems around the person (Kitwood, 1997), meaning that individuals become increasingly dependent on support from those around them, often from spousal partners (Norton, 2016). As discussed above, dementia has historically been understood through a biomedical model, with a primary focus on symptoms and carer burden. For example, Zarit and colleagues' seminal study on caregiver burden highlighted issues of carer burnout and stress (Zarit et al., 1980). However, work by Kitwood (1997) heralded a considerable shift away from the biomedical framework of dementia towards a more person-centred approach (O'Connor et al., 2007). This move has stimulated increased research into the subjective experience of dementia (O'Connor et al., 2007).

Despite recognition of the importance of the views of both members of the relationship, several authors have argued that research continues to explore the impact of dementia from the perspective of either the person with dementia or more frequently from the perspective of their care partner (Prakke, 2012). This poses challenges in examining spousal relationships in-depth, as people with dementia may experience different stressors than their care giving spouse. Specifically, Daniels et al. (2007) stress the impact of dementia on spousal relationships and argue that the experience of each individual within the relationship influences a sense of shared experience and

couplehood. To provide appropriate support for people with dementia who are part of a couple, the impact on and experiences of the couple as well as how they cope and adjust need to be better understood. Arguably, in order to gain better understandings of the experience of both members of the couple, research is required that not only includes both spouses, but also frames their experiences as individuals who are part of a couple. This current study therefore adds to and expands the existing body of knowledge by interviewing four couples in which both spouses are included equally in the research. Each partner was interviewed separately to their spouse in order to provide opportunity for open discussion (See section 4.16 for discussion on data collection).

As has been discussed, the progressive nature of dementia is likely to result in changes to relationships and more specifically between partners in affected couples (Molyneaux et al., 2011b; Hellström et al., 2007; Daniels et al., 2007; Robinson et al., 2005).

Dementia caregiving has frequently been associated with stress and burden (Zarit et al., 1980) as well as to poor health outcomes such as care partner depression and anxiety (Pinquart and Sorensen, 2003). Keady and Nolan (2003b) advocate for research to be more inclusive, stating that caregiving is not a uniformly negative experience, but can be simultaneously challenging and satisfying (Andrén and Elmståhl, 2005).

The next section discusses treatment for dementia, both from a medical perspective to provide background and then, more relevantly, from a psychosocial perspective.

## 1.7 Treatment

There is no cure for dementia. However there are pharmacological and non-pharmacological treatments available which can lessen the symptoms of dementia. The next section discusses the use of medication as a treatment option.

### 1.7.1 Acetylcholinesterase Inhibitors (AChEI)

As there is no cure for dementia, there are however certain anti-dementia drugs which can be used to slow its progression. These licensed medications, known as Acetylcholinesterase Inhibitors AChEI (Donepezil, Rivastigmine and Galantamine) and NMDA (Methly-D-Aspartate, which is an amino acid derivative) receptor antagonists (Memantine) were developed through ground-breaking studies in the 1970s (Bores et al., 1996; Perry et al., 1978). These studies established that the loss of a specific type of nerve cell in the brain (the cholinergic nerves) is strongly linked the severity of dementia (Prince et al., 2014; Bores et al., 1996). Numerous clinical trials suggested modest but significant changes in cognition, function and neuropsychiatric symptoms in patients with mild to moderate Alzheimer's disease following treatment with these drugs (Prince et al., 2015). Additionally, the recent 2018 World Alzheimer's Report concluded that Acetylcholinesterase inhibitors medication may enhance cognitive function in people with mild AD (Patterson, 2018), while National Institute for Health and Care Excellence Clinical Guidelines (NICE) for dementia recommend that medication should be offered where it is considered that it will have a worthwhile effect on cognitive, global or behavioural symptoms (National Institute for Health Care Excellence, 2016). Numerous clinical trials have demonstrated that the memory and activities of daily living of people living with AD improve following drug treatment (Wilcock, 2001). The majority of these studies have focused on people with mild to moderate AD. However, memory

medication cannot prevent or cure dementia and is often only effective for a limited period (Constantine et al., 2000). There are no memory medications for VaD but they can be effectively used for LBD and mixed dementia (Wilcock, 2001). Other drug treatments can help with the challenging or distressing behavioural symptoms of dementia such as antidepressants or antipsychotic medication, however some of these drugs can have severe side effects including increased risk of stroke and falls and are not recommended for all types of dementia (Alzheimer's Society, 2015). Although pharmacological treatments are shown to slow down the rate of cognitive decline for some individuals, the effectiveness of these medications appears to be modest and time limited. Critics of these medications contend that on average, their effect varies from that of placebo in clinical trials by only a few points (Dekkers and Rikkert, 2007). They also argue that an increased risk of unpleasant side effects such as vomiting, diarrhoea and fainting may in some cases outweigh the benefits to memory (Dekkers and Rikkert, 2007). Individuals who are taking such medications require regular monitoring and review, with some being unable to tolerate the drugs' side effects.

There has been long standing debate over whether improvements gained when taking medication are meaningful (Casey et al., 2010; Alzheimer's Society, 2015). The paucity of qualitative research on dementia-specific quality of life (QoL) as well as a lack of qualitative studies researching non-cognitive gains means that this issue has not been adequately addressed. A survey of 4,000 carers of people with AD taking anti-dementia drugs conducted by the Alzheimer's Society highlighted that the majority felt that drug treatments did make improvements in terms of non-cognitive benefits such as social

functioning and confidence. However, these are often difficult to quantify in clinical trials (Alzheimer's society report, 2004).

Although the majority of research has tended to focus on pharmacological interventions, there is an increasing recognition that psychosocial interventions may be equally comparable in terms of effectiveness (Prince et al., 2014). With this in mind, a growing body of research has concentrated on the development and evaluation of both pharmacological and non-pharmacological interventions for people living with dementia.

### **1.7.2 Psychosocial interventions for dementia**

With an increase in awareness of the impact of dementia, research is progressively focusing on evaluations of various treatments for dementia, including both pharmacological and non-pharmacological interventions (Samsi and Manthorpe, 2014). As discussed, pharmacological treatments can slow the rate of progression of dementia for some individuals. However, these medications have limited effectiveness and can cause intolerable side effects for some individuals. As such, these treatments are not suitable for all. Orrell et al. (2017b) argue that interventions for dementia should offer choice, be accessible to a wide range of individuals, and be cost effective. There is therefore an increasing need to offer non-pharmacological alternatives which address both the cognitive and emotional impact of dementia (O'Brien & Burns, 2011).

Research has demonstrated that psychosocial interventions can impact positively on an individual's cognitive function, which in turn improves quality of life and helps to maintain social relationships (Aguirre et al., 2014). Additionally, research highlights that it is increasingly important for interventions to include the views of care partners as well

as the individuals with dementia themselves. The National Service Framework for Older People (NSF-OP) (Department of Health, 2001) and The National Dementia Strategy (Department of Health, 2009) both recommend that the treatment for dementia should involve non-pharmacological management strategies such as mental stimulation. A systematic review of psychosocial interventions of dementia care published in the World Alzheimer's Report also concluded that there is strong evidence to support the use of psychosocial interventions for dementia (Prince et al., 2011). Additionally, commentators suggest that dementia care should aim to maintain cognition while preserving functional abilities for as long as possible (Aguirre et al., 2014), as well as aiming to improve and maintain an individual's quality of life. The published guidelines for the treatment and management of dementia recommend non-pharmacological interventions as the first choice of treatment for mild to moderate BPSD (Department of Health, 2009).

Non-pharmacological approaches include the development of regular routine and involvement of family in daily activities (Gwyther 1998). Research suggests that individuals with mild to moderate dementia benefit from participation in cognitive stimulation and that cognitive interventions may enable individuals to better cope with functional impairment and reduce associated behavioural symptoms including anxiety and depression (Spector et al., 2008; Spector et al., 2010; Knapp et al., 2006; Samsi and Manthorpe, 2014). Statistics suggest that approximately 55% of people living with dementia are in the mild to moderate stage, which would indicate the wide demand for psychosocial interventions (Prince et al., 2014). Additionally, maintaining consistent and

regular participation in cognitively stimulating activities may help preserve the brain in enduring and compensating for neurodegeneration (Wilson et al., 2002).

One such cognitive intervention, Cognitive Stimulation Therapy, is gaining ground as an effective and appropriate intervention for individuals with all types of dementia (Spector et al., 2008; Spector et al., 2010; Knapp et al., 2006; Cove et al., 2013; Woods et al., 2006; Aguirre et al., 2010; Samsi and Manthorpe, 2014). However, despite growing evidence of the effectiveness of CST, there is no research into how couples experience CST and whether it impacts on their sense of couplehood. Given that evidence of the efficacy of CST points towards a higher perceived quality of life, improved communication and increased confidence, it may be expected that these gains would also impact positively on the relationship between the participating individual and their care partner. The lack of research in this area is of interest given that the majority of individuals with dementia are cared for at home by their spouse (Van Mierlo et al., 2012).

## **1.8 Cognitive Stimulation Therapy**

Cognitive Stimulation Therapy is a widely used, evidence based psychosocial group intervention for individuals with mild to moderate dementia (Spector et al., 2008; Aguirre et al., 2014; Woods et al., 2006; Orrell et al., 2017b). CST is the only psychosocial intervention for dementia recommended by the UK National Institute for Health and Care Excellence (NICE, 2018), which recommends that interventions to promote cognition, independence and wellbeing should be offered to individuals with dementia, specifically group cognitive stimulation therapy to people living with mild to moderate dementia.

The CST programme was developed from the findings of two Cochrane Reviews which researched the efficacy of psychosocial interventions for individuals with dementia (Spector et al., 2000; Spector et al., 2003b). CST is largely based on two therapeutic approaches which were shown to have the best outcomes by the reviews: Cognitive Stimulation (CS) and Reality Orientation (RO). CS, described by Woods et al. (2012), aims to enhance social and cognitive functions through involvement in group discussion and activity, and is firmly based on the principles of person-centred care (Spector et al., 2003b) (see section 1.6.2 for a discussion on person-centred care). Research indicates that cognitive activity can reduce cognitive decline in dementia and expected age-related memory loss (Small, 2002). RO, developed by Taulbee and Folsom (1966), was designed for disorientated war veterans who had been hospitalised in the USA. RO involves presenting information about time, place and person at regular intervals as a means of aiding an individual to understand and recognise their surroundings and situations. For example, clocks and calendars can be used as prompts during conversations in order to engage and orientate an individual, such as 'Do you like the warm spring weather?'

CST is based on a 'use it or lose it' principle (Aguirre et al., 2010), which proposes that cognitive stimulation may decelerate or reduce cognitive decline through the activation of neuronal function. CST focuses on implicit memory, which tends to be preserved longer than explicit memory, and more importantly responds to stimulation (Orrell et al., 2017a). Implicit memory refers to procedural memory which does not require conscious thought, for example remembering the words to a poem learned at school or recalling how to ride a bike. Explicit memory refers to conscious, declarative memory such as

recalling the names of neighbours or identifying animals begin with the letter R (Orrell et al., 2017a).

CST sessions are designed to offer stimulation of a range of cognitive skill through activities undertaken in a social setting. Research into CST suggests that it is the social aspect of the group environment which stimulates new thoughts and ideas. Participants are encouraged to make associations, which are the key principles of CST (Woods et al., 2012; Aguirre et al., 2014). The sessions are designed to orientate people in a safe, non-threatening environment which optimises new learning, thereby enhancing participants' social and cognitive skills. The key principle underlying CST is that of implicitly stimulating participants in a safe friendly group environment (Orrell et al., 2017b; Spector et al., 2010).

## **1.9 The CST programme**

The CST programme consists of 14 stimulating themed sessions, held twice weekly, which typically last around 45 minutes. Each session covers a range of themes with an emphasis on cognitive stimulation (Spector et al., 2008). Although initially designed as a 14-session group to be delivered twice a week, anecdotal evidence suggests that CST is routinely delivered once a week for 14 weeks (Cove et al., 2013).

The CST programme is governed by 18 guiding principles (see Table 2) which seek to maximise an individual's existing skills. The course has an implicit focus on sharing opinions rather than recalling facts in a fun, non-threatening environment.

Table 2: 18 guiding principles of CST

	Key principles of CST
1.	Person-centeredness
2.	Involvement
3.	Opinions rather than facts
4.	Mental Stimulation
5.	Stimulating language
6.	Stimulating executive function
7.	Maximising potential
8.	Fun
9.	Using reminiscence as an aid to the here and now
10.	New ideas, thoughts and associations
11.	Using orientation
12.	Providing triggers to aid recall
13.	Continuity and consistency between sessions
14.	Implicit (rather than explicit) learning
15.	Respect
16.	Building/strengthening relationships
17.	Inclusion
18	Choice

Source: (Spector, 2018)

## Chapter 1

CST is delivered by two health care professionals who act as group facilitators (Spector et al., 2006). It is recommended that the facilitators attend a one-day CST training workshop developed by Amy Spector, or that they get involved in a 'train the trainers' event in which those that have been on the course teach others. CST groups generally consist of five to eight participants, and the individual with dementia is not accompanied by their carer or spouse during the sessions.

The sessions follow the standardised CST manual devised by Spector et al. (2006). In order to enhance orientation and cognitive function, a board is displayed with orientating information such as day, date, month, season and year along with the group name. A group name is decided by the group at session one. This is in order to promote decision making and to encourage interaction between participants rather than being led by the facilitator (Spector et al., 2006). The sessions begins with a group song, again collectively decided at session one, followed by a light warm up exercise. This is to encourage optimal group participation and enhance alertness (Spector et al., 2006). The group then read and discuss a current news article which is followed by the main activity based on that week's theme. Themes include childhood, current affairs and word association (see Table 3 for full list of themes), and the main activity last for approximately 25 minutes.

Table 3: CST themes

	CST Themes
1.	Physical games
2.	Sounds
3.	Childhood
4.	Food
5.	Current affairs
6.	Faces/scenes
7.	Word association
8.	Being Creative
9.	Categorising objects
10.	Orientation
11.	Using money
12.	Number games
13.	Word games
14.	Team quiz

Source: (Spector, 2018)

The main session theme includes different types of activity with specific focus on concentration, memory and language skills. Sessions are intended to encourage participation and inclusion, and each session is tailored to the group's abilities. In order to achieve this, participants are generally grouped by level of dementia. The session closes with the group song. Anecdotally, there are subtle variations in the delivery of CST and within the group's studied in this thesis; the participants are given a folder

which they are able to take home after each session in which they can keep each week's activities, news events, week number and theme.

### **1.10 Evidence base for clinical effectiveness of CST**

CST was evaluated using a large multi-centre randomised control trial (RCT) by Spector et al. (2003b) in 23 care homes which demonstrated positive outcomes for individuals with dementia in terms of enhanced cognition and improved quality of life following their use of the programme (Leung et al., 2017; Woods et al., 2012; Spector et al., 2003a; Orrell et al., 2017b). A more recent clinical trial by Spector et al. (2010) identified significant benefits in cognitive function following the intervention, specifically in memory and orientation, in addition to language and visuospatial abilities. The study assigned 201 participants into either a 'treatment as usual' or a CST group and evidenced improvement in cognitive function of the CST participants as measured by the Mini-Mental State Examination (MMSE) and the AD Assessment Scale-Cognitive Subscale (ADAS-COG). The use of these particular outcome measures is significant as direct comparisons can be made to dementia drug trials which also use the same outcome measures.

These findings are supported by a Cochrane review which concluded that CST can benefit individuals with mild to moderate dementia over and above that of medication effects (Woods et al., 2012). However, the authors commented on the need for further research including larger RCTs in addition to research into the effects of the programme on all aspects of a participant's functioning including QoL and wellbeing.

A meta-analysis of RCTs examining the effectiveness of cognitive stimulation for individuals with dementia revealed improvements in quality of life and improved cognitive functioning in the areas of communication and social interaction (Aguirre et al., 2014). Additionally, an economic analysis undertaken by Knapp et al. (2006) demonstrated CST to be cost effective. Several studies demonstrate a positive impact on quality of life and communication following the intervention (Leung et al., 2017; Orrell et al., 2017a; Spector et al., 2011). It is the improvements to QoL and communication that are of specific interest to this present study as there is to date little research into the experience of CST from the perspective of individuals with dementia and their spousal care partner.

The ways in which CST impacts on global cognitive function have been proposed by Spector et al. (2010), who suggest that improvements to cognition mediate improvement to perceived quality of life and self esteem. Research by Woods et al. (2006) hypothesised that the social interaction between group members promotes verbal expression, thinking and questioning. Research demonstrates that these improvements may extend outside of the group setting, aiding participants to communicate more effectively in their daily lives. Improvements to perceived quality of life have been linked to improved relationships, energy levels and participation in activities of daily living (Logsdon et al., 2007). Additionally, improvements to language skills following CST suggest that individuals become more confident in expressing themselves verbally (Spector et al., 2010). There is a strong emphasis on strengthening language skills in the CST weekly themes such as word association and word games. Similarly, Hall et al. (2013) suggests that the neural pathways for syntax are promoted by

CST, which in turn promotes increased conversation with others including family members. Additionally, the positive group setting may mitigate the impact of malignant social psychology (see section 1.6.2) by improving self-esteem (Spector et al., 2003a).

Until relatively recently, most studies into the effectiveness of CST have tended to be quantitative. There is now a modest growth in the evidence base which utilises qualitative studies. A framework analysis by Spector et al. (2011) which undertook qualitative interviews with CST facilitators alongside CST participants and their carers revealed that participants reported feeling more relaxed and confident after attending CST. In addition, carers reported improvements in the verbal skills of participants outside of the group setting. A more recent mixed methods study by Bailey et al. (2016) undertook qualitative interviews with carers of individuals with dementia who had attended a 10 week CST course. The qualitative component of the study investigated carer's perception of the impact of CST and found that CST improved family interactions. Due to pragmatic reasons the authors did not interview individuals with dementia themselves who had attended the course so the results could be considered to be somewhat limited by proxy ratings which may not be fully accurate. However, the study is important as identified that carers views of CST alongside those of individuals with dementia are worthy of further investigation (Bailey et al., 2016). These findings corroborate the multiple studies by Spector et al. (2010) who demonstrated that CST aids improvements in language function and increases interactions between individuals with dementia and their carers. Research on CST by Aguirre et al. (2014), Spector et al. (2011) and Cove et al. (2013) are the only studies to date which explore the experience of individuals with dementia and their carers following the intervention. Additionally,

the research by Bailey et al. (2016) explored carers perceptions. These studies demonstrate the need for further qualitative research to support the earlier findings of the RCTs. The current study therefore aims to build on this by examining the views and experiences of individuals with dementia and their care partners.

### **1.11 CST in clinical practice**

Overall, there is good consistency in the design and results of the effectiveness of CST within the research literature. This may be because it is the same key researchers who have been involved in most of the studies on CST. However, despite a strong evidence base on the efficacy of twice-weekly CST sessions (Spector et al., 2008; Aguirre and Orrell, 2010) and the NICE guidelines recommending that CST should be delivered twice weekly (NICE, 2018), the intervention is routinely offered by memory clinics once weekly over 14 weeks (Cove et al., 2013). Anecdotally, this is due to the pragmatics of delivering weekly CST sessions, since time constraints and limited resources impact on possibility of delivering CST more frequently (Cove et al., 2013). The Cochrane review by Woods et al. (2012) suggests that the implementation of CST in real-life settings needs to be addressed. In particular, it must be asked whether the results obtained in the context of research studies are comparable to those within the context of clinical practice Woods et al. (2012). However, from my own clinical experience of facilitating CST groups, alongside anecdotal feedback from group participants and their carers as well as CST facilitators, weekly delivery of CST is comparable with that of the original study by Spector et al. (2003a).

Having discussed the notion of couplehood and the importance of a relational approach, the discussion was then followed by an overview of dementia and the challenges and

difficulties faced by spouses living with the disease. Following on from this was a reflection on psychosocial interventions of dementia and an overview of CST. The next section considers the rationale for this current study, the research questions and an overview of how the thesis will be presented.

### **1.12 Rationale for current study**

The notion of the 'lived experience' of dementia is envisaged as fundamental in aiding the development of proactive and effective care and emphasises the importance of involving individuals as 'active and dignified participants' in research (Steeman et al., 2006: p736). A major contribution of this research is the inclusion of spouses with dementia as well as their care partner, an approach which has largely been absent from research literature. The findings from the study have important policy and clinical relevance. Currently two thirds of people with dementia live in the community and as the numbers rise more family care givers and care partners may have to take up the caring role (Alzheimer's Research UK, 2018). This has implications for couples who may be concerned about how their relationship will be affected.

As discussed, research on CST has mainly focused on cognitive effects, although there is limited literature on the subjective experience of the CST participants and their carers (Cove et al., 2013; Spector et al., 2011; Bailey et al., 2016). Evidence thus far reveals improvements in language skills, social interaction and improved quality of life. This would therefore indicate that the gains of attending CST could be transferable outside of the group setting to include carers and care partners. The concept of couplehood is defined by togetherness, shared aims and goals and a sense of 'we' rather than 'I' (Kaplan, 2001). This sense of togetherness is reliant to some extent on the shared

memories of the couple in order to maintain notions of couplehood. However, as discussed, the symptoms of dementia, including damage to memory can impact on shared recollections which would indicate that maintaining couplehood becomes more challenging as dementia progresses. As dementia treatments have expanded to include inter-relational aspects such as couplehood and as CST focuses on implicit memories and improved language skills and communication with others including spouses, it is plausible to assume that CST would impact and possibly help sustain notions of couplehood. However, there is currently no known research specifically exploring the impact of CST on a sense of couplehood. Additionally, Olanzaran et al. (2010) purport that non-pharmacological interventions for people with dementia are beneficial for both the recipient and their care giver. Given that research on CST suggests improvements in social interaction and improved quality of life, it would be of clinical importance to build on this to include investigation on individuals and their spouses. The current study therefore aims to build on the research of Spector et al. (2011) by exploring the lived experience of individuals with dementia and their care partners after attending a CST group, with specific attention on their sense of couplehood. The findings can help to improve the facilitation of CST but also highlight the specific needs of spouses that services may be in a position to respond to. As discussed earlier the wellbeing of one spouse impacts on the wellbeing of the other (Bielsten et al., 2018) which indicates the importance of adopting a relational approach to care and interventions in sustaining notions of couplehood.

As discussed, the notion of couplehood is important when undertaking research into the lived experience of couples. Additionally, psychosocial interventions such as CST are

proven to be beneficial for people with dementia and their carers. However the discussion has identified a gap in current knowledge. This gap includes whether CST has the potential to impact on couplehood and the importance of exploring the experiences and opinions of CST from the perspective of spouses. This therefore can only be achieved by adopting a relational approach in which both spouses are included equally in the research. In order to gain a rich, deep insight into the lived experience for couples this thesis aims to explore how couples make sense of couplehood and whether CST impacts on perceived couplehood.

### **1.13 Research questions**

The thesis seeks to address the following research questions:

***Research question 1: How do couples make sense of perceived couplehood when one spouse has dementia?***

***Research question 2: What is the lived experience of couplehood when one spouse has dementia?***

***Research question 3: Does CST impact on perceived couplehood?***

In order to answer these questions, this current study employed Interpretative Phenomenological Analysis (IPA), which focuses on understanding the lived experiences of individuals as well as how they make sense of those experiences (Smith et al., 2009) (See Section 4.8 for discussion on IPA). Four couples were interviewed separately to gain a rich description of their experiences and enable a greater understanding of how dementia impacts on spousal relationships.

## **1.14 Summary and overview of thesis**

The current study is innovative as it aims to explore the subjective and psychological experiences of individuals with dementia and their spouses as well as to understand couplehood by interviewing both members of the couple about their relationship.

As discussed above, dementia has immense consequences for both the individual and their spousal care partner. While there is evidence of the benefits of pharmacological interventions, there is also an increased awareness of the efficacy of psychosocial interventions such as CST.

The next chapter comprises a literature review of couples and couplehood. The review explores the nature of caring for and being cared for when one spouse has a diagnosis of dementia as well as the arising factors that impact on perceived couplehood. A thematic review of the existing literature was performed, and revealed two overarching themes: Disruption to Couplehood and Maintaining Couplehood, under which subthemes relating to diagnosis, loss and shifting identities all represented a disruption to couplehood whilst commitment, relationship quality, history, reciprocity and adjustment indicated the ways in which couples worked together to maintain their sense of couplehood.

Chapter 3 introduces the reader to theoretical models and frameworks in relationship theory and how they might help explain and improve knowledge of the lived experience of dementia for couples. Five main theories are considered: Biographical Disruption, Attachment Theory, Equity and Investment, Lazarus and Folkman's Theory of Stress and Coping and The Stress Process Model.

## Chapter 1

This is then followed by a discussion and evaluation of Interpretative Phenomenological Analysis (IPA) and why this method was chosen (see section 4.8 for discussion IPA). Four couples in which one spouse has a dementia were interviewed twice, once at the beginning of the CST course and again at the end of the 14-week sessions. Each participant was included equally in the research. In order to gain independent views and provide opportunities for each participant to talk openly and freely, the spouses were interviewed separately. It was felt that this approach would afford rich, deep descriptions.

Chapter 5 presents the analysis of the couples' interviews using IPA. Four master themes are outlined: Navigating Disruption, Re-Appraisal, Mindfulness and Living the New Normal. These themes demonstrate the lived experience of dementia and couplehood. The spouse with dementia benefitted from the sharing their experience of memory loss with others in the same boat. However, these gains were short lived, since once the course was over; participants were left to navigate the disruption to their relationship once more.

Chapter 6 offers an in-depth discussion and conclusions of the research, including a discussion of the implications for practice and policy and recommendations for further research. Limitations of the current study are also considered. Recommendations for future research are discussed. The thesis closes with a reflective statement on the research journey.

## Chapter 2    **A thematic review of literature**

### **2.1    Introduction**

The aim of this literature review chapter is to explore existing research which is relevant to the thesis topic. At present, there is no literature which explores CST and spousal relationships. The focus of this review is therefore to explore how dementia impacts on spousal relationships, and more specifically on an individual's sense of couplehood.

In order to achieve this, the chapter offers a synthesised view of existing research that has explored the impact of dementia on marital relationships in which both members of the couple have been included. The importance of developing a relational understanding of couplehood is also considered.

The chapter describes the methods and results of a thematic review (Guest et al., 2012) which was undertaken on the current literature in order to understand the impact of dementia on sense of couplehood. Six key themes emerged which are considered to be fundamental to the experience of dementia within marriage: 'reaction to diagnosis', 'loss', 'shifting identities', 'commitment', 'relationship history, quality and reciprocity' and 'adjustment' which are subsumed under two master themes: Disruption to Couplehood and Maintaining Couplehood.

Section 2.2 discusses the literature search and strategies for chosen articles whilst Section 2.3 provides an overview of the study characteristics. Following this, section 2.4 critically reviews the existing literature on dementia and couplehood. Strengths and limitations is discussed in section 2.9 followed by a critical evaluation of the review.

Gaps in the literature are considered in 2.11. The chapter concludes with a discussion on the implications for current practice while recommendations for future research are also deliberated.

Using a systematic database search of CINAHL, Medline and other databases, further details of which can be found below, 21 papers were identified which investigated couplehood and dementia. As the overall aim of the literature review was to reveal the nuances of the experience of couplehood and dementia, only qualitative papers were chosen as would be more appropriate to this current qualitative study. This is because an additional three quantitative papers were identified and considered, however despite including both members of the couple in the research, the results revolved around discussion on caregiver stress and burden rather than the spousal relationship. The use of quantitative methods can arguably restrict the level of insight that research seeks to gain about the lived experience of dementia due to the intrinsic limitations that quantitative measures impose. For example questionnaires may not allow for greater exploration of a particular phenomenon (Galasiński and Kozłowska, 2010). Additionally, building understandings of the impact of dementia from a relational perspective can not be developed solely on the basis of care partner's perceptions (Merrick et al., 2016). It is also intuitive that qualitative methods would enable the couples to offer deeper, more personal expressions of couplehood without the restriction of explicit quantitative measures (Merrick et al., 2016). Therefore only qualitative papers were considered for review as were most relevant to this current qualitative study. 21 studies were identified, two of which were mixed methods but were included in the review as the qualitative component formed the focus of the discussion.

The articles reviewed submit that couples' commitment to each other helps preserve their 'us' identity (Davis et al., 2011; Malthouse and Fox, 2014) and that this commitment is central to maintaining couplehood (Molyneaux et al., 2011b). Coping with the onset of dementia also involves an ongoing process of transition as people oscillate along a continuum of loss and acceptance (Merrick et al., 2016; Davies and Gregory, 2007). However, despite a plethora of research on the experience of dementia from the viewpoint of person with dementia (as patient) or their care partner (as carer), there has been relatively little research which focuses on the impact of dementia on spousal relationships (as husband/wife) and the ways in which individual spouses cope and adjust. Additionally, there is a paucity of research which gives equal weight to the views and experiences of both members of the couple (Hellström and Torres, 2016; Wadham et al., 2015). To this end, articles were selected on the basis of including both members of the couple.

This current review aimed to synthesize the qualitative research that has explored the shared perspective of couplehood for spouses living with dementia. This was to enable depth of discussion regarding couplehood and to ensure that the lived experience of dementia could be analysed which would not have been possible by including quantitative studies.

The questions underpinning the review are:

***In what ways does dementia impact on couples?***

***What are couples shared experience of dementia?***

## 2.2 Strategy search and article selection

A preliminary systematic search of the literature pertaining to 'dementia' and 'marriage' was conducted using Embase, OVID MEDLINE, PsycINFO and CINAHL and ProQuest. This search yielded 5,985 papers. The search terms was then refined to include 'dementia' and 'couplehood' which yielded 31 papers from peer-reviewed journals. The search was then expanded to include various terms for dementia (dementia OR Alzheimer's Disease OR vascular dementia OR mixed dementia OR FTD), which were then combined with terms for spouses (spousal caregiver\* OR spouse\* OR husband\* OR wife\* OR partner\* OR couplehood). This yielded 511 articles. The title and or abstract of these papers was read and articles which explored marital relationships from the perspective of both spouses was chosen. This considerably reduced the literature down to 35 articles. Two further papers were located after searching reference sections of those papers by hand. A separate search of the above terms including \*Cognitive Stimulation Therapy\* OR \*psychosocial intervention\* was also undertaken in order to pick up any additional articles which were not captured in the initial literature search. The search terms above were developed from previous literature reviews which investigated dementia within marriage (Steeman et al., 2006; Evans and Lee, 2013; Braun et al., 2009) and also from relevant papers from an earlier scoping of the literature.

Due to the high number of studies and the focus of this review being both members of the couple, only studies which described the impact of dementia on marriage and in which both spouses were active partners in the research methods have been included. This is in line with a more recent, modest growth in literature which examines the experience of dementia from a relationship centred perspective (Molyneaux et al.,

2011b; Merrick et al., 2016; Bielsten et al., 2018). Research papers were included if they were written in English. Additionally, mixed methods articles were also included if firstly the qualitative component was clearly stated in the methodology and secondly the impact of dementia on relationships was clearly separated and discussed in the results section. This was to enable a deeper understanding of couplehood which may not be reached if quantitative methods were included.

Five articles were excluded as they related to couples and co-morbidities; one was excluded as it focused on dementia and younger couples. This article was excluded on the basis that young people with dementia have a different set of stressors including younger children and employment which would not be expected in an older cohort, while eight more were excluded as they focused on dementia and family caregivers/adult children. Additionally, research relating to couples and mild cognitive impairment (MCI) was also excluded on the basis that an MCI would not be expected to impact on the activities of daily living to the same extent as a dementia. One article by Hellström et al. (2005) was excluded as it discussed a single case study taken from a larger dataset reviewed in a later Hellström et al. (2007) paper and was therefore presumed to share the same theoretical framework which would generate the same results and discussion. A further paper by Derksen et al. (2006) which investigated relationships and partnerships was excluded as it stated that the research sample 'ought to be accompanied by their partner or a close friend' (Derksen et al., 2006: p526) but did not explicitly state who was in the sample.

Thus far, there are only three research papers which have explored CST and the views of participants and carers: Aguirre et al. (2014), Spector et al. (2011) and Cove et al. (2013).

However, two of these were not included in the review as they were quantitative studies (Cove et al., 2013; Aguirre et al., 2014). Additionally, the study by Spector et al. (2011) was undertaken with family caregivers rather than couples and was not included in the review since the impact of dementia on couple's marital relationship did not form part of the analysis. A further qualitative study by Bailey et al. (2016) which investigated the views and experiences of CST was excluded as did not include the person with dementia. This process did, however, highlight that further study of the experience of CST from the perspective of participants alongside care partners and other carers was needed.

This left 21 papers, chosen because of their relevance to this current research, which investigated couples' relationships from a variety of standpoints and subject disciplines. The articles chosen are demonstrative of a range of ideas and issues found in research on dementia.

### **2.3 Characteristics of reviewed studies**

The chosen articles range from 2002 to 2019, which reflects the relatively recent shift towards including both members of the couple in research on couplehood. Most of the studies stated that the aim of the research was to explore spousal relationships. Other studies explored relationships more generally, such as by identifying coping strategies or reactions to receiving a diagnosis of dementia. One study by Atta-Konadu et al. (2011) investigated role change in connection to gender roles of preparing and cooking food within the marriage, but was included in the review as it featured a specific discussion on spousal relationships. A study by Malthouse and Fox (2014) investigated physical activity and dementia and highlighted the impact of dementia on the couples and their relationships, so was therefore also included. A further study by Unadkat et al. (2017)

investigated a singing group but was also included in the review as provided a discussion on the benefits of singing as a shared activity and the impact on the couple relationship.

The studies reviewed utilised mostly grounded theory (Molyneaux et al., 2011, Hellström et al., 2007) or interpretative phenomenological analysis (IPA) (Robinson et al., 2005; Clark et al., 2017; Merrick et al., 2016; Hernandez et al., 2017; Clare, 2002).

One study employed thematic analysis (Malthouse and Fox, 2014). Samples ranged from a single case study (Daniels et al., 2007) to 20 couples (Hellström et al., 2007). Ten studies utilised joint interviews of the couple while eight utilised separate interviews.

Three studies utilised both joint and separate interviews.

Nine studies were undertaken in the UK, four in the United States, five Sweden and three in Canada. Of the participating couples, the partner with dementia tended to have a diagnosis of Alzheimer's Disease.

## **2.4 Review of selected papers**

Hart (1998) suggests that there is no one specific way to conduct a literature review; rather the method of review may be determined by how the researcher chooses to engage with the text. For the purpose of this literature review, I chose to approach the analysis in two ways. Firstly, a description of the methods, aims, quality appraisal techniques and results of the review and secondly, as a thematic synthesis of the literature (Guest et al., 2012).

Each article was read and re-read numerous times in order to ascertain a general understanding of the main themes. Subsequent readings allowed an appreciation of the text within a broader context of the selected paper and promoted comparison and

analysis across the literature (Attride-Stirling, 2001). This was in order to derive an interpretative account of the impact of dementia on couplehood. This process illuminated emergent themes and identified patterns within the body of the literature alongside any contradictions. Papers were analysed for use of quotes, language and contextual features (Attride-Stirling, 2001). The findings are presented in a thematic manner. This method, which is congruent with phenomenological study, enabled immersion in the text and promoted a process of free association (Tong et al., 2012) (see section 4.8 for discussion on IPA and section 4.17 for data analysis).

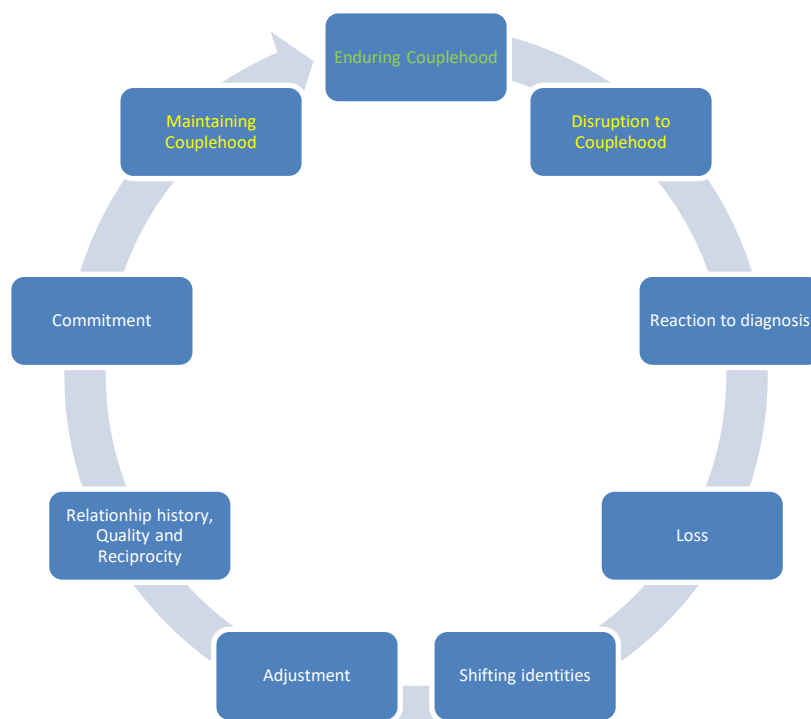
An overarching theme of 'Enduring Couplehood' was identified as central to the experience of marriage and dementia. The papers can broadly be divided into two separate foci in which two master themes and six sub themes were identified: Maintaining couplehood (sub themes: 'commitment', 'relationship history, quality and reciprocity' and 'adjustment') and Disruption to Couplehood (sub themes: 'reaction to diagnosis', 'loss' and 'shifting identities').

The term 'Enduring couplehood' refers to the ways in which couplehood is maintained through a sense of duty, love and responsibility but also experienced as distressing as the quality of relationships are eroded by the onset of dementia. The themes have been depicted as a circular diagram (see figure 3 for thematic representation of literature) to demonstrate the cyclic nature of couplehood in dementia as couples oscillate between factors which are a disruption to their couplehood but also work together towards maintaining couplehood. This sense of movement between positive and negative experiences, which can be seen in each sub-theme, highlights the fluctuating nature of

couplehood following a diagnosis of dementia (see section 2.8 for discussion of literature).

Master and sub-themes are listed and discussed below, with excerpts from the papers provided as exemplars of how interpretations were reached. Double speech marks (“”) indicate direct excerpts from the research participants themselves, while a single speech mark (‘) indicates excerpts using the research authors own words. Some of the included studies refer to participants by name (for example Mrs Peters, as PWD (person with dementia) or by a participant ID number (for example P01)) and these have been included, however there are times where the paper does not explicitly state which spouses made the quote and this is stated out throughout.

Figure 3: Thematic representation of literature



## **2.5 Methods**

A thematic synthesis method was adopted to address the key themes in the current literature. This method was chosen as it is considered an epistemologically neutral approach for synthesising study results (Booth et al., 2016), which in this case will deepen understandings of the impact of dementia on sense of couplehood. A thematic synthesis of the literature was chosen over other types of review such as a narrative review for example (Sylvester et al., 2013) as is well suited to large amounts of data and allows multiple theories to emerge from the data from a variety of epistemologies which may not have been captured using other types of review (Braun and Clarke, 2006).

The next section provides an overview of the themes and issues within couple research in which the views and experiences of both spouses have been elicited, and discusses the selected papers by themes.

## **2.6 Master theme one: Disruption to Couplehood**

All of the papers reviewed recognised the enormous impact of dementia on spousal relationships. The literature revealed that people living with dementia and their care partner are likely to experience the most important changes within their relationship as compared to couples without dementia. The impact of dementia on marital relationships was considered a heavy, life-changing burden, particularly for the care partner. However, there was notably little research on the impact of burden on the person with dementia. The couples highlighted anxieties about the associated life changes of dementia, and both partners experienced fear over what the future may hold.

*“I worry about (wife’s name), I hope she forgives me, she would be better off without me at times, I think. You know the worrying, I know I’m worrying about, what can I do about that? Can’t change the worry. If I could, I would”* (Clark et al., 2017: p8).

### **2.6.1 Sub-theme: Reaction to diagnosis**

UK researchers Robinson et al. (2005) used IPA to conduct joint interviews with nine couples and explored their reaction to receiving a diagnosis of dementia. A secondary study aim was to consider the impact of diagnosis on their relationship. Two overarching themes emerged from their analysis: ‘Not quite the same person, tell me what is actually wrong’ and ‘Everything’s changed, we have to go from here’. The authors suggested that adjustment to the diagnosis is a joint cyclic process of change and acceptance. In particular, the authors suggested that the diagnosis created a power imbalance between spouses as the care partner increasingly took the lead in the relationship.

Given the magnitude and impact of dementia, it is perhaps surprising that only one paper (Robinson et al., 2005) specifically investigated how couples cope with receiving a diagnosis of dementia. Most of the papers instead commented on changes that prompted couples to seek help, in which initial strategies to normalise cognitive decline became increasingly hard to maintain (Clare, 2002). The unpredictable and progressive nature of dementia and its cognitive, behavioural and emotional impact resulted in multiple disruptions to couplehood. The excerpts below from spouses with dementia highlight how profoundly the couple’s lives had changed.

*“You adjust to it, I mean the abnormal has become normal (laughing) as you might say”*

(Robinson et al., 2005: p342).

*“This is intensely irritating to Kath, as you can imagine, because she knows that I’ve done something, but I’ve forgotten I’ve done it”* (Merrick et al., 2016: p45).

*“well, we began to realize that if I took messages on the phone, if I didn’t write down what I was told, you know, come to dinner on Friday night, and then put it on the calendar ...”* (Mrs Campbell) (Davies, 2011: p223).

The enormity of the impact and consequences of dementia was also voiced by care partners as can be seen in the extract below from a care partner.

P01: *“well I would say it has changed my life completely and maybe stressed. I often feel stressed, tired. Because it’s tiring and we don’t go anywhere now whereas we had a full life”* (Clark et al., 2017: p7).

A US study by Johnston and Terp (2015) in which five couples were interviewed together demonstrated the process of diagnosis as being particularly stressful for couples.

Interestingly the study highlighted that despite couples suspecting that something was wrong and looking for answers, the way in which the dementia diagnosis was delivered was often more traumatic than the diagnosis itself. For example, the dispassionate treatment from care staff alongside lack of information compounded couples sense of grief and shock at the diagnosis appointment. As one care partner wife noted:

*“We just got the diagnosis from, this probably third year neurology resident”* (Johnston and Terp, 2015: p291).

All of the couples in Johnston's study reported that they would have benefitted from dementia related information around the time of the diagnosis.

Davies (2011) utilised narrative analysis to identify specific time points which impacted on relationships, including a 'pre-diagnosis' stage, in which couples expressed increasing awareness of memory issues, 'diagnosis' where couples moved on with life despite the dementia and 'post diagnosis', in which couples began to renegotiate their relationship. This process prompted fear and anxiety around how dementia would impact on the couple. The research also highlighted that the spouse with dementia, who may have lacked awareness of their memory difficulties, was compelled to acknowledge the disparity between their self-image and the reality of their worsening memory. Spousal relationships now functioned differently and couples were faced with accommodating changes within the relationship itself (Davies, 2011; Clark et al., 2017).

All papers demonstrated the couples' early awareness of cognitive decline and a gradual acceptance that something troubling was happening. Difficult and unusual behaviour could no longer be ignored or explained, and couples sought confirmation through a diagnosis.

*"Mrs Peters: My was mum was bad, very bad and I know her sisters were and I thought, oh I'm going down the same path"* (Davies, 2011: p225).

Mr Gladstone: *"My memory is really gone and I just hate it"*

Mrs Gladstone: *"It's called Alzheimer's dear"* (Davies, 2011: p225).

In contrast, a grounded theory study undertaken by Beard et al. (2012) in the USA interviewed 10 couples jointly and found that they experienced the impact of dementia

in contradictory ways. Previously harmonious, shared experiences may be threatened by the onset of dementia. Interestingly, the care partner spouse generally tended to see the impact of the dementia diagnosis on themselves more than on their spouse.

*“It’s harder for me to perceive than for him to experience from what I gather because he is so content”* (Beard et al., 2012: p7).

Care partners also indicated that their own independence was increasingly restricted in order to provide support for their spouse (Molyneaux et al., 2011b; Merrick et al., 2016; Malthouse and Fox, 2014; Svanstrom and Dahlberg, 2004; Johnston and Terp, 2015). All of the couples observed a change in the balance of the relationship as spouse with dementia became more dependent (Johnston and Terp, 2015). The switch from independent roles towards dependent ones was identified as one of the key disruptions to couplehood.

Papers highlighted the complexities of living with a diagnosis of dementia while demonstrating that this was something couples viewed as needing to be shared and overcome (Merrick et al., 2016; Molyneaux et al., 2011b; Robinson et al., 2005). More research into how each member of the couple views the impact of dementia on both self and self as part of a couple would be useful in order to help develop interventions to support couple-specific coping.

### **2.6.2 Sub-theme: Loss**

Consistently, research on chronic illness and couples highlighted the psychological experience of loss shared by both members of the couple (Berg and Upchurch, 2007; Wright, 2005). Disruption to relationships and relational loss were cited in all articles

reviewed. Examples included loss of physical intimacy, loss of togetherness and loss of a planned future.

*“About how I miss him, how I miss that closeness of the relationship that you had for all that time. Forty years, over 40 years at the time, you know” (Clark et al., 2017: p9).*

Loss was also identified as a ‘gradual theft of the unique couple relationship around which both members have formed a shared emotional life’ (Johnston and Terp, 2015: p284).

The papers highlighted how the changing nature of dementia made the process of loss complex due to the sporadic reappearance of the ‘former self’. Robinson et al. (2005) highlighted that ‘making sense and adjusting to loss’ is an ongoing, ever-evolving response to dementia, and that there is a gradual realisation that cognitive changes are permanent and irreversible (Robinson et al., 2005: p343).

In the main, it was the spouse without dementia who reported experiencing the most crucial losses, including loss of affection and intimacy as well as the loss of a confidant. Alongside this, care partners felt increasingly needed by and responsible for their spouse but not appreciated by them which resulted in anger and resentment (Johnston and Terp, 2015). This was possibly compounded by the sense of discontinuity (Hellström et al., 2007), where the care partner viewed themselves as a spouse but also experienced increasing separation from their partner due to a loss of shared activities and understanding (Svanstrom and Dahlberg, 2004). The quote below highlights the loss of interest in undertaking a once pleasurable and shared activity of looking through binders

of collected postcards and travel information that the couple had collated from various holidays.

*"I: do you ever look through the binders together?"*

*L: not now, no not now, no, no*

*E: we used to do that but now (.) we've lost interest a little I guess*

*L: time flies oddly enough anyhow"* (Hydén and Nilsson, 2015: p728)

The sense of loss of togetherness was also identified by care partners.

*"I think the fact that you are the sole carer and you lose that not togetherness, you lose that coupleness"* (Clark et al., 2017: p5).

Several of the studies indicated that the development of dementia resulted in couples feeling increasingly separated from each other (Svanstrom and Dahlberg, 2004; Molyneaux et al., 2011b; Hellström et al., 2007) which resulted in both spouses feeling increasingly lost within the relationship itself (Svanstrom and Dahlberg, 2004). A tendency to refer to themselves as 'I' rather than 'we' was notable in their interactions (Hydén and Nilsson, 2015). This demonstrated a disruption to couplehood and challenged the previous sense of the 'couple as a social unit' (Hydén and Nilsson, 2015: p10). This was also reflected in the 'erosion of the we' (Hydén and Nilsson, 2015: p13), and resulted in the spouses 'become strangers in their own world' (Svanstrom and Dahlberg, 2004: p677) as the couples increasingly referred to themselves as separate entities.

PWD *"well, actually I have no aims anymore. Life is over"* (Svanstrom and Dahlberg, 2004: p680).

Several studies identified that care partners felt increasingly lonely (Merrick et al., 2016; Daniels et al., 2007; Hellström et al., 2007; Svanstrom and Dahlberg, 2004). Increased social isolation was also found to be a disruption to couplehood by Hellström et al. (2007), who identified that the couple were now made up of 'two small worlds' (Hellström et al., 2007: p403). Increased loneliness deepened the couples sense of despondency and isolation as contact with friends and family tended to become much reduced.

A loss of shared memories (Daniels et al., 2007) as well as the loss of interaction and communication (Merrick et al., 2016) were all identified as a meaningful disruption to couplehood.

*"the bit that really gets me down is when we've had a bit of a laugh ... I try and carry on the joke or conversation and he can't remember the conversation"* (Merrick et al., 2016: p41).

(s) *"no, he he doesn't react, He doesn't care. Surely that's why it's getting worse so quickly. If you have just a little ... will to live and just a few interests and little, then, then you cope with things ..."* (Svanstrom and Dahlberg, 2004: p679).

While the grief of the care partner was established in the literature, little attention has been given to the grief and loss of the spouse with dementia. Loss of relationship and loss of togetherness has been likened to that of a 'living bereavement' (Clark et al., 2017: p5). Relating these findings to theories of grief and loss may help target couples who are more vulnerable to a loss of wellbeing.

### **2.6.3 Sub-theme: Coping – loss as coping**

Anticipatory grief - that is, a grief reaction that occurs before an impending loss - was highlighted as both a source of stress and a potential coping mechanism for couples. Accepting and coming to terms with dementia was a process of continual renegotiation as the situation and circumstances changed. The extract below demonstrates the complex process of acceptance.

*“I think the coming to terms with the matter is, um, well it has to happen ... still in the middle of that process, I think” (Clare, 2002: p145).*

The first paper to investigate couples' relationships in which both partners were included equally in the research was an IPA study by Clare (2002). This pivotal paper interviewed 12 couples separately over three months and aimed to identify and conceptualise coping strategies in couples where one spouse was in the early stage of Alzheimer's disease. The paper found that the acceptance of limitations and loss was an important coping mechanism. While the couple relationship was not a specific aim of the research, data analysis determined that couples 'valued the intimacy of a loving relationship' (Clare, 2002: p144) and actively engaged in developing a 'fighting spirit' (Clare, 2002: p145). Stages of acceptance ranging from 'reasonably accepted' to 'a little bit more at ease with it' (Clare, 2002: p145) were seen as a self-protective strategy for some participants.

Rather than being a static concept, the acceptance of the diagnosis and an acknowledgement of loss may take place on a multitude of levels. Papers highlighted the many stages of loss and demonstrated the intense and often complex set of emotions that couples journey through in the experience of dementia. Results indicated

that couples' process of coping moved along a continuum of developing self-protecting responses at one end and adjustment at the other. Couples were actively engaged in compensatory strategies such as using memory aids and emotional coping including the hope for a cure. Clare (2002) conceptualised this as a continuum between hope (coping) and despair (adjustment) and highlighted the continual sense of shifting between the two points that couples engage with in order to find some sense of equilibrium. This process of adjustment is ongoing and ever-evolving.

In contrast, issues of loss were explored in a UK study by Merrick et al. (2016), who carried out joint interviews with seven couples and used IPA to analyse the data. They determined that couples were reluctant to acknowledge issues of loss, which may have been a coping mechanism against challenges to their couple identity (Molyneaux et al., 2011b).

*“well, we’ve always been very close, so it’s not a big change .... I think we’ve become closer”* (Merrick et al., 2016: p4).

Despite multiple loss being evident for care partner, there was little on the impact of loss for the spouse with dementia. Exploring this loss from the perspective of both members of the couple may provide a more holistic understanding of the lived experience of dementia (McGovern, 2011). Considering the lived experience from other perspectives will ultimately challenge the fundamental belief that living with dementia only affects the care partner and will open up possibilities for the development of approaches which can support both members of the couple in adapting and maintaining their sense of couplehood in the face of dementia.

#### **2.6.4 Sub-theme: Shifting identities**

Consistent across all the research papers was the notion of shifting identities and role change. Self-identity is defined as the perception of one's own individual characteristics in relation to others (Jiska Cohen-Mansfield et al., 2006). Being a care partner or a spouse with dementia can be a turning point in an individual's sense of identity and the relationship as a whole (Calasanti and Bowen, 2006). Molyneaux et al. (2011b) identified the impact of shifting identities within couplehood as a disruption to couplehood. Challenges to traditional gendered roles were highlighted as the most crucial change to couples' sense of self-identity. Molyneaux et al. (2011b) suggested that for female spouses, the desire to maintain the masculinity of the male counterpart was an important way of maintaining and preserving their own feminine identity. This is verified by Beard et al. (2012), who highlighted the dilemmas for females as they challenged traditional gendered roles; this challenge impacted on both their own sense of feminine identity as well as their 'stronger concern with how other people perceive their husbands' (Beard et al., 2012: p7).

Female participant, husband with AD: *"(Alzheimer's is) the loss of self as others know you, as others knew you"* (Beard et al., 2012: p7).

P01: *"Well our time together and his role as my husband, it's more now looking after an invalid, like a child, if you like"* (Clark et al., 2017: p7).

The role adjustment from spouse to carer was also interpreted as a disruption to couplehood by Robinson et al. (2005).

Caregiving wife: *"You've got to think ahead all the time... I try and think of everything"*  
(Robinson et al., 2005: p342).

The papers also demonstrated significant marital change, as the spouse without dementia was gradually repositioned as a care giver (Davies, 2011), meaning both spouses were faced with re-evaluating their own identity (Molyneaux et al., 2011b).

The increasing dependence on their care partner resulted in spouse with dementia 'controlling' their partner (Svanstrom and Dahlberg, 2004) and uncertainty and anxiety increasingly governed their lives.

The increased dependency on care partner as a result of dementia impacted on both spouses as created tensions within the relationship as one care partner spouse noted:

*"now we're together all the time, 24 hours a day .... we don't do anything apart. And I get really angry sometimes"* (Johnston and Terp, 2015: p291).

Maintaining the self identity of the spouses with dementia was important for the care partners. This was achieved by negotiating roles in order to maintain the involvement of their spouse rather than taking over completely (Hellström et al., 2007; Merrick et al., 2016).

This was verified by Malthouse and Fox (2014), who used thematic analysis to demonstrate the impact of dementia on the couple unit and found that changing roles within the couple were a result of increased symptoms. Taking on more physical as well as emotional roles within the household resulted in care partners feeling more tired and restricted their ability to undertake activities away from their spouse.

Carer 3B: *"I do feel he's sort of sat there and I do wish he'd do something but I tried yesterday. I said could you clean the silver? but I ended up have to do it myself and that's what happens"* (Malthouse and Fox, 2014: p173).

Daniels et al. (2007) explored the meaning of closeness within the marital sphere and found that identity changes in the person living with dementia were influential on the care partner's sense of self-identity. This is consistent with the wider literature, particularly within cancer research, in that female care partners are more likely to report changes to their own sense of identity in response to perceived changes in their partners' identity (Kramer, 2005). Identity changes were closely linked to roles and were influential in how spouses viewed their marriage and their ability to maintain marital closeness. Similarly in the grounded theory study by Hellström et al. (2007), it was demonstrated that the care partner increasingly took the lead, prompting couples to hand over and let go of previous roles. Role change was also experienced as stressful since the care partners struggled to manage the loss of their independence alongside the increasing dependence of their spouse with dementia. As Molyneaux et al. (2011b: p492) contended, couples felt trapped by 'enforced togetherness' as they were unable to spend time apart and are 'metaphorically and literally bound' (Svanstrom and Dahlberg, 2004: p678).

There were also key gender differences within this, as female carer partners appeared to struggle to cope with role change more than male care partners. This is likely to be due to the habituated divisions of labour established throughout the marriage, since female spouses generally tend to undertake household chores whilst male partners tend to be

the decision makers (Pinquart and Sørensen, 2006). This can be seen in the exchange below between a wife care partner and her husband who has dementia.

*“Rose: Because erm, now you know where he’d sort of like be the leader in a way, it’s come round to me you know. I make the decisions and erm, you know he’d sort of earn the, alright I mean neither of us earn the money now, our pensions and what not come in but I mean he always erm he was like the man of the house be er now I’ve er*

*Roy: Now I’m the woman of the house (LAUGHS)*

*Rose: Well you’re not. I’ve sort of taken over, well everything really” (Molyneaux et al., 2011b: p489).*

In line with wider research, caregiving in dementia is demonstrated as more burdensome than non-dementia caregiving. Additionally, research would suggest that there are further gender differences, as female spouses consistently report higher rates of depression, stress and burden than male care partners (Youngmee and Schulz, 2008). There is also some evidence to suggest that dementia is experienced differently by care partner wives and care partner husbands, as male care partners tend to concentrate more on problem solving and the practicalities of care tasks, and demonstrate a general tendency to minimise their emotional reactions to the situation (Molyneaux et al., 2011b). This is line with research by Clare (2002), who identified that male and female care partners tended to utilise the same two coping styles but with subtly contrasting goals, as male care partners focused on managing their sense of self whilst female care partners focused on preserving a sense of connection to their partner. This is

corroborated by Beard et al. (2012), who suggested that care partner wives are more focused on maintaining reciprocity in the relationship.

The struggle to accept changes to one's identity was also highlighted as a theme in a UK study by Clark et al. (2017), who adopted an IPA methodology and interviewed six couples separately. The impact of dementia was seen as substantially life-changing, especially for the care partner and more so for female care partners.

*P01 "I'm not getting any younger myself you know, at 79 I'm suddenly 24 hours on the job, a carer and not being looked after myself, apart from my family who do. But its almost, just as if the roles have completely switched" (Clark et al., 2017: p6).*

*I'm kind of a teacher now ... if he forgets a name or forgets something, I go to him remember your vowels ..." (Merrick et al., 2016: p4).*

'Responsibility for managing the link between mood and activity rested mostly with carers' (Malthouse and Fox, 2014: p173).

Spouses with dementia also found this changing of roles stressful as the realisation of their increasing dependence on their care partner began to emerge.

*"It still annoys me that I've got to have that help" (Clare, 2002: p143).*

A feeling of 'discomfort' (Svanstrom and Dahlberg, 2004: p677) begins to seep into the relationship as both spouses begin to realise the impact of the changing identity of the couple.

In a different approach, a longitudinal study from the US on the role changes experienced by married couples where one spouse has dementia (Atta-Konadu et al.

(2011), in which nine couples were interviewed over three years, demonstrated that couples who actively seek to promote each other's self-worth experienced role change as less challenging. All female participants in this study were living with dementia, whilst all male participants were the care partner spouse. In line with Hellström et al. (2007), couples sought to maintain couplehood for as long as possible, and the gradual withdrawal from roles set within the marriage was not a linear process but was negotiated and renegotiated throughout the dementia journey. The authors also observed that the process of coming to terms with and negotiating role change, as also identified by Clare (2002), is continual and recurring for both spouses.

The notion of 'I/me' versus 'We/us' was also highlighted in a US mixed methods study by Daley et al. (2017), who interviewed 11 couples together and expanded on the couplehood typology described by Kaplan (2001) (see section 1.2.2 for discussion on couplehood). Findings suggest that spouses who engage in the 'we/us' standpoint perceive their relationship more positively compared to those who use the 'I/me' approach. Similarly, a study by Hydén and Nilsson (2015), who interviewed 11 couples jointly, highlighted that couplehood is an ever-evolving concept in which couples must constantly renegotiate a sense of 'we-ness' in light of threats to self-identity. The papers reviewed highlight that people with dementia continue to be socially responsive despite their diagnosis. Care partner spouses viewed themselves as individuals but also as individuals who were in a couple, and as such negotiated a complex labyrinth of personal and interpersonal connections. Indeed, creating a sense of shared identity was established as a key determinate in reframing a sense of couplehood (Davies and Gregory, 2007; Molyneaux et al., 2011b).

In contrast to the majority of research, which has found a middle ground between positive and negative aspects of dementia and couplehood, the findings of Svanstrom and Dahlberg (2004) portray a wholly hopeless existence for couples following the onset of dementia. Adopting a phenomenological approach, the authors conducted interviews with five couples. Each participant was interviewed individually and separately from their spouse. An analysis of the interviews was combined to produce a joint construction of meaning. In addition, the care partner was asked to keep a diary of events to combine with the interview. The findings of this study suggest that the lived experience of dementia for both spouses is one marked by distress, futility and hopelessness, as each spouse's life is controlled by the dementia and each partner unable to regain control of their circumstances. The authors conclude that the spouses were unable to adjust to dementia and became powerless to devise strategies for coping and adjusting (Svanstrom and Dahlberg, 2004).

Understanding ways in which couples negotiate and cope with role transition and shifting identities is an area for clinical intervention and could be used to help couples maintain their sense of couplehood. By increasing understandings of the ways in which role change impacts on identity, services may be better positioned to help couples cope and adjust to the changes associated with dementia. This highlights a need to explore these factors further.

Having discussed dementia as a disruption to couplehood, the next sections discuss how couples maintain couplehood in dementia

## **2.7 Master theme: Maintaining Couplehood**

The research also highlighted that despite significant changes as a consequence of dementia, couples continued to view themselves as an 'us' identity and were determined to uphold their marriage vows by 'staying together through thick or thin' (Davies, 2011: p223). Couples chose to 'keep on keeping on' (Beard et al., 2012: p4) in order to minimise the impact of dementia. Themes of holding on to what remained and staying positive were also identified across the papers (Molyneaux et al., 2011b; Clare, 2002; Merrick et al., 2016). Additionally, couples were not defined by dementia but worked together despite it. The impact of dementia was experienced as less traumatic if it was viewed in the context of age-related changes.

The spouse with dementia also felt an increased dependence and loss of their previous independence. This lack of control led couples to feel powerless to the process of change, with one participant passively saying "it is as it is" (Svanstrom and Dahlberg, 2004: p678).

However, far from being static, the couples' responses to dementia fluctuated depending on their perspective, context and levels of stress.

The next sections explore the three subthemes which were revealed under 'Maintaining Couplehood'. These are firstly 'commitment', secondly 'relationship history, quality and reciprocity' and finally 'adjustment - changing relationships and adapting to dementia'.

### **2.7.1 Sub-theme: Commitment**

Strong sense of commitment, togetherness and closeness were identified in the majority of the reviewed papers as being key to maintaining couplehood. The papers suggested

that a shared history and strong sense of commitment motivated couples to work together to maintain a bond in light of dementia. For example, this was supported in a US single case study by Daniels et al. (2007), who interviewed one couple three times over a period of two months. Daniels et al. (2007) argued that lifelong commitment was fundamental to couples' experience of coping with and adjusting to dementia. Shared histories, closeness and relationship continuity were further explored by a mixed methods study by Hernandez et al. (2017) in the USA. They used a quantitative scale to investigate the degree of relationship closeness for 19 married couples. This was then followed by open-ended questions, with the arising data analysed using IPA. Their work echoed that of Davies (2011), Merrick et al. (2016), Hellström et al. (2007) and Molyneaux et al. (2011b), in that couples worked together to maintain roles and concentrated on the remaining strengths of spouses with dementia to sustain their relationships. Love and mutual commitment strengthened the couples' devotion to maintain their lifelong partnership.

*“now my partner is dependent on me in many ways so our lives are intertwined by both his dependence and our shared history”* (Hernandez et al., 2017: p8)

P06: PWD *“... relationship wise we just kept going because the commitment kept us going. I'm aware of that”* (Clark et al., 2017: p4).

P09: *“... I mean years ago, I was brought up when you were married, you were married for life, unless you know. Unless, just never got into the equation”* (Clark et al., 2017: p4).

A narrative in action analysis of joint qualitative interviews and observation of three couples by Riekkola et al. (2019) explored the couples shared life story over time and demonstrated the ways in which couples strive to maintain togetherness despite the challenges of dementia. The study revealed four themes of couples togetherness; 'our everyday life became a challenge' in which the couples experienced a shift in responsibilities, 'we do things together and in other ways than before' in which couples began to share more activities, 'our ways to handle the challenge of being separated' in which regular respite placement was a useful strategy for coping for care partner and demonstrated strategies that the couples adopted in order to sustain their sense of togetherness despite being separated and lastly 'we have rearranged our social interactions with family and friends' in which strategies to maintain social engagement helped couples to stay connected to each other. The excerpt below from a care partner wife demonstrates how the couples had started to do more routine activities such as shopping together and this was experienced as a positive strategy to create an overall experience of togetherness in the present.

Ann: *"We have done so many things separately in the past, well not separately but we have been working and then done separate things and been away on job-related events and everything. So far it is nice that we can do things in everyday life together"* (Riekkola et al., 2019: p64).

Additionally, 'partnership for life', 'reciprocity', 'resilience' and 'forgiveness' were themes highlighted by Davies (2011) which reflected the ways in which couples worked together and demonstrated that a sense of lifelong commitment preserved their 'us' identity. Research by Hellström et al. (2007) supports these stages, although they

highlighted that working together often involved the care partner spouse also working separately to cope with their emotional reaction to dementia. The authors established that despite attempts to work together the couples gradually drifted apart, rupturing the relationship, as the care partner spouse was gradually repositioned into that of carer, moving into the working separately stage (Hellström et al., 2007). The literature highlights the disruption to couplehood over time which gradually erodes the togetherness of the couples resulting in a move from 'we' to 'I' (Hydén and Nilsson, 2015).

The papers also demonstrated that the process of maintaining couplehood was increasingly dependent on the energies of the care partner spouse as the disease progressed. The papers highlighted that couples viewed the challenges of dementia as a shared undertaking and worked collaboratively to retain their 'us identity'. Dementia was viewed as a new life stage for the couples to face together.

Mrs Smith: *"It's kind of a partner deal"* (Davies, 2011: p226)

P01: *"It will just carry on as we are, we will always be a couple and that's it"* (Clark et al., 2017: p5).

P08: PWD: *Keep together and stay together, you know. I mean one day one of us will go when we... You can't get out of it can you. Nobody can.* (Clark et al., 2017: p5).

However, in keeping with the sense of fluidity, even positive feelings of commitment were tempered with undesirable experiences, as commitment was also related to a sense of duty and a suggestion that 'you simply cannot abandon your partner' (Clark et al., 2017: p6). There was also some variation in the couples' accounts of maintaining

couplehood as some participant's derived pleasure and satisfaction from standing by their partner, whilst others felt anxiety about the prospect of separation. Some continued to perceive it as a duty to honour their vows, whilst others felt trapped and suffocated by the increasing dependence of their partner (Svanstrom and Dahlberg, 2004; Molyneaux et al., 2011b). Despite striving to maintain couplehood, care partners expressed increased anger and frustration towards the situation and ultimately towards their spouse (Riekkola et al., 2019; Johnston and Terp, 2015). In spite of initially positive strategies of doing more things as a couple to maintain a sense of togetherness, this ultimately led to strain within the relationship as care partners expressed a need to spend time with friends and family away from the responsibility of providing care to their spouse (Riekkola et al., 2019).

Despite efforts to remain committed, some couples inevitably grew apart, losing their sense of connection and closeness (Davies and Gregory, 2007; Hellström et al., 2007), which resulted in a gradual erosion of the couples' shared identity. This provoked feelings of loneliness and loss of the relationship altogether (Svanstrom and Dahlberg, 2004).

The next subtheme reveals important notions of relationship history, quality and reciprocity in maintaining couplehood.

### **2.7.2 Sub-theme: Relationship history, quality and reciprocity**

Consistent with the wider literature on couples and dementia, the quality of the premorbid relationship (premorbid refers to a person's functioning or state prior to the onset of a disease) was also indicated to impact on the experience of dementia. Care

partners who described a poor relationship quality prior to the diagnosis also reported higher levels of distress and depression than those who reported good premorbid relationship quality (Baikie, 2002). The quality of the premorbid relationship was highly important as it was considered as a foundation on which the couples' current relationship was built. The history of the relationship meant that couples who had successfully faced adversity in the past were able to remain emotionally connected despite the onset of dementia.

Following the onset of dementia, changes in marital relationships highlighted a decline in the quality of the relationships, specifically in the areas of intimacy, reciprocity and communication (Svanstrom and Dahlberg, 2004). Perceived relationship satisfaction and happiness in the marriage were also highlighted as meaningful. Discrepancies in and changes to one's perceived marital relationship quality were observed by Clare et al. (2012), who highlighted that higher stress levels in the care partner were related to a lower perceived relationship quality. Interestingly, the spouse with dementia often rated the relationship quality higher than their care partner. An explanation proposed for this was that from the perspective of the spouse with dementia, the quality of the relationship may not have changed as crucially as it had for their care partner. This is in line with research indicating that the loss of balance in the relationship may be more evident for the care partner (Clare, 2002; Svanstrom and Dahlberg, 2004; Merrick et al., 2016).

The quality of previous relationships was also an important dynamic for shaping the couples' experience of dementia. Several studies propose a positive standpoint in which the couple had an impact on dementia rather than dementia impacting on the couple

(Daniels et al., 2007; Molyneaux et al., 2011b; Hellström et al., 2007; Davies and Gregory, 2007; Hernandez et al., 2017). In this way, the quality of the pre-morbid relationship was an influential factor on continued sense of couplehood. Similarly, the quality of the pre-morbid relationship was linked to the care partners' levels of resilience and motivation to continue to work together (Davies and Gregory, 2007; Daniels et al., 2007).

A further IPA study by Clark et al. (2017) investigated the impact of dementia on the couples' relationships. Three overarching themes of 'maintaining a bond', 'change and adjustment' and 'the challenge of coping' were captured in this analysis and highlighted the complex and interdependent features of the lived experience of dementia. In line with the study by Davies and Gregory (2007), mutual determination and a sense of shared commitment were key for the couples to remain connected. The history of the past relationship was also an important marker of how couples cope, which resonates with previous research findings in the wider literature (Baikie, 2002; Davies and Gregory, 2007).

P11: *"I mean we have had a happy marriage which we've had no problems along the way, when I listen to some people I think how lucky I have been"* (Clark et al., 2017: p5).

The quality of couples' pre-morbid relationship was viewed as an important foundation upon which current functioning was based. Feelings of closeness and affection helped couples to maintain their sense of couplehood following the onset of dementia (Hellström et al., 2007; Molyneaux et al., 2011b; Merrick et al., 2016; Hydén and Nilsson, 2015; Daniels et al., 2007; Davies and Gregory, 2007). Couples also maintained the ways

in which they had previously related to one another and remained appreciative of each other despite the onset of dementia (Molyneaux et al., 2011b; Hellström et al., 2007).

Some couples also demonstrated a new closeness in the partnership as a result of dementia (Merrick et al., 2016; Hydén and Nilsson, 2015). The role of reciprocity has been well documented in studies on the nature of care giving (Carbonneau et al., 2010; Boerner et al., 2004; Pearlin et al., 1990). For spouses, the role of reciprocity was seen as a way of repaying their partner for care they had provided over the years, and was identified as a motivating factor to continue caring. A sense of appreciation for each other and the reciprocal nature of the relationship were highlighted as having a buffering effect against the onset of dementia (Molyneaux et al., 2011b; Merrick et al., 2016; Davies and Gregory, 2007).

*“she had a rough time with me, I had a serious accident ... so it’s my turn to look after her”* (Merrick et al., 2016: p40).

*“we feel we have engaged with life, met with life, we’ve coped with life and can cope with life, and we do cope with life and so the future”* (Clark et al., 2017: p5).

This literature supports the idea that the quality and history of the couple relationship can meaningfully influence the experience of dementia, either positively or negatively. Therefore, the background and context of caring have been demonstrated to be either a mediating or moderating factor for relationships. This resonates throughout much of the wider literature on caring within dementia (Pearlin et al., 1990). Conversely, a poor quality pre-morbid relationship may put couples at risk of stress and strain. However, literature around this has been limited (Steadman et al., 2007).

Feelings of connection, shared history and the importance of long relationships were also highlighted as ways in which couples maintained a sense of couplehood. Papers by Hellström et al. (2007) and Molyneaux et al. (2011b) revealed that continuity with the past meant that care partners felt better able to adapt to their changing roles, with continuity cited as meaningful to the overall experience. Being able to face adversity in the past aided the couples' coping in the present (Clark et al., 2017). This was viewed as a positive experience for remaining connected to each other.

P09 *"as long as he can keep going on like he is, he will be fine. He is just as determined to fight it as I am I think"* (Clark et al., 2017: p8).

Whilst the papers suggested that the concept of couplehood is about exploring relationships, a sense of continuity emerged as informing the ways in which couples' relationship might change in the face of dementia. Relationship history, quality and reciprocity are also indicators of how couples can and will cope with dementia.

Research would suggest that previously positive and supportive relationships are indicative of greater sense of wellbeing for both spouses, but that dementia ultimately impacts negatively on spousal relationships (Boylstein and Hayes, 2012; Braun et al., 2009). Intuitively, interpersonal dynamics and the quality of the relationship between spouses could be expected to be a contributing factor in the experience of spouses where one partner has dementia, however surprisingly most studies in the literature have failed to discuss relationship type and quality as part of the analysis. However, questions regarding an individual's sense of their past relationship can only be rated retrospectively. As such, accounts are often based on how a person is feeling in a

particular moment in time rather than being a precise account of feelings, which may make measuring relationship history and quality difficult (Baikie, 2002).

Similarly, Davies (2011) also suggested that receiving a diagnosis of dementia requires couples to create a joint sense of identity through a shared journey. Davies (2011) suggested that encouraging couples to undertake a marriage biography in which couples discuss their relationship history, quality and current functioning may act as an important protective factor against the stress of dementia, as the process of the joint activity encourages a shared perspective.

### **2.7.3 Sub-theme: Adjustment – changing relationships and adapting to dementia**

The papers highlighted that in order to maintain couplehood and continue doing things together, couples were required to renegotiate and adjust to new roles and perspectives. This adjustment promoted an increased sense of connection (Daniels et al., 2007; Molyneaux et al., 2011b). Using narrative analysis to consider their story as a whole, Daniels et al. (2007) conducted three joint interviews with one couple and identified four themes in relation to thoughts about the future, the role of family and friends, life review and experiences related to dementia. Adjusting to the onset of dementia required couples to regularly review and modify aspects of their relationship. Building on the couplehood typology of Kaplan (2001), an extensive study by Hellström et al. (2007) recruited 20 couples living in Sweden to explore the strategies they used to live positively with dementia. The authors of this grounded theory paper proposed three broad phases that couples adopt to preserve their sense of couplehood: 'sustaining couplehood' (the efforts made by couples to promote shared wellbeing), 'maintaining involvement' (strategies adopted to minimise the impact of dementia) and

'moving on' (how couples coped with change) (Ibid). During the 'sustaining couplehood' phase, the care partner worked actively to maintain a sense of continuity with the spouse with dementia and within their relationship. Undertaken over five years, this is to date the most extensive longitudinal study on couplehood in the existing literature on the impact of dementia. This novel approach therefore aided an in-depth understanding into the importance of relationships and enhanced understandings of couples' efforts to maintain couplehood as well as how the relationship is challenged over time (Ibid).

Clare (2002) identified that couples were able to devise compensatory strategies to hold onto their relationships and remained hopeful despite deteriorating memory.

Iain: *"I mean, I'm hoping that they're all wrong ... I might get a miracle cure any time, you never know"* (Clare, 2002: p142).

Over half of the papers highlighted positive strategies adopted by couples to maintain couplehood. These strategies included normalising and reframing experience in light of dementia, which resonates with the work of Molyneaux et al. (2011b). Couples sought to maintain a sense of normality in their relationship and 'move on with life' (Davies, 2011: p9). This was done through preserving routines and reminiscing about past times (Malthouse and Fox, 2014; Hellström et al., 2007; Molyneaux et al., 2011b). The shared home was also seen as enhancing a sense of security and familiarity (Svanstrom and Dahlberg, 2004).

PWD *"I do more or less what I have always done and it's not a big a problem. Often we consult each other, there have not been any deeper problems, there might be discussions in that way to go, and then we try to solve it together"* (Hellström et al., 2007: p393).

An novel finding from Johnston and Terp (2015) revealed that taking trips and continuing to travel together after diagnosis was identified as important to maintaining couplehood. As one care partner noted in the quote below:

*“we’re going to London for a week. We just sort of decided that we would do it now when he can enjoy it to a certain degree”* (Johnston and Terp, 2015: p293).

However, adjustment was also seen as a difficult process as spouses with dementia had to adjust to dementia whilst also adjusting to changes within the relationship.

P02: PWD *“I don’t like charity, and I don’t like it, and I think at times I don’t like her to feel like she’s got to stick by me because I’m ill. I don’t want that, I hate that”* (Clark et al., 2017: p6).

However, research which focuses on the decline in marital relationships can be misleading and does not depict the complexity of relationships. This is evidenced by research which highlights that some aspects of the marriage improve following the onset of dementia, specifically warmth, closeness, intimacy and respect (Hernandez et al., 2017; Daley et al., 2017; Atta-Konadu et al., 2011; Molyneaux et al., 2011b). This is an intriguing finding as many of the papers revealed that loss of intimacy resulted in a disruption to couplehood. This again perhaps demonstrates the sense of flow and fluctuation as couples experience a Disruption to Couplehood but also work together in Maintaining Couplehood. Such a point would therefore indicate that there are both positive and negative aspects of change to relationship quality, perhaps highlighting the complexity of those relationships. Robinson et al. (2005) propose a model in which

couples oscillate between acknowledging difficulties and developing resilience. Letting go and holding on are common themes throughout the literature.

Despite the negative effects of caregiving, there is also an emerging body of literature which suggests that caregivers derive fulfilment and benefit from their caregiving role (Carbonneau et al., 2010). Feelings of acceptance, empathy and positive life view have been described. However, despite a concerted effort by both spouses to maintain couplehood, overall the findings revealed a gradual erosion of a familiar relationship and an emergence of a new relationship in which care partners gradually become engulfed in caring for their spouse. The spouse with dementia also became aware of cognitive decline, and so feelings of increasing burden and dependence permeated their accounts. Evidence also suggests that not only is the quality of current relationships important, but also that perceptions of the relationship history determine how couples cope with the onset of dementia (Carbonneau et al., 2010).

However, there is a considerable gap in knowledge surrounding spousal relationships in dementia and more specifically in understandings of how therapeutic interventions impact on sense of couplehood for both members of the dyad. There is a lack of understanding about how couples negotiate day to day stressors and plan for the future whilst simultaneously maintaining marital relationships and lifestyles in the face of deteriorating health and cognition (Baikie, 2002). Specifically, couples coping with illness face a new reality in their relationship, an area of interest which informs the basis of this thesis. In order to ensure that the complex nuances of caring relationships can emerge, the experiences of both spouses are sought, which reflects the premise that care within later life relationships is based on a shared and joint sense of partnership.

The next section provides a discussion on the reviewed articles and demonstrates the importance of adopting a relational approach to research on dementia.

## **2.8 Discussion**

This review aimed to identify the key themes which aid deeper understandings of the experience of dementia and couplehood. While the research methods were different, many of the findings complimented each other and when combined, this modest body of literature has established how couples adjust and cope with memory loss by relying on their sense of couplehood. The papers represent a wide range of issues commonly found within the wider literature on dementia research.

As discussed, 'dementia is not experienced in isolation' (Robinson et al., 2005: p337), and difficulties often impact on those in a relationship with the person with dementia as much as on the individual themselves (Bielsten et al., 2018). The concept of couplehood has emerged as a means of understanding the ways in which couples manage and maintain their relationships in the face of dementia and suggests that rather than the individual coming first (as in the case of personhood – see section 1.6.2) it should be the couple as a unit which is considered as an holistic whole. Research has highlighted the importance of a refined, nuanced relational understanding of couple as a means for identifying appropriate ways to support spouses. The 21 articles chosen for review provided a valuable holistic view of the impact of dementia on couplehood. Papers highlighted the key consequences of dementia on marriage as each spouse adjusts both as an individual and as a couple (Molyneaux et al., 2011b). Adapting to dementia involves a process of balancing components of the past relationship whilst adjusting to and building a shared understanding of a new relationship. Issues of loss are also

important for both members of the couple, although each spouse may experience such issues differently (Robinson et al., 2005; Svanstrom and Dahlberg, 2004). The papers also indicated that couples are motivated to sustain couplehood and maintain involvement with one another (Hellström et al., 2007; Merrick et al., 2016) by developing a shared construction of their relationship (Molyneaux et al., 2011b; Merrick et al., 2016). The research also identified that the process of maintaining couplehood was increasingly dependent on the care partner spouse, especially as the dementia progressed (Clare, 2002).

A number of important methodological implications arose from the review. The first of these is the importance of including both members of the couple in research. The research also demonstrated that changes to role and identity were key for both partners and that maintaining a sense of couplehood identity was raised by couples as they worked to preserve identity as a shared undertaking (Molyneaux et al., 2011b; Merrick et al., 2016; Hellström et al., 2007; Hernandez et al., 2017). Whilst dementia was experienced as life changing and burdensome, not all changes were viewed negatively. Indeed some couples reported increased closeness. The research also suggests that the historical context in which caring takes place is instrumental in shaping the relationships of couples (Davies, 2011; Hellström et al., 2007; Merrick et al., 2016). Those who rate their pre-morbid relationship as poor are likely to experience greater stress and burden than those who rate their pre-morbid relationship as stronger. This indicates that those couples who have a poorer relationship quality will be at a greater risk of developing depression and ill health.

Relationship history also played a significant role in how couples adjust to the progression of dementia (Merrick et al., 2016; Davies, 2011; Molyneaux et al., 2011b). The strategies employed by couples include reminiscing and maintaining a positive outlook. The research also highlighted different gendered responses to dementia with care partner wives experiencing more depression and emotional stress than care partner husbands. Interventions which tackle this imbalance are needed, and further research which explores the experience of the concurrent marital relationship from both perspectives would be beneficial. Additionally, the papers indicated that there are differences between spouses' perceived relationship quality; further research is needed to explore this more fully (Molyneaux et al., 2011b; Hellström et al., 2007).

Results indicated that couples were often incongruent in their perceptions of closeness, as care partners reported higher levels of loneliness and depression than their spouse. Interestingly, a loss of reciprocal relationships was experienced by both male and female care partners, whereas feelings of loneliness were only reported by female care partners. This supports earlier research that the demands of caring are experienced differently by husbands and wives (Pinquart and Sörensen, 2006). Maintaining a sense of couple identity was a consistent theme throughout as couples worked equally to preserve both their individual and couple identity. The onset and progression of dementia often resulted in feelings of fear and anxiety. Issues of loss were seen as saddening but also as coping mechanisms (Clare, 2002). Research which considers this perspective is needed in order to provide spaces in which couples can express their grief, but can also be supported to adjust to the changes brought about by dementia. Furthermore, reacting to and adjusting to dementia is not a one-off experience; instead,

couples continually amend and redefine their relationship in response to changes (Clare, 2002). This is linked to different types of coping strategies employed by the couple and by the individual.

There were a number of studies which focused on interviewing couples separately (Svanstrom and Dahlberg, 2004; Hellström et al., 2007; Clare et al., 2012; Clark et al., 2017; Hernandez et al., 2017; Beard et al., 2012; Daley et al., 2017) and so aided the free expression of thoughts and feelings, whilst the rest of the papers interviewed couples together. Although this was informative, the authors did note that joint interviews were challenging at times as one spouse tended to dominate the discussion. Further research into how to support couples to express themselves fully would therefore be of benefit.

A number of the studies in this review used IPA, which indicates that this research method is appropriate for understanding the rich, nuanced experiences of spouses who are living with dementia and would aid depth of knowledge into the lived experience (Smith et al., 2009) of dementia and couplehood. It is interesting to note that it was the UK studies which utilised this method the most. This may be due to the IPA support groups which have emerged in the UK. Taken together, the use of qualitative methods aided credible and appropriate means by which to understand the impact of dementia on couplehood. Specifically, the use of IPA enhanced richer and more detailed perspectives from the couples (Robinson et al., 2005; Clark et al., 2017; Merrick et al., 2016; Clare, 2002).

## 2.9 Strengths and limitation of reviewed articles

All of the articles provided a clear rationale for including both members of the couple in their research which aided depth to the discussion on couplehood. This perhaps mitigated the tendency for research to focus on care partner burden and loss rather than the lived experience for both members of the couple. All of the research authors should be credited for the innovative and creative ways in which they undertook research, particularly Clare (2002) who has led the way in dementia research and couples. Atta-Konadu et al. (2011) interesting study on food related role change demonstrated how the impact of dementia is not static but ebbs and flows as couple negotiate changing identities. Additionally, Daniels et al. (2007) biographical approach was novel and has aided a further perspective on understanding the relational aspect of dementia. All of the research articles were interesting and although varied in their approach have aided and deepened understandings of what life is like for couples living with dementia.

The IPA by Molyneaux et al. (2011b) was well presented and has been the template for further research papers including that of Merrick et al. (2016) and Hernandez et al. (2017). Despite its entirely bleak outlook the phenomenological paper by Svanstrom and Dahlberg (2004) provided perhaps the most logical discussion as to why this particular method was chosen and gave justification throughout the paper on how the research findings linked to the 'essence' of the lived experience of dementia.

However, despite the positive advances in understandings of couplehood in the research noted above, there are some limitations which require discussion. The 21 reviewed studies highlighted meaningful changes which occur in spousal relationships where one

partner has dementia. However, there were considerable differences in how studies conceptualised the notion of couplehood and indeed some studies did not offer an explanation on what couplehood meant at all. This made it difficult to ascertain whether reported changes in the relationship were the result of dementia or due to the methodological differences in the studies reviewed. In order to aid our understanding of the impact of dementia on couplehood, greater consistency in how the term couplehood is conceptualised is needed, as this would allow comparisons between the studies to be drawn.

Additionally, issues of equal representation were a concern in a number of studies. Most of the studies conducted joint interviews with spouses, and while this did provide valuable insight in terms of the couples' interactions, this is likely to have influenced how participants responded to questions (Daniels et al., 2007). The desire to protect each other's feelings or to avoid discomfort may have resulted in participants' reluctance to discuss issues in depth. This means that research in which both spouses were interviewed jointly was simultaneously enhanced and restricted by this approach. This issue could be mitigated by interviewing couples separately, as doing so would promote free expression of thoughts and feelings.

The separate voices of people with dementia and their spouses was only represented relatively equally in two studies (Daniels et al., 2007; Molyneaux et al., 2011b), which are also the only two papers which offer discussion on this issue. However, even these papers had some notable issues concerning equal representation. In Molyneaux et al. (2011b), there were variations within themes and the voice of the spouse with dementia is primarily heard in the first order themes, whilst the care partner spouse is primarily

heard in the second order themes. This would indicate that despite attempts to demonstrate equal representation in the study, Molyneaux et al. (2011b) struggled to represent each spouse proportionally. Several of the studies noted that one voice would dominate the interviews; Davies (2011) noted the issue of one respondent dominating the interview as a limitation in the results discussion, although the author does not indicate which spouse tended to dominate or whether this was in one interview or all of them. The researcher noted that this led to tension and disagreement during the interviews but did not frame this as part of the analysis. This issue could be mitigated by conducting separate interviews in order to ensure that personal feelings and expressions are captured (See Section 4.16 on data collection).

Similarly, Daniels et al. (2007) has an unequal representation of voices in the higher order themes, with the first and fourth themes (perspective and evaluation) mainly represented by the care partner spouse. In Daniels et al. (2007), the authors acknowledge that the spouse with dementia was more cognitively impaired than anticipated and that the care partner husband would often talk over his wife.

Molyneaux et al. (2011b) also acknowledge the unequal contribution of spouses. However, the paper still presents equal contributions of spouses under each theme. This could represent a researcher bias towards presenting couplehood as equal and reciprocal, when in fact dementia within marriage results in a relationship which is unequal and non reciprocal.

Moreover, the research conducted by Svanstrom and Dahlberg (2004) utilised diaries which were managed by the care partner spouse and so may have resulted in a bias towards one participant. Additionally, it was unclear at times which spouse was being

quoted, as often quotes were not attributed to one specific participant. A peculiar aspect of the research is that the authors presented information on behalf of individuals who chose not participate in the study, meaning that some of these views on the impact of dementia may be somewhat speculative and indeed not in line with ethical expectations. Additionally, meanings could have been lost or gained through the process of translating accounts from Swedish to English, and thus it is unclear whether the voice of the interpreter dominated the data analysis.

Furthermore, despite the positive approach utilised by Clare (2002) in which both members of the couples were interviewed together, the perspectives of participants with dementia were triangulated by care partner spouses as a means of a 'credibility check' (Clare, 2002: p141). This indicates that the author may have been unsure of the trustworthiness of the accounts provided by the spouse with dementia.

The voice of the care partner spouse was represented with greater frequency in all of the papers. The concept of the couple's voice, that is, the voice which is representative of the couple rather than the individual, was found in half of the papers. For example in Robinson et al. (2005), the process of acceptance was voiced by the spouse with dementia, whereas adjustment was voiced by the care partner spouse. This may imply that the onset of dementia was experienced differently in and between spouses.

A consideration of ethical issues was discussed in most of the reviewed papers.

However, the researchers' perspectives on ethical values were varied. For instance, issues of informed consent differed noticeably as one paper reported that agreement to take part in the research was reached with the care partner spouse and not the spouse with dementia (Svanstrom and Dahlberg, 2004). Another paper reported that one

participant was not aware of their dementia diagnosis which would indicate ethical difficulties in terms of the informed consent of the participant (Robinson et al., 2005) (See Section 4.14.1 for discussion on informed consent). Additionally, the paper by Johnston and Terp (2015) reported on observations and experiences from a larger cohort of couples who chose not to participate in the research.

A pathway for how informed consent was reached was missing in the majority of studies and was only explicitly discussed in four papers (Merrick et al., 2016; Robinson et al., 2005; Hellström et al., 2005; Davies, 2011). Additionally, a worrying quote from one paper (Svanstrom and Dahlberg, 2004) indicated that a male spouse with dementia was physically aggressive towards his female care partner, but there was no discussion about whether this was later followed up as a safeguarding concern.

Additionally, disparity in Mini-Mental State Examination (MMSE) score (see section 4.14.1) varied across the studies. This is likely to impact on the level of participation of the spouse with dementia. Two papers' MMSE eligibility for participation (Hernandez et al., 2017; Hydén and Nilsson, 2015) were as low as 15 (which would indicate a more moderate dementia) and as high as 29 (which would indicate a mild cognitive impairment). Additionally, the stage of dementia varied across the studies, which is likely to have impacted on couples' experiences. Some studies indicate that a participant was experiencing mild dementia while their MMSE score suggested they were at a much later stage. The type of dementia may also influence couples' experiences; most of the studies indicated Alzheimer's disease, with only a few indicating vascular or mixed dementia. Symptoms, personality and behavioural change

differ considerably between sub-types of dementia, which may again influence the experience of couples and the impact of dementia on relationships (Braun et al., 2009).

Most of the papers provided a discussion, rationale and or examples of a research question guide. This was useful as it allowed greater transparency between research questions and plausibility of analysis. However, Davies (2011) indicated that the use of the word 'commitment' in her questions may have been leading, as participants may not have used the word to describe their relationship if this had not been proposed by the interviewer. Clare (2002) indicated that care partners were asked questions about changes to their spouse and how they coped, but the same questions were not asked of the spouse with dementia, as this would indicate that despite both spouses being included in the research, representation was not equal.

Due to the nature of qualitative research, the sample sizes were generally small, making it difficult to generalise findings. However, this point is noted in the majority of the articles and as in keeping with qualitative research, a smaller sample size was justified and appropriate.

Many of the studies recruited participants who were already in receipt of dementia-related services, which could have incurred a sample bias as couples who may be struggling to cope with dementia or have an already strained or difficult relationship history may not have been recruited.

Four of the reviewed papers utilised IPA as their methodology. However, whether studies accurately subscribed to the theoretical principles of IPA varied across the papers. Three papers (Merrick et al., 2016; Robinson et al., 2005; Hernandez et al.,

2017) provided a clear rationale for utilising IPA. Member checking was conducted in Robinson (2005), Clark (2017) and Clare (2002), meaning analysis was refined in light of discussion with participants and an external researcher, a process which does not meet with the hermeneutic and interpretative principles of IPA (Smith et al., 2009).

Additionally, triangulation by an independent researcher was undertaken in Clare (2002), and themes were modified as a result. Additionally, there was a lack of discussion in terms of the level of interpretation, meaning themes were somewhat descriptive rather than interpretative at times (Smith et al., 2009).

The sample interviewed by Merrick et al. (2016) was non-homogenous; while most couples had been together for 45-61 years, one couple had only been together for five years and another were in their second marriage.

For the IPA studies in particular there was little discussion on how analysis of data was reached, and it was unclear why some quotes were chosen as they did not always fit with the analysis. However, that said it is likely that word count restrictions for journal articles may have resulted in authors having to balance between a deeper discussion of their findings and an in depth discussion of the principles of IPA.

Researcher reflexivity was only explicitly discussed in Molyneaux et al. (2011b), while the use of bracketing was discussed in Clare (2002). Additionally, the philosophical position of researcher may influence the interpretations of findings. For example, researcher training and occupation will impact on analysis and interpretation of data. This possible influence can be seen in various papers. For example, Svanstrom and Dahlberg (2004) are nurses, whereas the principal author in Daniels et al. (2007) is a medical doctor, which could explain the dominant biomedical framework in these two

papers. Likewise the authors of Molyneaux et al. (2011b), Robinson et al. (2005) and Merrick et al. (2016) papers are clinical psychologists, which may have influenced their focused on systemic psychosocial themes such as relationship, identity and concepts about ageing. An exception to this rule is presented in Hellström et al. (2007), where the authors stem from medical backgrounds and Hernandez et al. (2017) who have a social work background and nonetheless present studies based on psychological frameworks of identity and aging theories.

However, despite the limitations noted above, all of the studies aided a deeper understanding of what the experience of dementia is like for couples, how they cope and adjust and highlighted the ways in which couples could be supported in order to enhance their emotional wellbeing and to promote their sense of couplehood in light of the dementia.

Having discussed the chosen papers in depth, the next sections provide a critical evaluation of the review.

## **2.10 Critical evaluation of the review**

It is important to state that synthesising the literature to derive an interpretative understanding of dementia and couplehood has in some ways resulted in a triple hermeneutic (Weed, 2005), reflecting my interpretations and understanding of the literature. That is to say that I, as a reviewer, have reached an interpretation of other researchers' interpretations of their participants' data (See Section 4.11 for discussion on reflexivity). Additionally, due to the limited number of papers which included both members of the couple equally in their research, a relatively small sample of papers

were reviewed. However, this has resulted in depth rather than breadth, and so produced a richer and deeper understanding of dementia and couplehood which may have been missed if a larger volume of papers had been reviewed. Additionally, with regard to quality and transferability, all of the studies were undertaken with predominately white, middle-class couples with the exception of Hernandez et al. (2017), who included BAME participants in their cohort. This therefore means that the results may not be representative of couples from across different cultures.

### **2.11 Gaps in the research literature**

As discussed, there is at present a limited number of research papers which focus on the spousal relationships of people with dementia in which both members of the couple have been included. The papers which do exist highlight how couples adjust and cope with dementia within marriage. However, what are missing from the present studies are efforts to measure the impact of dementia on both members of the couple equally as well as asking whether spouses have different conceptualisations of their sense of couplehood. Additionally, there is a lack of focus on issues of loss and burden for spouses with dementia. There appears to be little explanation for couples about what to expect from dementia, and no discussion with them about the consequences and implications of dementia on their relationships. Planning for the future and making sense of changes will be important in supporting couples to adjust. The present study aims to address these gaps by examining the nature of couplehood and couple identity. Additionally, there is to date a lack of research which investigates whether psychosocial interventions such as CST impact on sense of couplehood. The current literature suggests that individuals adjust differently to dementia, often within the context of a

spousal relationship. Understanding the ways in which couples adapt psychologically and emotionally is important for maintaining the wellbeing of both spouses. In a review of the experience of living with dementia, Steeman et al. (2006) contend that more research is needed to 'refine and deepen our present understanding' (Steeman et al., 2006: p736). In order to address this notable gap, the current study seeks to explore the lived experience of couples in which one spouse has dementia in order to facilitate understanding of the concept of couplehood, how dementia might manifest itself within different relationships and whether couplehood can be maintained by undertaking a 14-week course of CST. Both members of the couple are included equally in the research. Additionally, the study seeks to understand ways in which spouses may influence the impact of dementia on each other. The majority of research focusing on couples has typically been undertaken at one time point. A novel aspect of this current study is in comparing descriptions of the impact of dementia on spousal relationships at the beginning of a 14-week CST course and again at the end of the course. Furthermore, in order to build on and expand the existing knowledge base, IPA has been chosen as an appropriate methodology helping to gain the rich, deep descriptions of experiences required for understanding couples' unique stories.

## **2.12 Conclusion**

The purpose of the review was to appraise existing research into how dementia impacts on spousal relationships. Two main themes emerged: disruption to couplehood and maintaining couplehood, which are submitted under an overarching theme of 'enduring couplehood'. The papers reviewed suggest that spousal relationships were in a constant state of flux, with various factors affecting each individual. Overall, this is consistent

with the wider research, which demonstrates that living with dementia is challenging for both partners (Wadham et al., 2015).

The notion of the 'lived experience' of dementia is envisaged as fundamental in aiding the development of proactive and effective care and emphasises the importance of involving individuals as 'active and dignified participants' in research (Steeman et al., 2006: p736) . A major contribution of this research is the inclusion of spouses with dementia as well as their care partner, which has largely been absent from the literature.

In summary, there is good evidence to suggest that marital relationships and specifically the notion of couplehood are affected by the onset of dementia. The findings from this literature review furthered understandings of the ways in which couples seek to maintain a sense of couplehood (Molyneaux et al., 2011b). The findings suggest ways in which loss and changes to roles and identity impact on couplehood as well as the processes and strategies couples adopt in order to maintain sense of couplehood (Molyneaux et al., 2011b; Hellström et al., 2007; Hydén and Nilsson, 2015). The literature also echoes wider research which suggests that gender plays a key role in determining the impact of dementia, and that marital closeness can be maintained despite the insidious nature of dementia (Pinquart and Sörensen, 2006).

As discussed, there are some methodological weaknesses in the articles reviewed, but overall the quality was consistently high. Further research into the perspectives of both members of the couple is therefore important to consolidate findings and expand the existing knowledge base.

Results from several of the studies reviewed point to the importance of addressing people with dementia and their spouses not just as individuals but as part of a couple. This is important on several levels and serves as a reminder that couples' relationships should not be confined to a caring/cared for relationship, but instead should be viewed as an ongoing, evolving relationship between two individuals confronting a challenge which jointly affects the sense of couplehood as well as each individual. The findings furthered our understanding of the processes couples can implement in maintaining sense of couplehood and highlighted ways in which couples experiencing distress and discord may be supported. An emphasis on maintaining 'we-ness' also implies an approach which takes couplehood as a natural starting point rather than positioning people as an individual with dementia and their care giving spouse. In this way, clinical support could be directed towards both spouses jointly by also enhancing and maintaining interactional strategies which sustain couplehood and wellbeing in the face of the challenges posed by the progression of dementia.

As discussed, the experience of living with dementia is multidimensional and highly complex. The experiences and accounts of spouses living with dementia should not be detached from the marital context in which they live, as this context provides a more nuanced, sensitive and deeper understanding of how couples negotiate transition and maintain couplehood in the context of a deteriorating condition. It therefore follows that research which seeks to understand the experiences of both members of the couple should also seek to capture the voice of both members, and that the dementia experience should be viewed in a holistic way which embraces multiple realities from the different perspectives of both spouses within the relationship.

## Chapter 2

The following chapter introduces the reader to theoretical frameworks which are relevant to this thesis; these are biographical disruption, attachment theory, equity and investment, stress and coping and the stress process model.

## Chapter 3      **Theoretical Frameworks**

### **3.1      Introduction**

The purpose of this chapter is to introduce the reader to theoretical models and frameworks relevant to the thesis. This chapter is not an exhaustive review of all the literature on theories in dementia. Instead, it will outline salient concepts in relationship theory and how they might help explain and improve knowledge of the lived experience of dementia for couples. Five main theories are considered: Biographical Disruption, Attachment Theory, Equity and Investment, the Theory of Stress and Coping and the Stress Process Model.

Linking notions of couplehood to theories is important in order to increase knowledge of the relational experience of dementia and may also help to inform the development of comprehensive and appropriate services which are focused on the couples' needs. Additionally, identifying specific stages of the dementia journey and addressing the transition through these stages will optimise couples' chances of successfully coping with and overcoming the difficulties of living with dementia (LoboPrabhu, 2006). What is clear is that reducing care partner stress is directly correlated to maintaining the wellbeing of the spouse with dementia and vice versa as the wellbeing of one spouse is influential on the wellbeing of the other (Evans and Lee, 2013).

The chapter begins with a view of dementia as a biographical disruption, following this Section 3.3 discusses Attachment Theory. Section 3.4 then turns attention on Equity and Investment models whilst Stress and Coping is discussed in Section 3.4 and the stress process model in Section 3.5. The chapter concludes with a discussion on the ways in which these theories are relevant to the thesis.

### **3.2 Dementia as a biographical disruption**

There is a significant body of literature which has explored the experience of chronic illness in relation to the notion of biographical disruption (Bury, 1982). That is, chronic illness can be conceptualised as a distinctive disruptive event which affects the familiar, taken for granted structures of everyday life, including perceptions of identity, biography and the future (Bury, 1982). Indeed, Giddens (1979) described the disruption of chronic illness as a 'critical situation' (Giddens, 1979: p123) which invokes specific responses from individuals in redefining and reconceptualising their sense of self in light of the disruption of illness. Bury (1982) proposed that biographical disruption contains three essential elements; firstly a disruption to assumptions and behaviours. This may revolve around changing bodily conditions and where to seek help. Secondly, there is disruption to explanatory systems and frameworks. This phase revolves around an individual having to reassess their self concept and identity resulting in changes to their personal biography. The final phrase revolves around an individual's response to disruption, including summoning support, caused by a transformed sense of self. In this way chronic illness, such as dementia, is theorised as a biographical disruption that threatens an individual's physical and emotional self that can impact on identity and self worth (Bury, 1982).

During chronic illness, individuals restructure themselves to accommodate their changed condition – thereby representing a disruption to self and biography. The notion of biographical disruption is aligned to the notion of couplehood and as can augment understandings of the consequences of the disruption of dementia within the context of the lives of couples. The couples in this current study demonstrated the ways in which they navigated the disruption caused by dementia to their relationship and helped inform the ways in which biographical disruption is a unique experience for couples.

Additionally, the theory may be used to identify couples who may be at risk of disruption

to their relationship and thereby be enabled and supported to sustain their couplehood (McGovern, 2011).

There are many similarities between accounts of chronic illness and the experience of dementia (Karner and Bobbitt-Zeher, 2011). For example research by Bury (1982) on the impact of rheumatoid arthritis demonstrated that individuals with chronic illness reported that the illness was all encompassing, impacting on all aspects of their lives.

Living with chronic illness therefore, results in feelings of uncertainty regarding the impact, prognosis and course of illness. This influences how people will behave and respond. These issues are also likely to be relevant for individuals living with dementia (Karner and Bobbitt-Zeher, 2011). Furthermore, whilst some individuals in Bury's study believed that medication would help alleviate the illness, many were aware that they would need to learn to live with the condition. This again has strong parallels with couples living with dementia and the disruption to couplehood due to the uncertainty about the cause, diagnosis and treatment options of dementia. Furthermore, Bury (1982) contends that when faced with uncertainty surrounding their illness, individuals are driven by a need to make sense of their experience. What is evident is that individuals draw on multiple explanatory systems including biographical and cultural frameworks in order to seek out causes and explanations in order to make sense of their experience. For example, Williams (2000) proposes stages of meaning making in order to make sense of illness. According to Williams (2000) there are two types of meaning making; the first has physical consequences such as disruption to everyday life including medication regimes, socio-economic costs associated with long term illness and secondly, symbolic significance including the changed bodily self. Again this is relevant to the study of couplehood as demonstrate that the search for meaning in their experience may be

important to couples in coming to terms with the disruption of dementia on their relationship.

It is evident that the experience of chronic illness includes notions of meaning making – which is often complex and multidimensional. Biographical disruption therefore is a useful framework in which to view the lived experience of dementia as sense of self is under threat alongside disruption to expectations about the life course. This may be also true for couples where one spouse has dementia as expectations about the future are disrupted. This is compounded by uncertainty concerning the trajectory of the illness, the fluctuating nature of cognitive decline and doubts about the future. This threat is further emphasised by the relinquishing of social roles that were once self defining.

Alongside biographical disruption a further model has been developed – the Shifting Perspectives Model (Paterson, 2001) – this model proposes that rather than being a static notion, living with chronic illness is an ongoing and continually shifting process. Again it could be argued that the lived experience of dementia shares some features with this model in that living with and adapting to dementia is an oscillating and ever-changing process (Steeman 2007). Therefore viewing dementia as a biographical disruption provides important notions on loss and grief, changes to identity and insight into how a spouse may be supported to cope and adjust.

Alongside the changing self of the individual with chronic illness, caregiving has also been linked to notions of biographical disruption - as becoming a care giver also involves an altered identity resulting in reconstructed relationships (Karner and Bobbitt-Zeher, 2011). The disruption of dementia affects the individual with dementia alongside their care partner. For couples, dementia can be understood as a disruption to the identities of both spouses – the changing cognition and increased dependence of one spouse and the

increasing care responsibility of the other (Karner and Bobbitt-Zeher, 2011). Notions of couplehood also become interrupted as a once familiar relationship is altered into one based on dependence and need.

As discussed the notion of biographical disruption may be important in order to understand how couples navigate the disruption to their relationship. Having considered this as being relevant to this current study, the next section deliberates the theory of attachment and discusses its relevance to couples living with dementia.

### **3.3 Attachment theory and dementia**

Current insights into the lived experience of dementia recognise the importance of an holistic understanding of an individual including life history, personality and social and personal psychology (Górska et al., 2018). Literature suggests that attachment theory is a useful framework to understand the social and relational experiences of people with dementia and their carers (Nelis et al., 2014). Attachment theory as proposed in the seminal work of Bowlby (1969) in his 'Attachment and Loss' series submits that all human beings are biologically pre-programmed to form attachments to others (primarily a parental figure – usually a Mother but can also be significant others who provide care). Bowlby defined attachment as a 'lasting psychological connectedness between human beings' (Bowlby, 1969: p194). According to theories of attachment the principle role of attachment is the notion of a sheltered and safe bond with an attachment figure which provides a secure base from which to explore the world and which bestows shelter in times of distress (Browne and Slosberg, 2006). Although Bowlby argued that attachment behaviour was specifically relevant and crucial during infancy, he also argued that attachment behaviours play a necessary and important role throughout the life course. Interactions with primary caregivers in early life will result in cognitive schemas or

### Chapter 3

attachment orientations whereby an individual will develop either a secure attachment style in which they feel comfortable with interpersonal closeness or may develop an insecure attachment style which can result in a tendency to feel discomfort and ambivalence in close relationships (Monin et al., 2013).

The development of attachment theory has been expanded to include explanations of how attachment orientations, which are developed during infancy, guide behaviour and expectations into adulthood. It is influential in other types of relationships, specifically between spouses (Monin et al., 2013). It is particularly pertinent for older adults given the potential for loss and age related vulnerabilities (Bradley and Cafferty, 2010) and as such a diagnosis of dementia may result in a breakdown of attachment behaviours resulting in helplessness and fear of abandonment. The idea that attachment and caregiving are closely correlated is widely accepted (Bowlby, 1969; Browne and Slosberg, 2006) and some researchers have argued that these issues also become a fundamental developmental concern in older age (Bradley and Cafferty, 2010; Nelis et al., 2014).

Specifically, attachment theory is important for understanding how older couples maintain feelings of security in the face of one partner's deteriorating cognition (Monin et al., 2013). The literature within attachment theory proposes four main attachment styles: secure, anxious-preoccupied, dismissive-avoidant and fearful-avoidant (Mikulincer, 1998). Research also suggests that attachment orientations can be influential in the lived experience of dementia for couples. Attachment orientation may play an important role in influencing the level of psychological distress that an individual can experience during specific stressful situations and the strategies they may call on in order to cope with these events (Mikulincer, 1998). Attachment styles which are either avoidant attachment (in which individuals cannot tolerate intimacy and dependence on others) or anxiety

attachment (in which the individual perceives themselves as unworthy of love and support) of one spouse can be influential on the physical and psychological health of the other (Monin et al., 2013; Perren et al., 2007). Insecure attachment may be a risk factor which increases emotional vulnerability and distress whilst secure attachment is seen as the most adaptive style. Maladaptive attachment styles can lead to pathological caregiving/care receiving behaviour which can then lead to a cycle of depression and despair for both spouses (LoboPrabhu, 2006). Additionally, the relationship itself may provide emotional shelter in times of distress or disruption of dementia where couples can withdraw in times of uncertainty. With respect to these situations attachment theory provides a basis for understanding the complex interplay between couples. It helps to explain support seeking behaviours such as proximity behaviour (the constant need to look for reassurance from an attachment figure) of the spouse with dementia and the care giving style of the care partner spouse (Monin et al., 2013). It may help those who support couples to better understand how to provide appropriate and tailored care (Braun et al., 2009).

### **3.4 Equity and investment**

Equity theory (Walster et al., 1978) has also been proposed as a useful way of understanding the impact of dementia on spousal relationships (Baikie, 2002; Braun et al., 2009). Equity theory proposes that relationship satisfaction is achieved when the perceived 'rewards' from a relationship outweigh the perceived 'cost'. Equity theory therefore emphasises establishing whether the sharing of resources (such as care and support) is equal and fair to both relational partners. The theory proposes that individuals will experience distress if they perceive themselves to be either under or over rewarded in a relationship which then results in efforts to restore equity and balance

(Hatfield and Traupmann, 1981). Relationship satisfaction can be compromised by the introduction of 'costs' such as a diagnosis of dementia. Equity theory proposes that caring for a loved one is costly since taking on a caring role can disrupt reciprocity (Quinn et al., 2009).

In dementia the balance of the spousal relationship alters, which is significant to relationship quality. Braun et al. (2009) propose that when inequality exists within a relationship, the care partner spouse will experience high levels of distress although Quinn et al. (2009) suggest that overall relationship quality may remain intact.

Theories of equity and investment are important in understanding the experience of dementia as they offer insight into care giving and care receiving in spousal relationships. In a review of literature on marriage and dementia alongside qualitative interviews, (Baikie, 2002) contends that notions of reciprocity are highly important for care partner spouses because being able to pay their partner back for what they have done for them in the past is related to why care partners are motivated to remain invested in their relationship. Research also suggests that mutual trade of care and support between spouses and quid pro quo notions of an equal exchange between couples in the past may be significant in protecting and maintaining notions of couplehood in the present (Baikie, 2002). Similarly, the investment model was also proposed by Braun et al. (2009) who asserts that individuals remain in relationships whilst the rewards are equal to the costs and that if one partner invested in the relationship in the past, this will be consequential to their partner providing care in older age. Despite losses to the relationship associated with dementia, feelings of belonging and reciprocity remain important for couples (Forsund et al., 2014) and are significant for sustaining couplehood (Hellström et al., 2007). Although the literature on equity and investment acknowledges that relationships

are not always in balance all of the time, they are usually made equitable over time (Braun et al., 2009). Despite theories of equity and investment being increasingly linked to couples' experience of dementia (Baikie, 2002; Braun et al., 2009), this has mainly concentrated on care partner experiences and little attention has been paid to spouse with dementia (Quinn et al., 2009). However what is clear is that spouses do reflect on the characteristics of their relationship, including pre-morbid relationship and notions of reciprocity (Braun et al., 2009) and this is likely to impact on the experience of care giving and care receiving in spousal relationships.

Further investigation into notions of equity and investment from a relational perspective would be useful in order to support spouses and to identify couples who may be at risk of stress and strain due to imbalance in their relationship (See Section 6.10 for discussion on future directions of research).

### **3.5 Stress and coping**

Whilst stress and coping is not the main focus of this study, a reference to the literature is made in order to explore the ways in which individuals with dementia and their spouses maintain couplehood in the face of a deteriorating condition and the ways in which they may cope and adjust. Literature on coping suggests that the ability of individuals to manage stressful situations is dependent upon the difficulty of the stressor, the personality and characteristics of the individual, their capacity to accurately appraise the challenges of the situation and to also implement the most appropriate coping strategies (Lazarus and Folkman, 1984). In their model of stress and coping, Lazarus and Folkman (1984) propose two primary features which define coping; **problem-focused** coping which refers to strategies around addressing the challenges of the situation such as information seeking, problem solving and making changes to the person-environment. The second

feature is **emotion-focused** coping which refers to strategies which regulate the emotions individuals can experience in response to stressors and challenges. Emotion-focused coping is generally used when a situation or event is viewed as unalterable – whereas problem-focused is used when the situation is viewed as being changeable (Folkman 1986).

The theory posits that stress emerges when an individual perceives a stressful situation as surpassing their individual resources. It is at these times that stress is considered as being a threat to wellbeing. Coping is determined by three cognitive, behavioural and interpersonal processes: cognitive appraisal, coping strategies and coping resources. Within dementia research, problem-focused coping is associated with positive outcomes when compared to emotion-focused coping (Quayhagen et al., 2000). However, research suggests that both emotion-focused and problem-focused coping are important for successful overall coping (Gilhooly et al., 2016).

Furthermore, Lazarus and DeLongis (1983) suggest that the dynamics of stress and coping can be highly complex throughout the life course. This is because an individual's beliefs and values, which influence personal appraisals of stress and the manner of coping can alter over time alongside changing circumstances associated with the ageing process. As such, an individual's coping style that may have worked in the past, may not necessarily work in the present.

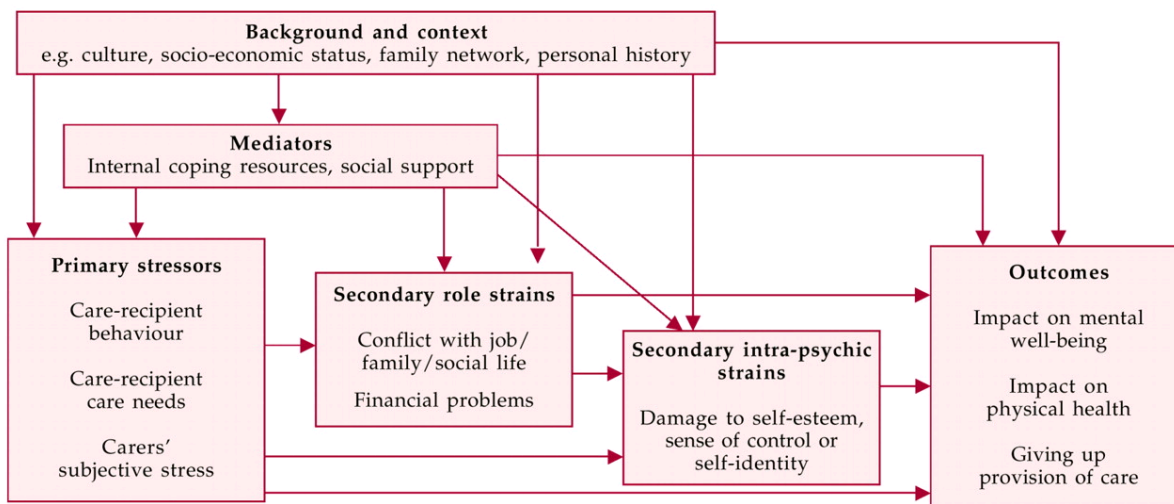
However, applying stress and coping processes could lead to over simplistic explanations in describing life events. Stress, coping and personal resources are not static. The unique and individual variability in the ageing process with the sources of stress and processes of coping arise from both environmental and personal attributes which can change considerably over time (Lazarus and DeLongis, 1983). However, applying theories of

stress and coping to couples can be important as they may provide ways to support couples facing dementia. Research also suggests that the way of coping and strategies adopted can be adapted and improved through learning. This could mean that individuals and couples could be supported to achieve a more successful way of coping (Lazarus and DeLongis, 1983). However it is important to acknowledge that everyone is different and that the same stressors can result in different responses from individuals (Zarit et al., 1980). Models such as these are not a one size fits all; however these theories of stress and coping can help inform explanations of how dementia may impact on couples and how they can experience a wide range of emotions. This also links with a life course perspective in that vulnerability to negative consequences such as susceptibility to stress and burden arise from factors accumulated over the life course and may present as discrete threats in later life (Schröder-Butterfill and Marianti, 2006). It also support the view of this research that couples can and do manage to cope and adjust to the disease by using a multitude of strategies accrued throughout the life course which may be utilised in times of stress to support successful coping.

### **3.6 The Stress Process Model**

A similar model to explain stress and coping is now considered in order to understand the multiple stressors associated with the experience of living with dementia. The Stress Process Model (SPM) (Pearlin et al., 1990) has been widely used in the literature of caregivers of individuals with dementia and is a useful framework for understanding stress and coping from diagnosis to later stages (Judge et al., 2009). Figure 4 below demonstrates how background and context of caregiving variable can affect different parts of the stress process, resulting in implications for type and severity of stress.

Figure 4: Carer stress adapted from Pearlin's Stress Process Model



Source: (Pearlin et al., 1990).

The main postulate of the SPM is that stressors and coping resources arise out of an individual's social context and merge in ways which determine mental health risks (Pearlin et al., 1990). Stressors refer to the negative symptoms of dementia with the resulting strain and psychosocial effects resulting from the stressor (Kneebone and Martin, 2010). According to the SPM, caregivers progress through four developmental stages in adapting to stress, each of which comprise numerous components: the background and context of stress (such as levels of support required and impact of other adverse life events alongside relationship quality (Zarit et al., 1980)), primary caregiving stressors of the illness (such as level of cognitive function and the behavioural and psychosocial symptoms of dementia), secondary strain (such as the role and demands of the care giving situation and family conflict) and lastly intrapsychic strains (such as personality and capacity for caregiving and levels of competence) (Brodaty and Donkin, 2009; Judge et al., 2009; Quinn et al., 2009). According to the model, risk and protective factors are socially distributed so that individuals who are socially disadvantaged confer more stressors and have reduced social and personal resources to call on. The

combination of high stress exposure and fewer protective factors results in negative mental health outcomes (Pearlin et al., 1990). Brodaty and Donkin (2009) suggest that factors such as relationship quality may act as either a mediating or moderating stressors on caregiver wellbeing. Mediating stressors influence the perceived sense of burden and stress which may result in a reappraisal of the marital relationship as dementia progresses. Moderating factors have the potential to act as a buffer against negative emotions as a care partner may feel that the emotional bond with their spouse creates a positive appraisal of the relationship. In the context of this thesis, the model is relevant to research on spousal relationships, couplehood and dementia as provides some explanation of the factors which may lessen or increase stress for care partners as well as for the spouse with dementia.

Rather than identifying one singular stressor in isolation, the SPM provides a useful guide for examining the multiple stressors and strains which can influence the emotional wellbeing of care partners. Indeed the SPM has been expanded for use with individuals with dementia themselves (Judge et al., 2009) in order to identify the unique stressors, secondary strains and moderating factors which are fundamental to the experience of living with dementia. The framework is significant for the findings of this thesis as provides a useful framework from which to increase understandings of what may be useful in helping and supporting couples to understand and cope with the changing circumstances of their lives. However, a criticism levelled at the SPM is the over reliance on care giver proxy reports and lack of discussion on individual with dementia. Applying the SPM to research on couplehood, may help to explain why there is variability in stress and coping and why some couples may experience higher perceived stress than others. It may also help professionals provide a space for spouses to understand their own

behavioural response and when to ask for help. This may lead to spouses feeling less overwhelmed and more able to cope and adapt to the changes to their relationship.

### **3.7 Summary**

This chapter has introduced the reader to five main theories and frameworks within the literature on the relational perspective of dementia. Couples where one spouse has dementia face particular challenges with living and coping with the illness (Braun et al., 2009). These theories and frameworks have examined the ways in which individuals make sense of their experiences, understand the impact on sense of self and the impact of biographical disruption on self, care partner and relationship. These factors include a complex array of interactions which may have accumulated over the life course. Whilst stress and coping models are useful for helping to identify the stressors and strains inherent in the experience of caregiving and care receiving, the lived experience of dementia is immensely complex and not all of the challenges of dementia can be confined to models. However these theories offer some ways in which to understand the behaviour and experiences of dementia and why some people are better able to cope than others. The models can be utilised in order to provide appropriate and tailored care and support to couples where one spouse has dementia.

Together, these theories of biographical disruption, attachment, equity and investment and stress and coping have helped inform the discussion of results of this thesis as have offered some insight into the mechanisms behind why couples may develop feelings of depression, anxiety and stress. They also offer some hope that by increasing professional's understandings of the processes that couples may navigate in coping with dementia may be used to help improve their lived experience of the disease in order to support them to sustain their sense of couplehood.

The following chapter provides a detailed discussion of the methodology chosen in which to investigate dementia and couplehood and CST.

## Chapter 4 Methodology

### 4.1 Introduction

The aim of this study was to explore how couples make sense of the impact of dementia on couplehood as well as how this is influenced by the experience of attending a 14-week Cognitive Stimulation Therapy (CST) course.

The following chapter describes the study design, sample, setting and method of data collection and analysis. Interpretative Phenomenological Analysis (IPA) was the chosen methodology for this study due to its specific interest in understanding how people make sense of their experiences. The outcome of any successful IPA study is to give voice to and make sense of an individual's experience; IPA offers an established, phenomenologically-driven approach to the interpretation of these experiences (Biggerstaff and Thompson, 2008; Brocki and Wearden, 2006b). In order to uncover rich, reflective, detailed, first-person accounts of couplehood, both partners were included equally in the research.

This chapter begins with an explanation of the main research questions, followed by the theoretical perspectives underpinning the study. Qualitative methods are discussed in section 4.4, whilst section 4.6 defines the role of phenomenology in the current research. Section 4.8 presents an in-depth discussion of IPA, followed by a critique of the strengths and limitation of using IPA.

Following on from this, sections 4.10 and 4.11 discuss researcher reflexivity and theoretical perspective. Section 4.12 discusses a pilot study and 4.13 discuss the research sample whilst section 4.14 discusses its recruitment. This is followed by a description of the research participants. The processes of data collection and analysis are presented in

sections 4.16 and 4.17. The subsequent sections, 4.18 and 4.19, discuss ethical approval and related issues. Research limitations are discussed in section 4.20.

In order to remind the reader, the research questions which underpinned this thesis are presented below.

## **4.2 Reminder of research questions**

The delivery of quality care lies at the heart of all health and social care services (England, 2013). In order for anyone working in the sector of health and social care to appreciate the depth of their patients' journeys, they must engage in recognising and validating the whole person as well as their individual experiences and circumstances. This study is therefore meaningful as it aims to fill the gap between the experiences (of individuals with dementia and their care partner) and understanding (of the experience of CST and couplehood). This research is unique as there are no prior studies linking couplehood and CST. Additionally, there is limited research into the impact of dementia on couplehood from the perspective of both partners in the couple (Robinson et al., 2005; Quinn et al., 2008; Braun et al., 2009), and it is this shared perspective which adds to and expands the existing body of knowledge. The current study involved interviews with both partners in four couples at two time-points, and sought to elicit the life view of each participant, affording equal weight to the voice of the person with dementia and their care partner.

The main research questions addressed are:

***Research Question 1: How do couples make sense of perceived couplehood where one spouse has dementia?***

***Research Question 2: What is the lived experience of couplehood where one spouse has dementia?***

***Research Question 3: Does CST impact on perceived couplehood?***

The following section provides an overview of where qualitative research sits within the research paradigm and discusses why IPA was chosen for this study.

**4.3 Theoretical framework for the research design and methodology**

As discussed above, this study sought to understand the experiences of couples, the impact of dementia on their sense of couplehood and whether CST impacts on couplehood. In order to achieve this aim, a research design and theoretical framework were applied to enable the development of appropriate research methods. This led to a flexible blueprint which guided the research and enabled the organisation of ideas. A theoretical framework is an important starting point as it enables links between the abstract and concrete, and provides a context in which the research is positioned (Lederman and Lederman, 2015).

A theoretical framework operates at two distinct levels: the micro, which seeks to explain individual behaviour; and the macro, which seeks to explain the behaviour of large groups in terms of ethnicity, age, gender or class, for example Neuman and Robson (2012a).

Theory and research are inextricably interrelated in multiple ways, as theory frames what the researcher looks at and gives meaning to how the researcher thinks. Theory also suggests strategies for making sense of data, provides basic concepts and directs the researcher towards the important questions (Reeves et al., 2008). Lastly, theory increases the researcher's awareness of interconnections and the wider importance of data (Neuman and Robson, 2012a).

The theoretical perspective of this study is inextricably linked with the method of data analysis, and therefore guided the research process. Interpretative Phenomenological

Analysis (IPA), developed and directed by Smith et al. (2009) was chosen for this study of couplehood and dementia because IPA seeks to explore the participants' views in detail in order to "illuminate the subjective perceptual processes" (Smith et al., 1999: p219) from which individuals attempt to make sense of their experience (see section 4.8 for discussion on IPA). This study is therefore phenomenological as it acknowledges that the experiences participants discuss are important and relevant to them as well as being part of their ongoing biography. Positioning this study within a theoretical framework of phenomenology was therefore central in guiding the research in order to stimulate the advancement of further knowledge (National Research Council, 2004).

As well as an understanding of theory, it is also necessary for a researcher to have an understanding of the related research philosophies that underpin the principles of research (Lederman and Lederman, 2015). In this study, the research philosophy lies within the qualitative paradigm. As will be discussed, qualitative research offers the most appropriate methodology for this study, which aimed to explore the thoughts and experiences of couples, examine the ways in which they cope with dementia and how they made sense of their experience of CST.

#### **4.4 Justification for the use of qualitative methods**

A qualitative approach was chosen for this research study on dementia, couplehood and CST. This is because such methods are the best fit for research that is concerned with the experiences of individuals as they enable the emergence of details relating to thoughts, feelings and emotions. These are details which may be difficult to capture through quantitative research (Strauss and Corbin, 1998). Quantitative research methods are generally utilised to measure attitudes, behaviour, opinions and other variables, which are then generalised into usable statistics, but do not extend to an explanation of why a

particular trend, behaviour or opinion is meaningful (Neuman and Robson, 2012b).

Qualitative approaches adds insight, delving deeper into the phenomena under investigation and captures richer explanations by giving voice to participants (Creswell, 2013). More specifically, literature suggests that when qualitative research is applied to healthcare topics, it is effective as a means of understanding the significance of particular outcomes to patients (Bradley et al., 2007), understanding motivators for compliance (Vermeire et al., 2001) and improving service user involvement (Bastiaens et al., 2007).

As such, applying qualitative methods generates understandings of an individual's experience and has been used as an appropriate methodology in many fields of research, including the subjective experiences of dementia on individuals as well as their families, carers and the broader community. For example, Gibson et al. (2004) argued that qualitative methods can generate new measures of efficacy in dementia care, whilst Carmody et al. (2014) described the increasing need for a qualitative focus in dementia research, and Beattie et al. (2004) conclude their research by arguing that engagement and consultation with services users is imperative to guiding good quality care. In a literature review of qualitative research, Steeman et al. (2006) argued that knowledge of the lived experience of dementia is central to promoting an enhanced quality of life. For example, Wawrziczny et al. (2014) employed qualitative methods to understand how interactions between couples evolve in dementia, whilst Merrick et al. (2016) conducted a qualitative study exploring couples' experience of a dementia diagnosis. These authors contend that qualitative methods provide optimal conditions in which to gain insight into the lived experience of couples and dementia; insight which could not be achieved within a quantitative approach. Capturing each individual's unique experience of couplehood

and dementia was fundamental to the current study and fits well within the structures of the qualitative methodology and worldview perspective.

Quantitative methods revolve around the systematic, logical, empirical investigation of observable phenomena and, as such, are used to develop theories and hypotheses (Creswell, 2013). Such methods tend to be concerned with the prevalence, patterns and rates of dementia, as well as utilising larger participant groups. They are less concerned with personal experience and views. In other words, quantitative research is less focused on the quality of an experience and more focused on the numerical expression of causal relationships. It is the indiscernible, abstract, less concrete aspects of the human experience – that is, the experience of dementia for couples and their notions of sense of couplehood – which is the focus of this research, and this is better captured through qualitative methods of research (ibid).

#### **4.5 Epistemological stance**

Epistemology refers to the study of the nature of knowledge and attempts to answer questions such as ‘how do we know that we know?’ and ‘What are the sources of knowing?’ Researchers must adopt a particular stance towards the nature of knowledge which will influence their entire research process and direct the particular theoretical perspective selected.

Two overarching ontological stances within research are realism and relativism. These represent two polarised opposites between objective reality on one side and multiple realities on the other (Andrews, 2016). A realist position disregards the ways in which a researcher may construct interpretations of findings, whereas a relativist approach takes the position that nothing can ever be known for certain. Andrews (2016) argues that

both positions are problematic for qualitative research since the realistic approach is incompatible with the principles of qualitative research and the relativist approach invokes questions about the utility of findings. Society, Andrews argues (2016), exists in both an objective and a subjective reality. To this end, I have adopted what Hammersley (1992) refers to as 'subtle realism', which is a pragmatic midway point between the two positions. This position states that research is based on common-sense knowledge. As a viewpoint, it acknowledges an independent reality in which the world can exist independently of our perceptions, but also acknowledges that direct access to knowledge is always contextual and multidimensional. As will be discussed, the theoretical framework for this research lies within the phenomenological hermeneutic paradigm. The following section introduces phenomenology and its importance to this research.

#### **4.6 The role of phenomenology in the current research**

Phenomenology refers to the philosophical study of structures of consciousness as experienced from the first-person point of view. In literal terms, phenomenology is the study of 'phenomena' or the ways in which we experience things, the meanings we attach to our experience and how we describe the real life world (Groenewald, 2004; Donalek, 2004).

The phenomenology movement was founded in the early 20<sup>th</sup> century by Edmund Husserl (1859-1938). In his seminal book 'Ideas' (1913), Husserl contended that phenomenology is simply the study of the nature of what it means to think; that is the 'science of the essence of consciousness' (Husserl, 2012: p340). Specifically, Husserl argued that phenomenology revolves around the central characteristic of intentionality (Husserl, 2012), which is the ability of the mind to form presentations and interpretations. The concept of intentionality states that consciousness is perpetually conscious and aware of

something, through structures such as memory, perception and retention. Therefore, according to Husserl, phenomenology is always represented from the first-person perspective.

Husserl's definition of phenomenology was developed from the ideas of other philosophers such as Franz Brentano (1838-1917), whose introspective approach proposed that all knowledge should be founded on direct experience, which again, can only be described from a first-person perspective. Husserl proposed that every intentional act is related to a sense of meaning (*noema*), through which an individual moves towards the object, with object referring to a form of consciousness rather than a specific thing or item. Noema is not the object itself but the parallel way in which the object is both experienced and becomes manifested in the experience (Farina, 2014). Husserl believed that the examiner cannot be separated from the object being examined and proposed that in order to understand what the researcher knows about the phenomenon under investigation, prior knowledge should be 'bracketed' (Reiners, 2012: p1).

Despite its ground breaking nature, Husserl's original concept of phenomenology was criticised and expanded by other notable philosophers such as Martin Heidegger, Maurice Merleau-Ponty and Jean-Paul Sartre. Specifically, Heidegger argued that Husserl's pursuit of the 'essence' of experience was too abstract to be helpful when researching real life experience. As such, he revised the concept of phenomenology by arguing that consciousness is about being involved in one's immediate world and the consequences of that involvement (Reiners, 2012).

Heidegger also argued that the object and subject under investigation cannot be separated, and proposed that individuals are 'thrown' into the world (Shinebourne,

2011). This 'thrownness' means that the context of an individual's life world will always influence their perspective, and that shared states of being can be revealed through investigation of experiences. Heidegger's particular interest was making sense of our capacity to make sense of our experiences (Drayfus, 1991). He refers to this as concept of being-in-the-world as 'Dasein', which is literally translated as 'being-there/there-being' (Heidegger, 1996). Heidegger offers an existential explanation of Dasein as being-in-the-world in one of two modes: authentic or unauthentic. Both are possibilities in which Dasein can understand itself. For Heidegger, the authentic Dasein refers to the ways in which an individual chooses to understand and realise their own potential in the world. Conversely, the inauthentic Dasein refers to ways in which an individual may choose to reject individual meaning, destiny and existence.

Furthermore, Heidegger proposed that we are all self-interpreting beings and that fundamentally, to be human is to derive meaning from the world around us.

Heideggerian phenomenology upholds the notion of self-knowing and contends that the truth of an experience is multifaceted and context-specific; it is as the individual perceives and understands it (McConnell-Henry et al., 2011).

Since different authors and philosophers have offered varying explanations on the experience of being as phenomenology has developed over time, it has no one unitary description. Farina (2014) contends that phenomenology is not a philosophical stance but rather a mode of thought; it is an approach and open-ended, ever-renewing experience which results in continually evolving insights. However, despite the many different emphases between phenomenologists, they all tend to share the belief that reflection and interpretation are key in seeking meanings about the experience of the human existence. Therefore, phenomenology is a mode of enquiry (whether

philosophical or methodological, dependent on school of thought) used to determine what an experience means to an individual. For the purpose of this research, I have adopted Farina's (2014) stance that phenomenology is a continued reflection on the meaning of things, and that all experiences acquire substance, value and meaning. As Farina (2014) points out, even Husserl's thoughts on phenomenology evolved throughout his lifetime, depending on the themes under discussion and the period of thoughts to which they refer.

What is clear from the debate is that phenomenology remains relevant and valuable today since it offers a rigorous and scientific research methodology by which to study the experience of others. According to Walton (1999), phenomenology advocates the possibility of studying human experience in the context of the informant's own world, which includes environment alongside personal history, concerns and aspirations. It is through the process of exploration that meanings are developed and shared.

Furthermore Walton (1999) suggests that through sharing these experiences, the individual contributes greater knowledge of the phenomena under study.

The sharing of personal experiences was relevant to this current research on dementia, CST and couplehood, as it gave voice to those who often go unheard as well as supporting individuals to feel valued and useful, thereby negating the effects of 'malignant social psychology' (Kitwood, 2002: p230) (see Section 1.6.2). Almost all the participants in the study stated that they hoped that their story would help others. Consequently, a data collection method which stimulated and encouraged participants to 'tell their story' and was endorsed by a data analysis method which upheld their personal narratives was of central importance to this study. This is relevant as phenomenological studies aim to investigate phenomena from a viewpoint that is outside of theoretical commitments and

seeks to be critical and avoidant of theoretical prejudice (Gallagher and Zahavi, 2012). Such studies also aim to be directed by what is experienced as opposed to what is expected. As such, phenomenology aims to be critical of what is potentially foreknown of the relevant theoretical constructs. This means that the analysis of data and the literature review in the current research have not been performed in the way that such sections in traditional quantitative research would be. For example, new literature and relevant theories were discovered after the analysis of the data. This is because the research was data driven by the participants' stories, alongside the intentional presence of the researcher-self throughout the whole of the research process.

However, as Larkin et al. (2006b) assert, simply 'hearing' others tell their story does not do justice to IPA; it is the interpretation of those stories which is the cornerstone of interpretative phenomenological research (Larkin et al., 2006b), meaning that the process of hermeneutics is the second foundation on which IPA is based.

## **4.7 Hermeneutics**

Hermeneutics is derived from the Greek verb "Hermeneuin", which translates as "to interpret" (Pietiewicz and Smith, 2012). In the context of qualitative research, the term is used to denote interpretation of an event or experience. However, hermeneutics originally emerged as a result of debates within the Catholic Church revolving around the interpretation of biblical text. Academics within the Catholic Church argued that scripture could only be inferred through the lens of traditional Catholicism. However, reformers believed that the true meaning of texts could be derived from ordinary readers regardless of their understanding of traditional values. Hermeneutics was revised by Freidrih Ast, who argued that the concept involved not just the interpretation of biblical scripture but could also reveal something of the spirituality of both the reader and the author of the

text. Hermeneutics were further developed by Schleiermacher, whose vision of the 'hermeneutic circle' encompassed not just the process of interpretation of text but also the historical context in which they were written, alongside the idiographic perspective of the reader (Ormiston and Schrift, 1990).

As in phenomenology, Heidegger is a prominent figure in the development of hermeneutics, as he contended that the meaning of phenomenology sits in interpretation. He therefore presented hermeneutics as a pre-requisite of phenomenology (Smythea et al., 2008). Since phenomenology is the in-depth, detailed study of conscious experience and hermeneutics is the study of interpretation, Smith et al. (2009) contend that, "without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen" (Smith, 2009: p37).

When applied to research, the terms hermeneutics and phenomenology have many aspects in common. Both terms refer to a mode of analysis used within qualitative research in order to interpret data and both modes assume that the interpretation of experiences is key in enabling understanding of another individuals' lifeworld. This links with the Heideggarian view of phenomenology in that the object being studied cannot be separated from the studying object (Draucker, 1999). The relevance of both hermeneutics and phenomenology to modern qualitative research methods is the role and level of interpretation on behalf of the researcher. Researchers' identify and acknowledge existing presuppositions whilst being guided by the data during their analysis and interpretations. Gadamer asserts that social scientists must knowingly and purposely engage with their prejudices in order to arrive at meaningful understandings (Shinebourne, 2011). In his view, prejudice is not used to describe narrow-mindedness

and intolerance but is part of an individual's openness to the world (Shinebourne, 2011). For example, my own prior knowledge as a clinician working with dementia patients and facilitating CST means that I often consider multiple perspectives from various sources in order to provide the optimum frame of understanding a person's journey (See section 4.11 for discussion on reflexivity).

Having discussed phenomenology and hermeneutics, the discussion will now focus on interpretative phenomenological analysis and how this links to this thesis.

#### **4.8 Interpretative Phenomenological Analysis**

IPA is a method of investigation developed by Smith et al. (1999) which aims to understand in detail how an individual attaches meaning to life events and makes sense of their experiences. As a research methodology, IPA is the exploration of lived experience which is framed within a subjective, reflective process of interpretation (Reid et al., 2005).

IPA is founded on three key theoretical orientations: phenomenology (specifically the Heideggerian concept of phenomenology), hermeneutics (the theory of interpretation) and ideography (the study of the individual in order to illuminate the whole) (Shinebourne, 2011). IPA involves a combination of phenomenological and hermeneutic insights which require intimacy with the idiographic experiences of an individual. Since these insights can only result from an interpretative process, this therefore positions IPA within hermeneutic phenomenology. IPA is also idiographic as it is concerned with how a particular experience has been understood by a particular perspective in a particular context by a particular individual (Smith et al., 2009). During the research process, the experience under investigation is always considered on its own terms and is not classified

into pre-defined categories. Research within this framework is therefore an inductive, dynamic, bottom up process. Results of such studies are applied cautiously, with an awareness of the context and culture within which both the individual and phenomenon are situated (Smith et al., 2009).

Interpretation is the cornerstone in determining the extent to which the researcher will gain access to and make sense out of the participants' subjective experience. In IPA, the participants' own perspectives are of great importance, whilst the researcher's interpretation of the data is also a key factor in enabling the development of comprehensive investigation (Biggerstaff & Thompson, 2008).

This study is firstly phenomenological in that it seeks an insider's perspective of the lived experience of dementia and couplehood. Secondly, it is hermeneutic as it acknowledges my own beliefs and viewpoint whilst simultaneously accepting that my understanding also requires interpretation (Larkin et al., 2006b). Thirdly, it is idiographic as it acknowledges and analyses the distinctive complexities of each participant in order to provide an holistic understanding of couplehood, dementia and CST.

Despite an early emphasis on health psychology (Biggerstaff and Thompson, 2008), IPA is increasingly used in a diverse range of applied psychologies, including counselling, education and occupation (Smith et al., 2009; Pietiewicz and Smith, 2012). Additionally, IPA has been successfully used in dementia research. For example, Clare (2002) investigated coping strategies of people in the early stages of dementia. Twelve individuals with dementia and their spouses were interviewed twice about the process of adjusting to diagnosis. The researcher describes the benefits of using IPA to get as close as possible to participants' subjective responses to illness. Research on other people's reaction to a diagnosis of dementia was undertaken by Langdon et al. (2007), who

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interviewed 12 men and women, and highlighted the individuals' reluctance to share their diagnosis further than close family. In an IPA study of how people cope with dementia, Preston et al. (2007) interviewed 12 individuals and identified 'making sense' and 'coping' as overarching themes. Each of these studies highlight the value of using IPA as a data generating and analysis method with the potential to acquire rich descriptions from individuals' living through the experience of dementia. It is IPA's idiographic commitment to uncovering a phenomenon which is unusual even within qualitative methodologies and which marks the approach as a discrete, valuable research methodology (Pietiewicz and Smith, 2012).

IPA differs from descriptive phenomenology as it is concerned with 'giving voice' to an individual's experience of a phenomenon as well as making sense of that voice within the context of wider social and theoretical frameworks (Larkin et al., 2006b). The approach assumes that there is a pattern of associations between what an individual says and how they think or feel. As discussed above, the strength of phenomenology is in being able to view the world from an individual's perspective as opposed to generating an objective statement about the event. According to this viewpoint, phenomena cannot be separated from the context in which they are being studied. IPA draws upon the more contextualised phenomenology of Heidegger alongside recognition of the individualisation of experiences. In this way, the method seeks to create an interpretation of the nature of human experience (Van Manen, 2007).

IPA also differs from other types of qualitative enquiry as it is focused on an interpretation of the lived experience of a phenomenon. A particular strength of IPA is that the researcher is fully immersed in both the data collection and analysis and it is the multiple levels of interpretation which contrast IPA with other qualitative methods.

Rather than being a passive recipient of knowledge the researcher is actively engaged in the process of interpretation (Draucker, 1999). As such, the researcher's own presuppositions are integrated into the research and closely examined rather than suspended. This is in contrast to grounded theory (Corbin and Strauss, 1990), for instance, which aims to develop an explanatory theory of social processes through constant comparison of cases.

Further to this, while both are concerned with language, IPA differs to discourse analysis (Brown and Yule, 1983), which aims to understand how individuals use language to create and enact identities and experiences. A distinctive characteristic of IPA is that it seeks to examine experience which is of "existential import to the participant" (Smith, 2010b: p9) by interpreting an individual's use of language to reveal a hidden meaning.

Fundamentally, existentialism asserts that the essence or nature of a particular phenomenon is supplementary to the fact of its existence. IPA further asserts that individuals create their own values and derive meaning in order to make their existence more significant (Larkin et al., 2006b; Smith, 1994). According to the theoretical underpinnings of IPA, variations in the meanings individuals ascribe to experiences are welcome, as everyone has a different experience of reality (Fade, 2004). IPA therefore goes beyond standard thematic analysis because it is the depth of interpretation of data which is fundamental to the research process. So for example, whilst thematic analysis also explores the experiences of participants, IPA seeks to focus on the idiographic and existential elements by revealing individual meaning making about their experience (Smith, 2009). What makes this interpretation of data unique to IPA is the role of the researcher's constant reflection on their interpretations (Larkin et al., 2006b). IPA acknowledges that analysis is highly interpretative and therefore subjective. As such,

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results are not assumed as fact but presented as a plausible explanation of participants' idiographic experiences and views. This is achieved by using extracts from individuals' transcripts, using their own words to evidence interpretations made. IPA is not concerned with simply questioning or describing the meaning of an individual's experience, but rather attempts to get as close to that experience as possible (Smith, 2010b; Palmer et al., 2010). Smith (2010b) also maintains that the process of engagement and interpretation on the part of researcher, who is attempting to make sense of the participant making sense of their experience, is unique to IPA. He terms this process 'double hermeneutics' (Smith, 2009: p10) and positions this as the cornerstone of IPA. I was acutely aware of this double hermeneutics during the data collection period, since all of the participants described the experience of dementia as encompassing something lost, whilst I in turn would attempt to understand the impact of those experiences and their sense of loss. For example, participants described how household chores had changed as a result of dementia. By applying the hermeneutic lens (Smith, 2009) to enable multi levels of interpretation I was able to recognise the ways in which the participants were making sense of these changes. A first level of interpretation was descriptive (the type of chores) a second level was linguistic, i.e. the type of words used to describe this 'sad' 'frustrating' and a third level analysis was conceptual in illuminating that for these participants these changes reflected personal as well as emotional loss.

This study therefore takes a phenomenological approach because it aims to capture the subjective experience of individuals which may be overlooked or missed if using other types of qualitative method. Consequently, the approach provided rich descriptions that aided understanding rather than merely describing participants' experiences. The process of interpretative phenomenological research does not seek to break down the

experience under study, but rather to understand what it means for that participant to be operating in their particular world. The researcher therefore is committed to understanding the experience of the phenomena as a whole, rather than parts of that experience, and to develop a 'pathic' understanding (Van Manen, 2007: p29). The term 'pathic' derives from pathos and indicates suffering in a particular way which arises from feelings of compassion or sorrow (Buytendijk, 1970). Although concerned with feminist phenomenology, Buytendijk describes a 'pathic' understanding as being emotionally moved or touched, and draws a distinction between pathic experience and intuitive practice. This pathic reasoning is therefore pertinent to IPA, in being able to grasp a situation from another perspective which rests on a desire to understand and empathise with the experience of others. All qualitative methods attempt to reach understanding about the participants and there are similarities between IPA and other types of qualitative research in that studies seek to move away from mere descriptions towards an understanding which is informed by interpretation.

Throughout this research process, the issue of pathic understanding has been fundamental to my understanding of the dementia journey, as I am a clinician working with older people with dementia but also have elderly parents who, during the course of this study, have displayed signs of cognitive impairment. This has therefore naturally influenced my own understanding of couplehood and dementia in interpreting the participants' stories and this issue has been discussed in greater detail later in this chapter (see section 4.11 for discussion reflexivity).

#### **4.9 Limitations of IPA**

Despite being used in numerous high quality studies, IPA has been criticised for what has been perceived as a lack of rigour (Larkin et al., 2006b; Hefferon and Gil-Rodriguez, 2011;

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Brocki and Wearden, 2006a), as well as being perceived as a merely descriptive methodology rather than providing an interpretative explanation of the participants lived experience (Brocki and Wearden, 2006b). This may in part be due to the esoteric 'insider' perspective of the researcher and a lack of conceptual exploration after a first level of analysis of data (Larkin et al., 2006b). In a relatively recent paper Giorgi (2010) also criticised IPA for being what he viewed as being methodologically weak and lacking in clear focus. In response, Smith (2010a) countered this claim by arguing that Giorgi's critique was unjustified and has identified numerous books and papers which have explored the relationship between IPA, hermeneutics and phenomenology in depth (Smith, 2011; Smith, 2010a). This has clarified the position of IPA as a thorough and authentic research methodology. Smith's book also provides clear guidance on IPA methodology whilst remaining flexible and spontaneous to the data. The focus on researcher reflexivity and reflection is also key in demonstrating to the reader the trustworthiness of the data (Smith, 2009).

As IPA seeks to give voice to participants and therefore relies on an idiographic representation of participants' experiences, this study has followed the advice of Larkin et al. (2006a) in that the research questions were carefully formulated alongside regular, open reflection on the process of data collection and analysis. This ensured that the interpretation of the data was authentically developed into a plausible thematic account. As will be seen, the narratives of the participants, my own presuppositions and the process by which these different viewpoints merged will be described in detail, thus enabling the reader to evaluate the quality of the analysis. Alongside this, the research reflected on the distinction drawn by Shinebourne (2011) between Heidegger's phenomenology (that is, the illuminating of an object as of itself) and the process of

interpretation, which involves the revealing of something through interpretation of the data.

A further limitation which has been levelled at IPA concerns its claim to be immersed in the participants' world as a means of understanding their experience. Access to another person's world can only ever be partial, as it would be impossible to truly attain a first-person account unless you are that person giving the account. IPA relies on the accounts of participants and the experience of researchers to understand these accounts (Tuffour, 2017). Furthermore, the question of whether IPA can accurately capture the meaning of another person's experiences and rather than just a version of those experiences has been under debate (Brocki and Wearden, 2006a). However, any research which relies on the accounts of others will only ever be reliant on a participant's perspective at a particular time within a particular context. IPA acknowledges that any account is co-constructed by researcher and the participant and the specific focus on double hermeneutics throughout this thesis aims remedy these issues.

Lastly, IPA relies on the integral role of language and the participants' ability to articulate their personal accounts in a way that the researcher is able to understand them. It has been argued that this could discriminate against participants who do not have the required level of fluency to describe their experiences. However, IPA is growing in popularity, particularly with individuals who experience mental health challenges (Pietewicz and Smith, 2012; Biggerstaff and Thompson, 2008; Clare, 2003). This has resulted in researchers being creative in their data collection methods. The use of video diaries and journals are being increasingly used in IPA, and there is an encouraging growth in utilising these methods (Lee and Skewes McFerran, 2015; Idczak, 2007). These

positive modifications could result in individuals even in the very later stages of dementia being included in research.

Below is discussion on my own theoretical and ontological position which has guided and influenced the ways in which I have conducted this research study and the choices I have made.

#### **4.10 The researcher's own theoretical and ontological orientation**

It is important to be explicit about my own background and potential biases so that the reader can judge the extent to which they may have influenced the research. As previously stated, as a mental health clinician, I have a professional interest in the participants' experiences of living with dementia and the impact this has on the systems around them.

Additionally, it was important for me that both the individual with dementia and their care partner were included equally in the research as I felt that the different perspectives would add a richness and depth to the data which would have been missed if both parties were not included equally. This has enable comparison to other studies which have included both spouses (Hernandez et al., 2017; Clark et al., 2017; Svanstrom and Dahlberg, 2004). Therefore, it is essential to identify that throughout the study, the care partners were viewed as participants in their own right, rather than invited to validate what their CST participating spouses had discussed. Adopting this stance enabled me to approach each couple's experience in the knowledge that I was not attempting to uncover one objective reality. Additionally, it was my responsibility to represent the participants' perspectives and ensure that the findings were grounded in their actual accounts; in doing so, I was continually engaging in double hermeneutics. In keeping

with the interpretative framework of the study, the meanings that participants assigned to their experiences were of central importance and the research interviews were led by the participants. I was therefore mindful that the aim of this study was not to give a precise picture of the participants' studied worlds, but an interpretative representation of it (Charmaz 2006).

As a researcher, my ontological position is that of hermeneutic phenomenology. Specifically, I acknowledge that each participant's account of their unique story is influenced and shaped by a multitude of perspectives including personality, cultural background and the context within which they shared their stories. I was also acutely aware that my own cultural background, training and professional standing had the potential to impact on my interaction with the participants and my interpretation of their experiences. For instance, one participant asked during their interview for validation that they were employing the right strategies to support their spouse. This made me aware of my dual role of researcher but also as a clinician working with individuals with dementia.

Below is a discussion outlining my personal reflection through the research journey and how it may have affected the research process.

#### **4.11 Researcher reflexivity**

Reflexivity is customarily used in qualitative research and is viewed as an appropriate and acceptable way for the researcher to consider and validate their research practice (Pillow, 2003; Pietiewicz and Smith, 2012). Due to my previous knowledge of CST and work with patients with dementia, I came to the PhD with some considerable foreknowledge, and was concerned about how this would influence my analysis. However, between the interview stage of the research and the data analysis, I changed professional roles, staying

within the same team but no longer being responsible for the delivery of CST. This meant that my initial reservations about potential bias and vested interest altered as I felt that I could potentially be more impartial about my findings, as I felt more able to identify and acknowledge my presuppositions about CST and the potential need to present it in a positive light.

Mauthner and Doucet (2003) propose that ethics, research practice and epistemology are all interlinked. Ongoing reflexivity throughout the PhD journey has been an important way of illuminating issues that may otherwise have remained hidden. Smith et al. (2009) describe reflexivity as a 'deliberate controlled reflection' (Smith et al., 1999: p189).

Reflexivity has also been seen as means to enhance the rigour and validity of a research study (Finley 2014). In any phenomenological study, reflexivity is an ongoing process that is applied throughout the entire process, from the early design and rationale through to the data gathering and analysis (Smith et al., 2009). Given its theoretical foundation, reflexivity for IPA researchers is concerned with more than checking for researcher bias but is instead an avenue which supports the rigour and validity of the study (ibid).

The inclusion of the researcher's reflections is highly deliberate and should not be avoided. As such, this thesis is interwoven with my presence. For instance, my viewpoint and theoretical persuasion guided my choice of research method as well as the research topic. Being mindful of reflexive methodology, this thesis is in line with the approaches of Etherington (2004) and Morley (1996 pp.128-48.), the latter purporting that, "we need to acknowledge that as researchers we are people with our own responses, values, beliefs and prejudices" (Morley, 1996 pp.128-48.: p139). Through reflexivity, I as the researcher intentionally and self-consciously engaged with my own experiences and contexts which impacted on the enquiry and outcome. This was achieved by keeping a research diary in

which thoughts, impressions and experiences of note were documented throughout the research and later reflected on during the writing up process. Further to this, I applied the notion of 'epistemological reflexivity' (Pietkiewicz and Smith, 2012: 361), which is concerned with questions about the methodological framework applied, such as 'am I asking the right questions?' or 'how does the research question strengthen or limit my study?'.

However, as Smith (2009) counsels, it is unlikely that any person is aware of all their pertinent experiences and foreknowledge prior to the research process; rather, continued reflexivity supports ongoing awareness of research-activated self-experiences. A transparent discussion about reflexivity affords the reader the opportunity to better understand and place the research in context as they are informed about the position the researcher has adopted. The use of continual reflexivity which aims to be transparent means I am 'present' throughout the entire thesis, without the research becoming about me and my personal experiences.

A meaningful question when positioning myself in this research is that of how dementia, CST and couplehood connect to me? As a clinician working in an older adult's community mental health team, I have been confronted with the impact of dementia on many domains of an individual's life. I have seen first hand how dementia can erode relationships and how unintentionally inappropriate care practices can result in the individual with dementia becoming diminished until they are virtually absent from discussions about them. This can be linked to the model of 'malignant social psychology', (Kitwood, 2002: p230) in which individuals with dementia are denied their full range of potential experiences (see section 1.6.2 for discussion on personhood).

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As a trainee occupational therapist some 23 years ago, my first placement was with an intermediate care team where I met an elderly gentleman who could not understand the fact that his wife had recently died. On my way into the placement each morning, I would pass him sitting on a bench in tears as he asked of everyone who passed him, "Please help me, I can't find my wife". I remember that sometimes the health care workers would quite bluntly tell him that she had died, not through intentional cruelty, but as a means of trying to re-orientate him. For some workers, this conversation would take place multiple times during the day. I remember vividly how distressed this gentleman was and how helpless I felt. However what I now come to realise is that in looking for his wife, he was also looking for a connection to the world around him that had been lost through his dementia.

Some years on from that experience, I can reflect on the ways in which views about dementia have changed over the years. I would hope that this thesis acts as a reminder that people with dementia are still people, with thoughts and feelings and a whole life story and biography that deserves to be heard and understood. The incident with the elderly man had such a profound effect on me that it has stayed with me throughout my professional life and helped define who I am as a clinician as well as my approach to mental health and individuals living with dementia. Throughout my career, I have witnessed many upsetting events in which an individual with dementia may not recognise family members, may forget that their partner has died, or may refuse to believe that they have been married to the person sitting next to them for many years. All of these potential scenarios affect not just the person living with dementia, but also their chosen life partner. I am interested in understanding how to support couples in the face of such a deteriorating illness. This thesis is therefore intended to stimulate, captivate and

inform, and I highly appreciate and am grateful to the four couples who have shared their reality with me to give meaning to this journey.

In addition to these personal feelings, the reality of conducting research about the experiences of people with dementia was not without its challenges. Capacity, vulnerability and so on required careful consideration, so I was mindful about such issues throughout every stage of the research (Manthorpe et al., 2011) (see section 4.19 for discussion on ethics). In their research on the life values of 15 people with dementia, Beuscher and Grando (2009) argue the importance of including people with dementia in research in order to understand the impact of the condition on their wellbeing. They further argue that employing a qualitative approach is in itself holistic as such methods promote a focus on the health and wellbeing of the whole person rather than just the illness. Including people with dementia in research requires active listening from the researcher and enhances inclusivity by giving a voice to the person with dementia and supporting individuals to feel that their contribution is meaningful and valued. These important issues were at the forefront of this thesis. I attempted to embrace this position throughout the research and to hear participants' own sense making of their experiences (Willig, 2001; Smith et al., 2009). In this research, that meant capturing the nuances of the impact of dementia on spousal relationships. Thus the inclusion of both members of the couple was critical to my decision to utilise IPA as both a methodology and as guidance for my epistemological approach.

Having discussed the methodological framework which has underpinned this current study the next sections will focus on the practical steps taken to undertake this research.

## 4.12 Pilot study

Sampson (2004) highlights the usefulness of undertaking a pilot study as this provides a practice run for research which enables evaluation and feasibility of any study. Pilot studies are also useful for revealing research problems, highlighting gaps in data collection and framing broader research considerations such as validity, ethics, sample representation and researcher role.

I conducted a pilot study of two couples in which one partner had a diagnosis of dementia and had attended the 14-week CST programme. These two couples were recruited from within my own locality but were not from a CST group that I had facilitated. One couple were interviewed together, the second couple interviewed separately. This was because the first couple assumed they would be interviewed together and declined the opportunity for separate interviews. However, it was useful to undertake the two interviews following this different pattern, as this helped determine whether simultaneous interviewing would impact on the openness of discussion, as suggested by Ablitt et al. (2009), who interviewed couples separately to ensure open and frank discussion without upsetting their spouse.

I felt that a combined interview, although useful in terms of noting nonverbal cues such as hand holding and reassuring gestures, did not allow for an equal voice. For instance, during the pilot study, the partner with dementia often lacked insight into their capabilities and appeared surprised at times when their spouse corrected them. In addition, there were times where it was difficult to ascertain whether the partner without dementia was expressing their true thoughts and feelings as they may have been underplaying the impact of dementia on their relationship to spare the feelings of their partner. As an example, the spouse agreed with his wife over the mildness of her

memory problems but would then shake his head towards me to express his secret disagreement. Data from the pilot interviews was omitted from the final analysis. However, they provided a valuable experience of how interviews might proceed and were helpful when formulating the interview questions. Interestingly, all couples were frank and honest in their discussions about the future, despite my initial uncertainty about whether this line of questioning would be distressing or overly emotive.

Based on the pilot studies, I decided that in order to achieve an open discussion with participants, separate, one-to-one interviews with each individual was the most appropriate choice. This choice was later inadvertently verified as being favourable as during the interviews with one couple (Robert and Alex), both partners kept interrupting the interview such as by coming into the kitchen to make a drink and joining in the interview. Both were vocal and argumentative with each other and the interviews were fraught with tension. At the time I felt quite harassed and worn out by their interactions, and so was relieved that I had chosen to interview them separately. Interestingly, both of their individual accounts verified their fraught relationship, which helped form the later analysis but also verified that nothing was lost by interviewing spouses the separately.

#### **4.13 Sampling**

As discussed, the main concern of any IPA study is a detailed and focused understanding of each participant's first-person account of a particular phenomenon. For the purpose of this research, and in line with the theoretical underpinnings of IPA (Larkin et al., 2006a), participants were intentionally selected using purposive sampling. Purposive sampling is useful as it enables the selection of relevant cases (couples) who illustrate an experience or process (CST) of interest (Silverman, 2001). Smith et al. (2009) purport that in IPA,

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participants are selected on the basis that they characterise a perspective rather than a population and should therefore be a reasonably homogenous sample for whom the research question is meaningful and relevant.

A purposive, homogenous sample means that participants were intentionally selected in order to enable rich in-depth narratives about an experience. Utilising such a sample allows the researcher access to a particular phenomenon and facilitates understanding from more than one perspective (Smith et al., 2009). Silverman (2001) points out that while this enables choices based on a particular characteristic or process, it also ensures that the sample is chosen rationally and systematically. Patton (1999) suggests that this type of sampling is appropriate for studying cases in depth, meaning it is therefore appropriate for the current IPA study, which aims to address the impact of dementia on couples in an in-depth, exploratory manner.

Purposive sampling contrasts to other types of sampling used in qualitative research. For example, grounded theory uses theoretical sampling to seek comparisons and exceptions in order to produce dynamic, multidimensional theory of how various factors may influence experiences and behaviours (Pietkiewicz and Smith, 2012). The use of a purposive homogenous sample for this study led to a sample of couples who shared the same experience (CST for dementia) from a specific perspective (couplehood) in order to examine in detail patterns of similarity and difference. However, Smith et al. (2009) do advise some caution around purposive homogenous sampling; participants should not be viewed as a uniform group. Rather, it is through the similarity of their experience (CST and couplehood) that themes of convergence and divergence will emerge.

In order to uncover rich and full personal accounts, IPA sample sizes are usually small. This enables participants to “think, talk and be heard” (Reid et al., 2005: p25). For

example, in their research on how older women who live alone make sense of dementia, Frazer et al. (2012) interviewed eight women. Eatough and Smith (2006) have published a case study looking at data from just one participant.

While there are no hard and fast rules on sample size, Smith et al. (2009) suggest that between six and eight participants is appropriate for an IPA study, but also caution that sample size is always contextual and must be reflected on a study-to-study basis. A smaller sample provides an opportunity to examine differences and similarities between individuals in detail whilst ensuring that the amount of data to analyse is not overwhelming. Generally, in any IPA study, it is depth rather than breadth of data which is important. With this in mind, and in order to fulfil IPA's ideographic commitment (Reid et al., 2005), four couples were recruited for this study, meaning there were eight participants in total. While this number is relatively small for a PhD study, it is well within the parameters of IPA research and afforded a deeper, richer and more intimate worldview of couples' experiences. For the purpose of this study, each participant was interviewed prior to the spouse with dementia starting the CST group and again after they had finished the CST course. This resulted in 16 transcripts, which generated a sizeable yet manageable amount of data.

#### **4.14 Recruitment**

In line with existing research (Cove et al., 2013), participants were identified from memory clinics within a Southern Health Trust in England. There are six memory clinics within the trust, all of which run CST groups. This particular Trust was chosen purely on pragmatic grounds, since all six memory clinics run more than one CST group a week. Additionally, I work in a memory clinic within the Trust and was therefore able to access participants and CST groups more simply than if I had approached other Trusts. Since I

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work at one of the locations of the Trust, I decided not to include it in the research as I felt it may lead to potential ethical and power issues (see section 4.19 for discussion on ethics). I initially anticipated that participants would be recruited from all five of the remaining locations.

I regularly met with CST facilitators during trust-wide peer supervision, where I was able to introduce the research and requested that during the routine CST assessments, facilitators would give out information sheets for my research and take note of any participants who may be interested in taking part in the study. Facilitators would then obtain consent for the potentially interested participant's details to be passed to me, after which I would contact those potential participants by telephone and recruit them to the study. Unfortunately, two locations did not respond to any of my emails requesting support with the research, meaning that it was difficult to ascertain who was the lead facilitator for these locations. A third location reported that they felt that these particular cohorts were 'over researched'. This was due in part to a research study which had recently taken place in which facilitators were tasked with completing two large qualitative questionnaires pre and post CST, and which took up a lot of time and resources. In hindsight, I feel this previous research may have impacted on the facilitators' lack of motivation to support a second research project.

An additional challenge was that facilitators regularly reported that recruiting to CST groups was already a struggle, without the added burden of recruiting for yet another research project. Despite my reassurances that this would not burden facilitators, three locations did not take part in the research. Patel et al. (2003) outline the challenges of recruiting health care staff in supporting research projects and recommend a checklist for maintaining collaboration. However, despite clarifying that facilitators would not be

tasked with collecting data as well as following the checklist for motivating staff, staff did not become enthusiastic about recruiting to the study. Again, I believe this was due to the challenges of participating in the previous research, which impacted on the CST groups. On reflection, it could be that facilitators had reached 'burnout' with CST research (Kuittinen and Meriläinen, 2011). These challenges highlighted that research is always at the mercy of time and circumstance; the difficulty with recruiting facilitators was a problem I had not anticipated. I was also on tenterhooks throughout data collection as participants were free to withdraw from the study at any point. While this did not happen, it did raise my awareness of how valuable research participants are and how grateful I was for those who did take part. This in turn bolstered my commitment to present their stories and experiences as accurately as possible.

The two locations within the trust which did consent to participate helped me to recruit two couples each (four couples in total): two in which the wife was the person with dementia and two in which the husband was the person with dementia. I interviewed each couple prior to starting CST and once again when the 14 week course had been completed. Interviews at these two time points were chosen as they would provide a way of comparing individuals' expectations of CST with their reality of the experience. I was unable to interview the couples at exactly the same time point before and after attending CST as each participant attended a different CST group, and arranging interviews was dependent upon their availability. For instance, one couple were on holiday in the week preceding CST, and another couple had hospital appointments post CST. I did not feel that this impacted on the quality of the data collection; however, I was keen to interview participants fairly soon after finishing CST so that the experience of the

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group was not forgotten. Table 4 below denotes the time scale of pre and post CST interviews.

Table 4: Time scale of pre and post CST

	Timing of interview pre CST	Timing of interview post CST
Couple A	One week	Three weeks
Couple B	11 days	Two weeks
Couple C	Three days	One week
Couple D	One day	One week

None of the participants attended the same CST group, meaning they did not know each other. I felt that this was important for reducing potential bias as participants may have discussed their responses to the interview questions with each other. I also considered that if the research participants were from the same CST group, the study may be interpreted by them as a typical element of CST rather than a stand-alone research project.

I initially considered the option of conducting a further interview three to six months after the second interview to explore any further changes in experiences and attitudes. However, I decided against this on the basis that since dementia is a deteriorating condition, an interview too long after the CST course may no longer be meaningful. The goal was to explore couples' experience of dementia, couplehood and CST, and therefore a before and after interview was sufficient to capture this.

In order to recruit patients to CST groups, each location of the trust undertake the same process. Patients who attend memory clinics are routinely referred to CST if their Mini Mental State Examination (MMSE) score sits with the range of 15 to 28 and they consent to referral. CST facilitators then contact patients, confirm that they are interested in attending CST and visit them at home to undertake pre-CST assessments.

Facilitators from the two locations which agreed to take part in the research asked patients and their spouses who met the inclusion criteria whether they would be interested in taking part in a research project on couplehood. Potential participants were given a brief description of the study and asked if they would like further information (see Appendix A for separate participation sheet for patient and care partner). If couples showed their interest in the research, consent for their details to be passed to myself was sought by the CST facilitator. I then contacted any interested participants by phone to answer any questions and to confirm whether they would like to participate. Potential participants were then each sent a separate research information sheet and my contact details. I did not have any preconceived plan as to which spouse I spoke to during the call, however it was the care partner in all cases who answered the phone and who I made the arrangements with. Each couple was given at least a week to read the information sheet, at which point I contacted them again to answer any questions they might have and ask if they would like to take part. I then arranged to meet each couple at their home or at the trust location from which they had been recruited. All couples chose to be interviewed at their own homes. On meeting the couple, I asked if they had any further questions, referred to the information sheet regarding participation, and made it clear that I would be digitally recording the interview. Each individual was asked to sign a consent form (see Appendix B for separate consent form for patient and care partner) at

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the start of each interview. Each couple member had a separate participant sheet and consent form. The use of consent forms follows good practice guidelines whereby consent is always checked prior to proceeding with the research (Hellström et al., 2007).

Four couples were recruited to the study. Additionally, a further couple were recruited who cancelled on the day of the interview. I initially felt disappointed by this, but was reassured from an ethical stand point that they did not feel obliged to participate. In the end, I recruited enough participants to gather a meaningful corpus of data, but this experience did highlight a sense of vulnerability in that all research is dependent upon willing participants.

Additionally, the couple who withdrew were a younger, same sex married couple; at the time, I felt their experiences may have added an interesting dynamic to the theme of couplehood in terms of the relatively shorter length of their relationship. Dementia affects a wide age range of people. However, research by Millenaar et al. (2016) suggests that there are greater differences in the impact of dementia between younger (under 65) and older cohorts. Furthermore, Kaiser and Panegyres (2007) suggest that spouses of individuals with young onset dementia experience greater psychosocial distress than older spouses of individuals with dementia.

Although I had not specified an age limit for the research participants, the unintentional homogeneity of age within the sample turned out to be an advantage as it was apparent during data collection that older couples experience specific stressors which may be unique to their cohort. Issues such as multiple loss and physical frailty may not have been experienced by the younger couple, which may have influenced the study's findings. For example, all participants had experienced a time of difficulty in their married lives which was moderated by the fact that they had been together for a longer amount of time. On

reflection, I feel that had the younger couple taken part, it may have resulted in a less homogenous sample (see section 5.4 for participant biographies), as they had been married for a shorter time than the other couples. IPA ideally utilises samples who are as homogenous as possible in order to uncover meaningful convergences and divergences between participants. The strength of this approach became clearer to me once data analysis was underway.

Below is a discussion on the inclusion and exclusion criteria for the research participants.

#### **4.14.1 Inclusion criteria**

To meet the inclusion criteria:

- One member of the couple had to have a diagnosis of mild dementia as defined by ICD-10 (World Health Organisation, 1992). It was important that only one member of the couple had dementia, as the research centred on the impact of dementia from the perspective of a spouse with dementia and a spouse without dementia. This also negated any potential ethical issues regarding consent and capacity, for example if only one spouse had capacity to consent to the research. Ironically, this did generate a potential ethical issue in that I assumed that the spouse without a diagnosis of dementia did not in fact have dementia. The NHS research ethics committee did not specify that I tested the capacity of spouse without diagnosis of dementia; instead, this was a clinical decision I took during recruitment.
- The individual with dementia had to have the capacity to consent, as per the Mental Capacity Act (MCA 2005). The purpose of the MCA is to enable and safeguard decision making within a legal framework, and involves the following

two-stage functional test of capacity: 1) is there impairment/disturbance in the functioning of an individual's mind/brain If so, 2) is the impairment/disturbance to a degree that the individual lacks the capacity to make a specific decision

(Department of Health, 2009). The act states that all individuals are deemed to have capacity unless there is evidence of impairment; in this case, dementia.

However, according to the act, all assessments must be made on the balance of probability (that is, is it more likely than not that the individual lacks capacity), and participants were deemed to have capacity as they were in the mild to moderate stages of dementia. This was further verified by a four-stage application of the MCA: 1) that each participant was able to understand relevant information about the research; 2) that participants retained the information long enough to make the decision whether or not to participate; 3) that participants were able to use, weigh up and evaluate the research information as part of a decision-making process; and 4) that participants could communicate the decision to participate.

- The individual with dementia needed to score 22-25 on the MMSE, which is a 30 point questionnaire which is extensively used in clinical settings to measure cognitive impairment (Folstein et al., 1975)

Table 5 below denotes cut off levels that are used to classify the severity of cognitive impairment and the impact on day to day functioning.

Table 5: MMSE score

Score	Degree of impairment	Day to day functioning
26-30	Questionably significant	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living
20-25	Mild	Significant effect. May require some supervision, support and assistance
11-19	Moderate	Clear impairment. May require 24-hour supervision.
0-10	Severe	Marked impairment. Likely to require 24-hour supervision and assistance with Activities of Daily Living (ADL).

Source: (Folstein et al., 1975)

The MMSE score was significant in determining who was eligible to participate. I used a cut off of 22-25 for inclusion as wanted to ensure that I was well within the parameters of the mild dementia range. For instance, an individual who scores 20 on the MMSE may present as having a more moderate dementia than their score would indicate. Utilising this score would yield participants who face challenges in their activities of daily living that were significant enough to be of note but not disabling. Additionally, I did not want to recruit individuals in the 26-30 range since these individuals are generally high functioning and impairment will be present but not significant. Conversely, I did not wish to recruit participants in the

moderate or severe range as they may not have had the required capacity to consent or insight into their impairment, meaning they may not have been able to provide the rich descriptions and perceptions I was seeking. In my experience of working within a clinical setting, individuals within the moderate to severe range can become easily distressed and agitated. Spousal distress is also more likely due to challenging behavioural issues, so I felt that from an ethical perspective it was better not to include these participants as I did not want to cause anyone unnecessary suffering and anxiety.

- The individual with dementia and their spouse should both be willing to take part in the research and should each sign a separate consent form at each pre and post CST interview.
- Both members of the couple had to be aware of and understand the diagnosis of dementia. This was important as the research sought rich descriptions of the participants' experiences, which would have been obscured if individuals or their spouse lacked awareness of their diagnosis.
- Both members of the couple had to be able to follow the thread of a conversation and to articulate thoughts and feelings. This was assessed by the CST facilitator when recruiting to the study, although I also intuitively assessed this when arranging interviews.
- Both individuals were able to communicate in English.
- Both individuals had to identify as part of a couple. This was reaffirmed at the start of the first interview that each individual viewed themselves as part of a married couple. This aspect was a crucial component of the inclusion criteria as

the goal of the research was to examine the experience of couplehood and dementia as opposed to the experience of care giving and dementia.

- Couples had to live together at home without a live-in carer. Again, this was an important feature as I aimed to collect data on the day to day impact of memory impairment on relationships. This aim would have been obscured if couples lived apart or if a meaningful portion of their care was undertaken by a formal carer.

#### **4.14.2 Exclusion criteria**

It was intended that individuals with speech problems would be excluded as I felt this may impede data collection since the study relied on transcription of digitally recorded interviews. However, what constitutes a speech problem was, in hindsight, open to interpretation (Clark, 1994); one facilitator who was a speech and language therapist recruited a couple where a care partner had Parkinson's disease, which had some impact on their speech. It was initially a challenge to capture accurately what was being said. I had to listen to this recording multiple times to become accustomed to this participant's particular way of speaking; having done this, I was able to use their interview for the data analysis.

#### **4.15 Description of participants**

Four couples participated in the research: two males with dementia and two females with dementia as well as their spouses. The participants' ages ranged from 78 to 89, and each couple had been married between 55 and 67 years. All couples had remained in their first marriage and all lived with their spouse in their own homes (see section 5.4 for full biographical details of participants).

Spouses of those with dementia had not been referred to the memory clinic and were therefore assumed not to have dementia themselves (see 4.14.1 for inclusion criteria). Using my clinical judgement during the interviews, it became apparent that this assumption was correct. Of the spouses with dementia, two had Alzheimer's disease, one had vascular dementia and the remaining individual had a mixed dementia. Three of these individuals had commenced memory medication acetylcholinesterase inhibitors. Time since diagnosis and starting the CST group ranged from seven months to fourteen months. MMSE score at first interview ranged from 22 to 24. This score was measured by a facilitator during the routine CST screening interview. As I did not have ethical approval to access the clinical notes, it was the CST facilitator who had conducted the MMSE and who indicated that the participants fell within the eligibility criteria.

#### **4.16 Data collection**

The primary aim of the current study was to obtain rich, descriptive, detailed, first person accounts of the experiences of CST and couplehood. In order to remain true to the principles of IPA, questions revolved around how participants described and made sense of their experiences. Phenomenological interviewing, as described by Van Manen (2007), was chosen as this involves 'borrowing' the participants' stories as a way to acquire understanding; this is a data collection method which enabled participants to elaborate and clarify their individual biographies. Semi-structured, face-to-face interviews with each individual were conducted (Smith et al., 2009). Each participant was interviewed separately, on their own, without their spouse being present. This was in order to promote open and honest discussion with each participant without fear of upsetting their spouse. I went into the interviews without any preconceived ideas of who should be interviewed first, but left it to each couple to decide this. According to Pietkiewicz and

Smith (2012), semi-structured interviews are the most popular and optimal method of IPA data collection, although data can also be collected via focus groups, diaries, surveys and internet forums. As discussed, the research sought to capture rich data, which relied on a data collection method which would empower individuals to speak freely and reflectively in order to express, describe and convey their unique story in their own words. Warren and Karner (2005) define the qualitative research interview as a means to encourage the interviewee to share rich descriptions of phenomena whilst leaving interpretation and analysis to the interviewer-researcher. The purpose of the interviews was to encourage participants to share their experiences in as much depth as possible. An additional goal was to elicit a shared understanding of their account by entering their life-world.

A face-to-face, semi-structured interview is characterised by synchronous communication in time and place. Unlike other some methods of data collection such as diaries or internet discussion, the interviewer benefits from being able to observe social cues such as voice, intonation and body language. Face-to-face interviews also promote an interactive rapport between the interviewee and the interviewer, and permit space and time to think, speak and be heard (Smith et al., 2009). The interviewer and interviewee can react directly to what each other has said. An advantage of this method is that answers are more spontaneous. However, as a result of this, the interviewer has to engage in “double attention” (Wengraf, 2001: p50), meaning they must simultaneously listen to and comprehend the responses of participants whilst also being mindful that the questions asked are being answered with a level of depth which meets the research question. As discussed above, this can present a challenge to undertaking a good quality interview.

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Other data collection methods such as questionnaires and focus groups have been applied to IPA research (Palmer et al., 2010), and I could have chosen one of those methods instead. Focus groups, for instance, enable multiple voices to be heard in one session. However, the interaction between group members may make it more challenging to develop the phenomenological aspect of IPA (Smith et al., 2009). As discussed earlier, this research aimed to give voice to those who often go unheard, and it is possible that a focus group may have discouraged reticent or apprehensive individuals from contributing. This was another reason for my decision to interview each member of the couple separately. Separate interviews helped to obtain comprehensive descriptions from the participants in their own words and to provide a basis for a reflective, structural analysis in which to illustrate the essence of experience (Moustakas 1994). Face-to-face interviews encouraged individuals to discuss topics in detail and allowed the opportunity for difficult topics to be openly discussed.

Hefferon and Gil-Rodriguez (2011) argue that good-quality data requires more open-ended questioning, whilst the researcher must maintain a balance between guiding the interview and being guided. This is another justification for the use of semi-structured interviews. The use of an interview schedule allowed the conversation to flow whilst providing a loose agenda of topics to be discussed. As Smith et al. (2009) cautions, the schedule should only be used as a guide, as the basis of IPA interviewing is to listen attentively, engage deeply and probe sincerely in order to make way for a view into the lifeworld of participants.

Within any healthcare setting, there is the potential of a power imbalance between healthcare professional and patient (Henderson, 2003). This can also be true within a research context. The semi-structured interview afforded space to discuss issues that

may not have been contained in an interview schedule. At the start of the interview, I asked general, warm up questions in order to gain a rapport before honing in on the more focused questions. I endeavoured to be friendly and conversational throughout the interview and tried to memorise the schedule as much as possible so I wasn't distracted by looking down at my papers. I asked questions about participants' lives and experiences, and paraphrased participants' words to demonstrate active listening where appropriate (Ryan et al., 2013). However, I was mindful to be circumspect when paraphrasing to avoid adding to or subtracting from the topics articulated by participants. The aim of the paraphrasing was not to amend the content of the data but to confirm the accuracy of my interpretation of what was being said by using the participants' own words.

Indeed, utilising the language of the participants was important throughout the interviews, in order to remain true to IPA's tenet of hermeneutics. The goal was to interpret hidden meaning during the interviews; delving deeper to explore what the participants really meant helped expose their 'inner voice' (Seidman, 2006: p16). Alongside this, I aimed to present my questions as someone who was interested in listening to the participants' life stories, was non-judgemental in my approach and held the participants as 'expert' throughout the interview. This type of interviewing is recommended by Smith et al. (2009) as it affords maximum opportunities for participants to tell their own story in their own words. The semi-structured nature of the interview encouraged discussion on themes identified in previous research into dementia and couples whilst allowing for issues which have not been previously raised. It also enabled interviews to be flexible and informal.

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An interview schedule was developed to address participants' thoughts, feelings, opinions and expectations of CST (See appendix C for interview schedule). The same questions were generally asked of the individual with dementia and their spouse. The use of an interview schedule ensured that relevant questions were asked of all the participants but was not a fixed template of questions. This is substantiated by Silverman (2001), who contends that a rigid sequence of questions would be unsuitable for all participants. At the start of the interview, I stated that I had some questions to ask, but would be guided and led by the participants. I also made it clear to participants that they could stop the interview at any time and that they did not have to answer any questions with which they were uncomfortable. I also verified that there was no time limit on the interviews and took care not to rush, while remaining aware that couples were giving up their time for the research. To this end, the schedule supported a way of finishing interviews without cutting individuals short. For example, I thanked the participants for their time and an ending sentence was to ask the participants if they felt there was anything else they wanted to add or comment on. This therefore signalled that the interview was closing but also gave opportunities for additional comments.

Interviews lasted on average for one hour, although one interview lasted 25 minutes and another more than 90 minutes. I was acutely aware of the importance of making the most of my time with the participants and sought clarification where necessary to ensure that the data generated would be reflective of a shared understanding of a co-constructed story between myself as researcher and the participant as an individual who was also part of a couple.

Each interview was digitally recorded. I found this to be the most distracting aspect of the interviews as I felt the temptation to keep checking whether the recorder was

working. As I used an iPad for these recordings, I was conscious of the battery running low and so checked and triple checked the charge as I knew I would not be able to replicate the interviews if the recorder failed. The recordings ensured I was able to capture everything that was being said, including pauses, laughs and hesitations (DiCicco-Bloom and Crabtree, 2006). They also enabled data to be retrieved during analysis to clarify sentences. Listening and re-listening to the interviews kept them fresh and alive in my mind, and it was useful to read the transcripts while simultaneously listening to the recordings. I also had pen and paper at hand so that I was able to note items of interest, but I tried not to do this often as thought it could be distracting for the interviewee.

Each participant was interviewed twice, once before the start of the CST group and again after the end of the CST group. The first set of interviews aimed to understand the impact of dementia on the sense of couplehood. The second interviews investigated whether attendance at CST impacted on the participants' sense of couplehood. Points of interest arising from the first interview fed into the second interview schedule, which was an evolving document throughout the data collection period. Utilising two interviews was useful as I was able to re-address issues raised in the first interviews and further address issues raised by the other participant in each couple. This design also meant that topics raised by some participants could be discussed with other participants in order to build on and expand my understanding of their lived experience of being in a couple and facing dementia. Undertaking two sets of interviews allowed me to elaborate on topics in order to improve my understanding of the participants' life-views and further my understanding of their lived experience. The interview schedule followed four main areas of discussion including: what couplehood meant for participants; their experience of dementia; their expectations and experience of CST; and the strategies (if any) they developed to cope

with dementia. I based the interview schedule on common themes that I had identified during a scoping review of the literature on couplehood and CST as well as gaps identified during the literature review. As there were no prior studies investigating CST and couplehood, this aspect of the interview was entirely open-ended.

I was nervous throughout the interview process. As each interview was a 'one off', I wanted to capture everything I possibly could, and felt keen that my interview schedule should be structured enough to capture rich data but flexible enough to be led by the participant. I was also conscious that the interviews should not turn into a clinical assessment and that I was professional without presenting myself as a clinical practitioner imparting advice or offering an intervention. This again reflected the dual role of researcher and clinician that I felt I was balancing throughout the research.

After each interview, I switched off the iPad, but once in my car I switched it back on so that I could digitally record any immediate impressions before they were forgotten. This would generally be a description of how I felt the interview went, including any elements that went well and any room for improvement. Shortly after each interview I transcribed the data verbatim. This was a useful process as I was able to reposition myself within the data during the data analysis.

### **4.17 Data analysis**

Data analysis was conducted in three ways. Firstly, analysis focused exclusively on each individual. For example both interviews with each individual spouse was analysed as one separate set of data before then analysing their partners two interviews. This provided an understanding of the similarities and divergences amongst individuals with dementia's thoughts and experiences of CST, dementia and couplehood, and the same understanding

for their spouses. As this research is based on understanding couplehood, it was important that the final element of analysis focused on the couple. This helped to reach an understanding of the experiences of couplehood from each spouse, and to compare this across the cohort of couples. In support of this analytic strategy, Molyneaux et al. (2011b) suggests that in any research which focuses on couplehood, the couple itself must be the centre of the analysis.

Each interview was transcribed verbatim. Each interview was read and reread, often in conjunction with the tape-recorded interview as a means of embedding the individual in their own story. In line with the steps outlined by Smith et al. (2009), I created three columns on a page. The main body of the text was put in the middle column and insights and observations were noted in the right hand margin of each transcript (See appendix D for example of a transcribed interview). I moved through the text, jotting down thoughts and feelings about the interview, the wording, the language used and the general feel of the interviews until I felt that I had reached a degree of 'gestalt'. This helped identify any specific objects of concern for each individual (Larkin et al., 2006b). Interpretative impressions and comments were then noted in the left hand margin. This enabled me to move from exploratory, analytical themes towards emergent, interpretative themes.

Although Smith et al. (2009) explicitly state that there is not a pre-set list of instructions for how to conduct IPA, it was useful to follow their template for data analysis (Smith et al., 2009). Rather than employing a theory at this stage, analysis consisted of immersing myself in the data. As IPA is intensely idiographic, with a focus on individual uniqueness rather than developing theories of behaviour which can be generalised to the population, I took each of the two separate interviews from each participant and wrote this up as a freestyle case summary so that I could focus on each individual's personal accounts. I

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identified a number of exploratory themes from each interview, which I then grouped into emerging themes (Smith et al., 2009). A number of master themes were identified from these groups.

Since I tend to see things pictorially rather than in a written form, I found it easier to colour code the interviews by couple, for example light blue for one individual and dark blue for their partner. I then cut out each line of the interview and formed them into themes of general clusters of similar statements which I had identified from each case study (see Appendix E). This revealed connections between the emerging themes. For example, couples' comments about the future were clustered into similar phrases. Page and line numbers of extracts were also included as an audit trail so that I could go back to the whole transcript to check the meaning and context of each extract. At this stage, some emerging themes were abandoned as new insights gained from further reading of all the participants' interviews had an impact on their relevance. For example, 'relating to dementia' appeared to be an emerging theme (and possibly a master theme), however when all the transcripts were analysed this theme transitioned from 'relating to dementia' into 'navigating disruption' demonstrating the couples strategies to adjust and cope.

The emergent themes from all transcripts were then grouped together to form the master themes and subthemes of an overall table of themes (see appendix F). This demonstrated how exploratory notes and comments were transformed into emerging themes. Using extracts from interviews also illustrated ways in which the hermeneutic circle was developed throughout, as each part of an interview was interpreted in relation to the whole, and the whole interview was interpreted in relation to its parts (Pietiewicz and Smith, 2012). Excerpts from participants were regularly read to identify differences

and similarities and to ensure themes were representative of individuals' idiographic experiences. Grouping extracts under each master theme enabled me to highlight what the participants shared as well as the similarities and differences in their life views. In this way, the generic as well as the idiosyncratic was illuminated. I revisited the sections of the transcripts associated with these emergent themes and then further condensed these into four master themes. Undertaking the analysis in this way helped to illuminate changes to couples' thoughts and perceptions over the 14 weeks between the first and second interview and enabled changes to be woven into participants' stories. This is in line with longitudinal IPA studies described by Spiers et al. (2016) and McDonough et al. (2008).

Throughout the process of data analysis, I debated whether or not to use a specialist software package to help organise data but decided that, despite these being used regularly in IPA studies, I favoured a more 'hands on' method of data analysis in which I could see the emergent themes pictorially. While this method was at times demanding and painstaking, I believe it enabled me to build up a persuasive account of each couple's story. For example, the line by line, colour-coded strips of paper from the interviews enabled me to see at a glance how the comments fitted within each sub theme, so I could easily group them or move them in and between sub-themes and themes. These were laid out on a table and enabled me to see whether an individual's response dominated or was under-represented in each sub-theme.

The reading of the transcript from smaller sections to reading the transcript as a whole helped to identify what was said elsewhere in the interview in light of the larger text thereby undertaking double hermeneutics. Additionally, each time the transcripts were revisited, interpretation of the data developed, meaning interpretative analysis was still

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underway during the writing up of the results. This is in line with (Smith et al., 2009) who suggests that IPA is context-specific since it alters as the researcher's perceptions alter.

In order to remain grounded in interpretation, Smith (2004) advises that the early stages of the analysis should be initially conducted with empathy and subsequent analysis approached with critical reflection. This ongoing interpretation made it hard to decide when the 'right' amount of analysis had been completed. However, as Smith et al. (2009) advise, IPA studies are often based on a 'good enough' (Smith, 2009: p46) analysis and realistic endpoint. I am confident that I have uncovered and understood the participants' worlds and so developed a shared understanding of their experiences.

I did not engage in 'member checking', that is, presenting the findings of analysis for participants to validate their contribution. This is because this interpretive phenomenological study was not underpinned by a positivist need for 'correct', provable answers, but rather one possible understanding of the participants' individual stories. However, as a condition of ethical approval, I did provide each participant with an overview of the interviews and a thank you letter. Hellström et al. (2007) have reported taking a potted plant to their research participants as an interview opener; on reflection, I wished I had also done that. However, I felt that a thank you letter hit the right note whilst also adhering to the ethics criteria.

Additionally, member checking would have been difficult as the amount of time which lapsed between interview and analysis write up was several years. It would have been inappropriate to ask participants to revisit interviews that had been undertaken such a long time previously. Also, Smith (2009) contends that member checking is extraneous in IPA research as would involved 'triple hermeneutics' which is the researcher making

sense of the participant making sense of the researcher . However, in order to clarify how the interviews had been analysed, I shared a template with my supervisors which was discussed during supervision meetings. Furthermore, I discussed analysis with my colleague, who is a clinical psychologist and leads the memory clinic service in another location. She is experienced with IPA, and so was able to provide a second audit and ensure that my interpretation was plausible and authentic. This also provided some triangulation of data. A methodical audit trail was kept throughout the process to ensure that analysis and results remained credible. Tables of emergent themes, initial thoughts and structure of the analysis were also completed. As analysis was undertaken by hand, this table ensured that interpretations remained fresh in my mind and provided a pictorial audit trail of how themes were developed over time.

#### **4.18 Ethical approval**

Ethical approval was granted by the National Research Ethics Service (NRES) Committee South Central – Hampshire B. I was required to attend a meeting with the ethics board and discuss issues raised by the committee. I also gained ethical approval from University of Southampton and from the National Health Service (NHS) Research and Development at the Trust in which the research took place (see Appendix G).

#### **4.19 Ethical issues**

Throughout the research, I was mindful of a number of potential ethical issues, one of which revolved around the ability of individuals with dementia to make informed choices (Forbat, 2003). In order to be eligible for this study, participants had to have a diagnosis of mild dementia (see section 4.14.1 for eligibility criteria). Such a diagnosis indicates that functional impairment is at a mild level. Each participant was assumed to have capacity in

line with the Mental Capacity Act (MCA). In addition, as a qualified health professional working within a clinical setting, I have completed training and conducted assessments of capacity in line with the Mental Capacity Act (Act, 2005) and felt competent to make clinical decisions regarding an individual's capacity. In their research on informed consent, Florey and Emanuel (2004) argue that practitioners carrying out research is an effective way of enhancing participants' consent and understanding.

In order to safeguard against including participants who were unable to give informed consent, all participants were given written information about the study and were provided with the opportunity to ask questions. All participants were asked if they understood the information sheet, what would be required of them and whether they were happy to proceed. This was also verified by a consent form which was signed by all participants at both interviews. Participants were also given opportunity to ask questions before each interview proceeded. However, ethical approval did not require me to assess the capacity of spouse without a diagnosis of dementia. This posed an ethical dilemma for me, in that if a spouse did display cognitive issues or appeared not to understand the research, I was unsure how I would proceed. Again, this raised potential issues of researcher power versus participant vulnerability when undertaking research.

However, in the event, I did not find that capacity was an issue. If the issue of spouses' capacity had come into question, I would have gently probed their understanding of the research, and if I felt they did not have the capacity to participate, I would have not proceeded with the interview. I anticipated that the insight and capacity of the care partner would have been evident during the initial telephone contact, and also anticipated that the original CST facilitator who approached the couples would have let me know if there were any concerns regarding the care partner spouse.

A further ethical issue exists around the practitioner/researcher element since I have also previously facilitated CST sessions. This required a focused effort to overcome potential bias, as I am a keen supporter of CST as an intervention. Thus, as researcher I acknowledged the interpretative elements to data analysis whilst being mindful that the analytical process requires participants' voices to be firmly imprinted in the data (Smith et al., 1999) (see section 4.11 on researcher reflexivity).

Of the five couples identified by the two memory clinic locations, four participated (this does not include the participants from the pilot study). If any one member of the couple did not wish to discuss the impact of dementia, appeared to be distressed by the line of questioning or did not understand the rationale for the research, then I would not have proceeded with the interview. While gaining knowledge into the impact of dementia on couplehood was central to the study, it was essential that this was not undertaken at the expense of participants' emotional well-being. In reality, one of the participants with dementia refused to discuss the term dementia, which made that interview challenging. He was prickly at times and I found that I had to tread carefully to be sensitive and avoid causing him distress. As we were talking, I initially wondered whether to continue with the interview. The participant had a copy of his information sheet – which specified memory – with him during the interview, so I mentioned this several times in order to be sure of his capacity to continue. I felt that although the participant was masking the extent of his cognitive impairment, he did in fact have capacity to consent to the research and did indeed wish to participate. Once I analysed the results of his interview, I interpreted his denial as a coping mechanism rather than a blanket lack of insight and interestingly, once the data analysis had been completed for the couples, I re-interpreted his presentation in light of my reformed understandings.

## 4.20 Research limitations

It is worth noting some limitations to this current study and critiquing these in turn.

Hefferon and Gil-Rodriguez (2011) argue that the increase in IPA research has resulted in studies which are inclined to be thematic in their analysis and subsequently tend to produce results which are descriptive rather than interpretative. To counter this, I sought to move between an “emic and etic perspective” (Pietkiewicz and Smith, 2012: p13) in that I was as immersed in the data as much as possible, standing in the participants’ shoes in order to get as close to the experience as possible. Alongside this, I continuously engaged in documenting how I interpreted participants’ sense making around their experiences whilst documenting and evidencing my own sense making. For example, I was aware of my thoughts and feelings about the couples themselves that the interviews evoked specific feelings in me. This constant checking enabled the development of higher-level theories and insights, of which participants may not have been consciously aware. In this way, I believe I have produced a methodologically rigorous study.

Additionally, each of the participating couples were white, middle class, heterosexual couples, the majority of whom were ostensibly in encouraging, affirming relationships. As discussed, the sample was chosen in accordance with the recommendations of IPA and was therefore relatively small. It could be argued that this sample is therefore not representative of anything other than itself. Therefore, results from the study may also not be generalisable to a wider population.

However, in the tradition of qualitative research, issues of generalisability are an internal characteristic rather than a limitation per se (Horsburgh, 2002). Qualitative research may not be generalisable because of its idiosyncratic nature. However, as the sample was relatively small, this meant that richer, deeper and more detailed information about this

particular cohort of participants was elicited. It is this situational representativeness which was sought rather than demographic representativeness. That said, qualitative researchers have referred to the extent to which theory developed from one study may be transferred to provide explanatory theory for the experiences of other individuals in comparable situations (Popay et al., 1998). The nature of interpretation is highly contextual and unique, and as such, I recognise that other researchers may generate different findings, using a different theoretical lens and the results of this thesis are one of a number of explanations of the lived experience of dementia but nonetheless, I believe a credible one. Nevertheless, I would hope that a researcher using the same lens as I would achieve similarly plausible, credible and so potentially transferable results (Lincoln and Guba, 1985).

Due to the highly idiographic emphasis of IPA, transferability of results to wider populations can be challenging (Smith et al., 1999). IPA researchers have therefore suggested that a theoretical rather than empirical generalisation of results can be made. IPA research often makes connections with existing literature to illuminate the wider human experience rather than generating theories from data. Advocates of IPA have argued that the method is not about finding the 'right' answers but rather fostering empathic understandings of a participant's account whilst acknowledging that the meaning and truth of an experience are multifaceted and context-specific.

I believe that I have remained true to the theoretical principles of IPA and have included a level of transparency which allows the reader to see what I have done and why. I also believe that I have undertaken a coherent and plausible analysis and included sufficient sampling to evidence the way themes have been built and developed (Smith et al., 2009).

Lastly, the issue of linking my findings with phenomenology was always at the forethought of my mind. For instance, the need to categorise extracts from the participants could be considered to reflect a more positivist stance rather than reflecting the idiographic nature of the participants' stories. However, I believe that using the ideas and concepts of IPA informed and enriched the findings, as demonstrated by the ways in which my interpretation of participants' accounts aided a deeper understanding of their experiences. Providing a summary of participants' life stories (see section 5.4 for participant biographies) also enabled an appreciation of each couple before their stories were abstracted in to themes and patterns.

#### **4.21 Conclusion**

This chapter began with an overview of the philosophy and theoretical perspectives that underpin IPA. It provided a rationale for choosing IPA, followed by a critique of the method's strength and limitations. The chapter then discussed sampling and data collection, and provided an in-depth discussion on the processes and analysis undertaken.

The chapter then reviewed the methodology chosen and provided an in-depth discussion on researcher reflexivity and the role of hermeneutics and interpretation. It was important to be open about the epistemological stance which led me to undertake this research and why I chose this particular research focus with this particular cohort as well as how I achieved the research aims.

As discussed, the theoretical foundation of IPA study is built on a triadic relationship of phenomenology (the Heideggerian interpretative perspective), hermeneutics (specifically double hermeneutics) and ideography (a commitment to the particular) (Shinebourne, 2011). These three constructs have therefore informed the methodology and theoretical

framework of this study. The framework therefore is made up of cautious inference in the analysis and the lens through which the findings are analysed (Smith et al., 1999).

The following chapter presents the results of two separate interviews undertaken with four couples in order to explore the lived experience of couplehood and whether attending CST impacts on perceived couplehood.



## Chapter 5     **Results**

### **5.1     Introduction to the analysis**

This chapter presents findings from the separate interviews with four couples, undertaken pre and post CST, by analysing in depth the common themes across their transcripts using IPA. Analysis of the interviews provided a rich understanding of the lived experience of dementia and couplehood. In order to provide continuity and avoid repetition for the reader, both sets of interviews (that is, pre and post CST) have been combined into one continuous analysis. This enabled the couples' stories to be presented in a way which reflected their dementia 'journey'.

Four Master Themes emerged from the data: Navigating Disruption (see section 5.6), Re-appraisal (see section 5.7), Mindfulness (see section 5.8), and Living the New Normal (see section 5.9).

### **5.2     Analysis structure, themes and selection of extracts**

Utilising the IPA quality evaluation guide designed by Smith (2010b), the above themes are reflective of my interpretation and understanding of couples' lived experience of dementia and its impact on couplehood. Whilst acknowledging that each participant had a unique experience and world view, it is my belief that the themes identified reflected the couples' shared experiences both as individuals and as part of a couple, whilst also recognising the variations within each theme.

When deciding how to present my data, I referred to Smith et al. (2009) and Willig (2001), and chose the 'theme within a case' (Smith, 2009: p 109) approach. This was in order to present each theme sequentially as they appeared in my master table, with individual

cases presented within each theme. Master themes are displayed in turn and will begin with a brief overview of the theme before discussing in-depth how the participants have contributed to this theme. I have aimed to produce a coherent narrative of the shared as well as the particular aspects of the lived experience of participants alongside my interpretation of participants' meaning making. This is in order to focus on the meaning and importance of themes as determined by the couples; the focus will remain on the experiences of dementia and couplehood and CST.

Whilst the themes have been developed through a process of inductive data analysis, it is important to note that not all couples discussed all the concepts identified and as such, the findings do not represent a universally shared view or experience of the impact of dementia on couplehood. This is discussed throughout.

Master themes have been divided into sections which present a comprehensive analysis and interpretation which reveals theoretical and psychological concepts relevant to the research question. Each section contains a master theme which has been divided into sub-themes, highlighting dimensions of each theme. Sub-ordinate themes have been identified and are evidenced by direct quotations from the participants. Some sub-themes were mainly confined to either the partner with dementia accounts or the care partner. For example, when discussing the style and structure of the CST course, this tended to be from spouse with dementia who attended the course. This resulted in data relevant to this sub-theme occurring multiple times in those participants' accounts, and rarely in the care partner accounts. The sub-themes demonstrated either notable temporal change or concepts of continuity, which are also discussed in the analysis. Changes in an individual's attitude, knowledge or functioning from the pre and post CST

interviews are woven into master themes. For example, if an individual with dementia had deteriorated in a certain area, this is highlighted within the relevant sub-theme.

Included in the analysis is my own hermeneutic discussion, which encompasses the idiographic and phenomenological principles of IPA (See Section 4.8). It is also worth noting that throughout the analysis and resulting emergence of themes, there was considerable overlap between the impact of dementia on the couples' relationship and the impact of the couples' relationship on dementia, meaning that couples experienced changes to their individual selves as a result of dementia and changes to their relationships as a result of dementia. The common sentiment shared by the couples is that dementia impacts on an individual's way of being throughout everyday life.

While all identifiable information has been changed, it is anticipated that the application of pseudonyms will help bring authenticity to participants' accounts and support the reader to be able to step into their experiences.

Direct quotations from the interviews are used throughout the chapter to demonstrate to the reader how analysis and interpretations were reached. Quotations were chosen which best reflected the concepts being discussed and so demonstrated prevalence and variability across the data set (Smith et al., 2009). Extracts were selected as being illustrative of a particular theme or sub-theme, or because they provided an opportunity for a rich analysis. Though quotations are presented separately, there was interrelation between themes and sub-themes. Concepts such as the impact of dementia occurred in multiple subordinate themes and are therefore addressed where appropriate in sub-themes as well as in the general analysis. In order to illuminate perceptions of couplehood, the spouse with dementia and their care partner are analysed together as one unit where possible. Additionally, some extracts were equally relevant to more than

one sub-theme. Where this is the case, extracts which provided the most interesting and informative analysis were used. This also aided, where appropriate, an equal representation of all participants. Additionally, some experiences or memorable moments were expressed by participants with such strength of emotion that they were felt to be important for the analysis even if these views were not expressed by the majority of participants. These crucial moments often provided important perspectives on the experience of dementia and its impact on sense of couplehood, and are identified where appropriate within the analysis (Smith et al., 2009). In order to add depth and breadth of analysis, contradictory or polarised views which were of interest as well as similar views were also included, as suggested by Smith et al. (2009). These diverse extracts helped to illuminate the 'convergent and divergent, commonality and individuality' (Smith et al., 2009: p 107) aspects of participants' experiences.

### **5.3 Transcript guide**

Any text within brackets ( ) denotes comments from the author for clarification purposes, for example (participant laughs). Additionally, a row of five dots (.....) indicates where some text has been omitted, such as where a pertinent quote has been extracted from a long, detailed commentary without impacting on the context and meaning of the original text. Three dots in a row (...) indicate where the participant has paused during their commentary. This aids the readability of the results section and ensures continuity.

Extracts are denoted with the participants' pseudonym and interview number as well as the page and line number from the transcript. For example, Richard (1: 2 138-144) refers to Richard's first interview, page 2, lines 138-144. Longer extracts appear in italics within apostrophes, while shorter extracts used within the sentence structure are written as

continuous italic text. To aid the flow of the chapter, each participant is denoted as (SWD), meaning spouse with dementia or (CP), meaning care partner.

The following section provides the reader with an overview of the four couples as well as a summary of their life history and experiences in the context of the research questions.

## **5.4 Participant biographies**

The following biographies were composed from information provided by participants during the interviews. In order to preserve anonymity, each participant has been assigned a pseudonym, and certain demographic details have been altered or omitted.

### **5.4.1 Richard and Harlee**

Richard and Harlee have been married for 56 years. Harlee has a diagnosis of a mixed dementia (Alzheimer's Disease plus vascular dementia). Harlee worked as a university lecturer and has travelled the world with her studies. Her husband Richard has been registered deaf since contracting meningitis as a child. He lip reads and has various hearing devices. He describes himself as having Obsessive Compulsive Disorder (OCD). They met at university when they were in their early 20s; Harlee described how Richard would cycle 15 miles each day to see her. When discussing their relationship, Harlee stated that *"quite a lot of people said oh I wouldn't marry someone who's deaf well I said well I fell in love with him"*. The couple were unable to have children of their own and adopted a son who died suddenly in his early 40s. He was married, and they have two grandchildren. Their daughter-in-law has since remarried, and they do not see the family as much as they would wish.

### 5.4.2 John and Gwen

John and Gwen have been married for 49 years. Gwen was diagnosed with vascular dementia approximately one year before the interviews. After a fall in the kitchen, she sustained a blood clot on her brain, later followed by a blockage in her bowel which meant she was in hospital for approximately eight months. During her admission, Gwen was screened for dementia, and was later diagnosed at the local memory clinic. She has also had four mild strokes since being diagnosed with dementia. Much of John and Gwen's retirement has been dominated by hospital visits due to Gwen's ill health. Gwen also had polio as a child, which requires her leg to be strapped up daily. The couple met through friends at the local dance evenings. They "*just knew they were meant to be together*" and courted for four years before marrying. John was a sales manager, and the couple lived abroad for many years. Gwen had various office jobs, but mainly stayed at home to look after their children. They have two daughters and three grandchildren, and their family all live locally.

### 5.4.3 Elliot and Liv

Liv and Elliot have been married for 55 years. Elliot has a diagnosis of Alzheimer's Disease. They met when they were children, after Elliot was evacuated to Liv's village during the war and met again in their 20s where "*the rest as they say is history*". Elliot worked as a technical translator and continued to work into his late 70s. Liv worked as a primary school teacher. Elliot had a stroke about four years ago and had recovered from cancer some 10 years ago. Most recently, Liv had an accident where she fell down the stairs and sustained a severe fracture to her leg which required several operations. They have three children and four grandchildren. They recently moved from their home town to be closer to one of their children, and the move has been a source of ongoing stress for

them. Liv recently lost her brother and a cousin, who had both died suddenly and unexpectedly.

#### **5.4.4 Robert and Alex**

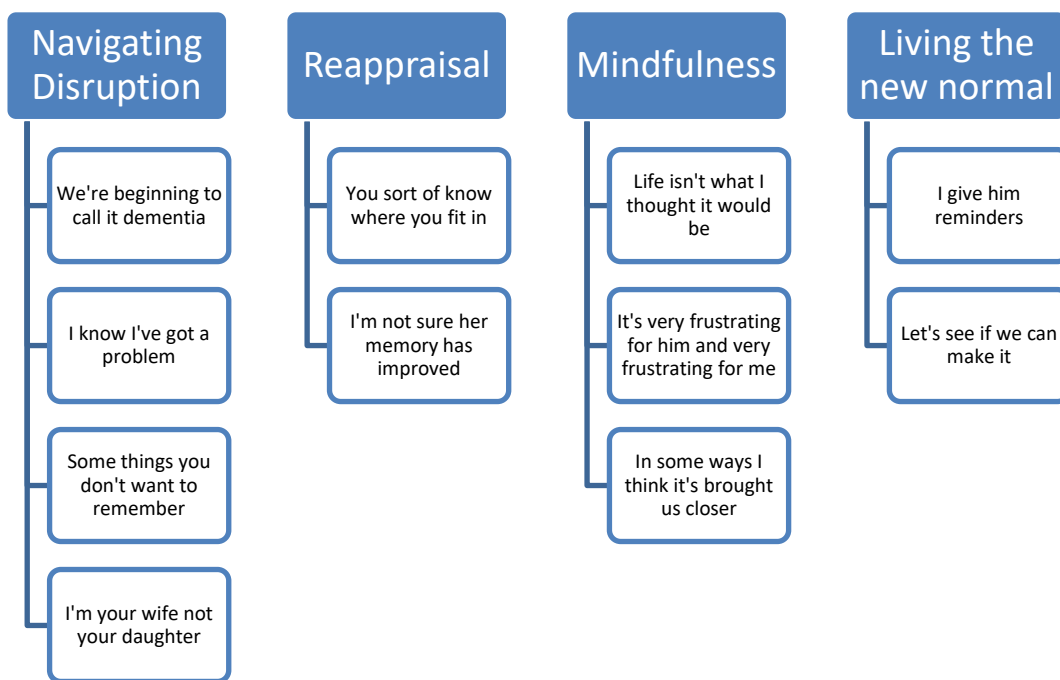
Robert and Alex have been married for 47 years. They met through mutual friends and have enjoyed working around the country. Both describe themselves as '*very proud northerners*'. Robert has mixed dementia. Robert had experienced multiple childhood illness and accidents. He reported that he was from a deprived background and that this drove him to a career helping others. Robert worked as a residential social worker and later as a university lecturer on a social work course. Alex was a social worker at an adoption agency and retired in her 50s due to Parkinson's Disease. Robert is her full-time carer, despite his dementia. They have one daughter and two grandchildren.

### **5.5 Results**

Data is presented in accordance to the figure below. Presenting the data in this way reflected the participants' passage from diagnosis to their current situation and helps the reader gain a sense of all of the couples' journey. Organising the themes in this way also contributed to uncovering new areas within dementia research which could be appropriate for further investigation in the future.

Four master themes and eleven sub-themes emerged from the data and are shown in Figure 5 below.

Figure 5: Master table of themes and subthemes



## 5.6 Master Theme 1: Navigating Disruption

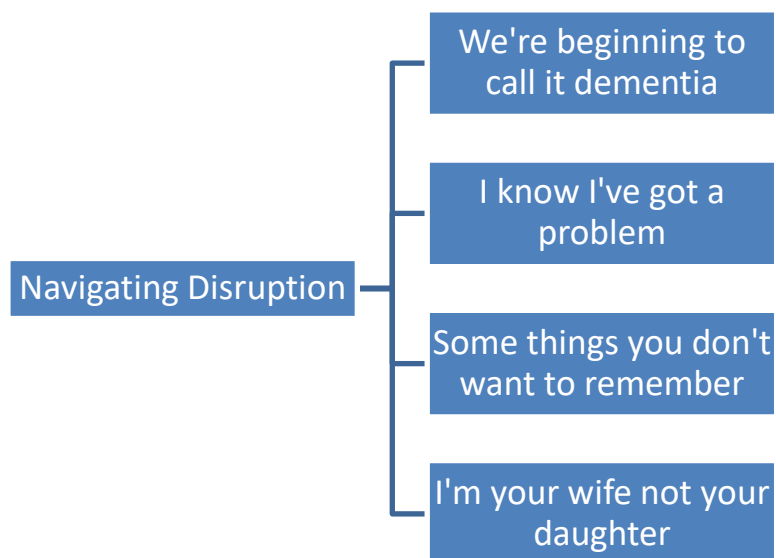
*Interviewer: "Does that help"?*

*Richard: "Yes, to give it a name yes it is yes yes I think it does yes..."*

This first master theme revealed the couples awareness of a gradual onset of cognitive decline which couldn't be explained by the anticipated ageing process alongside their thoughts, feelings and understanding of dementia. In many ways, this theme marked the beginning of each participant's 'story' where they acknowledged the presence of dementia in their lives. The theme also represents the sense of stages that couples traverse in their experience of dementia. It also highlighted the couples' desire to talk about their experience of receiving a diagnosis, the meaning and impact it had on them while also providing some contextual information about their current understanding of dementia and how they cope with this as a couple.

This master theme is divided into four sub-themes which are presented in figure 6 below.

Figure 6: Master Theme 1: Navigating Disruption



#### 5.6.1 Sub-theme 1: We're beginning to call it dementia

This sub-theme reflected the couples' thoughts and feelings about dementia as an illness. As all couples had been living with dementia for several years, I had assumed that the process of adjustment to that diagnosis had been reached; in fact, adjustment to this change was ongoing. Most of the couples described dementia as a disruption to their lives which had an impact on their relationship; they also offered a range of individual perspectives on dementia. While the onset of memory problems was different between couples, they all consistently reported the impact it had on their day to day lives.

Harlee (SWD) (1:17 94) *"oh I mean I do forget things on a regular basis and I don't like that"*

Richard (CP) (1:7 128-129) *"she does get confused and she does do things incorrectly because that generates a bit of stress and I tend to avoid it by doing it myself"*

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Gwen (SWD) (1:10 193-196) *"I can't cope with new things and I can't read a book anymore... I can't remember... what and... when I read the paper...I read the paper everyday the Telegraph but I don't take it all in... I don't take things in"*

John (CP) (1:23 177-180) *"she can't do things and she has to rely on me...erm and if she can't go out and about like she used to and nobody pops in to see her then she sits and thinks about all the things she used to and now can't do and gets rather depressed about it but then the next day everything is alright again"*

The extract above by John demonstrates the loss and sadness experienced by Gwen as she mourns the things that she used to but can no longer do and Robert in the extract below demonstrates his sense of frustration. Most of the couples reported a range of emotions in response to the impact of dementia.

Robert (SWD) (2:10 189-190) *"part of my memory problems is that I don't make the connections that I would normally make... it's frustrating"*

Alex (CP) (1:15 117-120) *"Yes you notice changes... there again in his memory... the form that we had to fill in... I was asked to fill in... he was asked to fill in... didn't really measure the... the things we'd noticed or had bothered us the most... like not being able to remember when he was going to an appointment"*

In the extract above, Alex makes a valid point that changes to memory may present in different ways and what may be important for one couple may not be important for

another. This suggests a conflict between the medicalised focus of diagnosis and symptoms, and the actual lived experience of dementia in their daily lives. Couples reported their confusion around this mismatch. For Alex and Robert, issues such as missing appointments were distressing and anxiety provoking; it was this consequence of dementia which '*bothered us most*' since they felt at a loss to know how to deal with such issues.

Two of the couples talked about receiving a diagnosis of mild cognitive impairment one to two years before a full diagnosis of dementia. These couples talked about their first awareness of memory loss which could not be explained by the expected ageing process. For these couples, the pre-diagnosis was presented as a forewarning that their spouse was likely to develop dementia. However in reality the couples were often left in the dark about what a mild cognitive impairment actually was or the likely consequence of it. This resulted in a period of uncertainty about actual cognitive changes and what it meant for the couple. For example, Alex struggled to see the difference between a mild cognitive impairment and dementia in terms of the impact on the couple's lives and suggested that memory loss is memory loss whichever category it falls into. Understanding the boundary between mild cognitive impairment and dementia was also apparent in other couples' narratives as again they had some difficulty understanding what, in real terms, the difference was between these two diagnoses.

Alex (CP) (1:1 18-20) "*..... had an actual diagnosis of mild cognitive impairment... that in a way we were still looking at it from the point of view... just putting a label on... on a degree of memory loss... and we didn't see... we didn't see it as a separate... diagnosis*"

When asked to describe his reaction to Harlee's diagnosis, Richard spoke about the relief they both felt following Harlee's full diagnosis as this explained her worsening memory and validated Harlee's increasing feelings of fear and distress.

*Richard (CP) (1:1 16-22) "so erm yes I think it was a relief really to have the diagnosis so that erm you know she she was wondering what was happening to her erm and she got very distressed by it and she frequently uses a term going doolally which I discourage very much it's not a very good, it's very negative I don't like it and I I say no you know there's no such thing really you're quite good you know you do have memory problems erm erm and we we're beginning to call it dementia yes"*

This was a significant statement for Richard as it clarified his feelings about dementia and demonstrated that being able to put a name to the illness helped restore a sense of control over the disease in a way that was not replicated in the other care partner's narratives. Richard indicated that prior to the diagnosis Harlee was already questioning her sanity and can now be reassured that it is the dementia that is causing the symptoms. This also indicated a distancing of self from the diagnosis – that the diagnosis is separate and therefore not a part of the couple. Richard acknowledges Harlee's memory loss and states that the couple can talk about dementia. Throughout their separate interviews, Harlee and Richard presented as having an open and trusting relationship which was now starting to become strained as a result of Harlee's illness.

Richard's account was echoed by Harlee, who commented on how frightening and daunting it is to lose your memory. There was a sense of bereavement and loss throughout her narrative, which was reflected in the accounts of all the couples. Harlee's

symptoms are real and frightening, whereas Richard found it harder to fully imagine what life was now like for his wife.

Alex found that getting a full diagnosis for Robert was important as it opened doors for different kinds of support, such as access to memory medication, which again reflected the struggle for couples to cope with memory loss when in limbo between having MCI and dementia.

*Alex (CP) (1:7 125-126) "so erm... that... that dementia... diagnosis seemed to... seemed to... move him into the category of being able to receive... medication"*

Spouses with dementia demonstrated that they were able to assimilate how dementia was likely to progress whilst also acknowledging fear and uncertainty as a result of the presenting symptoms as well as some awareness of the deteriorating nature of the illness.

*Gwen (SWD) (1:1:2-4) "when I was told I had dementia erm just before Christmas I did take it badly because I'd been so poorly and I've got a lot of problems now erm and I did find it very very difficult so erm and I've got used to it now"*

*Robert (SWD) (1:32 294-295) "...it's it's I find myself in a funny position because sometimes I'm not quite sure what...who I am"*

Harlee (SWD) (1:12 12-15) *“well erm I had episodes where I have... people have given me information and then I’ve completely forgotten that they gave me information that sort of thing you know real blanks in the memory, that’s latterly but it’s really scary because I think it’s gone, where’s it gone”*

The repeat of the word gone in the extract above also echoed the ever present awareness of the lessening of abilities and the impact on Harlee. Throughout the interviews there was also a sense that the world was shrinking around the respondents and that treasured skills were vanishing but also irreplaceable. These types of statements were common across the transcripts; spouses with dementia trying to understand the processes behind their memory lapses by reporting that their mind would ‘go blank’. There was a sense that this unpredictability made it more difficult to come to terms with dementia but also made it harder to define what was happening. It was evident that memory lapses were increasing for the spouse with dementia, and by the second interviews, Harlee, Gwen and Elliot all declared that *‘it’s got a bit worse’*.

Harlee (SWD) (2:1 18-19) *“I think its gradually getting a bit worse... I often have to say to Richard I’m sorry I’m a bit confused... (laughs)... yes”*

Gwen (SWD) (2:3 80) *“yes... I’m just wasting time because it’s got worse”*

Elliot (SWD) (2:6 122) *“well I... no because I’m quite well aware that my very short-term memory is not good”*

This was also verified by all the care partners, who recognised notable cognitive changes, even over the relatively short period of the 14-week CST course.

John (CP) (2:24 51-52) *“she does tend to get more flustered more frequently now and everything is down to my brain”*

Richard (CP) (2:20 92-95) *“she she has become more... I think more forgetful of late... I’m aware that it is progressive... its erm she... I think she knows what’s happening to her and it’s a bit scary for her.....”*

In the statement above, Richard hints that Harlee’s insight into her diagnosis is now more distressing than the actual changes to her memory. He talks about his awareness of the progressive nature of dementia but there remained a degree of uncertainty in all of the couples’ accounts of how dementia was likely to develop and the implications this may have on the couple unit. The quotes below from care partners Alex and Liv also demonstrated other subtle changes including a reduction of motivation and confidence of their spouse.

Alex (CP) (2:5 82) *“I think he’s doing lesser tasks automatically”*

Liv (CP) (2:24 148) *“oh yes... I think he is... that’s why he’s losing confidence... he’s quite nervous”*

In contrast to the other participants, Elliot had no desire to acknowledge the onset of dementia and throughout the interviews made pains to minimise and downplay any

potential impact of the disease on his life or that of his wife, Liv. For Elliot, the word dementia is unmentionable. This was interpreted as a self-preserving coping strategy and, although he acknowledged some memory problems, he would not name dementia, preferring to call it '*my condition*'. Again this represents Elliot trying to separate and distance the illness from a sense of self as having '*a condition*'. Throughout the interviews, Elliot maintained a steadfast refusal to acknowledge dementia, almost as if saying the word out loud would make it more real. When talking about why he had been invited to the CST course, Elliot laughed, again demonstrating a strategy to divert attention away from talking about his memory. This strategy was evident at times in other individuals' accounts and is discussed again further in the chapter.

Elliot SWD) (1:2 33-34) *"er... and that's why I've diagnosed with (taps his folder) whatever the problem is and asked to attend the cognitive stimulation therapy (laugh) so I assume there must have been things that I... I can't recall now but I'm yeah normal activity of life I am coping perfectly well"*

In order to be certain of Elliot's capacity and willingness to continue with the interviews (see section 4.14.1 for a discussion on capacity), I found myself checking his understanding of the interview but found that Elliot was aware of his diagnosis and happy to take part in the research.

This strategy of denial was more difficult for Liv, who despite her awareness of the impact of dementia on their relationship appeared at times reluctant to be seen as being critical of Elliot. Throughout the interviews, Liv was seeking other reasons for the apparent changes in her husband.

Liv (CP) (1:18 28-32) *“really that was the start of it well that is what happened and er then I was noticing that he was not remembering things and that so... but we didn’t... it was all happening together so we just didn’t go back to our doctor but I was talking to our daughter who is very good and sensible and er (sighs) and she was saying you know we really ought to go to someone”*

Liv’s narrative implies that it was their daughter who urged the couple to go to the doctor. This almost absolves Liv of being responsible for seeking confirmation of Elliot’s memory problems, since the issue was taken out of her hands. However, that said, Liv and Elliot took some sense of self-ownership over dementia and identified their own methods to alleviate the disease.

Elliot (SWD) (1:8 143-146) *“but I do feel very fit we willing to do anything I can do... I do a lot of work in the house well to help of course... er so you know making beds, cleaning the place, gardening... well you name it... I’m not much of a cook so I don’t bother but er I can if I must”*

The extract above from Elliot is interesting as it provides some insight into the ways he was coping with dementia. Throughout his narrative he repeatedly spoke about being ‘fit’ and the list above, “making beds” is perhaps reminiscent of his army days. This sense of order and instruction was important for Elliot and was again reflected in all of the male spouses’ narratives. In some ways it reflects a metaphor for how the couples were facing dementia - similar to the ways in which a soldier may prepare to fight a battle. This may

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also reflect how the couples were arming themselves, battenning down and stoic in meeting the demands of their situation and circumstance.

Despite being aware of cognitive change, all the couples talked about varying levels of shock at receiving a confirmed diagnosis of dementia. While the care partner was able to express this, the spouse with dementia often suggested it was difficult to articulate the magnitude of the experience of memory loss, suggesting that it was outside the listener's experience. The extracts below from a spouse with dementia and another from a care partner reflected that for spouses there was no shared ground which would enable complete understanding for anyone.

Gwen (SWD) (1: 26 197-197) *"it's really shocked me how much it affected me... but what can you do... it's just one of those things"*

Alex further demonstrates this:

Alex (CP) (1: 4 72-73) *"yes... erm so I just had to sort of had to maintain a professional opinion on it... but it was not the same thing being in it"*

In the quote above Alex reveals a sense of conflict between being a care partner and her previous employment as a social worker with specialised experience of working with people in distress. She demonstrated how for her, the connected but confusing nature of these roles are intertwined as both roles say important things about her self identity. All of the couples expressed some sense of being able to transfer personal and professional life skills in order to meet the challenge of dementia.

Despite a confirmed diagnosis of dementia, there was some perplexity from the couples regarding memory symptoms, as the long-term memory of the individual with dementia mostly remained intact; a common feature of dementia. This led some to question the diagnosis itself, with Elliot saying *'as er my memory is extremely good going back'* and *'but my memories go back to the beginning of the war'*, leaving couples uncertain as to whether dementia affected memory or not. This was also reflected by Harlee who demonstrates her remaining skills and abilities; almost as if she believes these aspects of her activities won't be affected by dementia.

Harlee (SWD) (1:13 27-29) *"but I know I wasn't remembering things very well but in other areas I'm reasonably ok you know I go into the shops and I know what shops I'm going into and what I'm going to get"*

Despite varying levels of insight, most of the couples were able to take some relief from the explanation of dementia as responsible for short term memory loss. Couples expressed an emotional and intellectual response to diagnosis and there was a search for explanations within their experience of dementia. For instance, Liv described the trauma of moving home as having precipitated Elliot's worsening memory. Richard described *'the start of the problem'* as having been rooted in a distressing experience when Harlee was teaching abroad rather than the possibility that the incident may have revealed the onset of dementia. Perhaps more realistically, John described the onset of dementia as having been caused by Gwen's numerous strokes. These explanations appeared important to the couples in order to make sense of dementia. Alex and Robert, and to a lesser degree Elliot, demonstrated variable insight into dementia as an illness and also a variance of understanding. Throughout the interviews the couples showed clear insight to the symptoms and consequences of dementia on one level but also demonstrated that for them dementia was intangible and uncertain.

### 5.6.2 Sub-theme 2: I know I've got a problem

This sub-theme revolved around the couples' acknowledgment of and adaption to dementia. The couples reflected on dementia as a life changing experience and highlighted how the experience impacted on their own emotional wellbeing alongside that of the couple unit. During analysis of this theme, the couples demonstrated a growing awareness of dementia as something permanent and unyielding which was now subtly different from when they first acknowledged memory loss symptoms.

The theme also demonstrated that even after acknowledging dementia as a diagnosis the couples continued to experience variable levels of shock, which reduced over time but was replaced by other emotions. Despite having a confirmed diagnosis the couples continued to try to find meaning in their experiences. Finding a personal definition and understanding for dementia was also important for the couples. Richard provides an objective, medicalised account of his understanding of the different sub-types of the disease.

Richard (CP) (1:1 115-16): *"it's a mixed dementia what's it was most certainly erm to do with circulation erm but also possibly Alzheimer's as well"*

While Harlee, in contrast, did not use the word dementia, she was nonetheless able to frame the disease in terms of the impact on her ability to retain information. She appeared to have an almost passive acceptance of '*a problem*'. This was not a denial of dementia but more an unquestioning acknowledgement of its existence and a sense of helplessness towards its inevitable impact on both her and Richard. Throughout the interviews Harlee talked about how her dementia *"must drive Richard crazy"*

Harlee (SWD) (2:14 247-248 “..... *he’s very kind but it must be really annoying*”

Harlee (SWD) (1:12 4-5): “*I can’t remember exactly when it was but I I had saw it in writing so I know I’ve got a problem*”

Later in the interview Harlee indicates that what had started off as missing and forgotten information had turned into real gaps in her memory, resulting in a loss of connection to the world, causing her distress and anxiety.

Harlee (SWD) (2:2 23-24) “*yes... it’s really weird... I have to say sometimes... I don’t know what’s happening... you really don’t remember... hmmm*”

In contrast, the extract below from John, a care partner, uses a metaphor to explain his understanding of dementia. This non-medicalised perspective acknowledges how dementia is affecting Gwen’s processing of information. The excerpt suggests that, from John’s perspective, Gwen’s memory is slower and different rather than lost completely. He suggests that the memories are intact but are in the wrong order and the change from the singular “*she’ll be taking a long time*” to “*we tried that drawer*” suggests that he believes it takes a joint effort in which to retrieve these memories. There is no sense that John has any perception of the way in which dementia is likely to progress or affect their lives together.

John (CP) (1:18 65-69): “*so it it’s like a filing cabinet... all the files... the cabinets gone over and all the files have gone back in but they’re in different places and*

*she'll be taking a long time to go through all the files to try to find it... it's not in the drawer... we tried that drawer... which is why she'll appear to be very slow"*

Throughout the interviews, Gwen offered a more emotional response to dementia and the potential impact it may have on the couple. The phrasing of 'silly things' in the extract below suggests that Gwen feels foolish and lacking in common sense. She repeated throughout the interviews that she "should do better", as if the problem is down to the fact that she isn't trying hard enough.

Gwen (SWD) (1:11 202-203) *"that is dementia really... I'd forgotten anyway... I forgot how to... silly things..."*

Gwen later described how her dementia impacts on John

Gwen (SWD) (1:3 60-61) *"..... so John is with me all the time so he knows what's happening... I'm lucky to have a very good husband"*

In contrast, Robert and Alex had an entirely different explanation and understanding of dementia. Robert's memory difficulties were inextricably linked to his career as a social worker. Rather than seeing dementia as an illness with consequences for himself and Alex, he saw it as an extension of his professional life and something that needed to be understood and resolved. Similar to Alex, Robert also takes an academic stance on his situation by stating, "it's different for me because I've been on the other side if you like". The extract below also demonstrates his awareness that everyone is different and the

mind is complex. There is the sense that Robert is detached from his situation and is almost viewing it as an outsider.

Robert (SWD) (1:27 177-179): *"it's difficult because I can see... the pattern and... er... it's of interest to me... because I've always found... that when one's dealing with any mind... that we are so different... so complex"*

In contrast, Alex's understanding and assimilation of Robert's diagnosis revolved entirely around her discomfort throughout the assessment process. She quite justly pointed out *"I... I was .. (sigh) ... not very happy really erm because he had an appointment for one and a half hours and we didn't even get a drink"*.

The couples demonstrated varying responses to and understandings of dementia and had a variety of strategies to assimilate the diagnosis however there were some variance in and between the couples as can be seen from the extract below from Elliot, a spouse with dementia. This again demonstrates that the lived experience of dementia may be felt as a set of stages in which transition between acceptance and rejection of diagnosis was ever changing and ever shifting. The phrasing of 'weird' and 'odd' used throughout the interviews also suggests that the participants were still on a journey of understanding their experiences. Elliot's response, however, was markedly different to those of the other participants.

Elliot (SWD) (1:13 226-228) *“well I as I feel very fit er and having come through two very difficult periods in my life involving medical treatments I feel very fit and well er I think interested in just about everything”*

Again the multiple use of the word *‘fit’* throughout this extract and throughout his interviews indicated that Elliot saw dementia in terms of a physical illness that could be overcome through *“hard work and willpower”*. Liv also verified this and described Elliot as *‘determined’* to get better. The comment that Elliot remains interested in *‘just about everything’* again reinforced his need to minimise his limitations and perhaps reflected an important strategy to preserve his sense of self as both he and Liv were keen to record aspects of his character that have remained constant.

By the time of the post CST interviews, it became evident that individual understandings of dementia had not changed, but that couples’ experience of dementia was an ever-shifting presence in their lives. In his second interview, John continued to use a metaphor to describe Gwen’s dementia, while other care partners’ understanding of dementia also remained static.

John (CP) (2:24 62-65) *“..... and doesn’t remember them because her brain is saying... that’s not very important erm I won’t put it at the top of the memory box... I’ll just put it at the back somewhere”*

In this extract, John indicated that he believes Gwen doesn’t remember things because they are not important, rather than as a result of memory loss due to dementia. This quote demonstrates the coping strategies with which most of the couples negotiated the disruption of dementia as being both rooted in blame of the individual but also as a result of the disease.

Most of the extracts in this sub-theme demonstrated that dementia is a disruption to the couples' lives and to their sense of couplehood. This disruption revolved around changes to what the couples had expected from retirement and how the changing abilities of spouse with dementia impacted on them both. This disruption also highlighted the personal resources open to the couples and the modes and methods of explanations they employed to explain memory loss. There was also a sense of the unfairness of the situation and that understanding and assimilating dementia varied across the couples. The couples all acknowledged that dementia was worsening and that as time progressed, there was an increasing awareness of the reality of the impact of dementia on their relationships.

### **5.6.3 Sub-theme 3: Some things you don't want to remember**

The narrative of this sub-theme reflected couples' levels of acceptance and attempts to normalise dementia. Many of the couples indicated that they were accepting of dementia on one level but rejecting of it in many other ways. There was a continued search for the meaning of their experiences within the couples' narrative but also a resolute determination that life continues, albeit in a different way. These strategies resulted in a lessening of the impact of symptoms on everyday life, but also led to an increase of uncertainty in self.

Robert was almost dismissive of the impact of dementia, suggesting that what was lost wasn't worth remembering.

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Robert (SWD) (1:21 48-50) *"I know I've done it... sometimes... but it's gone... but that doesn't bother me... I'm not going to use that... very much again I mean what I've retained has won by repetition and and hard work"*

Alex also suggested that despite the difficulties of Robert's deteriorating memory, she did not see it as anything odd or concerning. The suggestion that it *'happens to all of us'* perhaps normalised the experience and suggested that she believes her own memory decline may be inevitable.

Alex (CP) (1:1 8-9) *"erm... no I can't... I can't really remember... I was aware that his memory was bad and I've looked at it er as something that happens to all of us"*

Much like Robert, Elliot normalised his worsening memory and suggested that he doesn't remember things because he doesn't want to, and that this wasn't a cause of concern or worry for him.

Elliot (SWD) (1:14 242-245) *"Yes it's a strange thing to happen really because you don't necessarily pick up on it straight away... you have to be examined by a medical...I don't know... what triggered it I don't know... some things you don't want to remember"*

Liv also normalised Elliot's dementia, saying: *"A lot of things you have to get used to..."* as if this is the same experience for every couple and that their situation is no different.

A sense of acceptance was more forced throughout Gwen's narrative, particularly when she spoke about coming to terms with the loss of driving and the loss of her sense of

independence. For Gwen, and in many ways all the spouses with dementia, the sense of being swept along by the increasing changes to their lives was apparent throughout the interviews. Gwen found that this sense of helplessness almost coerced her into having to accept her dementia.

Gwen (SWD) (1: 1 7-9) *“when they said we can’t let you drive I knew I had to give it up and that hurt too and so it was all around dementia that things weren’t really right with me so I just have to accept it”*

Later in the interview Gwen stated:

Gwen (SWD) (1:12 222-224) *“yes... I thought I’d had enough... I’ve had enough I can’t handle more as well... that’s how I took it but er... then you have to accept it... because you have no choice”*

The magnitude of loss for Gwen is apparent throughout her narrative. She felt that she had little choice or control over how dementia affected her and John’s lives. Gwen repeatedly spoke about having to *“get over it”* and that *“life goes on”*, almost as if having to convince herself of this during her interview.

The sense of rapid changes was also apparent for John. He also talked about acceptance, but this felt more regulated than for Gwen. The narrative below suggests that John has more control over whether he accepts the dementia or not. The statement *‘we just accept’* suggests that from his perspective, the couple have accepted the impact of change which has been negotiated between them, whereas Gwen’s narrative (*‘I have to accept it’*) suggests that her sense of acceptance has been more isolating and forced. This

also demonstrated that John continued to view himself as part of a couple, whereas Gwen had started to see herself and her dementia as separate from the couple.

John (CP) (1:21 117-120) *“erm so I had time to get used to it and adjust and I just accepted that things are never going to be quite the same erm there are certain things we are never going to be able to do again which I would like to do and she would like to do but we just accept we’re not going to be able to do it erm”*

Memory-related changes were apparent for all the couples, and there was a feeling that worsening memory was an enduring and omnipresent reminder of their limitations. For spouse with dementia the experience of ‘blanks’ in their memory highlighted that it was difficult to plan, or to anticipate how dementia was impacting and likely to impact on the couples. Being unable to recall information that was once familiar was distressing for those with dementia, and for their spouses, who often felt helpless and so unable to support and reassure their partners. The narratives also suggested that the couples felt a sense of empowerment over dementia if they were able to normalising memory loss. Promoting the existing abilities of the spouse with dementia was also important but even this strategy was at times fragile.

#### **5.6.4 Sub-theme 4: I’m your wife not your daughter**

Much of this sub-theme revolved around changes to the couples’ everyday lives. The gradual changing of roles within the relationship was evident across all the couples’ interviews. This mostly revolved around the care partner taking on more responsibility and embracing an increasingly leading role in everyday life. There was a sense that as

well as everyday household tasks, there was also a subtle shifting of roles and responsibilities as well as a loss of the relationships that the couples once knew. Alongside this were evident changes in the personality of the spouse with dementia, leading to more conflict in the relationship.

Richard discusses his increasing roles around the house.

Richard (CP) (1:8 158-164) *“well no I do the shopping and I do the washing because she has been known to erm (pause) to put dirty clothes back in drawers and cupboards believing that they’re clean and they haven’t been washed erm I (pause) so there is that and also erm (pause) erm no I think that’s it no she she does get confused about that”*

Within this quote, Richard acknowledged that he was doing more things for Harlee, but that he felt unsure of himself and what he should be doing. At one point in the interview, he asked me for verification that what he was doing was correct. This changing of roles was also confirmed by Harlee, who commented *“he does everything”* and suggested that Richard’s strategy for coping with her dementia is by taking over tasks around the home. There was a sense that Harlee passively accepted this change.

Harlee (SWD) 1:17 102-105) *“well because of forgetting I I there are certain things I don’t do now which isn’t good but he’s you know taken them on because he he feels that that’s the best way to cope with it but it’s difficult to talk in details because I I don’t remember erm lots of detailed examples of things anymore”*

Gwen also discussed John’s increasingly leading role in their life:

Gwen (SWD) (2: 8 166-167) *“he’s doing so much for me (cries) and I don’t do anything”*

The extracts above from Gwen demonstrated a feeling that was common across all the couples, that in addition to changing roles there was an increasing element of changes to the relationship dynamic itself, which warranted further exploration. Richard sums this up in the poignant extract below which demonstrated the sense in which he is being reframed away from the role of spouse and repositioned as a carer:

Richard (CP) (1:8 182-187) *“..... (pause) there have been occasions where she says erm I’m your wife not your daughter and that really hurts because what am I doing you know it’s it’s terrible thing for her to have to say so yes yes yes erm there are arguments but then but our relationship is such that we can recover from it and erm (pause) it’s the bad feeling doesn’t last”*

Richard’s quote is an apt example of the new roles that the partners are facing. Richard reported that he felt terrible for having to be reminded that, despite dementia, Harlee is still his wife; these alternating perspectives were difficult for him to navigate. Richard could acknowledge his dual role, but appeared uncertain of what his primary role is and whether he is a husband or a carer. Richard’s quote reflected all the couples’ ongoing struggle to find a balance in their relationships, as carers are unable to maintain both roles simultaneously. It was also apparent in this excerpt that despite the stresses and strains brought about by dementia, Richard and Harlee viewed their relationship as stable; they were both willing and able to *‘ride the storm’*. The bad feeling *‘doesn’t last’* and the couple’s relationship is such that they are able to tolerate and move on from arguments.

Richard later goes on to state:

Richard (CP) (1:6/7 121-126) *"I think er there are lots of things we do differently maybe I tend to take over and do too much and don't allow Harlee to do enough erm because erm I suppose it's quicker erm in in the morning I get up and take her some tea and and I get breakfast and and then I put all the tablets out which is a major job and erm I then she just comes and has that but I'm wondering whether I maybe should involve her a little bit more in in some of these tasks because it's not really very good for me to do everything. What do you think about that?"*

There is a sense within this extract that Richard recognised that he is taking over and becoming more of a carer than a husband. His uncertainty in his role was apparent as he looked to me for answers to this emotional dilemma. He later reported that he often tells Harlee *"you're very good,"* which suggests a subtle, paternal tone which became apparent throughout this couple's narrative.

It could be interpreted that Harlee had already begun to reposition herself into the role of a dependent. She was herself even childlike in her manner. Much of Harlee's narrative revolved around things she felt she *'should'* do. She likened her dementia journey to being back at school and *"being told off"* for *"not concentrating as I should"*. In the evocative statement below, we can see that she has begun to see Richard as her carer and is ambivalent about her feelings around this shift in roles.

Harlee: *"he's officially my carer"*

Interviewer: *how does that feel?*

Harlee: *"...weird"*

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Like many of the other spouses, Richard was now taking on more of a paternal role. This sense of shifting positions was a common feature of change across the couples' relationships.

Liv's narrative also presented the sense of a shifting dynamic:

*Liv (CP) (2: 23 132) "it is different and it's is tiring... yes... very it's made it more so for me"*

*Liv (CP) (1:23 173-176) "yes he is and he likes things just so and he doesn't give up because of course it was when he was in the forces you had to stand by your beds... all beautifully done... I always praise him for it because it's all beautifully done... did he say I've changed because of this?"*

The sense that Liv 'praises' Elliot suggests that there may have always been a child-parent dynamic in their relationship, but that this was becoming more acute for Liv. There is also a sense in which Liv has recognised the changes between herself and Elliot and has an internal struggle over whether she can accept these changes. She asked me whether Elliot had suggested that she has changed, reflecting her uncertainty in her role as a wife and perhaps indicating that deep down she realises the changes in herself but cannot bear to articulate or acknowledge them.

It was apparent throughout Robert and Alex's interviews that their relationship was already tense and strained, and that Robert's dementia and Alex's Parkinson's Disease were added burdens. Of all the couples, Robert and Alex stood out the most due to their apparently fractious relationship. However, while it appeared that this had always been

the style and level of their interactions with each other, Robert's dementia was now exacerbating this.

Alex (CP) (1: 7 137-140) *"well... this lack of memory... for people... really its erm... er... well I mean that happens he got very worked up over Christmas and I try to... it's very tiring and so not having... his hearing is worse... and his failure to understand the situation... he's got worse I can't tell which it is... he keeps saying what what what... and I don't know if he means what am I talking about"*

Robert (SWD) (1: 32 296-297) *"forty nine years married... we're managing to survive...we have our ups and downs... our difficulties"*

Alex (CP) (1: 11 223-224) *"perhaps his expectations of what I can do... are... not... oh... realistic... erm... and... but it's awful"*

The use of the words *'but it's awful'* suggest that for Alex, *'it'* represents both the dementia and their relationship, both of which are awful.

Carer partners described their spouse as having experienced a loss of confidence, commenting that their spouses were becoming more cautious of doing things, meaning they were compelled to take more of a leading role in the marriage.

John (CP) (16:17 24-28) *"..... lacking in confidence she was erm she'd never ask me barely anything... should I do this... can I do that but she wanted to be sure she didn't want to make mistakes... is it alright to do this... can I do that and that is*

*getting slowly better now erm but there's only two areas that I noticed that she's definitely worse now than before any of this happened"*

Liv (CP) (1:19 63-65) *"I think he knows now about where to go and but he will... he's lost confidence a bit and feels better if its written down I think or I've repeated it lots of times"*

Liv (CP) (2:22 121) *"well I do wonder sometimes... and he worries now (whispers) he's lost his confidence"*

In the excerpt above, Liv whispered '*he's lost his confidence*' almost as if she were unable to say it out loud. Her conspiratorial tone implied that she was able to talk to me, the researcher, about Elliot but felt unable to talk to others. This also reflected parts of most of the couple's narratives in that there was an increasing sense of isolation and loneliness with the marriage, despite being in the constant presence of their partner. This was often reflected by comments similar to Gwen's extract below; that the spouses with dementia did not feel that their partner fully understood them when discussing their worsening dementia.

Gwen (SWD) (2:3 63-66) *"you know... because I said to my husband... I've dementia... and he says how do you know how do you think your dementia is getting worse... it is difficult because you know erm it's a a erm a tiredness thing... and I think dementia they say people get tired... erm and sometimes I think it's a double whammy"*

It also became clear during the interviews that participants were continuously making an emotional adjustment to changes of role from partner to carer, or from spouse to being cared for.

John (CP) (1: 20 105-108) *“yes I mean we used to live separate lives... she did what she wanted... I did what I wanted erm without saying can I do this are you doing anything... like that we can just go and do it...”*

Alex (CP) (1:12 250-251) *“I have times I think this wretched thing... it’s... it’s spoiled our relationship... I’ve always put it under stress anyway”*

Again, in the extract above it is unclear whether *‘this wretched thing’* which is spoiling their relationship is Robert’s dementia or Alex’s Parkinson’s Disease.

Liv (CP) (1:21 103-105) *“well yes I do have to do that now and its tiring... I’m very tired... so I’m taking on the responsibility of both. If he goes to the shop I’m worrying about that”*

Liv stated that she took practical and emotional responsibility for both herself and her husband now. For the female care partners, taking on the practical roles within the marriage presented additional challenges as they indicated that this also reflected their husband’s vanishing masculinity – which in turn reflected on them as wives. This was most profound throughout Liv’s interviews with her concluding that dementia was *‘changing us both’*.

The reducing sense of reciprocity in the relationships was also a recurring theme, as Richard and John highlighted:

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John CP (2: 23 45-49) *"She never has... erm and I don't know whether it's her memory or whether she's getting more flustered trying to do two or three things at once but a couple of things have gone ooh two minutes over and I have have taken that out of the oven just now that sort of thing... but I don't know whether that's just doing less cooking or whether it's her memory getting worse"*

Richard (CP) (2: 20 92-97) *"she didn't use to be like that... she would remind me of things that needed to be done and sort of keep me up on the mark but erm"*

(sigh) ....

Richard also demonstrated in the extract above the ways in which the interdependence of the couples was also diminishing. Harlee as someone who would '*remind me*' reflects the multiple sense of loss that the couples were experiencing as declining abilities coupled with the sense of the spouse as someone who was starting to fade was also movingly evident throughout all of the narratives. This point was also demonstrated by Richard who commented that loss of confidence resulted in Harlee becoming more cautious, constantly double checking herself and "*becoming a bit more... well... like me*", referring to his OCD and indicating the emergence of unfamiliar personality traits that Harlee was now displaying.

Following on from changes to role, there was a sense of increased responsibility for the care partner spouse. This revolved around being more vigilant towards the safety of spouse, but also having a responsibility to remain healthy and well for as long as possible in order to carry on caring for their spouse. The sense of worry and impending doom was like a dark cloud hanging above most of the couples' narratives, without participants

being able to fully articulate their specific worries. When asked about her thoughts on dementia, the comment by Gwen below was common throughout the interviews.

Gwen (SWD) (2: 7 152) *"..... I don't know but its difficult ... I don't think ... I'm not coping"*

As discussed above, this master theme of Navigating Disruption demonstrated the differing ways in which all the couples offered a range of perspectives on dementia and its consequences on their relationship. Most crucially, changes to roles and identity impacted considerably on each individual's sense of couplehood, with care partners becoming increasingly responsible for the safety and well-being of their spouse. In contrast, there was a sense that spouses with dementia were repositioning themselves into the role of being cared for as a loss of confidence impacted on their willingness and ability to undertake previously taken for granted roles within the relationship. All but one of the participants described the onset of dementia as a linear story, starting with an awareness of increasing memory problems and leading to a diagnosis which resulted in ongoing changes to their marital relationship. Since none of the couples had a new diagnosis, there was a sense that they had already come to terms with situation. However, adjustment to the impact of dementia was an ongoing process. The couples were able to recognise the onset of memory problems, and there were individual differences in their responses to the diagnosis. Some of the couples spoke about being given a diagnosis of a mild cognitive impairment before moving into the category of dementia, and outlined a feeling of confusion around these different terms.

There was some variation in how each couple understood and explained dementia, with some couples describing a sense of relief that it was the dementia which was responsible

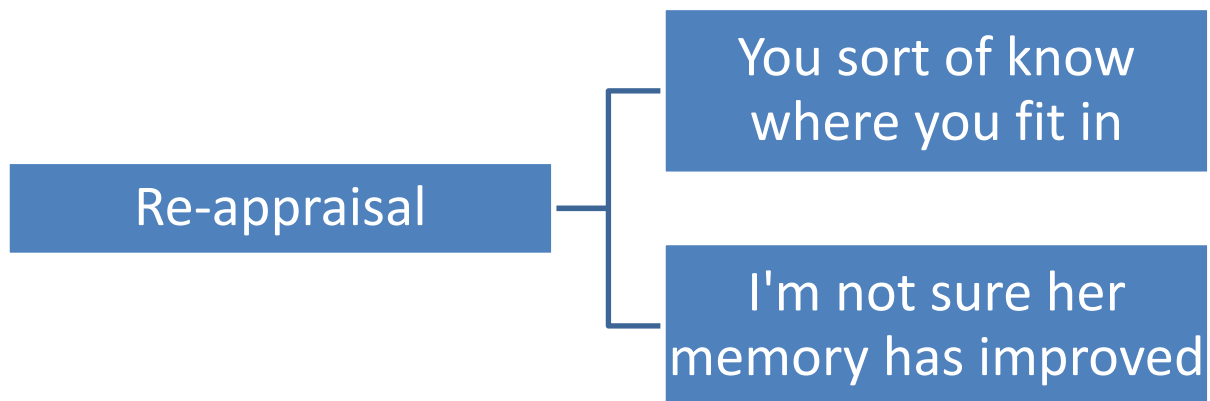
for the changes to their relationship. However, some care partners continued to assign some level of blame to their spouse with dementia.

## 5.7 Master Theme 2: Re-appraisal

This master theme reflects all of the couples' thoughts and feelings on the CST course which I have interpreted as 'reappraisal' as it was at this point that the couples were re-evaluating aspects of their relationship. The couples discussed CST and their experiences of either being in the group or of having a partner attend the group. The theme revealed the couples' changing perspectives and awareness of the extent to which dementia was impacting on their lives and would continue to impact on their relationships and their sense of couplehood.

This master theme is divided into two sub-themes which are presented in figure below.

Figure 7: Master Theme 2: Re-appraisal



### 5.7.1 Sub-theme 1: You sort of know where you fit in

Data from nearly all the couples were included in this sub-theme, which reflected participants' thoughts on CST and highlighted that it was an important experience as it enabled attendees to frame and plot their abilities in relation to others in the group.

Harlee, Gwen and Robert all reported that they had benefited from being with others who were *"in the same boat"*, and that they found the experience pleasurable. Additionally, all CST participants reported a sense of acceptance within the group which was important for their self-esteem and wellbeing. Issues of comparison with and contrast to others were also important. Although this was mainly relevant for the spouses who attended the group, care partners were also able to comment on the impact of CST as they saw changes in their spouses.

Harlee (SWD) (2:10 179-180) *"well I think it always (pause) erm... you find other people in the same boat as you are... it's you don't think you're an oddity... you fit in somewhere and that's helpful... very helpful"*

Harlee (SWD) (2:5 42) *"you sort of know where you fit in"*

Gwen (SWD) (2:4 1) *"I thought it was very good erm it was a nice group"*

Robert (SWD) (2:9 150-151) *"but I enjoyed it and I enjoyed meeting the group of people that were in the same position to myself"*

John (CP) (2: 30 191-192) *"erm yes Gwen is a fairly black and white person... I am to some extent too... it's nice erm... it's nice to have something to measure yourself against"*

John perceived that for Gwen to be able to measure and compare herself with others was important for her. It could be interpreted that this was helpful for John as well, as this

experience had the potential to reassure him that Gwen's dementia was no worse than that of others in the group. His phrasing '*something to measure yourself against*' implies that he was also including himself in this statement and so was also able to compare himself as a care partner to other care partners. It is perhaps interesting to note that care partners lacked a comparison group, as they themselves do not attend the CST sessions but that being able to relate to others in the same position was important for the self-image of the individual as well as the self-image of the couple.

Similarly, Harlee reported the benefits of being with people who shared a common experience and feeling able to talk about her symptoms of dementia with others. This also resulted in Harlee and indeed the other CST participants feeling less isolated in their experiences. The opportunity that the CST afforded in being able to talk to others and share experiences was an important feature of the group; the group provided opportunities which may not have been available to individuals outside of that environment. CST participants demonstrated that they were able to talk to others in a group in ways that were different from talking to their spouse, which is a key finding of the research. This perhaps suggests that the content of the group was less important to the participants than the social aspects of the group and the sharing of experiences.

Harlee (SWD) (2:7 124-126) *"it gave me time to think about... the situation and you know what's happening to me... why I'm being (laugh)... you know... forgetful"*

Gwen (SWD) (2: 128-129) *"we very much felt that you know if you've got a problem you mentioned it and dealt with it"*

Harlee (SWD) (2:10 165-167) *“well really... you know when you’ve been with the same people for a while and doing similar sort of things... you sort of feel... this is where I belong... you’ve got a niche there... that’s always nice”*

Harlee found reassurance from the group that is perhaps different from the reassurance she gets from Richard. She has found herself a place and position which had been lost in dementia. Outside of the couple unit she is once again important and valued, and is not seen as a person with special needs, but a person in her own right in a place she belongs. This sense of belonging represents an emotional attachment to the group – *“this is where I belong”* because the group is safe and familiar, and there is no sense of being a burden to others. This was also reflected by Robert who found the group had a positive impact on his self-esteem.

Robert (SWD) (2:10 171-172) *“yes... I think the gains were meeting the challenge of being in a group with similar people which it doesn’t always happen”*

The CST group was also important in negating the stigmatising effects of dementia as the participants valued the company of others and was important for the participant’s sense of self-esteem and wellbeing and this was reflected in participating spouse as well as their care partner as demonstrated in the excerpt below. John appears to take pride in the fact that Gwen can compare herself to the rest of the group.

John (CP) (2: 25 73) *“the one thing she said on occasion was I’m no better and no worse than any of the others there”*

John (CP) (2:29 171-173) “..... and it can be of quite a benefit because all the people who are there are the same as you... erm you’re not the odd one out.....”

However, John also noted that the focus on dementia was acting as a reminder of Gwen’s deteriorating capabilities, which was not always a positive experience for the couple.

Later in the interview, John stated that Gwen was more reluctant to do things “*because I have dementia*”, and that she was more likely to ascribe all the negative things in her life to dementia. John remarked that Gwen was preoccupied and over focused on dementia and viewed it as the root of all her sadness.

John (CP) (2: 25 85-88) “*erm now its two or three times oh it’s my memory but whether it’s because it’s got worse or whether it’s because of the course that’s reminder her that she’s got it because oh I’m on a course that’s why I’m on the course I’ve got a memory problem I don’t know*”

This feeling was echoed by Elliot in the quote below, where he reported that he found the limitations of the other participants “*disturbing*”. However, there was no sense in which Elliot considered that these limitations may happen to him. During his narrative, he distanced himself from others in the group by saying “*that was their problem*”. This was an important strategy for him as it helped maintain his sense of self-worth and wellbeing.

Elliot (SWD) (2:6 110-111) “..... well because... *disturbing... because it it... it er made it clear that... that was the problem... that was... that was their problem*”

Being in the group gave Robert a role and identity which may have been missing in his life. He saw the group as an extension to his past role as a social worker. Robert made several references to the other participants and the role of the group facilitators as being key to his enjoyment of the group environment.

Robert (SWD) (2:8 143-144) *"I think for me... there was a positive that I was able to sit and watch someone do the same style course"*

Harlee (SWD) (2:3 55) *"it was a nice group of people... I felt quite... at home with them"*

Participants also commented on the non-judgemental, safe environment of the group setting.

Robert (2:9 156-159) *"I think in a way that was the positive because people weren't threatened and there was a variety of people with different needs and some quite clearly had not been in a group like that before"*

Robert (SWD) (2:9 156-157) *"I was quite impressed with what I was going to say gentleness and I think in a way that was positive....."*

Gwen (SWD) (2:1 17-18) *"yes... erm but the actual course was very good and we enjoyed it erm and they said we were good"* (laugh).

The comment that *“they said we were good”* again reflected the sense of *us* (participants with dementia) and *them* (group facilitators), enhancing a sense of camaraderie and shared experience among those living with dementia. The phrase suggests that Gwen felt affirmed by people who she respected and trusted, and that this was beneficial for her sense of wellbeing. This perspective was shared, as the group was perceived to be a safe environment for participants to be themselves, as can be seen from the extracts below.

Harlee (SWD) (2:9 149-152) *“you just felt quite comfortable once you got to know people and you felt comfortable with them... and erm people were speaking quite freely about things... that were important to them... you know it’s good... to be free with one another”*

Gwen (SWD) (2:7 130-131) *“and it’s not your mind you’re getting the word wrong you know what you want to say... it’s just the wrong word coming out... I asked them and they said oh... that’s common”*

Gwen found the group useful, as she was able to check worrying symptoms and be given reassurances that what she was experiencing was *“common”*. This opportunity to check symptoms was important, since John’s commentary above indicated that he doesn’t feel that all of Gwen’s symptoms are due to dementia.

The CST group provided Robert with the opportunity to feel valued and important. He took his role as a group member seriously, saying *“I offered to write them a report”*. This perhaps reflected his internal struggle with attending the group while also wanting to run the group.

Robert (SWD) (2:9 146-149) *"I had tried to be a positive member of the group and I remember to keep myself... I am an elderly male which was challenging at times"*

Robert (SWD) (2:9 150-152) *"but I enjoyed it and I enjoyed meeting the group of people that were in the same position to myself... the good part was that it was varied as the students I had"*

This sense of role and identity was also recognised by Alex, who reported that the group was good for Robert's morale.

Alex (CP) (2:1 1-2) *"it went very well... he enjoyed it and he erm because he used to run a group and so he was very good... it was very good and it quite perked him up"*

Robert, along with Harlee, Gwen and to a lesser degree Elliot, commented on the style and structure of the group, which implied transposal of the implicit learning style which is central to CST. All of the participants, with the exception of Elliot reported feeling affirmed and reassured by the social structure of the group.

Robert (SWD) (2:10 174-176) *"let's say it was food erm... and that sort of exercise made me think in a way that I normally wouldn't... and that sort of thinking was positive knowing that I'd lost a lot of my memory"*

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Gwen (SWD) (2: 2 22-23) *“well we had to use our brains... we had to think erm it was all about different things and at times we..... (trails off)”*

Harlee (SWD) (2:6 97-98) *“well I suppose it was like little quizzes in a way but you know... it keeps our mind engaged”*

Elliot (SWD) (2:14 4-5) *“it always followed the same pattern... I wonder if it had been different if they’d kept it as one subject”*

To a lesser degree, Elliot commented on the group activities despite feeling less sure about how they related to him.

Despite not attending the group themselves, the care partners also commented on the learning style that CST utilised and the opportunity the group provided for learning new information.

Alex (CP) (2:2 29) *“yes you need sharpening up... they said he made a point... they tried names and that”*

In contrast with the other CST attendees, Elliot struggled to understand why he was attending the course and couldn’t make any connections with the other group members. He reported feeling uncomfortable in the group because members didn’t interact with one another.

Elliot (SWD) (2:1 15-18) *"it was difficult to see how what there were doing related to my condition"*

He again uses the word *"my condition"* and this perhaps reflects another way in which he is able to distance himself from both dementia and also others with dementia. It was clear that Elliot did not feel much benefit from the group and was ambivalent about it throughout his interviews. However, his care partner Liv pointed out that he *"didn't not go"* and that despite his lack of enjoyment, he appeared willing to attend each week. The skill and gender mix in the group had a negative effect on Elliot, and he made several references to being one of only three males in the group.

Elliot (SWD) (2:7 135-136) *"I wouldn't say I enjoyed it... I met some interesting people and some very uninteresting people... but that's it... that's life I guess"*

Elliot (SWD) (2: 13 250-251) *"it's such a difficult situation to deal with isn't it... especially when you're dealing with people who are in various stages and that's I suppose the real problem... they can't cope with everyone... they can't cater for everybody I should say"*

During this quote Elliot describes *'various stages'* which may be reflects his awareness of transition and change.

Non-CST attending spouses Alex, Richard and John all reported that the CST group brought a sense of purpose, routine and wellbeing for their partners.

## Chapter 5

Alex (CP) (2: 1 8-10) *“I think it... it brought back when he was running a course and made him feel a bit better I think because you can end up feeling like a... I don't know... a body being moved about”*

Alex's reference above to *“a body being moved about”* is a powerful statement and indicated her sense of the stigmatising nature of dementia, that perhaps people with dementia are viewed with a reduced humanity, like an empty shell being moved and deposited without any thought to their choice or feelings. It also perhaps reflected the way that she believes people view her as a spouse of someone with dementia and indicates her changing sense of identity and possibly self worth.

When talking about the ongoing impact of the CST course, the care partners were more ambivalent about whether the group was beneficial or not and appeared to struggle to find positive examples of change. For care partner, the CST group may also have highlighted an awareness of the declining spontaneity of their partner to undertake tasks within the marriage.

John (CP) (2: 23 39-40) *“no I can't think (pause)... she's tried to do more things at home... cooking and she finds great difficulty in doing more than two things at once... erm”*

John also questioned Gwen's understanding of the CST course and that she had commented that she would keep her CST folder as a keep-sake to show her grandchildren. He commented on how the folders weren't really designed for this and that he was saddened by her misinterpretation of the folders. This also perhaps served to

remind him of her worsening cognitive skills and that she was becoming less sophisticated in her general understanding. This also perhaps reflected that care partners were aware of the ways in which integral parts of their spouse were disappearing and someone unfamiliar was emerging. Richard also demonstrated this where he had to reassure Harlee about the bus

Richard (CP) (2: 18 48-49) *“... but she’s she’s quite enthusiastic about going on Fridays and she’ll get up and be ready and if the ambulance man is a bit late in coming she get a bit agitated and she oh he hasn’t come yet do you think he’ll come”*

Richard’s extract above also highlighted a dilemma for the care partner who felt a sense of responsibility in making sure their spouse was ready on time to attend the course. Care partners reported that this could sometimes lead to tensions and stress in organising attendance for their partner.

Liv reported that from her perspective, the group was beneficial as it gave Elliot some company and stimulation. This also perhaps reflects Liv’s increased awareness that she was the major and perhaps only source of interaction and company for Elliot.

Liv (CP) (2: 18 27-29) *“but I was very pleased that he was going... for several reasons because I think as well as he doesn’t usually mix with... everyone else because... he’s usually a bit quiet... a quiet person”*

## Chapter 5

CST as a form of respite for and from spouses was also identified by both spouse with dementia and care partner and was perceived to be important on several levels. For care partners, CST provided opportunity to engage in much needed leisure and hobby activities while knowing that their spouse was safe. For spouse with dementia it provided a sense of respite from being a burden to their partner and thereby important for their sense of self and wellbeing.

Harlee (SWD) (2:11 193-195) *“well I knew I wasn’t sort of burdening him... I was taken in a vehicle with others in the group so Richard had his own time... which I thought was good... you feel a bit bad if you’re too demanding”*

The extract from Harlee above was also reflected in the other spouses with dementia and demonstrated the ways in which they were becoming less secure about their sense of self and instead felt a burden to their partners.

John (CP) (2: 32 234-235) *“..... because I thought I know exactly what time you’re going and exactly what time you’ll be back... it was... I can say... a good thing to have time for myself”*

The sense of engaging in something meaningful away from their spouse was also important to the CST attendee.

Gwen (SWD) (2:5 96) *“yes... I think now I realise that it was erm... I suppose it was another day filled”*

The final statement above by Gwen also indicated some uncertainty about the CST course in general and perhaps is more indicative of the couples shrinking world and the loss of spontaneity within their daily lives.

#### **5.7.2 Sub-theme 2: I'm not sure her memory has improved**

This sub-theme reflected the ongoing changes noted by all care partners; despite the positive effect of attending the CST group, all these participants noticed a global deterioration in their partners. All the care partners reported that there was no tangible cognitive change following the group. In contrast, they noticed worsening behaviour and mood related problems. Richard reported his disappointment that, *"I did expect there to be more emphasis on practical things"*, which reflected his hope at the beginning of the course that there would be a notable improvement by the end.

Richard (CP) (2: 19 67-69) *"no nothing unhelpful no no but erm (pause) I didn't feel it was in any negative... but just erm... nothing to get excited about"* (laugh)

Richard (CP) (2: 16 11-15) *"I think that (pause) (sigh) I think that I expected erm there to be an improvement in Harlee's practical confidence from day to day erm... maybe I didn't fully understand the you know what the course was all about but I expected there to be more erm more noticeable outcome"*

Liv (CP) (2:22 115-116) *"I would think er... as the same as before he started... I think I have to say I can't say that it's really been a big difference"*

This was somewhat supported by John, who noticed no positive changes to Gwen's memory, but did report some proxy benefits from Gwen attending the group.

John (CP) (2: 27 161-162) *"erm I'm not sure her memory has improved... oh well I suppose if Gwen had not been going on the course I wouldn't have looked up odd things on the internet"*

By the time of the second interviews, the effect of memory loss had become a common and expected feature of participants' dementia. However, changes in behaviour were viewed as a new and often shocking consequence of dementia that none of the care partners had anticipated. Richard demonstrated in the extract the difficulty he had of reconciling how Harlee *"never used to be like that"*. It was difficult to pinpoint from the extract whether it is the changes to Harlee's memory that he is referring to or the fact that she was embarrassed about the changes to her memory. However what he does seem to be indicating is a facet to her character which was previously unknown to him.

Richard (CP) (2:20 92-95) *"I think she knows what's happening to her and it's a bit scary for her... and I think she's a bit embarrassed because she forgets things because she never used to be like that"*

John (CP) (2: 26 99-100) *"and this was in bed this morning and I just thought oh she's got a cold and she was sitting up sniffing and sitting here crying because she was getting a bit depressed"*

Liv (CP) (2:22 124) *"he sleeps so much more now"*

However, despite the lack of notable improvement in cognition, three of the couples reported improvement in other domains, specifically an increase in spontaneous interactions between spouses. The sense that CST provided the attendees with a topic of conversation was meaningful; this increase in interactions was important for both members of the couple.

John (CP) (2: 22 4-7) *“some evenings she would talk more about what went on that day than others... erm... if whatever the topic was, if she was interested in it then... she’d talk more about it if it was something that hadn’t particularly interested her then she wouldn’t talk much about it but erm”*

Gwen (SWD) (2:5 92-94) *“..yes I think it did at the time... erm that’s something to think about... I came home and I could tell John what I could remember... what we discussed that day... erm it did I think it was... when it was going on... but now it’s stopped I miss it”*

Alex (CP) (2:8 9-10) *“on a couple of times I looked in the folder and found that sheet for that day and we had a little chat about it but on other days he was very resentful”*

Again, the extract above from Alex demonstrated the care partner’s uncertainty about how involved in CST they should be. Alex stated that she would look at Robert’s folder but this caused some friction between the couple as Robert. Some days they were able to talk about the group and other days he was resentful of Alex’s intrusion.

Alex (CP) (2:6 111) *"I think there isn't the facility to work more... but it would be good if it could... to talk about the day"*

The comment above by Alex about being able to talk about the day again reflects all of the couples' narratives that something was now missing in the relationship and there was an ever-present sense of further losses between the spouses. Communication between the couples improved during CST and this was very important to both spouses. They talked enthusiastically about the increased interaction and the importance of having something new to talk about.

A second topic within this sub-theme revolved around care partners having little or no concept of what their spouse was doing in the CST course. Richard highlighted this as he didn't know whether he should have been *"encouraging [Harlee] to do a bit of homework"*. He later stated:

Richard (CP) (2:1 77) *"but erm not really knowing what she was up to erm... because she didn't seem to want to talk about it... er... I wasn't able to do that"*

Alex (CP) (2:8 8) *"I think it was more that he just couldn't remember what he'd done that day"*

Liv (CP) (2: 19 29-50) *"I don't think there was anything that really stuck out that he'd say he wanted more of it ..."*

John (CP) (2:28 142-144) *“what I can gather erm... talking about something topical each week that’s happened either in the last couple of days or on going during the week”*

All care partners reported that they could not get an indication of what happened in the group from their spouse as they would generally ‘forget’ what they’d done in the group. This was endorsed by Harlee.

Harlee (SWD) (2:9 161) *“yes but sometimes the details gradually slip away a bit”*

Liv (SWD) (2: 18 17) *but (whispers) he couldn’t remember”*

Elliot also reported that he found it difficult to articulate what had happened in the group. However, despite not being able to recall specific details about course, all the CST participants were able to recall how the group made them feel. It was this feeling of general wellbeing that had more of a lasting effect, and which in turn impacted positively on the couples’ time together.

Robert (SWD) (2:8 136) *“it was enjoyable but also challenging to me because I was... just part of an ordinary group”*

Harlee (SWD) (2: 5 85) *“yes... I enjoyed it... It was worthwhile”*

Richard reported that attending the group gave Harlee confidence and enjoyment, and indeed all of the care partners noticed a subtle change in their partners’ motivation to be

up and ready on the CST day. It was also apparent from the couples' narrative that their confidence and enjoyment developed as participants began to feel more comfortable in the group.

Richard (SWD) (2: 18 47) *"..... but she was she was quite enthusiastic about going on Fridays and she would get up and be ready"*

Richard (SWD) (2:17 38-41) *"yeah I think I think a slight improvement in confidence yes I think so... and she... she enjoyed going erm to start with she wasn't very enthusiastic and didn't want to talk very much about it when she got home but it sort of grew on her and whereas some mornings I find it hard to get her going"*

John (CP) (2: 32 252-254) *"yes there was never any oh no I've got to go today... some mornings she said she was really obviously looking forward to it and some days she was just right I'm going off now but there was never any oh I don't want to go today"*

Alex (CP) (2:6 103-105) *"it's not functioning to upset people... it gives them more confidence and you're more in charge I see it anyway... so lots on corporate decision... they choose a theme song"*

The importance of shared decision-making within the CST group was also recognised by Alex as being beneficial to self-esteem, confidence and wellbeing.

Despite the positive gains of CST, a second feeling highlighted by care partners was the sense that CST may have been a reminder of spouses' deficits.

John (CP) (2: 24 68-71) *"she's certainly more conscious but again whether that's anything to do with any little error she makes or thinks she makes... it's my brain and although she does say it's dementia her brain and dementia are one and the same thing really so she's any error she's blaming dementia which she wasn't doing six months ago"*

John's quote above reflects the concerns of the care partners that talking about dementia resulted in their spouse being overly focused on the disease. Feelings which may form the natural make up of the day were dismissed as being due to dementia rather than due to expected reactions to the frustrations of the day. This also resulted in care partners under estimating their spouses' natural responses to dementia. For example, feelings of anger, grief or sadness were dismissed by the couple rather than being acknowledged as an expected reaction to diagnosis and therefore worthy of discussion between them. Alongside this, it was evident that improvement in quality of life had a knock-on effect on the quality of relationships and despite a lack of noticeable cognitive change, the couples identified subtle changes and improvements in their communication and confidence. It is these changes which had the biggest impact on the couples' sense of couplehood as the person with dementia and their spouse were able to benefit from the meaningful activity of talking about their day.

The master theme demonstrated couples' expectations of CST, which were met in some ways but not in others. The theme demonstrated that CST supported individuals to feel

worthwhile and impacted positively on their sense of emotional wellbeing and quality of life at the time, but that these gains were short lived once the course had finished.

While there was a notable increase in arguments and frustration between the couples due to memory loss, participants were determined to '*stick with it for better or worse*'. Issues of role and identity were an ongoing theme throughout both sets of interviews, and these concepts are woven throughout the narrative and discussion. Despite improvements to their spouses' confidence and communication, all the couples noticed a global deterioration in memory, mood and behaviour, which is in keeping with cognitive decline. By the time of the post CST interviews, it was notable that couples were beginning to re-examine and reappraise their approaches to dementia. Despite couples viewing dementia as a shared experience, which hardened their resolve to fight it together, there was a sense that they were beginning to feel overwhelmed and overtaken by the changes.

## **5.8 Master Theme 3: Mindfulness**

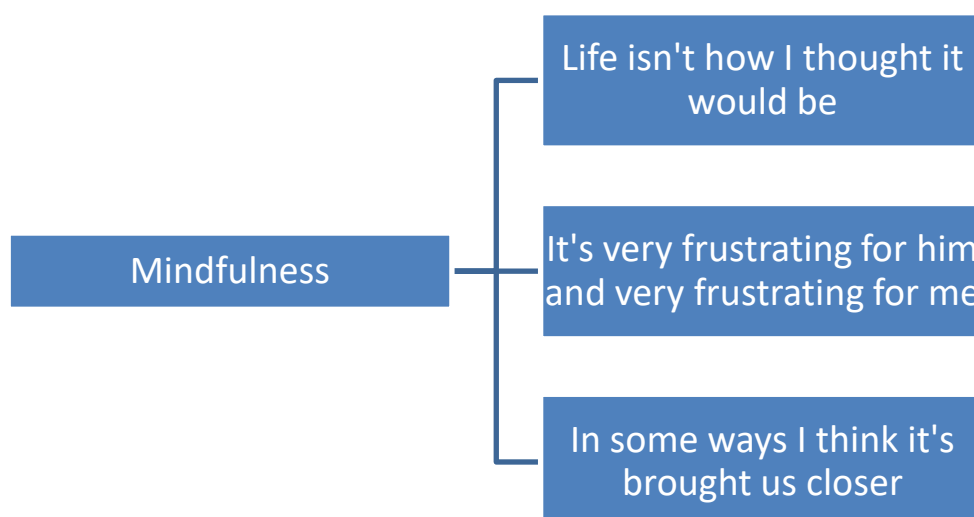
This third master theme, Mindfulness, refers to the couples' increased ability to put themselves in their partners' shoes. Throughout this theme I became aware of each couple's increasing sense of loss. The dialogue strongly suggested an awareness of gradual loss rather than any sudden defined change. This was also reflected in the increasing sensitivity and empathy towards each other. The couples' relationship showed commitment in adversity though again there was a notable shift in the nature of that relationship as greater responsibility was assumed by the care giver. So while a strong sense of commitment remained, nonetheless the nature of the relationship was fluctuating to adapt to the continued and growing challenge of dementia.

Throughout this theme there was a notable increase in the couples' mindfulness and reflection, the couples described an understanding of their own behavioural responses and the responses of their partner. This awareness has been grouped into three sub-themes: awareness of changes to self and impact on self - sub theme 'life isn't what I thought it would be', awareness of changes to self and impact on partner - sub theme 'Its frustrating for him and it's frustrating for me' and awareness of changes to self and partner and the impact on the couple relationship - sub theme 'In some ways I think it's brought us closer together' .

Throughout this theme, there was a sense of each couple's increasing sadness over time as well as a resentment of dementia and its impact on their relationship. However, there was also an increased sensitivity and empathy towards each other. Unsurprisingly, the sense of fluctuation is most prominent in this section of the analysis.

Figure 8 below denotes the master theme of Mindfulness.

Figure 8: Master Theme 3: Increased Mindedness



### 5.8.1 Sub-theme 1: Life isn't how I thought it would be

This sub-theme emerged by examining couples' accounts of how they perceived changes to self, brought on by the onset of dementia in the marriage. The narrative suggested that the majority of the couples had noticed subtle changes to their reactions and behaviours which were at odds with their normal sense of self, resulting in an inescapable awareness that their lives were altering. Additionally, the participants' with dementia described how routine tasks had become more difficult resulting in them questioning and double guessing themselves.

A surprising result in this subtheme is that the majority of individuals demonstrated a deep level of, and capacity for, self-reflection and self-awareness in the ways in which dementia impacted on their couple relationship. This is a novel finding which has not been discussed in the literature elsewhere.

Robert (SWD) (1: 29 218-224) *"sometimes I say did I or sometimes... I recognise that I did... promise... and that can be quite frustrating for her... that I don't always... recognise when I've actually said I'll do something... it's gone and that can be a bit of a hazard..."*

In the extract above Robert demonstrated his increasing awareness of changes within himself and the impact those changes have had on Alex. Through his self-reflection, Robert recognised that his worsening memory was a source of frustration for Alex, and he framed this as a recognition that his actions impact on his spouse.

In contrast, Alex suggested that reflecting on the impact of Robert's dementia on her made her sound selfish, as she was dealing with not only changes to Robert's abilities but her own limitations due to Parkinson's Disease. There was a sense that life was

particularly difficult for Alex and that she was doing the best she could. She was mindful that if she focused her attention inwards, this was somehow perceived as self-centred and divergent from her own sense of what couplehood should be.

Alex (CP) (1:2 33) *"I'm afraid I'm not... I... I'm... I've got enough to think about my ... it sounds selfish"*

Gwen reported that she felt increasingly burdensome to John and aware of how life has changed for him because of her. Throughout the interviews, she reiterated the sentiment of being *"lucky... everybody says... I'm so lucky"* and that John *"has to do everything for me now"*.

Gwen (SWD) (1:8 148-156) *"life isn't how I thought it would be... no I retired erm so that's sort of... his life's had to change more than mine probably... yes he's got... because he likes his sport... that's difficult sometimes... it's fitting... you see he's running me around he can't fit in as much golf as he'd like... he's fitted a bit more in recently er but that's difficult for him because he's always said... I'll run you to this and I'll run you here and you're not to get a taxi. I've had one taxi since I've been home .. that was last week... he's been... he says he's... no taxi and I'm no no... he wants to look after me"*

The feeling that *'life isn't how I thought it would be'* was strongly echoed in the narratives of all the couples. There was a sense of real sadness about this. Gwen felt that life was harder for John than it was for her, despite the fact that she is the one who has dementia. There was also a sense of double jeopardy in that her loss of abilities is coupled with how

that loss impacted on her husband. The loss of independence and increasing dependence on John was difficult to accept; Gwen says, *"I was free and I was very independent and now I can't be"*. The use of the word free suggests that she felt a prisoner to situation and circumstance. Gwen found it hard having to rely on John, which elicited feelings of being a burden to him. She tried to regain some elements of control by ordering taxis herself but also recognised that John *'wants to look after me'*. This nonetheless did not make her increasing dependence any easier. Even strategies which maintained her independence caused some friction and tension between the couple as John wanted to help, but in doing so was curtailing Gwen's need for freedom and independence.

John also addressed the issue of Gwen's increasing dependence on him and was able to recognise that Gwen *"resents"* having to ask him for help, perceiving that this had a restricting impact on him and his hobbies and interests. There was a sense in which all the couples were becoming increasingly compassionate towards and about each other; that they weren't blaming each other for the changes that were occurring, but were instead blaming the illness.

John (CP) (1:19 86-90) *"now she lost all confidence for driving... she's given up driving so I take her and she's erm... she doesn't like... she... I would almost go as far to say she resents having to ask me to take her somewhere... I say you know it doesn't matter its erm... the reason she resents it is because it stops me going out... just sometimes someone says to me fancy a game of golf next Tuesday I'll say oh yes... then I have to think oh hang on"*

Gwen appears to be a good observer of the impact of her changing abilities on John and was able to maintain feelings of empathy towards her husband.

Gwen (SWD) (1:9 171) *"..... and I feel sometimes it must be hard for him... having to put up with me like I am"*

John also recognised that he is at times more short-tempered towards Gwen, particularly in relation to repeating instructions for the telephone and the TV. He stated that, *"to start with I used to get cross"*, which indicated that he has been able to reposition himself in relation to Gwen and recognised that she cannot help forgetting the information he has given her. He also maintained a sense of empathy towards Gwen as well as a sadness that her abilities are changing as *"she always used to cope without any problems"*. Like Gwen, John discussed a sense that his freedom has been curtailed and his *'wings have been clipped'*, but he viewed this through a lens of the marriage vows he had made and saw that it was his turn to be self-sacrificing in meeting Gwen's changing needs in return for all she had done for him in the past. John was able to trade the *"better 47 years"* against the worst of the *"last two"* and felt that he was now repaying Gwen by looking after her.

John (CP) (1:23 166-171) *"not go anywhere without me and it's not fair that she sits here while I go out doing what I want to erm yes... I've had my wings clipped a little bit but erm... as I've said to her on numerous occasions you know when we got married it was for better or for worse it's been for better... for 47 years and it's been for worse for the last two but you know... I'm not bothered about that"*

## Chapter 5

This sense of being a burden was echoed in Harlee's narrative as she also made several references to "*poor Richard, he has to put up with me*" and repeated "*I don't want to be a nuisance to him*" throughout her interviews. Harlee hones in on Richard's strengths as a husband, almost as if she no longer possesses these traits herself and thereby feels grateful for his kindness towards her.

Harlee (SWD) (1:17 97-100) "*it's difficult to say erm because he is so loving and supportive and we do have a good relationship I feel that anyway (laugh) and he's very kind you know I feel secure in that erm but sometimes I feel bad because you know certain things I used to do but I don't do now*"

There is a sense in which Harlee feels "*bad*" as she recognised that she was not doing things as she once did, which impacts on Richard. As can be seen from this extract and several other occasions throughout the interviews, Harlee would laugh while she was commenting on particularly emotive and upsetting topics, which was perhaps a nervous strategy to downplay the enormity of the changes for both her and her husband. There was also a sense in which her responses were becoming less sophisticated and more child-like, which may also have reflected her changing cognition.

Harlee indicated an awareness that the changes to her memory and thinking that she was experiencing were increasingly unpredictable and relentless. Richard, who described himself as having OCD, was also acutely aware of how dementia was impacting his ability to care for Harlee, and that he too feels "*awful*" because of how his characteristics and personality impact on her.

Richard (CP) (1:5 95-97) *"I sometimes get a bit uptight and Harlee will very reasonably say but Richard I've got dementia you know I feel awful then because because you know I'm just thinking about my own erm discomfort and that's not good"*

He later commented that he was *"perhaps not the best person to care for her"* due to his personality traits, but also made it clear that he would do whatever he could to support Harlee, perhaps overcoming his own discomfort in an effort to meet her needs. Despite the obvious stress caused by the onset of memory problems, throughout Richard and Harlee's narrative, and indeed all those of the couples, there was a sense that all participants remained stoic and determined to make the best of their lives together.

Within this sub-theme, three of the four couples were able to demonstrate a good level of insight and could articulate how they felt about their changing sense of self. For the spouse with dementia, an increasing sense of becoming a burden on their partner was apparent throughout this sub-theme, whereas care partners highlighted their increasing frustration over the changes brought about by dementia. Each spouse was increasingly aware of how worsening cognition resulted in changes to self which in turn impacted on their partner, and there was at times a sense of being swept along by these changes.

### **5.8.2 Sub-theme 3: It's very frustrating for me and it's very frustrating for him**

This sub-theme reflected the ways in which couples were aware of how changing cognition in their partner and the impact this had on their own sense of self, demonstrating a sophisticated level of insight. Liv sums this up in her realisation that she

was once confident that she could rely on Elliot, but that the way the couple support each other had been subtly shifting. When asked whether dementia had an impact on their lives, Liv's response was typical of many of the participants.

Liv (CP) (1:18 38-41) *"..... so really that's what it is so yes it does make a difference to your life there's no doubt about it because I felt before I was someone who could lean on him a bit he always knew the answers to things but now it's... it's not like that"*

The way she described herself as *"someone who could lean on him"* is interesting and suggests that she is being critical of herself in order to boost Elliot. She later reiterated this sentiment by stating that she was *"disappointed"* that the dementia had occurred; again, perhaps this strategy of self-deprecating is a way of not having to recognise that it is Elliot who has changed rather than her. Again there is a sense that Liv views herself differently in relation to Elliot; that his changing needs reflect important things about her own self esteem, her identity and her role of a wife.

Liv (CP) (1:25 180-181) *"no... well only by knowing that I I'm disappointed that it's happened and therefore er whereas before I could rely on him... but that's changed"*

This reframing of perspective appears to be an important strategy for Liv as the couple do not want to address the many negative aspects of dementia and its impact on them. This excerpt suggested that Liv feels dementia has robbed her of Elliot, who was previously an

embodiment of a more reciprocal relationship; however, she couldn't bring herself to express this. Elliot, who was evidently struggling to come to terms with the situation, remained keen to impress upon me that having come through "*two difficult periods*", he would also come through this. Elliot likened his ability to beat physical illness as proof that he could get through anything.

Alex and Robert's struggle with change was evident in their communication and interaction with each other. There was a sense of highly expressed emotion in the household as well as a feeling that each were trying to come to terms with their own health issues whilst also acknowledging that this had an impact on each other. Each spouse was dealing with increasing feelings of frustration towards themselves and each other.

Alex (CP) (1: 8 143-144) "*..... and it's very frustrating for him and it's very frustrating for me... erm... you know he gets very annoyed... after... sometimes he gets me worked up and angry.....*"

This was reiterated by Robert, who also talked about his frustration and annoyance towards Alex while also recognising that it was the illness rather than the person that was the source of their frustration. Alex's Parkinson's Disease was also a challenge for them both, and had been a source of tension in the relationship even before Robert's dementia diagnosis.

Robert (SWD) (1:25 123-136) "*..... I still have to count to 25 sometimes because of the way Alex reacts... partly in terms of the Parkinson's she's she's got... and*

*sometimes I find that... a few weeks ago it got... it got to me... and I didn't seem to find ways of bringing it down to manageable... it seemed to be growing"*

Roberts's strategy of counting to 25 recognises that his reactions towards Alex have the potential to worsen the situation. This is evidence of his insight into how he has to curtail his own responses to reduce the risk of frustration from Alex. This was an interesting perspective which was also highlighted by Gwen, that rather than feeling obliged to her partner, she too had to deal with and overcome a sense of frustration with their care giving spouse. This is a novel finding as carer burden and frustration is well documented in the literature, but there is little research into feelings of burden, and loss and grief of spouse with dementia – especially in relation to feelings of frustration towards their spouse.

Unlike the other couples, Robert and Alex had already positioned themselves into care giver and care receiver roles, which was likely due to Alex's Parkinson's Disease.

However, the couple were now confronted by another change of position due to Robert's dementia. Robert has gone from being care partner to Alex to now needing care from her in his own right, leading to tension and confusion within the couple unit. However, even with the notable tensions in this relationship, it was clear that Robert and Alex cared deeply for each other.

The sense of tension and frustration was also evident at times in John and Gwen's narrative. Gwen recognised that John was more short-tempered with her because she was unable to remember how to use the remote control and telephone. There was a real sense in which Gwen was desperate to put across that it wasn't her who was the

problem, but her memory, which makes John cross because she *“can’t remember things”*. The use of this sentence twice in the extract below reiterates her sense of desperation that dementia and memory loss cannot be helped and are beyond her control.

Gwen (SWD) (1:3 77-79) *“he does everything... he does do a lot for me... I think sometimes he gets a bit cross with me because I don’t take it in you know... all these things that he shows me... I just can’t remember... I can’t remember things”*

Despite these tensions, John made it clear that he viewed this next phase of life as something the couple could surmount together and that he wanted to be a part of this effort. Like all the couples, John and Gwen clearly had a solid relationship and there is perhaps a sense that John felt some guilt for not helping out in the past, and now viewed it as his turn to look after Gwen.

The sense of things changing within the relationship evoked a feeling of sadness and pity from Richard, who expressed sorrow at Harlee’s disappearing abilities.

Richard (CP) (1:9 166-168) *“and she’s not very good at that and there was a time when she could cook a meal and I could go out and come back and she’d have it all ready but not anymore (pause) it’s sad”*

The narratives within this sub-theme suggested that most of the couples had noticed changes in their spouse, in a variety of ways. This may have been the spouse with dementia noticing that their care partner was becoming more frustrated, or the care partner noticing the changing abilities of their spouse. What is evident is that the couples

were able to recognise changes to self and were able to demonstrate compassion and empathy towards each other. The strength of their previous relationship and the depth of their ongoing commitment to each other was also clear throughout this theme and perhaps provided them with a sense of refuge during times of stress.

### **5.8.3 Sub-theme 3: In some ways I think it's brought us closer together**

This sub-theme addressed each spouse's awareness of changes to self and partner as well as the impact these changes had on the couple's relationship, resulting in a sense of uncertainty. This theme demonstrated that all the couples had been confronted with meaningful changes to their relationships as a result of dementia. During analysis of this theme, several components fundamental to the relationship and how it functioned were evident, and a key element within this sub-theme focused on change. When asked if the relationship had changed due to Harlee's dementia, Richard sums this up with his touching statement:

Richard (CP) (1:5 92-93) *"erm er I think I would prefer to say no but if I'm honest yes it does its does affect things a bit"*

This is confirmed by Harlee, who felt secure in their established relationship despite the challenges dementia now posed. There was a sense in which, despite dementia, the couple felt lucky and privileged to be with each other, with Harlee often stating sentiments such as, *"so you know I'm very fortunate, yes I'm very fond of him"*.

Harlee (SWD) (1:27 283-284) *"yes I mean we've always had a good relationship it's good that he hasn't said how am I going to cope with you?"*

However, despite this security there was a sense in which there were differences between Harlee and Richard's senses of coping. Harlee often stated how wonderful Richard was, whereas Richard reported that he did not feel particularly wonderful or patient towards Harlee.

Richard (CP) (1:4 69-72) *"so there's a sense in which I'm not the best person to be caring for her but I do I do care for her reasonably well but but because of my own personality problems it's it sometimes generates a bit more stress than it normally would because I'm not particularly laid back"*

John and Gwen's commentary on how their relationship was altering was similar to Richard and Harlee's in that they still viewed themselves very much as a couple, with a shared future and shared strategies in which to cope with dementia, but that this was becoming more fractured. John trailing off at the end of this extract perhaps reflected his uncertainty in how the couple would continue to 'work together' and that the relationship was indeed changed but in ways that were difficult to articulate.

John (CP) (1:25 210-211) *"Oh yes very much so... I guess romance changes over time but we are still a couple even with all the changes... it's about working together... erm... (trails off)"*

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John also discussed stresses within the relationship but did not see dementia as separate from those other stresses, but rather something to be worked at and shared together.

The sense that the pair could tolerate arguments and still view themselves as a couple is a powerful feeling throughout this section, and there was no indication at any point that any of the couples were thinking about ending their relationship with their spouse.

John (CP) (1:22 182-184) *"it's perfectly understandable... you always hurt the one you love at times... and I know I get a little bit short erm oh... I do snap out of it but that's... what I'm trying to say is that there's always people worse off... it's no consolation but there are..... "*

Liv's discussion of how the relationship was changing differed from those of the other couples and perhaps at times was more difficult for her to articulate due to Elliot's denial of his dementia. However, she did see changes to the relationship as bringing the couple closer together. Again, Liv sought confirmation of the change by saying *"he's probably told you"*. The below quote also reflects Liv's belief that the couple are in the situation, since together *"we"* are trying to help each other.

Liv (CP) (1:20 81-83) *"I think so... it's that we've become more clinging really... he's probably told you that... no no definitely... we are trying to help each other"*

And later in the interview:

Liv (CP) (1:26 238-240) *"I think we're closer because we know that every day is precious really it's like that... and we've always been very close I think it's been a good match"*

Liv described a sense that making the most of the time left is important to her and, like Richard and Harlee, John and Gwen, she felt that they have always been close as a couple. In contrast, Elliot's talk about his relationship with Liv revolved around how they have coped. The change of pronoun from 'we' to 'I' in the extract below is interesting. 'We' followed by 'I' suggested that Elliot perceives that when 'we' coped, that was down to him - *"I do a lot"* - and that he is the source of strength within the relationship rather than the cause of change. Elliot's belief in himself is a very important strategy for coping with dementia and this belief is also reflected in Liv's narrative.

Elliot (SWD) (1: 7 119-121) *"I think we've coped very well er... erm well what to say ... I do a lot of... on the house er both inside and outside particularly the garden er I think you can gather that from... "*

Surprisingly, despite the argumentative elements of Robert and Alex relationship, they also managed to retain a sense of shared relationship and couplehood. Robert indicated that the couple were still able to talk to each other but also that arguments were a natural part of being in a couple, *"like any relationship"*. The extract also leads one to suspect that the couple have interacted in a strained way for a while, and that they just accept that this is how it always has been and how it always will be.

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Robert (SWD) (1:32 296-300) *"..... Forty-nine years married... we're managing to survive... We have our ups and downs... our difficulties... but we've got two good... daughters... but I don't think we're any worse... or any better than some people... I'm told I'm too laid back sometimes... but again having gone through so many things... and helped people go through so many things... "*

Alex summed up the issue of couplehood by recognising that both individuals impact on each other:

Alex (CP) (1: 9 181-184) *"knowing what the situation is is quite vital for our survival... but nobody measures that or asks that... I noticed the word couplehood on your sheet... I've never seen that word before but I thought somebody's noticing the...the... interaction and it does make a difference"*

And later in the interview:

Alex (CP) (1:11 257-258) *" ..... I'm not saying that either of us has a greater need... but erm... it is very frustrating to have professionals who are only dealing with one of us... at a time"*

This is a key statement in which Alex succinctly summed up the difficulties of having two separate needs within the one couple unit. She acknowledged that one person's need is not greater than the other, but that each of their needs should be addressed in relation to each other.

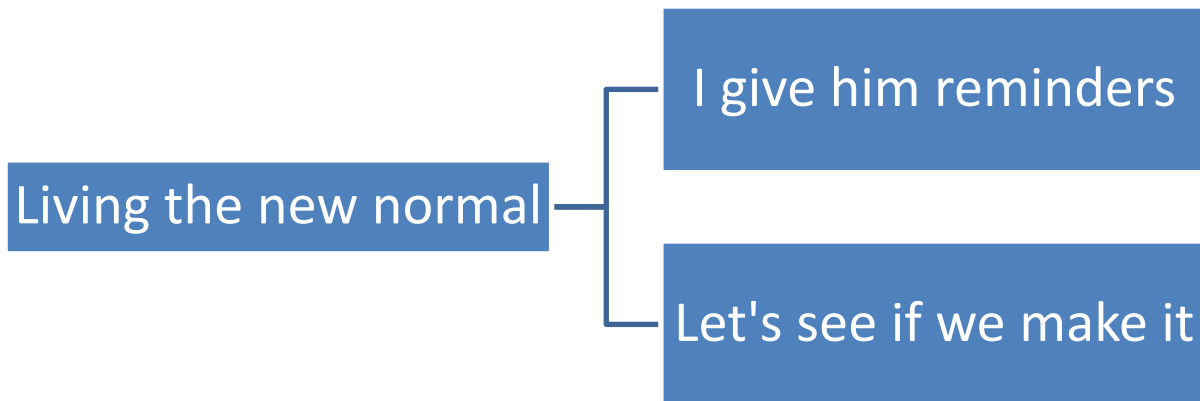
Despite the obvious stress of dementia, Richard and Harlee, John and Gwen and to a lesser extent Liv and Elliot all indicated that dementia can be positive, and that change can be in a positive direction, whereas Robert and Alex had a more static view of their relationship. All of the spouses demonstrated that they were grateful to their partner – both for the current support they provided but also for the support they had provided in the past and this was an important foundation on which their relationship continued to function. As well as positive and negative perceptions of change, some couples experienced change as daunting. While couples talked emphatically about how they would not let certain aspects of their relationship change, there was a sense that underneath, whatever plans they made, change was inevitable. The lack of control over dementia remained a focal point and despite plans and promises, there was an underlying sense of futility. The quality of the couples' past relationships was also an important element within this sub-theme, and the quote "*it's always been this way*" indicated the strength of the past relationship as being important in the here and now by providing a sense of attachment and ongoing commitment.

### **5.9 Master Theme 3: Living the New Normal**

The final master theme revolved around the couples' attempts to adapt to living with dementia. As the couples were still on a journey of adjustment, this part of the analysis is shorter but nonetheless an important part of their analysis. Couples saw dementia as external to themselves and something outside of their control, but also as something they had to live with and adjust to. Couples attempted a variety of strategies for absorbing dementia into their relationship. The new way of living involved the couples' views on changes in the present whilst being ever mindful of the changing future.

The figure below denotes the theme and subthemes of this master theme.

Figure 9: Master Theme 4: Living the new normal



### 5.9.1 Sub-theme 1: I give him reminders

This sub-theme describes the couples' attempts to devise strategies to accommodate dementia within their marriage. On some levels, dementia was perceived as being external to the couples, while on another level it was perceived as being a meaningful part of their relationships. Typically, strategies devised by spouse with dementia revolved around practicalities such as making lists for reminders. It was increasingly the responsibility of the care partner to remind their spouse of various appointments and memories. External strategies were seen as essential but also a reminder of worsening memory which could also be a source of conflict and tension. An example of this can be seen in Robert, Alex and Liv's excerpts below.

Alex (CP) (1:10 199-200) *"erm... we spend endless time... it seems to be... discussing who's going to do what... and er... he'll make little lists"*

Robert (SWD) (1: 24 105-107) *“oh yes I write things down more... I certainly put our appointments... I’ve devised a system for... using the basic letters and putting on the front what it is and what date it is... and put it in order... so...”*

Liv (CP) (2: 21 91-93) *“..... I love to talk about photographs and things and look at old photographs... and I think this is a thing that is very good to do to bring those out and do you remember from 1950 when we were doing this and that and er... it brings it all back... so I thought that was one way of helping”*

Being able to reminisce and remember happier times was also important for the couples, as demonstrated by Liv in the extract above. Being reminded of past abilities and shared memories served to help the couples cope in the here and now by providing a foundation on which new struggles could be overcome together and a reminder of the resources that they had always relied on in the past.

Alex (CP) (1: 7 120-121) *“but he manages... by using the calendar and diary... and... and me... I give him reminders”*

In many ways, Alex’s excerpt above regarding the use of memory aids summed up the care partners’ attempts to engage and support their partner, and demonstrated changes that were apparent in all the couples’ narratives which mean that ultimately, it is the caring partner who is responsible for developing and employing memory strategies.

The same example echoed through Liv and Elliot’s narrative, although for this couple, there was an element of the strategies being singular rather than combined.

Liv (CP) (1:17 43-46) *“yes I think he’s not getting on too bad and he’s very determined that it’s not going to get worse... he makes himself little sheets and things forces himself to do it but the thing is it’s partly his hearing as well... he doesn’t catch half the things I say”*

Harlee on the other hand demonstrated an increased need to be with Richard.

Harlee (SWD) (1:23 206-207) *“I suppose yes I do I think it’s important that we do do things together erm I need him and he needs me it’s like that”*

Many of the changes led to sources of tension between the couples, and thus highlighted strategies used by them to cope with this. Some of the conflict stemmed from forgetting or losing items, and there was a feeling of frustration on both sides. Memory-related changes were apparent for all couples, and there was a feeling that worsening memory was an enduring and omnipresent reminder of the spouse with dementia’s limitations. Being unable to recall information which was once familiar was distressing for the participants with dementia as well as for their spouses, who often felt helpless and so unable to support and reassure them.

Perhaps one of the most eloquent quotes came from Richard, who summed up how dementia impacted on the day to day lives of the couples. Dementia had entered the couples’ lives and as such they now needed to learn to live with it. This learning process was complex and dynamic, and was interwoven into their daily existence.

Richard (2:24 202-205) *“yes because she starts the new day but I still have the feelings of what happened the day before and the day before and the day before...”*

*it's very difficult... I do apologise a lot to her erm that helps me... but I'm not sure it helps her because it perhaps reminds her of something she's forgotten anyway"*

This statement is packed with emotion, with the phrase "*the day before and the day before and the day before*" demonstrating the relentlessness of dementia. Richard felt guilty about his angry feelings towards Harlee, which have built up day after day. He then felt the need to apologise and absolve himself of the guilt he was carrying, which then doubled in weight because Harlee had likely forgotten all the bad feeling anyway. This left Richard with a heavy burden. For all of the couples, everyday life as well as relationships with self and partner are affected, resulting in continual renegotiation.

#### **5.9.2 Sub-theme 2: Let's see if we make it**

This sub-theme revolved around the couple's thoughts about the future. During analysis of this theme, it became apparent that each spouse had their own perspective and view of the future and there were delicate differences between spouse with dementia and care partners viewpoints on this. This is best summed up by a spouse with dementia, Gwen, who spoke openly and frankly about her fears that her dementia is likely to worsen over time.

Gwen (SWD) (1:11 234-236) *"I just lose it... and that is the horrible bit I think... because you do get really bad... and I just have a feeling I will because I know now I know my memory is not as good as it was... even in a short while"*

Gwen demonstrated that she has thought long and hard about the future implications of her dementia and that there will come a time when John can no longer look after her.

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There was also a sense that the couples had little control over what was going to happen and that articulating their thoughts about the future is difficult. As Gwen points out in the extract below, *“everyone is different”*, which perhaps makes coming to terms with dementia more difficult to plan and anticipate. Despite having memory impairments, it was clear throughout the interviews that Gwen was insightful and reflective about her and John’s future together.

Gwen (SWD) (1:13 241-245) *“he just tells me I shouldn’t think of the future because everybody’s different and I might end up in a home and we need to save our money for going into a decent home erm he says no you’re not going into one and I say you’re not going to be able to help me when I get that much worse erm it’s not a nice future to think about... but as I say it’s just get on with things “*

In contrast, John demonstrated that he doesn’t want to think about the future as that may mean confronting its potential bleakness. There is a sense that John can remain optimistic about the future if he doesn’t think too much about it. The extract below demonstrates that he doesn’t want to know what’s ahead as knowing the future may increase his anxiety in the here and now.

John (CP) (1:23 206-208) *“but I don’t want to see what’s in the future... if I could see three years and it’s completely dark and black... it would mean I’m dead but did I die last year or the day before I looked and I’m worried for the next three years”*

Similarly, Liv has a realistic outlook and a desire to not think about the future.

Liv (CP) (1:24 165-167) *"I daren't really think about too much (crying) it's very emotional because I have no idea how long these things go on for six months a year before people notice differences"*

Similarly, Harlee discussed dementia in terms of getting worse. Rather than being overwhelmed and paralysed by an uncertain future, she suggested that this makes living in the moment vital for the couple's survival.

Harlee (SWD) (1:14 45-50) *"yes and also I'm wondering will I complete and you don't want to .. is it worth trying do to when you know something is going a little bit awry its finding something that's erm that doesn't stretch over a long period of time that's just in the moment you know I'm frightened to do that because if you've got sort of dementia you know it's going to get worse you don't really want to try something that's long term do you really better to stick with the moment and make the most of that"*

Far from avoiding thoughts about the future, most of the couples indicated that they wanted to discuss their views of the future. Like Gwen, Harlee also indicated that she had been thinking about the future. Interestingly, all the care partners indicated that they hoped their spouse would die before they did as they felt that no-one would be able to care for their spouse after they had gone. This was an emotive subject to address, but all the couples led the conversation to this point spontaneously.

If anything, it was the spouse with dementia who articulated their thoughts about the future more than care partner spouse. Richard and Harlee, John and Gwen had mixed feelings about the future. On one hand, they expressed a realistic, though bleak view but on the other hand, they described a determination to look at the positives and live in the moment. The positive outlook aided a sense of control over their future, while it was perceived that giving in would lead to despair. Subsequently, the couples worked hard to maintain a shared future, filled with strategies to enhance the abilities of spouses with dementia and to fight on as a couple. There was no sense in which couples indicated that they thought they would spend the future alone, and indeed the feelings expressed by Harlee in the excerpt below were echoed by all the couples.

Harlee (SWD) (1:26 254-256) *“erm well we grow along together if I suddenly found myself without Richard now that would be something that would take a bit of working out very definitely and I guess he would feel the same about me suddenly disappearing from his life”*

## **5.10 Summary of results**

In summary, this chapter presented the findings of the separate interviews with four couples, which were analysed using IPA. Underpinned by Heidegger’s interpretative philosophy, a qualitative phenomenological approach assisted the exploration of the lived experience of couplehood. From this vantage point, emphasis was placed on the notation of the lived experience of ‘being’ – both ‘being in’ a relationship and ‘being with’ others.

Analysis revealed four master themes: ‘Navigating disruption’, ‘Re-appraisal’, ‘Mindfulness’ and ‘Living the new normal’, which revealed how couples navigate the

changes and disruption of dementia as well as working together to maintain a sense of couplehood. For these spouses, couplehood was interrupted but not destroyed by dementia, and each individual was determined to uphold the commitment and promises made to each other in their wedding vows. It was clear that all the couples were determined to stick together and that despite dementia, they reported a new sense of closeness. However, much of this rested on the care partner, who was assuming more responsibility in the relationship. Changes to role and identity were a key theme throughout the analysis.

Attending the 14-week CST course had some positive effects on spouse with dementia which in turn had a positive effect on the relationship as a whole. However, these gains were short lived and once the course was finished, there was a sense that the couples were once again swept along by dementia. Most of the couples were able to demonstrate an increased capacity and reflection for empathy for their spouse, and were able to reflect on the impact of change by identifying how their changing selves impacted on their partner and ultimately on their sense of couplehood. Despite the frustration and uncertainty of dementia, all the couples spoke of their determination to fight on together and highlighted the shared nature of dementia. Issues such as grief, loss and burden were a shared thread throughout the couples' stories, while a novel finding was the ways in which the spouses with dementia were able to identify and articulate their feelings on these concepts.

All the couples demonstrated various levels of insight and a gratifying aspect of the analysis was the ability of the participants to articulate and share their rich and unique stories.

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The next chapter provides an in depth discussion on the results of the interviews with four couples.

## Chapter 6 Discussion

### 6.1 Introduction

The previous chapter revealed the experience of dementia for the participant couples as well as how they negotiated couplehood within the context of one spouse having a diagnosis of dementia and attending a 14-week CST course. The analysis of the couples' subjective experiences uncovered a rich, detailed portrait of couplehood in which the lived experience of couples was emotionally laden with fundamental feelings of fear and anxiety as well as secondary struggles to hold on to what remained of their relationship.

Although this particular study focused on couples, it is anticipated that the experience of CST and its impact on communication and quality of life could be generalised to the wider population, for example individuals with dementia and their adult children or informal care givers.

The results from this study are meaningful as they identified the demands and challenges placed on couples and demonstrated how both members of the couple experience dementia and the effect this has on perceived sense of couplehood. Attending CST was a positive experience for spouse with dementia and impacted on the overall experience of couplehood. However, these gains were often short lived as once the course was over, the spouses were once again left to negotiate dementia in isolation. Issues of grief and loss were also key, both for individual spouses and the couple unit. These issues highlighted the inter-relatedness of loss and transition as each change resulted in loss and each loss created further change in the relationship (Evans and Lee, 2013).

## Chapter 6

The chapter begins with an overview of the purpose of the study in Section 6.2. The ways in which this research has contributed to the literature on couplehood is considered, including a discussion on how the findings have informed clinical practice and delivery of CST groups. In keeping with the IPA approach of this thesis, it is not unusual to uncover unexpected themes during the analysis which were not identified in the literature review and this literature is also considered (Smith et al., 2009). Sections 6.3 to 6.7 provide a summary of the research findings, while section 6.9 provides a critical review of the strengths and limitations of the research including issues of validity and methodological limitations. Recommendations for future research alongside recommendations for future CST practice is also considered. Section 6.10 considers how this thesis has contributed to existing knowledge. The chapter concludes with a reflective statement about my personal and epistemological reflexivity.

### **6.2 Purpose of the study**

As discussed in the introduction of this thesis, the context and framework around dementia support highlighted the need for research into the lived experience of dementia. The literature review demonstrated an important but limited body of qualitative research concerning couplehood in which the voice of spouse with dementia and their care partner were included equally (Merrick et al., 2016; Hellström et al., 2007). Additionally, at the time of writing this thesis, there are no qualitative studies focusing explicitly on the experience of spouses undertaking CST. As discussed in the introduction chapter, available studies focusing on CST have tended to be quantitative in nature and have not included the views of participant with dementia and their spouse in depth (Cove et al., 2013).

This thesis aimed to provide an enquiry into the impact of dementia on sense of couplehood, which was not limited to Alzheimer's disease alone as other authors have done (Clare, 2002; Davies, 2011; Daniels et al., 2007; Daley et al., 2017) (see section 1.12 for study aims). Secondly, the thesis aimed to explore whether attending a CST course impacted on spouses' sense of couplehood. To the author's knowledge, this is the first IPA study which has investigated CST and couplehood. Given that the results chapter considered each master theme and sub theme separately, this next section gives less consideration to reviewing the themes in this way. The discussion is therefore structured according to the research questions presented at the start of this thesis whilst drawing on and linking to the theoretical literature on dementia, couplehood and CST.

### **6.3 Research questions**

Semi-structured interviews were undertaken with four couples, in which one spouse had a diagnosis of dementia and had attended a 14-week CST course. Each spouse was interviewed on their own twice, once before the CST course and again after the CST course. The research aimed to address the following research questions:

***Research question 1: How do couples make sense of perceived couplehood in which one spouse has dementia?***

***Research question 2: What is the lived experience of couplehood in which one spouse has dementia?***

***Research question 3: Does CST impact on perceived couplehood?***

The findings will now be discussed in relation to the research questions and will be supported by existing research and theoretical literature.

## 6.4 Research findings

The interviews were analysed with IPA. The analysis focused on the subjective experiences and participant meaning making in the context of the couples' wider historical, social and cultural perspectives. The results revealed four interconnected master themes: Navigating Disruption, Re-Appraisal, Mindfulness and Living the New Normal (see section 5.5), which together illustrated the lived experience of dementia from a relational perspective. These master themes can be divided into two main overarching foci: that of the direct **effect** of dementia on the individual spouses; and the additional challenges and **impact** on the couple. The themes revealed the manner and methods couples employ in order to enable them to adjust to the experience of dementia. In particular, the themes shed light on the day to day lives of the couples, which were often beleaguered with balancing being a care partner or being cared for against the role of being a spouse. This often had consequences for participants' personal and social functioning as well as their overall sense of wellbeing. Throughout the couples' accounts was the sense of the relentlessness of dementia, the sense of new and upsetting changes as well as that of new challenges being unpredictable and therefore inescapable. For the spouse with dementia, there was an increasing sense of being a burden whilst fighting to maintain their individual independence, whilst the care partner spouse was increasingly overwhelmed by the responsibility of monitoring and supervising their partner.

These themes have been generated based on my own interpretations and assumptions.

This is further reflected on in section 6.11.

## 6.5 Addressing the first research question

### *How do couples make sense of perceived couplehood in which one spouse has dementia?*

Central to the notion of perceived couplehood and the lived experience of dementia were the couples' reflections on what they identified as the security of their relationship and in particular their sense of enduring and continued commitment to each other. The four couples indicated that despite the multiple changes associated with dementia, the fundamental shared meaning of their relationship remained intact; that is, that the couples strived to sustain their couplehood (Hellström et al., 2007) as a shared undertaking that was valued equally by both partners (Molyneaux et al., 2011b; Merrick et al., 2016). This was highlighted in the master theme Living the New Normal, in which the couples embraced changes to their relationship and endeavoured to move on with their lives. There was no indication in the interviews that the couples had ever contemplated separation from each other; there was an assumed and unspoken agreement that they would always be together. This resonates with the separate findings of Daniels et al. (2007) and Davies (2011). These two studies of marriage in dementia found that commitment to partner and relationship was key in couples' ability to maintain their sense of couplehood.

Additionally and in line with the work of Davies (2011), the current study confirms that the ways in which couples perceive their history and marriage biography impacts on their here and now perceptions of their relationship as well as providing some insight into how notions of couplehood are interwoven with a sense of belonging and continued commitment to each other. During the interviews with the four couples, there was an increased and ever present awareness that the relationships were somehow operating

differently than they had previously. However, there was a shared commitment to accommodate these changes within the relationship itself. In other words, couples demonstrated a commitment to work together to maintain a shared future, albeit one day at a time (Clare, 2002).

This commitment to the relationship has been linked to theories of attachment within the wider literature of dementia and caregiving (Browne and Slosberg, 2006; Braun et al., 2009) (See section 3.3 for discussion on attachment theory and dementia). The current findings are also in line with those of attachment theory as a way to increase understanding about how couples may be supported to negotiate disruption to couplehood. Attachment theory as proposed by Bowlby (1969) remains a key feature of relationships throughout the life cycle (Browne and Slosberg, 2006; Miesen, 1992) and highlights how the notion of couplehood can provide a secure base from which couples are able to Navigate the Disruption of dementia together (as highlighted in master theme 1 of the current study) in order to maintain psychological wellbeing of Living the New Normal (master theme 4 of this study).

The theme of Navigating Disruption can also be linked to theories of Biographical Disruption (Bury, 1982) (See Section 3.2 for discussion on biographical disruption) in that the couples were confronted with changes and challenges to what they anticipated and expected their future would be. The disruption of dementia caused the couples to rethink about expectations and norms within their relationship and in many ways aspects of their relationship were in a constant state of disruption.

It was evident that being married was of great importance to the couples. This was echoed in their shared investment and goals. Couplehood encompassed notions of an 'us' identity (Hydén and Nilsson, 2015) which was reflected in areas of reciprocity,

forgiveness and resilience to withstand day to day tensions (Daniels et al., 2007). Despite the spouses' struggles and challenges of living with dementia, all couples maintained an enduring commitment to each other which was evident in their commitment to work together to sustain couplehood (Molyneaux et al., 2011b; Hellström et al., 2007; Merrick et al., 2016). This theme resonates with the work on couplehood typology as identified by Kaplan (Kaplan, 2001) (see section 1.2.2 for discussion on couplehood). However, in contrast to Kaplan's work, the current study highlighted that rather than being a static concept, an individual's sense of couplehood often oscillated along an 'I' – 'we' continuum throughout the course of a day. This more closely echoes the work by Hydén and Nilsson (2015), Merrick et al. (2016) and Molyneaux et al. (2011b) in that couplehood is seen as an ever evolving, ever changing concept. This point was driven home by Richard (care partner spouse), who reflected on how he started the day as a loving husband and ended the day as a weary carer. It is worth noting that all couples in this research had been in long-standing relationships and married for many decades. This may therefore indicate something about this cohort of post-war couples for whom traditional marriage vows were viewed in a certain way. Research which considers younger couples' sense of commitment and couplehood would be of benefit in order to provide care and support which upholds those couples' 'us' identity. Research may also inform understandings of whether there may be a cohort effect in terms of subtle differences between younger and older couples views of marriage, commitment and divorce (South and Spitze, 1986).

Relationship quality has been previously highlighted as being important to couplehood and the experience of dementia (Ablitt et al., 2009). Relationship quality has been linked to issues such as intimacy and communication (Clare et al., 2012). The type and quality of

interaction and communication between the four couples was also important in this study, as spouses highlighted that being able to talk to their partner was valuable to them. However, the care partner spouse indicated that there was a lessening of general interaction with their partner and that as a couple they had less to talk about.

Communication between the couples increased during the CST course (see section 5.7). However, while the amount of interaction had generally reduced, this instead made way for the couples to be content to be in each other's company. Again this indicates subtle nuances around notions of enduring couplehood and corroborates the view of McGovern (2011) in that all types of communication between couples can sustain a sense of relatedness and togetherness – which is also demonstrated to increase a sense of wellbeing for the couple unit.

Additionally, the findings of this current study are in line with those of Molyneaux et al. (2011b) and Clare et al. (2012) in that the care partner spouse felt more responsibility to keep conversations going and the reminiscence of past times was useful in providing stimulation as well as enhancing understandings of their current situation. In this way the couple continue to communicate their sense of commitment and couplehood by recollecting on past shared memories even if this is more dependent on care partner spouse. Similar arguments have been made by Marwit et al. (2005) who suggested that the quality of couples' interaction can be altered due to the onset of memory problems and that both members of the couple respond to this by changing their communication, whilst the care partner assumes the responsibility to maintain interactions.

Coming to terms with and incorporating dementia into the relationship was also identified by the couples as key to the perceived sense of couplehood (Clare, 2002). This was again reflected by a number of stages, as dementia served as an omnipresent

stimulus for couples to get on with their lives and regain a sense of normality within the relationship. Mutual adjustment in the relationship also enhanced perceived couplehood, and strategies to hold on to what remained as well as compensating for loss (Clare, 2002) were important for the couples. Stress and coping in dementia have been linked to theoretical models within the wider literature such as theories of stress and coping (Lazarus and DeLongis, 1983; Lazarus and Folkman, 1984; Pearlin et al., 1990) (See Section 3.5 for discussion on stress and coping) in which practical and emotional problem solving either enhances or mitigates adaptation. These resources are often accumulated throughout the life course and may have evolved from a life time of learning. The strategies that the couples in this study employed appeared to reflect some of the coping mechanisms outlined within the wider research and also suggested that couples, specifically care partners struggled to balance intense and complex emotions rather than the practical consequences of having a spouse with dementia. Clare (2002) linked this to a continuum of coping resources. This is consistent with the sense of couplehood as a continuum in this study as the four couples oscillated along positions of acceptance of dementia on one end and adjustment to the changes to their relationship on the other. This also verifies the notion that the couples' perception of their situation is determined by the selection of specific coping resources and could provide a useful framework of understanding strategies that couples may utilise that they have acquired over the years as a couple. In contrast to the dominant stress process model (Pearlin et al., 1990) it may also be beneficial for care partners to be supported to understand their emotional experiences rather than a focus on problem solving strategies as had been the dominant debate (Kneebone & Martin 2003).

Themes of acceptance have also been identified in the literature on maintaining couplehood (Robinson et al., 2005). The four couples in this study demonstrated that they had come to terms with the dementia diagnosis but that adjusting to dementia was a continual process. Acceptance was also demonstrated as being a coping strategy with levels of acceptance interlinked as each new change resulted in the need to develop more coping strategies (Robinson et al., 2005). What was clear in this study was that couples were able to integrate dementia into their sense of self whilst maintaining their sense of couplehood (Molyneaux et al., 2011b). This was also seen in the theme Re-Appraisal, in which CST supported individuals to maintain their sense of personhood. This is linked to stages of acceptance as described by Hellström et al. (2007) who demonstrated how acceptance of their situation enabled couples to reflect on changes and so sustain their couplehood. This also reflects research by Robinson et al. (2005) and Merrick et al. (2016) who describe the oscillating process couples engage in to reach acceptance of their situation. However, acceptance was different in and between the spouses, and the sense of movement between acceptance and loss was captured throughout all couples' narratives. The research demonstrated that it was important for couples to reach these stages as this enabled them to reflect on and sustain their sense of couplehood, as described by Hellström et al. (2007) and Merrick et al. (2016).

As such, some of the couples highlighted their joint interdependence which was interpreted as a means of promoting the self-identity of the spouse with dementia. The use of coping strategies was also seen as important for holding onto couplehood (Robinson et al., 2005). The wider research suggests that people with dementia often overestimate their level of interaction or engagement with activities (Farias et al., 2005). However, this was not apparent in the current study as all couples were aware of the

impact of dementia on their couplehood. This could indicate that the couples had altered their perceptions of the consequences of dementia to their relationships. As discussed, the four couples in this study demonstrated a shared awareness of dementia, as proposed by Hellström et al. (2007), which resonates with the sense of the couples moving through stages of dementia. However, the findings of this study also suggest that awareness of dementia is an individualised response as there was variability in and between the couples.

The difference between MCI and dementia diagnosis was also a source of confusion for the couples. This aligns with the work Prakke (2011) who similarly found that individuals in the MCI range remained uncertain about the reasons for their cognitive problems and whether their cognitive abilities may potentially worsen over time. An important distinction is that for the couples in this current study some aspects of care giving had already been introduced into the relationship prior to a formal diagnosis of dementia. An MCI had already made an impact on the couples and the results of this thesis suggest that couples within this range of cognitive impairment could be better supported by providing interventions targeting the symptoms that are already evident rather than having to wait for the symptoms to worsen before they 'are in the category to receive help' (Alex). The results also confirm that couples with MCI are often in the early stages of what may become an emotional journey for them (Samsi et al., 2014) and the early stages may be an important time and opportunity to make plans for a 'possibly drastically changed future' (Prakke, 2012)

(Prakke, p13 2011).

An important finding from this research was that spouse with dementia recognised and appreciated the care provided by their partner, which also enhances the notion of

couplehood. Again, this resonates with the findings of Hellström et al. (2007) and Merrick et al. (2016) in that couples actively work together to devise strategies to maintain their sense of couplehood. This includes shared activities and taking pleasure in the remaining abilities of the spouse with dementia.

Previous research on marital relationships and dementia has demonstrated that communication between couples is meaningful in determining marital satisfaction and relationship quality (O'Rourke et al., 2010; Braun et al., 2010). However, in contrast to Clare et al. (2012), the four couples in this study did not indicate that changes to communication resulted in greater levels of stress within the relationship, although they were communicating in a different way.

Stress and relationship quality have also been linked to the stress process model in dementia (Pearlin et al., 1990) (See Section 3.5 for discussion on the stress process model). Caregiver stress has been strongly associated with a reduction in relationship quality within the wider literature on dementia and relationships (Clare et al., 2012) since perceived loss of the relationship is a major factor of care partner stress. This has also been linked to equity and investment theories (See Section 3.4 for discussion on equity and investment) and notions of reciprocity in which the perceived costs of caregiving outweigh the perceived gains, leading to an imbalance within the relationship as well as to caregivers being at risk of high levels of stress. However as John (care partner) pointed out, he felt happy to be caring for Gwen in order to repay her for the care she had provided for him in their earlier married years. This was also reflected in the narratives of Liv and Elliot and Richard and Harlee. The sense of reciprocity was important for the couple's maintenance of couplehood and negated against possible

feelings of resentment. The sense of partnership for life (Prakke, 2012) also draws on notions of togetherness and commitment that the couples would always remain together.

Despite the obvious presence of stress for both members of the couple, the findings from this study contradict those of Svanstrom and Dahlberg (2004) in that couples were not overwhelmed by stress levels and were able to cope and adapt to stress in their relationship.

The notion of reciprocity was evident throughout the interviews as care partners described ways in which their spouses had invested in the relationship and had made sacrifices for them, resulting in a sense in which they wanted to repay them in kind. This has previously been linked to models of equity and investment (Baikie, 2002; Braun et al., 2009) (See Section 3.4) in which the sense of balance within the relationship contributed to overall relationship satisfaction (Quinn et al., 2015). Even Robert and Alex whose relationship appeared tense maintained that they had a strong sense of couplehood which was enhanced by the reciprocity of giving and receiving care for each other. However, it is worth noting that this may not be the case for all couples, since a lifetime of shared memories provided a foundation on which these particular couples had built their relationships so that they were firm enough to withstand day to day tensions. This again resonates with the findings of Molyneaux et al. (2011b), who demonstrated that pathology should not be automatically applied to couples who are observed as being argumentative, as assessment should consider whether this is typical of a couple's history of interaction. This current research verifies the assertion of Molyneaux et al. (2011b) that it is important to look at the quality of past relationships alongside current perceptions as they may reveal important indicators of which couples may be more likely to experience stress and strain.

## Chapter 6

The importance of how couples understand dementia has been highlighted in previous research (Robinson et al., 2005). In particular, the ways in which couples assign meaning to the illness and negotiate change has been demonstrated to be important. Perhaps unsurprisingly, the impact of difference as a result of dementia revolved around firstly memory changes but also changes to behaviour and temperament. Loss of confidence was highlighted as an outward sign of worsening memory. The couples had varying explanations for dementia including medical and ageing theories. Further research into spouses understanding of dementia may help to predict and anticipate how they negotiate dementia and may help identify the resources they utilise.

Relationship continuity was also considered important in enhancing notions of couplehood. A sense of continuity and discontinuity was a theme throughout the current study. There was a sense that the couples were experiencing some discontinuity in their relationship as the challenging behavioural symptoms of dementia (BPSD) (see section 1.6.2) resulted in a sense of the diminishing of someone who was once familiar and an emergence of someone new. Richard summed this up when he discussed the way Harlee was becoming anxious and “a bit more like me”, suggesting that the old familiar Harlee was disappearing and instead someone new and unknown was emerging. However, continuity in the relationship was also evidenced and this may link with the notion of shifting identities (Hellström et al., 2007; Atta-Konadu et al., 2011).

Whilst being a care partner or a spouse with dementia can be challenging, the couples in this study also demonstrated that these experiences can be simultaneously positive and negative. The current study struck some balance between these experiences, and as such can be seen to contrast with the findings of Svanstrom and Dahlberg (2004) who described an entirely bleak, negative experience of dementia and couplehood.

In answering research question one, findings from the current study resonate closely with those of Molyneaux et al. (2011b), Davies and Gregory (2007) and Merrick et al. (2016) in that notions of couplehood reflect the way in which the couples' relationship shaped the lived experience of dementia rather than dementia shaping the marriage. Notions of perceived couplehood were sustained if couples were able to separate dementia from their relationship and if changes were seen as resulting from the disease rather than from each other.

A novel finding of this research was that spouses with dementia were able to identify and articulate the impact that dementia had not only on themselves but also on their spouse and on the couple unit and resonates most closely with the work of Merrick et al. (2016) in that the increased ability of spouse with dementia for reflection on changes to self and others has not been previously identified in research on dementia. This thesis also resonates with the bulk of the literature on dementia and marriage in that the couples were able to find some balance between the positive and negative impact of dementia on their relationship.

The findings of the research contribute towards understanding the ways in which professionals could support couples to adjust to and cope with dementia in order to maintain a continued sense of togetherness (McGovern, 2011). Supporting couples to maintain their sense of couplehood (Hellström et al., 2007; Hellström et al., 2005) and co-construct new ways of relating (Molyneaux et al., 2011b) in light of changes could be a means of optimizing ways in which couples can protect what remains of their relationship as well as being supported to acknowledge, tolerate and mourn what has been lost (McGovern, 2011).

## 6.6 Addressing the second research question

### **What is the lived experience of couplehood in which one spouse has dementia?**

Central to the lived experience of couplehood were issues of loss and shifting identities.

Roles within the relationship were threatened, resulting in the emergence of a new reality for the couples. This was illustrated in the master theme of Living the New Normal.

The four couples demonstrated that the lived experience of couplehood revolved around an oscillating sense of movement through progressive stages. These stages involved the ways in which the couples understood, experienced and adjusted to dementia as well as how they worked to maintain their sense of couplehood (Hellström et al., 2007). The description of couplehood and dementia as a journey through stages is well established in the literature (Atta-Konadu et al., 2011; Hellström et al., 2007; Daniels et al., 2007; Vernooij-Dassen et al., 2006) and the process of diagnosis as well as the ways in which couples noticed subtle changes which impacted on their perceived sense of couplehood were seen as the natural starting point of the couples' stories. These changes were described in the master themes Navigating Disruption through to Living the New Normal. The start of the dementia journey was illustrated as a developing story, beginning with an awareness that something was wrong, which led to formal diagnosis. Couples described fears and anxieties when they began to notice memory changes. The process of diagnosis was experienced as a shock while also providing some relief. Couples offered several explanations for dementia and attempted to normalise their experiences, which helped them to regain some sense of control over the illness. Receiving a formal diagnosis was also seen as a confirmation of what the couples already suspected and acted as a stimulus for making decisions about their future (Hellström and Torres, 2016) as well as a means of expressing grief and sadness (Vernooij-Dassen et al., 2006). The stages of acceptance also

involved couples re-evaluating their relationships as a whole, alongside an appreciation of their spouses' remaining capabilities (Hydén and Nilsson, 2015). Furthermore, the results from this study confirm the importance of including both members of the couple in the research as despite being in the same situation there was vast differences in how couples coped and reacted (Hydén and Nilsson, 2015; Merrick et al., 2016; Molyneaux et al., 2011b). For example role change was experienced by both members of the couple, but the impact on sense of self was demonstrated as a highly individualised experience.

As discussed above, the analogy of the dementia journey as a process of stages is well documented (Hellström et al., 2007; Daniels et al., 2007). The results from this study are similar to those of the pre-diagnosis, diagnosis and post diagnosis stages described by Robinson et al. (2005). The four couples in the current study illustrated the ways in which they attempted to regain control of their situation and normalise their experiences in order to get on with their lives. Understanding the dementia journey as a process of stages increases knowledge of how couples attempt to 'Navigate the Disruption' of dementia. The findings from this study therefore corroborate the existing literature by demonstrating that the ways in which couples adapt to dementia involves stages of acceptance as well as attempts to normalise the situation and so regain some level of control over their lives.

The four couples in this study demonstrated that the process of accepting the diagnosis was static whereas the process of change was ongoing. Whilst the couples had come to terms with the diagnosis, there were marked differences in the methods and levels of acceptance. This can be linked to the findings of Robinson et al. (2005), who demonstrated that coping and acceptance are multifaceted and can be complicated by issues such as anticipatory grief. The couples in the current study all demonstrated a

motivation to get on with their lives and fight together to maintain their sense of couplehood. In contrast to Robinson et al. (2005), the four couples in this study felt empowered rather than overwhelmed by the dementia diagnosis. However, that said, there remained a level of denial over the fact that the dementia would get worse. Therefore, as the couples' understanding and experience of dementia develops, it may ultimately impact on how they are able to cope.

All the master themes in this study revealed the enormous sense of loss that the couples experienced, including a gradual and continual loss of the sense of self, the unrelenting loss of partner and loss of the relationship as it once functioned (Robinson et al., 2005). This is in line with previous research, which has demonstrated that the progression of dementia results in multiple losses (Evans and Lee, 2013; Baike, 2002; Quinn et al., 2009), meaning that couples must engage in an unyielding process of adjusting to loss (Robinson et al., 2005). Both the spouses with dementia and their care partners in this study experienced connected but distinctly different types of loss. The care partners' loss was associated with loss of a confidant, loss of reciprocity in the relationship and loss of someone familiar. The spouse with dementia's loss was associated with increasing dependence, worsening memory and decreasing sense of identity and connection to the world. For the couple unit, loss was associated with a lack of control over their situation and circumstance as well as a gradual reduction in shared activities (Svanstrom and Dahlberg, 2004). Furthermore, for care partner wives (particularly Liv), the loss of husband as the epitome of someone strong, fit and dependable also impacted on her sense of femininity. This has also been identified within the wider literature on dementia, gender and care giving/receiving in that female care givers experience greater levels of stress, burden and depression compared to male caregivers (Pillemer et al., 2018).

Additionally, female care partners spouses experience the impact of dementia on their husbands as a discrete threat to their own sense of femininity (Molyneaux et al., 2011c).

These multiple losses perhaps served to accentuate each of the individual experiences of loss. This links to theories of bereavement in dementia. Whilst the experience of loss and specifically anticipatory grief is well documented for care giving spouses (Meuser and Marwit, 2001; Boss and Kaplan, 2003), bereavement and loss from the perspective of spouse with dementia has been a less researched area. The ways in which each individual spouse copes with and experiences loss has also been largely ignored in the wider literature. For example anger and frustration of their spouse was often interpreted as being a symptom of dementia by care partners'. However these emotions could also be a natural and healthy grief response. Aminzadeh et al. (2007) demonstrated the wide range of emotional reactions to diagnosis that individuals with dementia can experience. The temptation to over medicalise these feelings may result in a negative impact on wellbeing and may miss the opportunity for individuals with dementia to express their grief and loss (ibid). What was clear from the couples' accounts was a continual sense of loss which was likened to a 'living bereavement' (Clark et al., 2017: p5), although this issue was not further investigated in the literature. The couples in the current study experienced a living bereavement which encompassed the emotional demands, grief reactions and complex responses of being witness to multiple losses within their relationship, highlighting the need for further research in this area. The term 'living bereavement', originally coined in an article on health care workers' responses to loss and grief on a continuing care ward for older people (Holman, 2008), is specifically pertinent here as it embraces the notion that grief and loss for couples where one spouse has dementia is an ongoing, ever-changing and emotionally demanding process (Holman,

2008). Literature on loss has thus far overlooked the complexity and multiplicity of loss in dementia and more so in relation to couplehood, specifically for spouses with dementia (Rentz et al., 2005). Grieving the loss of a pre-existing relationship and also the loss of an imagined future together was bound up in the couples' feelings of guilt and grief; the weight of responsibility was at times frustrating and burdensome. Witnessing the distress and anger of their spouse was disturbing and upsetting for care partners, who often felt helpless in knowing how to fully support their partner.

The resemblance of transition and grief to that of bereavement as well as the notion of the relationship as something that was diminishing demonstrates the intricate complexity of loss on an emotional level. The results from this study are consistent with wider research in that the spouse with dementia grieved the loss of past activities and lost skills while also supporting the view that an individual with dementia retains an integral sense of identity (Molyneaux et al., 2011b). Retaining a level of insight also resulted in worsening grief as both spouses were witness to multiple loss (Aminzadeh et al., 2007). Results from this study also indicated that spouses with dementia may take longer to accept changes and that the oscillating process is different for them than for their care partner. Despite a focus on care giver bereavement, there is little research on how the individual with dementia experiences and copes with bereavement. On this issue, this thesis echoes with the work of Evans and Lee (2013), who undertook a qualitative review of dementia and marriage and demonstrated that transition and loss are interconnected since loss results in changes to the relationship, which in turn results in further losses. More research is needed to increase understandings of how grief and loss impact on each individual spouse in order to create and develop services which facilitate couples in expressing their grief in a holistic, open environment.

The master theme Mindfulness also highlighted how self identity and changing roles presented further transition and loss in the relationship. This theme is in line with research from Molyneaux et al. (2011b) and Atta-Konadu et al. (2011) which demonstrated the notion of shifting identities. As previously stated, the couples in this study found that dementia is experienced as a set of stages, which is reflected in the ways couples worked through these stages in order to maintain their sense of couplehood.

Care partner spouses experienced conflict between aspects of their identity as a spouse and becoming engulfed by the role of care partner. For the spouse with dementia, the transition from being a partner to being cared for resulted in isolation as their sense of identity weakened. The shifting of roles also represented an imbalance of power in the relationship, as suggested by Robinson et al. (2005). Both partners struggled with these changes, albeit in different ways. These struggles were also demonstrated in the master theme Navigating Disruption, and represented a conflict of emotions as care partners wanted to provide care and support but also experienced this as disturbing and disruptive since their partners' sense of independence was diminished – this links closely with theories of biographical disruption (Williams, 2001). There was also notable areas of internal emotional conflict particularly for the care partners as they were often tasked with meeting their own needs alongside those of their partner (O'Shaughnessy et al., 2010) which increased their risk of becoming physically and emotionally overwhelmed in their efforts to meet these needs (Davis et al., 2011).

Most notably, all the current study participants identified a sense of shifting identities within couplehood. This also resonated with the work of Molyneaux et al. (2011a) in that as the couples noticed changes to their relationship, they often struggled to maintain a sense of normality. This is likely due to the transferring of roles within the marriage as

the care partner spouse was tasked with taking on more responsibility for their partner and also for the relationship as a whole. The sense of fluctuating identities (Molyneaux et al., 2011b) is consistent with the literature on holding on and letting go highlighted by Robinson et al. (2005). In particular, couples in the current study moved between positions of letting go of what had been lost in the relationship but holding on to what remained. This can be linked to the oscillating process in which individuals moved between positions of loss and restoration identified by Clare (2002), Robinson et al. (2005) and Merrick et al. (2016). However, despite these losses to self identity, the couples fought to uphold the identity of the spouse with dementia by promoting their engagement activities (Molyneaux et al., 2011b). This verifies research by Hellström et al. (2007) in that couples work together to maintain the involvement of spouse with dementia.

During the interviews, all of the participants' accounts were often emotionally charged, since negotiating psychological loss also resulted in changes to each spouses own identity. For the spouse with dementia, loss of their sense of self coupled with the loss of their self in the eyes of their partner was particularly distressing at times. It is important to understand how individuals experience their sense of self since this impacts on how they cope with dementia and how they relate to others (Caddell and Clare, 2011). This understanding also has the potential to enable beneficial support interventions as highlighted in initiative such as the dementia strategy (See section 1.7.2 for discussion on psychosocial interventions).

Additionally, changes to the reciprocal nature of couplehood as a result of dementia appeared to create a sense of isolation for each spouse. For spouses with dementia, an inability to undertake household chores coupled with witnessing their care partners

taking on more responsibility created a sense of loneliness. This is linked to the couples existing in separate worlds, as identified by Hellström et al. (2007). Both spouses were able to describe tangible changes to cognition, motivation and ability to undertake household chores, and most couples were able to offer a similar explanation of the impact of these changes alongside anecdotal stories which illustrated them. For example, while memory changes were an expected and anticipated result of dementia, changes to behaviour such as loss of motivation, irritability and subtle personality changes resulted in the emergence of the partner with dementia as someone new and unfamiliar. This supports the wider literature that behavioural change create more stress for care partners and that changes in roles also affected the sense of normality in the relationship (Braun et al., 2009; Feast et al., 2016). Additionally, changes to the relationship itself was also viewed by care partners as more distressing than the symptoms of dementia (Mitrani et al., 2006). For example the loss of Elliot as a reliable problem solver presented itself as more challenging for Liv than his worsening memory and this is consistent with wider research in this area in that the emotional impact of dementia can be more challenging for care partners than the practical demands of the disease (Feast et al., 2016; Carpenter et al., 2008).

However, in contrast to the dominant literature (Vitaliono, 2015; Quinn et al., 2009; Johnston and Terp, 2015) care partners in this study did not feel that their efforts to support their partner were unnoticed; indeed, the spouses with dementia demonstrated that they were grateful for their partners' efforts. Such a point confirms that acknowledging and incorporating dementia into their narratives was a way in which couples adjusted positively to dementia and was an adaptive coping strategy which is in

contrast to the conclusions drawn by Quinn et al. (2015) and Johnston and Terp (2015) and the wholly austere portrait offered by Svanstrom and Dahlberg (2004).

An important finding of the current study is that despite the intensity of dementia, all of the couples demonstrated an increase in empathy and understanding for their partner.

## **6.7 Addressing the third research question**

### ***Does CST impact on perceived couplehood?***

This study aimed to explore whether CST impacted on sense of couplehood. This is mostly explained in the master theme Re-Appraisal (see section 5.7) which illustrated that for spouse with dementia, opportunities to access social groups outside of CST was limited. Social isolation and loneliness were particularly significant for the spouses with dementia as they were reliant on their care partner for all aspects of their daily living including access to social opportunities. Reduced social interaction has been linked to cognitive decline in older age (Woods et al., 2006) which then results in a spiralling effect as deterioration in cognition leads to increased isolation which increases cognitive decline. People with dementia are at risk of limited access to socially stimulating activities, which this study confirmed.

Participants in this study reported that they had benefitted from the structure of the CST group and valued meeting other people who were in a similar situation. The safe, secure environment of the group provided participants with the opportunity to talk to others about new or worrying symptoms of dementia in a way that was different from conversations with their spouse. Being able to express their feelings and be understood by others was a validating experience which supported the participants in normalising and legitimising their thoughts and emotions. Realising that they weren't alone and that

their experiences and emotions were shared by others in the group provided opportunities that were not possible outside of the CST setting.

Attending CST also helped participants to feel useful. The activities were meaningful, and participants were able to use the experience to compare themselves to others in the group. This is in line with CST research undertaken by Allward et al. (2017) who suggest a modest improvement in personal autonomy and empowerment of CST participants but also suggest that the use of a quantitative measure may have limited exploration of this at a deeper level. However, the CST group in this study reminded one participant of his lost career, while another found it distressing to be with people who were more cognitively impaired than he was. Another participant became so preoccupied by her diagnosis that her spouse queried whether CST had served to remind her of her declining abilities. This highlights the need to ensure that CST participants are matched by ability and skill level. Further research into the impact of the CST group dynamics on participants would be of benefit. Future qualitative research could also further knowledge of the subjective and individualised nature of the impact of CST on individual wellbeing.

The role of group facilitator was also important as participants felt that their problems were understood in a non-judgemental and non-stigmatising environment. The current findings support earlier qualitative research by Spector et al. (2011), who demonstrated that participants valued the supportive environment provided by CST.

The current research also supports the finding of Spector et al. (2011) that there were noticeable gains outside of the CST group as care partner spouses observed an increase in spontaneous interaction and an increase in general wellbeing and self-esteem. This growth in conversation had a positive impact on sense of couplehood as spouses with

dementia felt that they were able to bring something new to talk about and care partners noticed that their partner was generally happier and more content after attending the group (Bailey et al., 2016).

However, despite CST aiming to improve overall cognitive function, none of the couples observed any improvement in cognition or new learning from CST, which has also been found in the wider literature on CST (Spector et al., 2010; Bailey et al., 2016). An explanation offered for this is that CST is based on general, overall stimulation rather than explicit learning per se (Woods et al., 2012). Improvements noted by care partners may have been due to improvements in confidence and self-esteem, and research verifies that for these participants, CST is invaluable in mitigating the effects of 'malignant social psychology' (Kitwood, 2002: p230) (see section 5.1.2). This is a principle which lies at the core of CST (Woods et al., 2006). Care partner spouses reported they initially felt relieved that treatment was being offered to their spouse (Bailey et al., 2016) but that overall they were disappointed that there were no tangible and practical gains of CST and did not ultimately understand the rationale for the group. However, improvement in mood was noted as a favourable outcome, supporting research by Bailey et al. (2016) but contradicting that of Woods et al. (2012), who found no evidence of improved mood following CST. An explanation offered for this is that the participants in the research of Bailey et al. (2016) also attended a 10 week carer session, which may have influenced the carers' perceptions of their relatives mood and quality of life and more significantly increased carers understanding and tolerance of some of the behavioural symptoms of dementia. Although this current study does not advocate for care partners to be included in CST sessions or a combined intervention, it does demonstrate the importance of informing care partners of the value and process of CST by which the overall value of

the groups could be enhanced. The benefits of combined psychosocial interventions for dementia are well documented within the wider literature (Brodaty et al., 2013) and a key feature of the success of these groups was the involvement of individual with dementia alongside that of their carer/care partner.

Therefore, the current study is of great value given that CST participants are generally in a relationship with a significant other: usually a spouse, adult caregiver or informal carer. This would indicate that further qualitative research into the subjective experiences of individuals with dementia alongside their significant other would be of high value in informing research of the motivators and stimulus of participation in CST.

The majority of the couples spoke favourably about CST and the participating spouses reported that they felt a general sense of wellbeing after attending the course even if they weren't able to remember specific details. This is in line with the CST study by Bailey et al. (2016) who similarly found that carers were generally enthusiastic about CST. However, despite being fundamentally optimistic about CST, couples were often at a loss as to what the group was about or what it hoped to achieve. Again this verified by the findings of Bailey et al. (2016) who similarly demonstrated that carers did not have any concept of the rationale for CST.

This indicates that the ways in which CST is marketed to couples could be misleading as the group seemingly did not meet expectations as care partners were hoping for more obvious and concrete cognitive gains. This is an interesting and novel finding which would benefit from further exploration in future research.

A final finding within this master theme revolved around the group ending, at which point the spouse with dementia who had attended the CST group felt they had been

abandoned and had no way of filling the social void that the had group filled. For these spouses, the group met their need for validation and endorsed their personhood (see section 1.6.2), which may have accentuated their sense of isolation once the group had finished. The care partner spouse was more ambivalent about the group ending and did not feel motivated to seek out new opportunities for their partner. This perhaps relates to the lack of perceived cognitive gains which may have prompted care partners to engage in further stimulating activities at home. Results from this study indicated that the social stimulation of the CST group was more beneficial and important for the attending spouse than it was for their care partner (Allward et al., 2017). This is an interesting finding which suggests that future research into the longer-term gains of CST would be beneficial.

## **6.8 Discussion**

The current study supports the importance of understanding dementia within the context of couple relationships (Nolan et al., 2004 ). The study verifies the importance of including both members of the couple in research since the results from the four couples indicate that the wellbeing of one spouse will influence the wellbeing of their partner (Vernooij-Dassen et al., 2006; Bielsten et al., 2018; Evans and Lee, 2013). Additionally, the spouses with dementia were able to acknowledge their memory problems, which confirms the view that individuals with dementia retain some insight into how their memory issues impact on their spouse (Robinson et al., 2005). The sense in which relationship quality, history and issues of acceptance impact on notions of couplehood (Ablitt et al., 2009) was also apparent, which contradicts some views within the literature that people with dementia are unable to reflect on changes to self (Rankin et al., 2005).

The results from this study emphasise the collaboration of both spouses in attempts to maintain couplehood; despite transition and loss, the couples actively worked together to sustain their sense of couplehood. This thesis therefore closely resonates with and expands the work of Hellström et al. (2007) and Molyneaux et al. (2011b) in demonstrating the efforts that couples engage in to maintain the identity of the couple unit despite dementia. Additionally, the results demonstrate the importance of viewing couplehood as a joint, working relationship rather than confining it to simply an exchange of care giving and receiving as has previously been demonstrated in the literature. Defining the care giving spouse as a care partner also demonstrates the inter-connectivity of both spouses working together to overcome dementia. Identity and 'we-ness' (Hydén and Nilsson, 2015) also help to support the notion that couples share identities through their couplehood and recognise the couple relationship as the natural starting point so that support can be directed to both spouses to sustain their couplehood (Hydén and Nilsson, 2015; Hellström et al., 2007).

Finally, I believe that this study offers a balanced, exclusive account of couplehood and dementia and is in direct contrast to the work of Svanstrom and Dahlberg (2004), who purport a completely bleak picture of couplehood and dementia. This may be due to the participants in this study being in a seemingly earlier stage of dementia than the participants in the Svanstrom study.

## **6.9 Strengths and limitations of the research**

This study has added to the existing knowledge around couplehood and dementia and also expands the existing literature of CST. This was the first qualitative study to investigate the lived experience of dementia, couplehood and CST. Interviewing both the spouse with dementia and their care partner equally enabled a perspective of

couplehood which would not have been achieved otherwise. Additionally, interviewing the couples separately promoted free expression of thoughts and feelings which may have been restricted if they had been interviewed together. This has therefore led to the development of a relational perspective of couplehood and CST. The importance of including the person with dementia in research is well documented and supports the notion of person-centred care.

Additionally, the use of IPA (Smith et al., 2009) led to a rich, detailed portrait of couplehood and despite lack of transferability the study is useful as indicates that any couple confronted with loss and transition in their relationship may undergo a similarly challenging experience.

However, there are some methodological weaknesses which need to be recognised. Firstly, despite the inclusion of the spouse with dementia in the research, the impact of cognitive deficits during the interviews must be acknowledged. This relates to wider considerations about people with dementia's ability to recall information or accurately describe their experiences. The deteriorating cognition of the spouses with dementia was evident even within the relatively short 14-week course, implying that individuals in later stages of dementia may have been less able to describe their experiences. However, that said, an interesting and positive finding of this research was that not only were spouses with dementia able to describe the impact of dementia on themselves, they were able to demonstrate a level of empathy and awareness of the impact on their spouse. This verifies the need to include the voices of spouses with dementia in research. Research into the impact on sense of couplehood with individuals in later stages of dementia would be of benefit. Individuals with dementia could be supported to participate through means other than interviews such as visual based methodologies.

Secondly, the small sample size of four couples was deemed appropriate for an IPA study and aided a detailed, rich description of the lived experience of dementia whilst providing an opportunity for the emergence of the idiosyncratic, convergent meaning making (Smith et al., 2009). However, the qualitative design may make it difficult to generalise the findings (Smith et al., 2009). Lack of generalisability is further compounded by the sample being white, British, living in the South East of England and in long term relationships; as such, social context may have impacted on their experience. Findings therefore need to be applied with caution in relation to other ethnic groups or individuals with different social and economic status or for couples in shorter relationships or second marriages. All participants were accessing support from the memory clinic, which may also have impacted on their experiences and therefore influenced the findings. Future studies may consider similar research in different geographical areas of the UK, or with participants from different cultural and ethnic backgrounds. Different types of relationship could also be considered for future research; for example, the voices of spouses in same sex relationships are under-represented in the literature.

Furthermore, spouses with dementia in this study were diagnosed with either Alzheimer's or mixed dementia, which are the most common variants of the disease. Therefore, it may be difficult to relate the findings to people with different sub-types of dementia. Different types of dementia can result in different signs and symptoms (see section 1.5 for discussion on symptoms of dementia) and may therefore impact on relationships in different ways. Future research which considers whether different sub-types of dementia impact differently on the couple relationship would be of benefit.

Lastly, including the person with dementia was a fundamental principle of the research. In addition, it was important to promote free expression, which meant that couples were

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interviewed separately from each other. As discussed, there are pros and cons of interviewing the couple together. Some research has yielded positive results undertaking this method (Hellström et al., 2007; Robinson et al., 2005; Davies, 2011). The research may have been enhanced by undertaking separate interviews as well as a final interview with both members of the couple. This could be considered in future research.

Despite there being no criteria for the gender of the care partner and spouse with dementia, it was a fortunate coincidence that I was able to recruit two male care partners and two female care partners. This led to a sample which was homogenous while also enabling divergence and convergence in the data. It was evident that gender played a role in the lived experience of dementia for the couples and that being a female care partner was discretely different to being a male care partner for these participants. This was likely linked to traditional gendered roles and societal expectations of who provides care (Pinquart and Sörensen, 2006). Two studies which explored dementia and marriage have been undertaken with male participants (Clark et al., 2017; Atta-Konadu et al., 2011); future researchers may consider carrying out further studies with all an all-male or all-female sample as the gendered experiences of these groups may differ.

Lastly, all participants volunteered to take part in the research, which may have unintentionally resulted in a positive bias towards participants who were more open and confident in discussing their relationships (Merrick et al., 2016). Future research with couples who are identified as being at risk of high levels of stress due to conflict and tensions in their relationship would be of benefit.

## 6.10 Clinical implications

The findings of this research demonstrated how an understanding of the marital relationship can inform clinical practice. The couples in this study experienced a wide range of emotions including connected but distinctly different types of loss. This highlights the need for spouses to receive support specifically related to issues of grief and loss.

Additionally, the results of this study demonstrate that changes to self identity were seen as integral to the experience of dementia and couplehood. Research has explored changes to sense of self from the perspective of either being a care partner or of being an individual with dementia (Caddell and Clare, 2011). This demonstrates a need for services to be mindful of theories which may help explain how changes to one's self identity impact on the couple in order to provide appropriate interventions which are relationship-centred.

Linking the lived experience of dementia to that of biographical disruption could increase knowledge of how to support couples to navigate the disruption of dementia.

CST was illustrated as being beneficial since the attending spouse was able to enjoy a safe space in which to discuss the changes associated with dementia. CST was thought to impact positively on the quality of the relationship as the spouse with dementia was engaged in activities which they felt were meaningful. Increased confidence and communication were also key in improving overall relationship quality. However, these gains were short lived as once the course was finished, spouses were left to cope alone. The research highlighted that the expectations of couples were not realised as well as a mismatch between how CST is marketed and what it achieves. The findings suggest that carers would benefit from attending a specific carer CST run in conjunction to the CST

course in order to inform them about what CST is. In line with Spector et al. (2011) and Bailey et al. (2016), the care partners in this current study also reported feeling frustrated that they did not know what was happening in the CST group as their spouse was often unable to recall the details of the course. This may encourage care partners to incorporate some of the core principles and activities of CST into their daily interactions and also may result in additional cognitive benefits of spouse with dementia.

The current study has initiated such a change, and based on the results of this study, this locality now invites carers to attend one CST session along with their spouse. Although this is for all types of carers including adult children and family friends, the research has been influential in initiating changes to the way CST is delivered. The group itself isn't to instruct carers about CST per se, but rather to give carers a flavour of the group and to observe the positive impact on morale and confidence. Preliminary feedback indicates that carers find this session useful. The carers are invited to attend one CST session in order to give them an indication of CST. It is hoped that carers may be motivated to carry on CST type activities once the group has finished. This was in order to address the criticism of carers that they have no indication of what CST is. An additional change that has been instigated by this study is how CST is marketed to individuals and their carers with a focus on the non cognitive gains. This was in order to address the criticism that carers expected more cognitive type change. To my knowledge a CST session which includes carers is not routinely run in memory clinics and this may be a unique position for this location within the Trust which has run such a group and is a beneficial addition to the CST groups. The value of combined interventions for individuals with dementia and their carer has been identified in the literature (Brodsky, 2012; Quayhagen et al., 2000). Research also demonstrates that the inclusion of care partners (including that of adult

children and informal care givers) in interventions can have a greater impact than individual interventions and have been shown to increase communication and interactions between care givers and care receivers. Woods (2006) explored CST with an additional carer training session but did not find any improvement in quality of life or cognition of individual with dementia, however these studies were quantitative in nature and did not explore the intricate nuances of the relationship dynamic. This would therefore indicate that further research which explores the views of both members of the couple would be appropriate given that CST is recommended as a treatment for individuals with dementia. However it is important to note that care partners are already overwhelmed by the responsibility of caring for their spouse and it could be that the added task of providing stimulation to their partner may in fact be more burdensome. The study indicated that care partners were not interested in doing CST at home per se, but rather wanted to be informed about what their spouse was doing during the CST intervention. However, it is hoped that carers may intuitively pick up CST type activities which would ultimately impact positively on the relationship as has been modestly demonstrated in the literature of CST and carers (Woods et al., 2006; Bailey et al., 2016). However, that said, research suggests that it is the social opportunities which are afforded in the group format which is more beneficial than carer led individual interventions (Scott and Clare, 2003; Quayhagen et al., 2000).

It is important to note that the aim of this thesis was not to investigate the efficacy of CST per se but rather to explore the potential impact on the spousal relationship. Further research into this phenomenon would be of benefit in order to find the right balance between informing the care partner and training/equipping them in CST type activities.

Alongside the benefits of CST, the study demonstrated a need for more social opportunities for spouses with dementia above and beyond that of their immediate family networks. The findings suggest that this should be offered in a safe and therapeutic environment in which individuals are able to discuss their symptoms with a group of people who are in a similar position. This would support individuals to feel that their experiences are validated and may mitigate against social isolation and loneliness.

### **6.11 Revisiting the concept of reflexivity as a researcher**

As discussed previously, researcher reflexivity was an important undertaking throughout the research process (see section 4.11 for discussion on reflexivity). This is the notion that I, as a researcher, have inevitably shaped and influenced the research and have been both a part of and apart from the research throughout (Goldspink and Engward, 2018). A reflective approach has enabled me to be inside and outside of the research and links to Heideggerian ideas of 'being there/ there being' (Dasein) (See Section 4.6 for discussion on phenomenology). I endeavoured to remain reflective about this throughout the research journey through self awareness and conscious attention of the process of the research (Finlay, 2011). This was achieved by attending regular supervision and utilising a research diary.

During the interview process and analysis, I endeavoured to bracket my pre-existing theoretical and clinical knowledge of dementia and CST and adhere to a phenomenological stance by being as close to the participants' lived experience as possible. During interviews I was struck by the couples' enduring love and commitment to each other but felt saddened that dementia would strip the couples of the life they had once known and shared. I felt this more so as I was writing up my thesis and felt sorrow for their loss as well as wondering what their situation was like now. As a clinician, my

natural human instinct was to reach out and help the participants by providing practical support or alerting them to other potential changes that dementia would be likely to create, an instinct that I had to resist. It was also difficult not to challenge unhelpful or maladaptive coping strategies but instead to bracket these thoughts from the research process. Throughout the research, I endeavoured to remain mindful that my role was that of researcher, rather than a clinician, and that the participant was the expert in their stories. This was a stance that felt unfamiliar at times as it was outside of my usual remit. Ensuring that the questions I asked were led by curiosity rather than to confirm what I felt I already intuitively knew was at times a challenge. For example, allowing silence and pauses in the interviews without feeling the need to fill these pauses felt strange as I am used to asking direct and frank questions about people's mood and functioning. I felt strangely nervous during the interviews; however, my confidence increased after each interview. I felt protective of the participants but also cautious not to offend them or put them off from further participation. The interview schedule was useful in helping me to keep focused whilst being led by the participant, while listening to the interviews back and my later reflection on those interviews was an important learning opportunity. There were times where the couples' stories would leave 'echoes' (Goldspink and Engward, 2018: P5) in which something that the participants said or the words they used would resound within my personal and professional life. It was important to be able to reflect on these experiences during supervision and through peer support. I have undertaken a number of presentations on the research and each time have been struck by the participants' honesty and willingness to open up about their lives. I felt it a privilege to listen to and represent their stories, and have been committed to doing justice to their experiences.

I am also aware that the questions and the way I asked them would have shaped the interviews. For example, the interview schedule specifically used the word 'couplehood', which was picked up by Alex (care partner). It is also likely that the word couplehood may have influenced how participants wanted to present themselves, as some may have only shared positive aspects of themselves and their relationship. Whilst reflecting on changes to the relationships, it was apparent that some of these changes were subtle and that couples may have only noticed them retrospectively during the interviews. Additionally, the interview process itself may have moderated the impact of dementia on couplehood as all couples commented that they enjoyed talking to me and had benefitted from the opportunity to voice their feelings.

Finally, couples may have also been reticent to criticise the CST course as this was a free course offered as an intervention from the memory clinic. I had been mindful of this issue during the recruitment phase and had specifically not undertaken the research within my own clinical location to ensure as much impartiality as possible.

Interviewing the participants in their own homes would also have influenced the analysis of data as I had access to their 'private lives' in a way which would not have been possible in a neutral setting. All participants were given a choice of where they would like their interview to be held and all chose to be interviewed at home. This is likely to have changed my perception of the participants as couples, as I was able to note family photographs, ornaments collected over the years, whether the house was tidy or untidy and so on, all of which were visual clues to their identity as a couple and their coping. I was also aware that during the interviews, the spouse who wasn't being interviewed would have had to sit out of the way, possibly underlining that their partner was talking about them but also acting as a reminder of their enduring 'enforced togetherness'

(Molyneaux et al., 2011b: p492). Access to this type of information goes beyond the spoken interview and the degree of couple closeness can be indicated in their physical environment (Lohmann et al., 2003). This issue further verifies the importance of reflexivity in order to heighten the interpretative elements of IPA (Brocki and Wearden, 2006b).

As a clinician who has facilitated CST groups, my pre-understandings would have been influential on my interpretations of the data. For example, my focus was drawn to certain elements of the lived experience of dementia and couplehood due to my prior knowledge. I found this often conflicted with my desire to adhere to IPA principles in terms of research design but equally did not want this to constrict or alter the data that was generated. For example, from my years of clinical practice, I am aware that the impact of dementia can be increased or lessened dependent on whether individuals have access to psychosocial support and I questioned whether I could be over focused on the ways couples used coping and compensatory strategies. However, I believe that I remained constantly open to the data and alternative perspectives and so was guided by what the participants said rather than what I expected to hear. I was aware that I had favoured one couple in particular and had indeed given them the pseudonym of a couple I admire. I was aware of this bias during the analysis and attempted to represent the other couples with the same zeal and consciousness that I had focused on that particular couple.

## **6.12 Conclusion**

IPA provided a credible means by which to understand the lived experience of couples and provided valuable insights into the notion of couplehood, in addition to the impact of CST on sense of couplehood. CST was a beneficial social experience which impacted

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positively on spouses' sense of couplehood. The findings highlight key areas for future research and have important implications in order to support couples to maintain their sense of couplehood. The study highlighted that couples were able to reflect on changes to their own self and the impact which such changes had on their partner and ultimately on their sense of couplehood.

The findings of this study contribute towards understandings that dementia within marriage is not solely about despair and burden but can be experienced as affirming life long commitment and reciprocity to each other. The study adds to assertions that professionals and services who seek to support couples should acknowledge and promote their relational experiences in order to support couples to sustain their sense of couplehood.

# Appendix A Participation sheet - patient and care partner



08/09/2014 - Ref: 14/SC/1131

## Participation Information Sheet – Patient (Version 3)

### **Research Study: Cognitive Stimulation Therapy and Couplehood**

I would like to invite you to take part in a research study about Cognitive Stimulation Therapy (CST) groups and couplehood.

This study is being conducted as part of a PhD degree programme. Prior to deciding whether or not to participate, it is important that you understand what the purpose of the research is and what will be involved, so please read the information below. If there is anything that is not clear or you would like more information please ask. My details are at the end of the information sheet. After reading the information, please take some time to consider whether or not you wish to take part.

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

The purpose of the study is to gain more understanding about how couples adjust to dementia and to explore whether CST groups make a difference. This is important because relationships may affect quality of life. Research studies like this may help to ensure that services provided are appropriate.

#### **2. Why have I been invited?**

You have been invited to take part in the study because you have been referred to a CST group and are in receipt of services from a Community Mental Health Team (CMHT) in Berkshire.

#### **3. What would I have to do if I take part?**

If you choose to take part in the study, you will be invited to take part in two face to face interviews, one before and one after the course of CST. Each interview will be conducted separately and individually from your partner and will be audio recorded. You will be asked questions about your experience about relationships and dementia before and after a course of CST. This will take approx one to two hours each time but can be shorter or longer than this depending on how much you want to say. All information would be kept private and names changed so you will not be identified.

**4. Do I have to take part and can I withdraw from the study?**

It is your decision whether to take part or not. A decision not to take part or a decision to withdraw from the study at any time will not affect your medical or social care in any way. You do not need to give a reason if you decide not to take part or withdraw at anytime. The completion of a consent form will be taken as your informed decision to participate. If you decide to take part you may withdraw at any time before, during or up to 30 days after the interviews.

**5. What are the risks and benefits to taking part?**

I cannot promise that this study will benefit you personally but your answers may help to improve groups and services. While your participation is valued, no expenses in relation to the study will be paid. The risks to you of taking part in this study are small, however should you find any questions upsetting, there will be opportunity to speak to a member of the Community Mental Health Team that provide services to you. This may be in the form of a telephone call or home visit.

**6. What happens if there is a problem?**

If you have any questions or concerns you can contact me, Sara Johnson or one of my supervisors Dr Athina Vlachantoni or Dr Rosalind Willis from The University of Southampton.

Dr Athina Vlachantoni (Senior Lecturer)

Dr Rosalind Willis (Lecturer)

Email: A.Vlachantoni@soton.ac.uk

Email: R.M.Willis@soton.ac.uk

Tel: (023) 8059 8940

Tel: (023) 8059 5367

If you require an independent source of advice, The Patient and Liason Advice Service (PALS) can be contacted on 0118 960 5027.

**7. Will my taking part in this study be kept confidential?**

Yes, all of the information collected will be made anonymous. The information you provide will be coded with a study number so you cannot be identified. All data will be kept secure adhering to the Data Protection Act 1998. Once the interview has been transcribed, the audio tapes will be deleted. Where a direct quote from an interview is used in a subsequent report or thesis these will be anonymised and unidentifiable.

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

The results of the study will form a PhD thesis and may be published in an academic journal. A summary of the results will also be shared with the Older Adult Community Teams in east and west Berkshire. A summary will also be made available to everyone who takes part in the study. At the end of the study data will be securely stored for up to 7 years at The University of Southampton.

**9. Who is organising and reviewing the research?**

The research is being sponsored by Berkshire NHS Trust and has been reviewed and approved by the NRES Committee South Central - Hampshire B REC (Research Ethics Committee).

Thank you

Sara Johnson (Occupational Therapist)

Email: [Sara.e.johnson@berkshire.nhs.uk](mailto:Sara.e.johnson@berkshire.nhs.uk)

Tel No: (01635 292070)

01/09/2014 - Ref: 14/SC/1131

**Participation Information Sheet - carer (Version 2)**

**Research Study: Cognitive Stimulation Therapy and Couplehood**

I would like to invite you to take part in a research study about Cognitive Stimulation Therapy (CST) groups and couplehood.

This study is being conducted as part of a PhD thesis. Prior to deciding whether or not to participate, it is important that you understand what the purpose of the research is and what will be involved, so please read the information below. If there is anything that is not clear or you would like more information please ask. My details are at the end of the information sheet. After reading the information, please take some time to consider whether or not you wish to take part.

**1. What is the purpose of the study?**

The purpose of the study is to gain more understanding about how couples adjust to dementia and to explore whether CST groups make a difference. This is important because relationships may affect quality of life. Research studies like this may help to ensure that services provided are appropriate.

**2. Why have I been invited?**

You have been invited to take part in the study because you have been referred to a CST group and are in receipt of services from a Community Mental Health Team (CMHT) in Berkshire.

**3. What would I have to do if I take part?**

If you choose to take part in the study, you will be invited to take part in two face to face interviews, one before and one after the course of CST. Each interview will be conducted separately and individually from your partner and will be audio recorded. You will be asked questions about your experience about relationships and dementia before and after a course of CST. This will take approx one to two hours each time but can be shorter or longer than this depending on how much you want to say. All information would be kept private and names changed so you will not be identified.

#### **4. Do I have to take part and can I withdraw from the study?**

It is your decision whether to take part or not. A decision not to take part or a decision to withdraw from the study at any time will not affect the medical or social care that your partner receives. You do not need to give a reason if you decide not to take part or withdraw at anytime. The completion of a consent form will be taken as your informed decision to participate. If you decide to take part you may withdraw at any time before, during or up to 30 days after the interviews without justifying your decision.

#### **5. What are the risks and benefits to taking part?**

I cannot promise that this study will benefit you personally but your answers may help to improve groups and services. While your participation is valued, no expenses in relation to the study will be paid. The risks to you of taking part in this study are small, however should you find any questions upsetting, there will be opportunity to speak to a member of the Community Mental Health Team that provide services to you. This may be in the form of a telephone call or home visit.

#### **6. What happens if there is a problem?**

If you have any question or concerns you can contact me, Sara Johnson or one of my supervisors Dr Athina Vlachantoni or Dr Rosalind Willis from The University of Southampton.

Dr Athina Vlachantoni (Senior Lecturer)

Dr Rosalind Willis (Lecturer)

Email: A.Vlachantoni@soton.ac.uk

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If you require an independent source of advice, The Patient and Liaison Advice Service (PALS) can be contacted on 0118 960 5027.

#### **7. Will my taking part in this study be kept confidential?**

Yes, all of the information collected will be made anonymous. The information you provide will be coded with a study number so you cannot be identified. All data will be kept secure adhering to the Data Protection Act 1998. Once the interview has been transcribed, the audio tapes will be deleted. Where a direct quote from an interview is used in a subsequent report or thesis these will be anonymised and unidentifiable.

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

The results of the study will form a PhD thesis and may be published in an academic journal. A summary of the results will also be shared with the Older Adult Community Teams in east and west Berkshire. A summary will also be available for everyone who takes part in the study. At the end of the study data will be securely stored for up to 7 years at Southampton University.

**9. Who is organising and reviewing the research?**

The research is being sponsored by Berkshire NHS Trust and has been reviewed and approved by the the NRES Committee South Central - Hampshire B REC (Research Ethics Committee).

Thank you

Sara Johnson (Occupational Therapist)

Email: [Sara.e.johnson@berkshire.nhs.uk](mailto:Sara.e.johnson@berkshire.nhs.uk)

Tel: (01635) 292070

# Appendix B Consent form



01/07/2014

**Consent form (Patient)**

**Research Study: Cognitive Stimulation Therapy and Couplehood (Version 2)**

- I have read and understood the information sheet and have had the opportunity to ask questions about the study
- I understand my participation is voluntary and I may withdraw at any time without consequence.
- I consent to my medical notes being accessed for study purposes.
- I consent to the use of anonymised and unidentifiable quotes in the Study report.
- I understand that data collected during the study may be looked at by individuals from the University of Southampton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I agree for my data to be used for the purposes of this study
- I agree to take part in this research project

Name of participant (print name).....

Signature of participant.....

Name of Researcher (print name) .....

Signature of Researcher.....

Date.....

01/09/2014 - Ref: 14/SC/1131

**Consent form (Carer) (Version 2)**

**Research Study: Cognitive Stimulation Therapy and Couplehood**

I have read and understood the information sheet and have had the opportunity to ask questions about the study.

I understand my participation is voluntary and I may withdraw at any time without consequence.

I consent to the interviews being audio recorded

I consent to the use of anonymised and unidentifiable quotes in the study report.

I understand that data collected during the study may be looked at by individuals from the University of Southampton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I agree for my data to be used for the purposes of this study.

I agree to take part in this research project.

Name of participant (print name).....

Signature of participant.....

Name of Researcher (print name) .....

Signature of Researcher.....

Date.....

## Appendix C Interview Schedule

### Interview Schedule – list of interview prompts and questions - PRE CST

The interview will begin with a social greeting, and thank you. The in-depth interview will start with warm up and ‘getting to know you’ questions. General orientation

How long have you been married? Where did you meet?

#### COUPLE

How would you describe yourself as a couple?

Are you still romantic as a couple?

What are you like as a couple – how would your spouse describe your relationship?

#### DIAGNOSIS

When did you begin to notice things were different with your (your spouses) memory?

Can you tell me what changes have occurred since you noticed memory change?

- are there things that are different?
- are there things that are more difficult?
- How do you experience this? How does it make you feel?
- Tell me about the day you learned about your (your partners’) dementia diagnosis – this is a prompt only and to be used if the participants use the words dementia etc
- . Additional open-ended question and probes that may be used to gain an understanding of this experience:
  - Tell me about key events that led up to diagnosis
  - Did your life change from the time of diagnosis? If yes, can you tell me more about those changes?
  - Did you talk about it together?
  - Can tell me what was or would have been helpful to you during the time of diagnosis?
  - How would you describe your relationship since noticing your (your spouses) memory is different?
  - How much does your spouse share their thoughts on your (their) memory?
  - Are there things you feel you are not able to talk about?

#### CHANGES

What changes have you noticed due to difference in your (your partners’ memory)?

Can you give me a summary of how memory changes have impacted on your (your partners’) daily life?

What strategies for coping with memory problems have you developed? - personally

- As couple

Do you think that your (your partners') memory has impacted on your relationship? If so how? Can you give me an example?

How has this affected you as a couple? Can you give me an example?

Have you noticed specific changes over time? Has this affected your sense of how you see yourself as part of a couple?

Are you able to talk about your (your partners') memory problems/diagnosis of dementia/memory loss?

How much do you think your spouse understands how you feel?

Do you feel that your roles have changed in any way?

do you do any hobbies/activities together/ alone? has there been any impact on how you spend your time together or how long you spend time together

Can you tell me about anything that hasn't changed?

### **CST**

What are your thoughts about the Cognitive Stimulation Therapy group? What do you expect to gain from CST?

We've talked about how your relationship was and how it is now... have you had any thoughts about the future?

Do you have any other comments?

Is there anything that I haven't asked that you would like to comment on?

Thank you for taking your time to do this interview, it has been really useful and interesting.

### **General Probes**

Can you give me an example?....

Tell me more about that....

Go on...

How did you feel?...

What did that mean to you...

Please recall an incident that best describes...

### **Informal cues**

What happened? What did you do? How did you feel?

What does it mean to you, what does it say about you, what does it do for you?

Is there anything else you'd like to say?

## **Interview Schedule – list of interview prompts and questions – POST CST**

The interview will begin with a social greeting, and thank you. The in-depth interview will start with a global interview question.

### **DIAGNOSIS (to compare understanding and attitudes post CST)**

Begin with open ended questions to recap on feelings around dementia diagnosis.

What is your relationship like now?

Please can you tell me:

- What life changes can you tell me about from the time of diagnosis? If yes, can you tell me more about those changes?
- Can tell me what was or would have been helpful to you during the time of diagnosis?

### **CST**

Now that the CST group has finished can you tell me your thoughts about the Cognitive Stimulation Therapy group? What do you expect to gain from CST? Did CST meet your expectations?

Have you noticed any changes in your (your partners) during or after the CST group? Can you give me an example?

What was your experience of CST – what did you (your partner) enjoy? What did you (your) partner not enjoy? Can you give me an example?

Since attending CST has your (your partners) view of your memory/dementia changed?

Do you think you've seen any areas of improvement for you (your partner)?

-in terms of memory

- in terms of behaviour

- in terms of confidence

- in terms of communication

Has CST made any difference to you (your partner) trying new things?

Are you able to tell me anything that was helpful about CST? Was there anything that was unhelpful?

Has CST made any difference to the way you see yourselves as couple?

Has CST opened up your (your partners) understanding of diagnosis? Has it made it any difference in being able to talk about dementia?

## **CHANGES – since attending CST**

Are you able to talk about changes to your (your partners) memory?

What strategies for coping with memory problems have you developed? - personally

- As couple

Do you think that your (your partners) memory has impacted on your relationship? If so how? Can you give me an example?

How has this affected you as a couple? Can you give me an example?

What are your thoughts about the near future?

Thank you for taking your time to do this interview, it has been really useful and interesting.

## **General Probes**

Can you give me an example?....

Tell me more about that....

Go on...

How did you feel?...

Can you tell me about this time?

What were your experiences like?

# Appendix D Transcript

*Keen to show struggles - specific historical regime - regiment*  
*not relying on words - march structures - stability*  
*train of thought recall moving between timeframes*

1. well just as a result of having a diagnosis and of the medication yes
2. er I think my short .. my long term memory .. difficult to define long term
3. memory but my memory long term goes back to pre-1939 war and it's very .. as far as I know it's very accurate. The closer I get to the current day the last couple
4. of years ... in other words my short term memory has been affected but er only in certain areas because I'm perfectly able to talk, write and read Russian as I've
5. always been
6. hmmm
7. which I find a little bit strange .. because my memory is not good but
8. obviously it's selective
9. hmm
10. er but er
11. does that become frustrating ? - leading
12. erm ... well I must admit the medication has improved it I've been on .. it started in (looks through papers) er mid-August last year and I'm carrying on ..
13. and it certainly has improved
14. Hmmm
15. yeah ... it's being regularly monitored and I as I say I spent a week no a for
16. ... no I'm going On this fourteen week for half a day every Thursday from for
17. fourteen weeks .. tomorrow I've got to go to the B... hospital where the group is

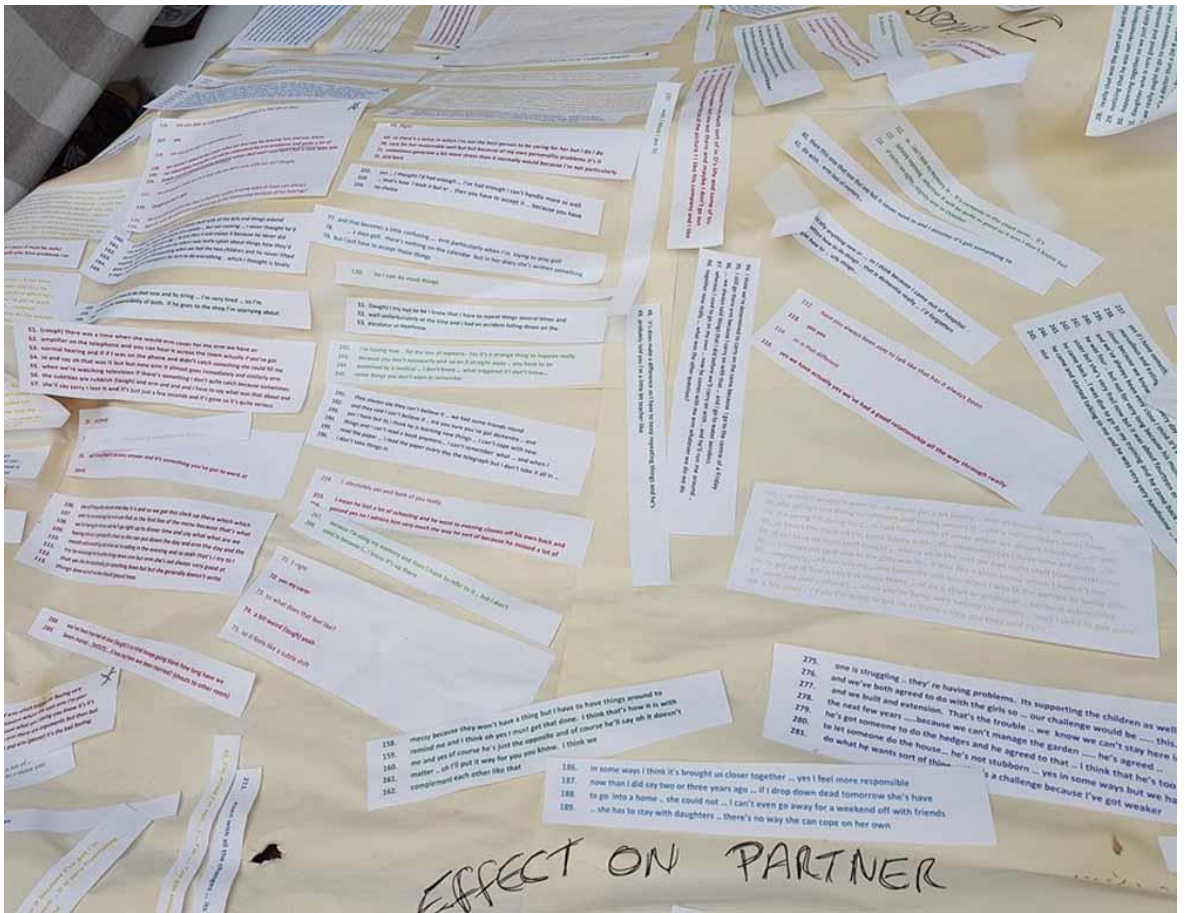
*noticing difference in long + short term memory*  
*"strange" memory not good*  
*improvements carrying on*  
*- defence to experts*  
*Happy + kill fact not curtain*

*statements*  
*coming thoughts*

75. so er are you able to talk to each other about things .. and including memory
76. and how you're feeling about memory and things
77. yes yes ←
78. how long have you been married .. I meant to ask that
79. we were married in 1960 yes er if you're interested I'll tell you something
80. Else
81. go on
82. in 1939 well the day war broke out if you'll excuse the expression ..er
83. my sister and I were evacuated from London to my wife's house.. the family in
84. Lincoln..no Rutland er ... do you know Rutland
85. I know Rutland yes
86. do you know any of the villages outside Stanford ... Essedine .. no it wasn't
87. Essindine .... Yes it was .. a tiny little village just outside Stanford and we were
88. evacuated to her parents my sister and I .. my sister is still alive and she lives in
89. Herefordshire I think ... yes that's right yes
90. oh right
91. she's still there .. she's about 10 years older than I am

*question - limiting facts?*  
*- distraction technique?*  
*- proving a point about memory?*  
*past important & hanging on to the past - memories & feels safe.*  
*RAF important - reference to quick march*

# Appendix E - cluster of themes



## Appendix F Table of themes

Theme	Sub theme	Extract	Concept
Navigating disruption		<p><i>(Alex line 72 page 4) he doesn't do it deliberately ,...</i></p> <p><i>(Alex line 82 page 5) I think he's doing lesser tasks automatically</i></p> <p><i>(Alex page 5 line 95).. I didn't have a concept of the group</i></p> <p><i>(Alex 101-106 page 6) it's not functioning to upset people ... it gives them more confidence and you're more in charge s I see it anyway .. and so lots on corporate decisions they chose a theme tune ... says something about their age .. but it doesn't matter because they chose it .. it was very good to see how they started and what they said I thought would have been more helpful to have thatat the beginning and perhaps a few more strategies for trying to get your partner .. erm to talk more about it</i></p> <p><i>(Alex page 6 line 111) I think there isn't the facility to work more .. but it would be good if it could</i></p> <p><i>Robert 124 -125 page 8) on yes ,.. I organised it to get the volunteers to take me each week for .. partly because I wanted to make sure J was alright before I left...</i></p> <p><i>(Robert 136 page 8) it was enjoyable but also challenging to me because I was ... just part of an ordinary group .....</i></p> <p><i>(Robert 143-143 page 8) I think for me .. there was a positive that I was able to sit and watch someone do the Same style course</i></p> <p><i>(Robert 146-149 page 9) I had to try to be a positive member of the group and remember to keep myself I am an elderly male which was challenging at times</i></p> <p><i>Robert 150-152 page 9 But I enjoyed it and I enjoyed meeting the group of people that were in the same position to myself ... to me the good part was that it was varied as the students I had ...</i></p>	

# Appendix G Ethics approval



## Health Research Authority

NRES Committee South Central - Hampshire B  
Level 3 Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT  
Telephone: 01173421334

15 September 2014

Mrs Sara Elizabeth Johnson  
Berkshire Healthcare Foundation Trust  
Beechcroft, Hillcroft House  
Rookes Way,  
Thatcham, Berks  
RG19 3HR

Dear Mrs Johnson

**Study title:** Cognitive Stimulation Therapy and changing relationships -  
An Interpretive Phenomenological Analysis  
**REC reference:** 14/SC/1131  
**IRAS project ID:** 143172

Thank you for your letter of 12<sup>th</sup> September, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Libby Watson, nrescommittee.southcentral-hampshireb@nhs.net.

### Confirmation of ethical opinion

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

### Conditions of the favourable opinion

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Approved documents**

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants	1	01 July 2014
Letter from sponsor		20 June 2014
Other [Dr Rosalind Willis CV]		
Other [cover letter]		04 September 2014
Other [Cover letter]	Version 2	08 September 2014
Participant consent form [consent form - carer]	version 2	01 September 2014
Participant consent form	version 2	01 September 2014
Participant information sheet (PIS) [PIS form - carer]	Version 3	08 September 2014
Participant information sheet (PIS)	Version 3	08 September 2014
REC Application Form [REC_Form_05092014]		05 September 2014
Research protocol or project proposal	1	01 July 2014
Summary CV for Chief Investigator (CI)		
Summary CV for supervisor (student research)		

**Statement of compliance**

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

**After ethical review**

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

**14/SC/1131**

**Please quote this number on all correspondence**

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

Yours sincerely



**Professor Ron King  
Chair**

Email: [nrescommittee.southcentral-hampshireb@nhs.net](mailto:nrescommittee.southcentral-hampshireb@nhs.net)

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Dr Rosalind Willis  
Ms Sylvia Warwick, Research & Development/Thames Valley CLRN RM&G



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