

**Developing a Relationship Intervention for
Couples Living with Dementia**

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I, Andrew Balfour, confirm that the work in my thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in my thesis.

Abstract

This PhD aims to develop an intervention to improve the life experience and mental health of older couples living with dementia. Drawing on psychoanalytic and attachment theory, as well as the dementia research literature, it seeks to contribute towards a psychodynamic understanding of relationships in dementia, exploring the implications of this for dementia care. The goal is to develop both a relationship intervention for couples who are living with dementia and a training programme for staff in delivering this intervention. The aim is to help such couples maintain, or recover, the protective aspects of their relationship and to support them in establishing interdependence and mutuality of engagement, using shared everyday activities as a vehicle for this. Whether the couple's relationship functions as a protective factor depends upon the resilience of the couple and on the development of interventions that support adjustment to the illness, change unhelpful patterns of interaction, and foster more satisfying interpersonal engagement in managing the illness together. This PhD seeks to develop a relationship intervention that achieves these outcomes for couples living with dementia. A small-scale, naturalistic study examines the feasibility of implementing both the intervention and the staff training programme, providing preliminary data on factors such as the acceptability and effectiveness of these components. The results of this study will help establish whether there is a case for progressing to a larger clinical trial and bring us closer to the goal of establishing a conceptually grounded, evidence-based relationship intervention for couples living with dementia.

Impact Statement

The prevalence of dementia is increasing globally, and the demand on health and social care services is rising correspondingly. In the UK, the number of people living with dementia is predicted to grow to 1.35 million, with the total cost expected to reach £80.4 billion by 2040 (LSE, 2023). This trend is reflected internationally, with approximately 50 million people worldwide currently living with dementia, a figure projected to rise to 152 million by 2050 (Wimo et al., 2015).

The care of this growing population represents one of the most urgent social concerns worldwide. National government policies typically promote care for individuals with dementia at home, given the substantial financial costs associated with residential care. Research shows that the majority of people with dementia around the world are cared for at home, usually by their spouse or other family members, with only about 30% entering institutional care (WHO, 2012).

However, research also highlights the significant negative physical and mental health impacts on spousal carers, and the strain on couple relationships as they manage the increasing care needs of the partner with dementia. Currently, there is limited support available for couples facing these challenges. After a diagnosis of dementia, there are few psychosocial interventions designed to alleviate the negative relationship impacts of dementia and reduce carer burden—this latter being a primary factor that can lead to residential placement for the person with dementia.

This PhD study has developed a relationship-based intervention for couples living with dementia, alongside a training programme for practitioners to deliver this intervention. Results indicate that the intervention significantly reduced carer burden for those experiencing moderate to severe levels at the beginning of the study, while other relationship factors, which typically deteriorate as dementia progresses, remained stable. Additionally, the training programme demonstrated its effectiveness by enabling a diverse range of practitioners to feel competent in delivering the intervention to couples living with dementia. These promising preliminary results support further development of both the relationship intervention and the training programme in the future.

Successful large-scale implementation of these interventions could have substantial social impacts by providing tools to improve the mental and physical health of couples living with dementia, enhancing their resilience, and reducing the likelihood of residential placement. Beyond contributing to better health-related outcomes, the financial savings could be significant, making this relationship intervention and training programme highly relevant to healthcare providers and commissioners. Thus, this PhD research is of substantial importance to social policy, representing a key priority for healthcare providers and policymakers globally.

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Chapter Summaries

Chapter 1: General Introduction and Overview. Background context to the project and epidemiological factors; problems faced by older people; the significance of the couple relationship in dementia care.

Chapter 2: The Importance of Family Caregiving and of the Couple Relationship in Dementia Care. Review of the literature on the impact of dementia on the couple relationship; issues and challenges facing couples; factors that are important in family and couple resilience.

Chapter 3: Psychological Approaches to Dementia. Review of the literature on psychosocial interventions developed for dementia: their strengths and limitations. What is missing and what needs to be developed, setting out the rationale for the proposed new intervention.

Chapter 4: Qualitative Exploration of Cases. Clinical and qualitative account of pilot work with couples living with dementia, which led to the design of the Living Together with Dementia relationship intervention.

Chapter 5: Development of the Intervention Manual. Outline of the conceptualisation, planning, and development of the intervention.

Chapter 6: Development and Evaluation of the Training Programme. An account of the development of the training programme in the intervention, including the implementation and initial trialling of this programme, reporting quantitative and qualitative results.

Chapter 7: Implementation and Quantitative Results of the Intervention

Programme. An account of the implementation of the intervention, with a description of the context of its delivery which took place in Camden, Bristol and Hackney. This chapter reports methods and quantitative results of the initial piloting of the intervention with couples living with dementia.

Chapter 8: Qualitative Results of the Intervention Programme.

Qualitative evaluation of outcomes of the intervention, reporting the qualitative analysis of data from interviews with couples who took part in the intervention.

Chapter 9: Discussion. Overall conclusions, consideration of next steps for research and future developments.

Chapter 1. Overview and General Introduction: The Couple and Dementia

Introduction

This introductory chapter provides an overview of the topics covered in this thesis, outlining the conceptual background, surveying epidemiological factors, and discussing the significance of the couple relationship in dementia. The chapter concludes by examining the experience of receiving a diagnosis of dementia, which marks the first formal stage in the 'dementia journey' for couples. Reaching this diagnostic stage raises the question of what post-diagnostic support is available to assist couples at this critical point in their lives. This consideration serves as the starting point for a review of research on the impact of dementia on couples and the literature on intervention development, which will be discussed in the following chapters.

To provide a summary of the overall structure of this PhD thesis, the first three chapters address why the couple relationship is pivotal in dementia care, reviewing research on the impact of dementia on couples and existing interventions developed to support them. The relevance of psychodynamic and attachment theories, as well as related research in the context of dementia, will also be examined. This discussion leads to a detailed account of the conceptual framework for the proposed intervention model, which is grounded in attachment-focused developmental theory and research and is linked to both clinical and research-based understandings of the impact of dementia on couples. Subsequent chapters will then provide an account of

the development of the intervention for couples and the corresponding training programme for staff, followed by the results of the implementation and evaluation of these components of the study. Finally, the thesis will consider conclusions and implications for further research and service development.

The ultimate aim of this project is to determine whether there is a compelling case for conducting a larger-scale training of clinicians and a clinical trial of this approach. Achieving this would bring us closer to the goal of establishing a widely accessible psychodynamic and attachment-based relationship intervention for couples living with dementia.

Conceptual Background

This PhD thesis explores relationships in the context of dementia, adopting an approach that places both the person with dementia and their partner at the centre of consideration, treating them as equal participants in examining the impact of dementia on close relationships. The research presented in this thesis aims to develop an intervention that mitigates some of the key negative effects of dementia on relationships, as documented in the literature, and, by addressing these issues, seeks to improve outcomes for both the person with dementia and their partner in terms of their experience of the disease trajectory.

Psychoanalysis has long examined the importance of human development and early relational experiences for psychological functioning throughout the lifespan. The idea that developmental challenges throughout life are rooted

in infancy is central to psychoanalytic conceptualisations. However, with few exceptions (Segal, 1958; Jacques, 1965; Hildebrand, 1995; Davenhill, 2007), old age has been largely overlooked in psychoanalytic theory. This neglect is particularly apparent in the limited psychoanalytic exploration of the psychological sequelae of age-related conditions such as dementia. As will be argued, just as psychoanalysts from Anna Freud and Winnicott to Klein and the post-Kleinians recognise the relationship between the infant and primary caregiver as foundational for development, so too must we, in the realm of dementia care, consider the significance of the relationship between the person with dementia and their spouse or partner—who, in most cases worldwide, serves as their primary caregiver (WHO, 2012).

As will be further discussed in subsequent chapters, just as an infant relies on its caregiver to meet its attachment needs and to contain its emotional states, so too does a person with dementia often become dependent on their spouse or partner to provide containment for their increasingly fragmented mental states. In dementia, as linguistic capacity diminishes and opportunities for intimacy and mutual understanding are reduced or lost, attachment relationships undergo significant changes. Cognitive and emotional disintegration leads to heightened attachment needs, placing increased pressure on the caregiving partner to 'contain' the emotional states of the person with dementia, all while they themselves are contending with profound emotional challenges due to the relational impacts of dementia.

This is why there is an urgent need for an intervention that addresses relationship difficulties and attachment issues in the context of dementia—an

intervention that synthesises research and clinical practice developed for relationships at earlier life stages with research on the relational impacts of dementia for couples in old age. Drawing on psychoanalytic and attachment theory, this PhD aims to contribute to a psychoanalytic understanding of relationship dynamics in dementia, as part of developing a relationship intervention for people with dementia and their partners, grounded in the insights and learnings from these disciplines.

Epidemiological Factors

Dementia is an umbrella term encompassing a range of progressive conditions that affect the brain. Each type of dementia impairs the functioning of neurons in specific areas of the brain, impacting an individual's ability to remember, think, and speak. According to Dementia UK (2023), there are over 200 subtypes of dementia. The most common include Alzheimer's Disease, Vascular Dementia, dementia with Lewy bodies, frontotemporal dementia, and mixed dementias. For the purposes of this study, dementia will be understood to encompass this broad spectrum, covering all stages of the disease.

In 2019, it was estimated that 748,000 older people were living with dementia in England, a figure projected to increase to 1.35 million by 2040 (LSE, 2023). The London School of Economics and Political Science estimated that the total cost of dementia in England in 2019 was £29.5 billion, with expectations that this will rise to £80.4 billion by 2040. This trend is reflected globally, with approximately 50 million people worldwide currently living with dementia, a number predicted to escalate to 152 million by 2050 (Wimo et

al., 2015). If this figure were to include all those affected by dementia, such as family and friends, the number of people impacted would be substantially larger. It is estimated that 5-8% of the general population aged 60 and over are living with dementia (World Health Organization, 2019). With the rising prevalence of dementia, there is also a corresponding increase in the number of couples and families living with the condition (Richardson et al., 2013).

Globally, evidence suggests that the majority of people with dementia are cared for at home by their spouse or partner, with only around 30% eventually entering residential care (Pozzebon et al., 2016; WHO, 2012; Kendig et al., 2010). Internationally, there is a significant push for government services to develop strategies that help couples and families support individuals with dementia within the community. As a result, governments are increasingly funding programmes and services aimed at enabling people with dementia and their carers to live in the community for as long as possible (Pozzebon et al., 2016). The majority of people with dementia reside in ordinary housing; in high-income countries, this figure is estimated to be nearly two-thirds (Wimo et al., 2013). Most individuals with dementia prefer to live at home with their family for as long as possible, and remaining in a familiar home environment supports feelings of attachment and helps preserve identity, roles, independence, and relationships (Gould & Basta, 2013; Wiles et al., 2012). Dementia is the leading cause of dependency in daily living, and the support needs of individuals with dementia increase as the illness progresses (Alzheimer's Disease International, 2013). Most people with dementia living in ordinary housing

reside with their partner, who often assumes the role of an 'informal caregiver' (Merrick et al., 2016).

In the future, such 'informal' care will become increasingly crucial, with estimates suggesting that 85% of couples, where one partner has dementia, will require some form of support to continue living together in their own home (Alzheimer's Disease International, 2013). There is a significant economic dimension to this, as the global costs associated with dementia care amount to more than 1% of gross domestic product (GDP). As Wimo et al. (2013) highlight, "if dementia care were a country, it would be the world's 18th largest economy." Thus, there are clear economic incentives for governments to promote home care, given the substantial financial burden that institutional care places on both public and private resources. However, family members who typically assume the role of primary caregivers face high emotional, physical, and financial costs in fulfilling this role (Merrilees, 2016).

A considerable body of research across various societies and cultures has demonstrated that caregiving for a person with dementia is linked to negative outcomes for family members, with depression being among the most severe and costly consequences, particularly among spouses (Huang et al., 2015; Joling et al., 2013). As will be discussed in more detail in Chapter 2, caregiver distress has consistently been associated with increased costs, primarily due to its impact on the risk of institutionalisation of the person with Alzheimer's disease (Foldes et al., 2018; Long et al., 2014; Mittelman et al., 2006). On average, the illness lasts about 10 years from diagnosis, and

diagnosis typically occurs nearly two years after family members first notice significant memory problems affecting daily living (Alzheimer's Disease International, 2013).

Given that there is currently no cure for dementia, there is an increasing focus on developing and evaluating psychosocial interventions aimed at reducing the psychological distress associated with living with dementia. Individuals, couples, and families require long-term support as they navigate the emotional, psychological, and financial challenges posed by many years of illness.

The Significance of the Couple Relationship in Dementia Care

It is often said that the physical and psychological health of older couples is linked “for better or for worse.” Hoppmann et al. (2011) found strong associations between depressive symptoms and 'functional limitations'—the physical inability to perform basic tasks of everyday living—between partners in older couples; the symptoms of each spouse tended to fluctuate closely in line with those of their partner. Relationship quality is a significant determinant of well-being across the adult lifespan (Rippon et al., 2019; Litwin & Shiovitz-Ezra, 2006; Walker & Luszcz, 2009), and this remains true when partners form a caregiving/care-receiving dyad (Hellstrom et al., 2007; Wadham et al., 2016). For instance, older couples with positive marital relationships demonstrate better psychological well-being, while negative relationships are linked to poorer mental health (Walker & Luszcz, 2009). For older married couples, relationship satisfaction is significantly correlated with

life satisfaction and overall well-being (Carr et al., 2014). These findings underscore the emotional and physical interdependence of older couples, highlighting the necessity for a health and social care system that addresses not only individual patients in isolation but also the relational context.

A report in **The Times** (Hawkes, 2008) indicated that the Public Accounts Committee was informed that carers of people with dementia save the taxpayer five billion pounds per year but often do not receive the support they need, with many feeling abandoned after a dementia diagnosis is made. It is crucial to recognise that the burden on carers is not merely economic. A Government strategy document for carers (DoH, 2008) notes: “Carer provision can place a mental and physical burden upon some of the six million carers in England leading to poorer outcomes and health inequalities.”

Care for a person with dementia is frequently carried out in an unseen and unacknowledged manner by family members caring for a spouse or parent. It is estimated that approximately one-sixth of these carers provide more than 50 hours of care per week. Health and social care professionals often recognise that, while the person with dementia may be their referred patient, the 'unit of care' around them—often comprising the partners in couples living with dementia—also needs attention (Balfour, 2014). However, such staff typically receive minimal training in working with couples affected by dementia, many of whom are likely to be aware of the diagnosis and its implications. The partners in these couples are often elderly themselves, and the daily reality of dementia care is that it is frequently carried out by partners who are physically frail, within the context of long-standing relationships. The

challenges they face are profound. If we pause to imagine these challenges, we can begin to appreciate their magnitude. The 'dementia journey' (Pozzebon et al., 2016) that the couple must navigate begins with normal functioning and progresses through stages of cognitive and functional decline, culminating in profound memory loss, severe disability, and eventually death.

It is important to keep in mind the progressive nature of dementia and that the needs of the couple will evolve as the condition advances. As Sinason (1992, p. 89) puts it:

“The difference between someone at the start of Alzheimer’s Disease and someone who is near the end is as large as someone who is normal and someone who is profoundly handicapped. The total continuum is experienced in the mind and heart of a single being.”

This 'continuum' from normal functioning to profound disability and death, known as the 'dementia journey,' unfolds within a relational context where the most significant relationship is often that between the individual with dementia and their partner. Living with dementia necessitates ongoing changes and adjustments within the couple's relationship, affecting "their shared identities, rituals, interaction patterns, and life plans" (Pozzebon et al., 2019). While the specific symptoms and progression vary depending on the type of dementia, all dementias generally exhibit a pattern of progressive decline in functioning, memory, and other cognitive and functional abilities. In the later stages, verbal communication may nearly cease, and both physical and mental functioning may deteriorate to the extent that even basic bodily

functions are lost, requiring 'total care' akin to that needed by a very young infant. However, this analogy is potentially problematic, given the historical context of infantilisation of older adults in institutional care settings.

Researchers in neurology, such as Reisberg et al. (2002), have coined the term 'retrogenesis' to describe how, in Alzheimer's Disease (AD), neurological functions are lost in the reverse order in which they were acquired during childhood development—an effective 'reverse ontogenesis.' As they state, "the functional stages of AD precisely and remarkably recapitulate the acquisition of the same functional landmarks in normal human development but in reverse order" (Reisberg et al., 2002). The authors emphasise that "because of appropriate concerns regarding dignity," individuals with Alzheimer's should be treated as adults with the mental and functional capacity corresponding to their developmental stage. This perspective can be helpful in understanding the emotional changes experienced by a person with AD.

This model powerfully illustrates the challenge faced by the caregiving partner, who is gradually losing their life partner as dementia progresses. The functional decline of their partner with dementia increasingly resembles the vulnerability and dependence of a young child. Yet, this analogy must be carefully qualified to recognise that it describes the decline and loss of function in an adult, within the context of an adult relationship. As Reisberg (2002) suggests, "If caregivers understand that Alzheimer's patients are like regressing children and provide the appropriate care depending on the stage, the descent will be less painful."

Receiving a Diagnosis of Dementia

People with dementia often undergo significant changes in cognitive functioning long before a formal diagnosis is made. These changes can profoundly affect social relationships, particularly the ability to engage in casual conversation and share interests and ideas with others. Research suggests that spouses may experience distress and anxiety well before their partner is formally diagnosed with dementia. Initially, before a diagnosis is confirmed, the partners of people with dementia may perceive the behavioural symptoms as challenges within the relationship rather than recognising them as symptoms related to the disease process or cognitive dysfunction. Indeed, studies indicate that a partner's first awareness of a 'problem' often begins with noticing behavioural changes, particularly those that negatively impact the couple's relationship (Pozzebon et al., 2016; de Vugt & Verhey, 2012; de Vugt et al., 2003; Eustace et al., 2007; Garand et al., 2007).

This difficulty is often compounded by the significant delay that typically occurs between the initial recognition of symptoms and the diagnosis of dementia. As Pozzebon et al. (2016) highlight, an average of 3–4 years can pass from the onset of symptoms to a confirmed diagnosis of dementia (Speechly et al., 2008; van Vliet et al., 2011), and only 20% to 50% of people with dementia are actually diagnosed (Morgan et al., 2014). In healthy couple relationships, a spouse is frequently regarded as the closest confidant and primary source of emotional support (Tower et al., 2002). Consequently, when an issue arises, both partners typically rely on each other. Within this

context, it is easy to see how the equilibrium of a couple's relationship can be disturbed by the earliest symptoms of cognitive decline, often long before a formal diagnosis of dementia is made.

While only some studies on the impact of dementia on couples report this detail, the average length of spousal relationships in the research literature ranges from 40 to 60 years, highlighting the substantial time available to these couples to consolidate emotional, intellectual, and physical intimacy bonds (Morgan et al., 2014). It is therefore unsurprising that partners are often the first to notice subtle changes in the behaviour or personality of the person with dementia, and they frequently experience confusion and distress as a result of these early symptoms of cognitive decline. Thus, it is often the caregiver partner's increasing anxiety about these behavioural changes that prompts the eventual diagnosis of dementia (Morgan et al., 2014).

Some researchers note that traumatic reports from patients regarding the mishandling of their initial dementia diagnosis suggest the need for a reassessment of how people are informed of their diagnosis (Johnston and Terp, 2015). The diagnosis of dementia can indeed be traumatic for all involved, including partners and other family members, as its impact extends beyond the individual diagnosed, affecting all those around them as they come to terms with the new and evolving reality of dementia. When a diagnosis is made, reactions often include shock, anger, denial, and grief (De Boer et al., 2007). Additionally, given the prolonged period between the emergence of the first symptoms and the confirmation of a diagnosis—a particularly stressful time for the couple—there can also be a sense of relief

when the diagnosis provides an explanation for what has been occurring (Balfour, 2014). However, this relief is often accompanied by profound difficulty, bringing with it anxiety and fears for the future. As Bryden (2005) writes from her experience:

“Dementia and Alzheimer`s are both words that create fear and dread. Many of us wish we had cancer. At least then there is talk of treatment, of chemotherapy, of possible remission. There is none of that with a diagnosis of dementia.”

Governments worldwide now emphasise the importance of early detection in their dementia policies, and in the UK, this is a key focus of the National Dementia Strategy (Dept. of Health, 2009). As a result, we now see a cohort of individuals diagnosed with dementia much earlier than in previous generations. The experience of receiving such a diagnosis is profoundly challenging, yet once it is made, there is often very little psychotherapeutic support available, and psychological help is scarce. This is starkly different from the support provided for people diagnosed with other terminal conditions, such as cancer. A study by Laakonen et al. (2016), which surveyed a large number of people to assess their experience of receiving a dementia diagnosis, found that while elderly spouse caregivers were generally satisfied with the information provided, they felt that the follow-up care did not adequately meet their needs. Robinson et al. (2005) suggest the importance of a joint approach involving both partners to help couples manage the losses and challenges associated with adjusting to a dementia diagnosis.

More than 30 years ago, when I was beginning my career as a clinical psychologist, I had the task of giving an elderly man a diagnosis of dementia. I had nothing to offer him and his wife, except an information leaflet (Balfour, 2023). I have never forgotten the image of the couple leaving the hospital, holding onto each other as they walked through the grounds in the rain. Many couples report the stress of receiving an initial dementia diagnosis (Johnston and Terp, 2015). These authors describe how couples found the diagnosis itself very difficult to hear, but the manner in which it was delivered was even more traumatic. One participant shared, *“I think it would have been really helpful to have some information. We got no information, none. ... We just got the diagnosis from this, probably third year neurology resident.”* In this study, Johnston and Terp (2015) also found that couples expressed a desire for counselling at the time of diagnosis, with comments such as “there are no real resources available” and “no counsellors really understand early Alzheimer’s Disease.”

These findings suggest that it is crucial to provide skilled psychotherapeutic support as part of the diagnostic process and in post-diagnostic care. As Johnston and Terp (2015) highlight, a healthcare response perceived as perfunctory or lacking sensitivity can significantly influence whether patients and families are willing to accept help later in the disease process.

Why Diagnose Dementia at All?

The question of whether it is right to provide an early diagnosis of dementia is often debated in the literature. Given that there is no cure and few psychological interventions available post-diagnosis (as Chapter 3

discusses), a sense of 'therapeutic nihilism' can prevail, leading professionals to question the value of delivering a dementia diagnosis. A senior GP writes: "Primary care physicians are often castigated for not recognising dementia; many reports have suggested that greater education, more awareness, and other exhortations will 'improve' the gap between estimated numbers of dementia within any given population and the actual number a GP may diagnose or have on a register. Reasons have been given for this gap... the most compelling of the reasons may be the judgement that, on the basis of evidence and experience, available interventions, if any, for that individual will do more harm than good" (Fox et al., 2013). This statement underscores that, without clear post-diagnostic intervention and support pathways, the benefits of diagnosis for patients may be highly uncertain.

Nevertheless, the objective of increasing diagnostic rates earlier in the disease process has long been a priority for government policy, both in the UK and globally. The rationale is that early diagnosis allows individuals and their families to begin adapting to the illness before it becomes too advanced. De Vugt and Verhey (2013) argue that early diagnosis enables caregivers to better adapt to the changes that dementia brings, feel more competent in caring for their partner, and experience fewer psychological problems themselves. Rippon et al. (2019) suggest that therapeutic interventions targeting changes in roles and relationships could strengthen spousal bonds, potentially reducing the negative consequences of caregiving at a later stage. Thus, early diagnosis might be a critical condition for timely intervention and the prevention of caregiver overburden. However, this

hinges on the availability of well-developed interventions for people with dementia and their partners following diagnosis. Additionally, both partners are likely to be older adults often managing other health conditions. As will be discussed in the next chapter, research shows that, currently, the diagnosis of dementia sets the stage for a profoundly challenging period in the couple's life together (Balfour, 2018).

Receiving such a serious diagnosis without adequate post-diagnostic support leaves couples grappling with a complex and devastating condition with limited understanding, skills, or resources to manage its symptoms. As reported in **The Guardian** (4th April 2024), new treatment approaches for dementia are being developed that rely on early intervention, making early diagnostic testing increasingly critical. However, as noted in the article, current diagnosis rates are only 64%, and the average wait time for a diagnosis in the UK is two years. While a cure remains distant, new medical approaches under development may slow the disease's progression. Moreover, the primary cost associated with dementia is the expense of care provided in nursing homes. Therefore, investing in early, effective psychosocial support for dementia may significantly reduce long-term costs. Given this context, psychological interventions that help couples manage the impact of dementia—an illness they may live with together for many years—are more crucial than ever.

When NICE developed its dementia guideline in 2018, it was noted that "the committee agreed there was value in testing a wider range of possible psychosocial interventions, in order to optimise the interventions available to

support people living with dementia." This PhD research project aims to contribute to this endeavour by developing an attachment-focused relationship intervention for couples living with dementia, which addresses costs that are not merely economic but also psychological, as subsequent chapters will demonstrate. Research into the emotional challenges of dementia care—specifically, the impact of dementia on the couple's relationship and, consequently, on both partners—is the focus of the next chapter. This research reveals that dementia profoundly affects couple relationships, and the quality of these relationships has significant implications for how well the couple can cope with the challenges of dementia, impacting health-related outcomes for both partners.

The evidence supporting these claims will be reviewed in the next chapter, reinforcing the argument that it is essential to develop evidence-based interventions grounded in meaningful theoretical frameworks to help couples navigate the challenges of dementia. We need to understand the lived experience of couples with dementia, identify the factors that support resilience, and use these insights to develop psychosocial interventions for the ever-increasing number of couples facing dementia. The following chapter will detail what is currently known about the impact of dementia on couple relationships and explore what research reveals about the relationship factors that may foster resilience and influence the trajectory of the illness and its outcomes for both partners.

Chapter 2: The Importance of Family Caregiving and the Couple Relationship in Dementia

Introduction

This chapter reviews the literature on the impact of dementia on couples and considers what are the issues or challenges facing them, as well as identifying factors that are important in family and couple resilience, and how the nature of the couple relationship itself might influence the experience of dementia for both partners. It details the findings of research which show how important the couple relationship is in dementia care and highlights the need to develop interventions for couples living with dementia, which are then discussed in chapter 3.

Methods

Review Strategy

In order to compile relevant literature, we undertook a systematic search on the key databases in the field, namely PubMed, OvidSP, and the Web of Science platform, the latter of which encompasses Embase, MEDLINE, global health, and APA PsychInfo resources.

We applied the following search parameters: "Couple relationship" OR "marital" OR "spouse" OR "romantic relationship" AND "dementia", while excluding "intervention". Our search spanned studies published from the year 1990 up to and including the year 2023. Further parameters included a focus on English language studies and those published in peer-reviewed

journals. We deliberately excluded intervention studies in this literature search, as the subsequent chapter will address interventions with couples, incorporating a separate literature review for this topic.

To further refine our search, we established certain inclusion and exclusion criteria. Our primary interest centred on how dementia affects the couple's relationship (and vice versa), and how relationship factors can influence the experience of dementia. Consequently, our inclusion criteria encompassed studies involving individuals with dementia (including Alzheimer's disease), or couples wherein one partner has been diagnosed with dementia (or Alzheimer's disease).

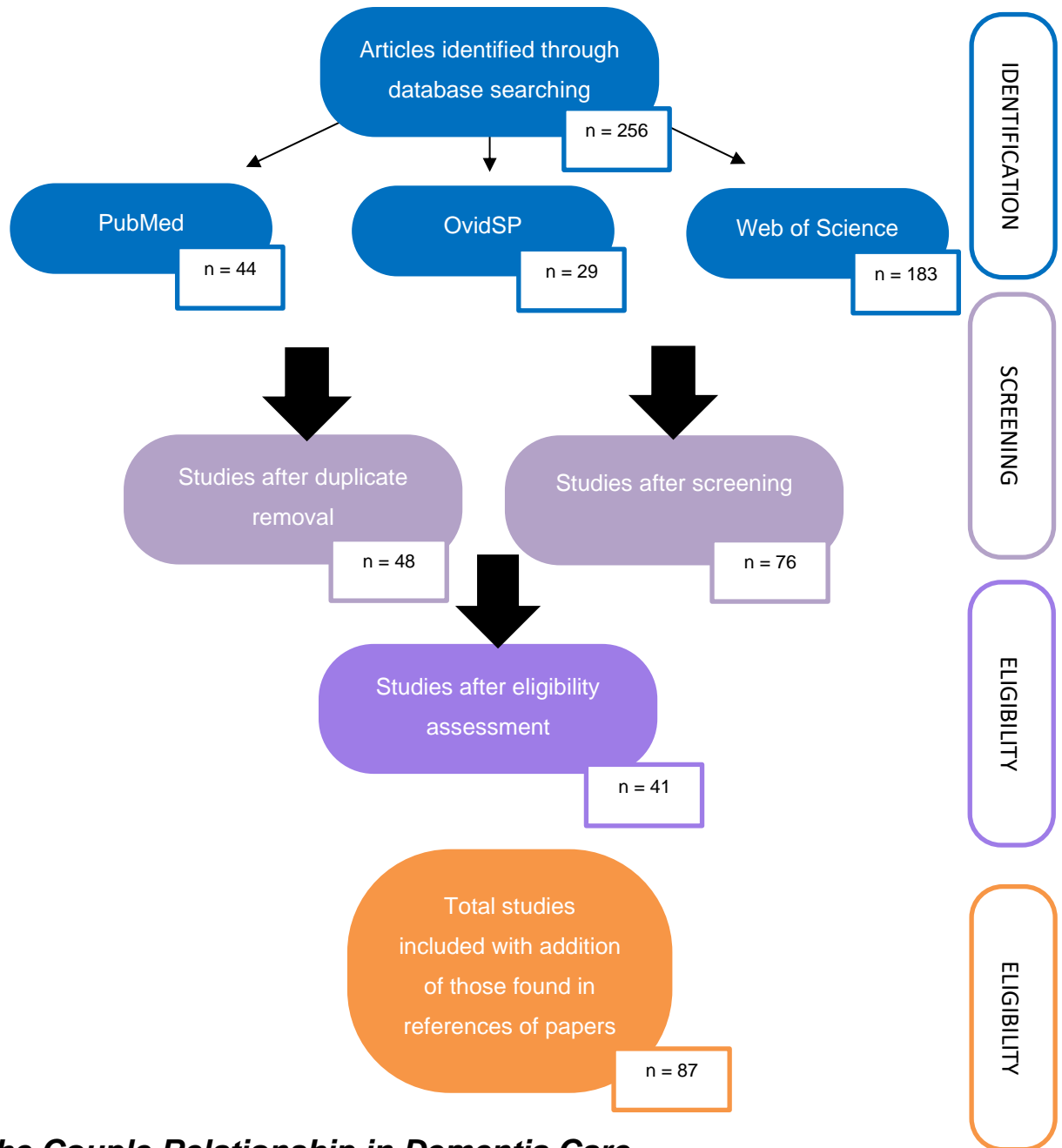
On the other hand, our exclusion criteria included studies involving participants with comorbid diagnoses of psychiatric conditions or physical ailments, such as strokes and heart attacks, as well as other degenerative disorders like multiple sclerosis, Parkinson's disease, or Huntington's disease. We also omitted studies where the diagnosis of dementia or Alzheimer's disease was not definitive (e.g., 'suspected Alzheimer's' or 'mild cognitive impairment'). Participants diagnosed with early onset dementia were also excluded, setting the age cut-off at 60 years and above. This is because we are primarily interested in the impact of dementia on older couples, and early onset dementia presents unique challenges for couples and families in mid-life that are distinct from those of late-onset dementia. Studies that mainly focused on dementia's risk factors in other life areas, such as contributing to other illnesses or mental health conditions, were also left out.

In order to assess the relevance, eligibility, and suitability of articles for inclusion, all identified studies were evaluated based on the pre-set criteria. The preliminary screening involved reviewing titles and abstracts, after which a compiled list was created. Duplicates and studies that did not meet the criteria were subsequently removed. A refined list of studies was then assembled for full screening.

The total number of articles identified across all three databases was 256. The PubMed search yielded 44 articles, OvidSP provided 29, and Web of Science contributed 183. There were 48 studies which were excluded due to duplication. After the initial screening of titles and abstracts, a total of 76 studies were selected for full assessment. Out of these, 41 papers met the established criteria and were finalised for inclusion in this review. Breaking down these results by database, PubMed resulted in 10 articles, OvidSP contributed two, and Web of Science provided 26 articles. Figure 1 offers a visual representation of this process.

Moreover, we augmented our selection by identifying additional studies through the reference lists and citation lists of the initial set of papers, which yielded an additional 46 papers for review, taking the total number to 87. This supplementary approach ensured a thorough and extensive exploration of the existing literature on the impact of dementia on couples.

Figure 1. Study selection process for the literature examining the effect dementia has on the couple relationship without the influence of intervention.



The Couple Relationship in Dementia Care

This chapter will survey the findings of research on the impact of dementia on couples, as well as considering relationship factors which are important in

strengthening the couple's resilience in the face of the challenges brought by dementia.

Reviewing the Literature: How Does Dementia Affect Couples?

Research indicates that dementia has a profound effect on couple relationships, placing them at the centre of dementia care. The alterations triggered by dementia necessitate adaptations at every level – emotionally, psychologically, and practically – within the context of a relentless process of loss as the disease progresses. Given these challenges, it is not unexpected that relationships might deteriorate, sometimes escalating into severe conflict, withdrawal, or neglect, or cease to function in other capacities. However, as I will demonstrate, the quality of the relationship that couples can maintain may significantly influence their experience of the disease progression and have substantial implications for the mental and physical health of both partners.

The research on this subject can broadly be categorized into quantitative and qualitative studies. The former typically consists of large-scale studies that measure the effects of dementia on individual partners and, more recently, studies that consider the impact of dementia on the couple relationship as a unit, employing a dyadic focus (e.g., Rippon et al, 2019). However, despite this recent shift towards including both partners in the couple, much of the quantitative literature has historically concentrated on either the experience of the person with dementia or their caregiving partner, in isolation (Egilstrod et al, 2019). Evidence suggests that in couples where one partner has

dementia, the condition not only affects both partners individually but also significantly influences their relationship (Daniels et al, 2007). Historically, the majority of studies have tended to focus on the caregiver partner, and only in more recent years has attention broadened to include the person with dementia themselves, as noted by Ablitt et al (2009).

Quantitative research involving caregivers of people with dementia often utilizes cross-sectional designs, employing questionnaires and scales, with a primary focus on spouses of partners diagnosed with Alzheimer's Disease (Pozzebon et al, 2016). Most of these quantitative studies examine the effect of living with a partner with dementia on the 'carer' partner, treating dementia as the independent variable and the carer partner as the dependent variable (Ablitt et al, 2009).

By contrast, the qualitative literature, which is quite extensive in this area, offers an in-depth exploration of the experiences of couples dealing with dementia. In a simplified sense, the quantitative literature helps to identify the areas impacted by dementia and the nature of its effects on individuals and the couple relationship. On the other hand, the qualitative literature allows us to better understand the details of how these variables studied in the quantitative literature affect couples living with dementia.

In the following sections, I will first review the quantitative literature in this field, before examining the qualitative studies.

What Does the Quantitative Research Tell Us?

Studies conducted globally demonstrate considerable agreement, with the dominant findings from the quantitative literature suggesting that dementia is associated with decreased marital satisfaction and poorer health (Kaiser & Panegyres, 2007; Clare et al., 2012; Fauth et al., 2012). Research suggests that the need to adapt to the progressive changes brought on by dementia, resulting from their partner's increasing disability, is linked to increased vulnerability to stress, depression, and anxiety in the caregiving partner (Knop et al., 1998; de Vugt et al., 2003; Garand et al., 2007).

For instance, a large-scale European study involving individuals with dementia and their family caregivers, which provided longitudinal data from 350 participants, revealed a significant decline in relationship quality over time for caregiver partners (Marques et al., 2021). An earlier study, which included more than two hundred couples across 14 of the 15 member states of the European Union, similarly identified high levels of burden and mental distress in spouses caring for individuals with Alzheimer's Disease across all European Community countries (Schneider et al., 1999). Family caregivers providing substantial care for individuals with dementia were found to be more than twice as likely to suffer from mental health problems compared to those providing more limited care, with over a quarter of those providing care for over 20 hours per week reportedly having mental health problems (Singleton, 2002).

Caregivers are also susceptible to physical health problems, which can interact with mental health issues. For instance, caregiver stress has been

linked to elevated cortisol levels (de Vugt et al., 2003). A recurring theme across numerous studies is the association between high levels of distress and burden and the caregiving role, with as many as 80% of spouse caregivers reportedly reaching their maximum limits of burden during the dementia disease process (de Vugt & Verhey, 2013). These negative health effects of living with a partner with dementia have been identified as critical factors in the partner's decision to transition the individual with dementia into residential care (Umberson et al., 2006; AIHW, 2014).

Furthermore, these negative impacts can extend to the risk of death for those caring for a partner with dementia. Caregivers who reported experiencing stress related to their role had mortality risks 63% higher than those caring for a spouse or partner with dementia without experiencing strain – the latter group did not show any elevated risk of mortality (Schulz & Beach, 1999). In order to understand in more detail which aspects of caring for a partner with dementia are likely to lead to such negative impacts, it is crucial to understand how dementia affects the different components of the couple's relationship. Several studies indicate that dementia changes the dynamics of the couple, as the partner without dementia often assumes the role of the 'caregiver', gradually taking on more care responsibilities for the other partner, and thereby altering previously established roles in the relationship. 'Caregiver' partners have reported changes such as reduced companionship and mutual support (Quinn et al., 2015). Carer partners have identified diminished communication as the most significant challenge, which has been linked with increased negative perceptions of relationship quality (de Vugt et al., 2003; Clare et al., 2012; Garand et al., 2007).

Apathy, along with depression and anxiety, has been consistently reported as one of the most common neuropsychiatric problems in individuals with dementia, even in early stages. These conditions undermine reciprocity, a vital element of a couple's relationship, reducing joint activities, communication, and shared experiences. Caregiving partners also report reduced shared activities and verbal communication, as well as the loss of emotional support from their spouse, which results in lower marital satisfaction (Baikie, 2002). Across many studies, a consistent picture emerges as dementia progresses and communication abilities deteriorate, reduced active participation in conversations diminishes the reciprocity of the relationship, with the caregiving partner assuming more and more responsibility. This shift appears to underpin the experience of 'burden' and is thought to lead to changes in the caregiver's feelings towards their partner with dementia (Wright, 1991; de Vugt et al., 2003; van Vliet et al., 2011), resulting in poorer relationship quality (Garand et al., 2007).

Research also suggests that many caregiving partners experience grief (Shutter et al., 2014), as well as anger and resentment towards their partner with dementia (Croog et al., 2006; Shim et al., 2012). Such feelings can provoke substantial guilt and anxiety, potentially adding to the psychological burden (Balfour, 2014; 2018). Caring for a partner with dementia may also result in increased physical and psychiatric morbidity, particularly depression and anxiety disorders (Garand et al., 2005; Schulz & Martire, 2004). It is clear that emotional factors are crucial in understanding the impact of dementia on the caregiving partner. Loss of intimacy and understanding of their partner with dementia have been identified as important factors (Morris

et al., 1988a and 1988b), with the experience of lost intimacy in the relationship associated with caregiver partner depression. Studies show that caregiver partners experience feelings of lost shared meaning and connection to their partner with dementia (Massimo et al., 2013). This loss of connection is also associated with a greater sense of burden, lower well-being, and fewer rewards from the caregiving role (Riley et al., 2018).

In summary, studies focusing on caregiving partners demonstrate how, as dementia progresses, the couple's relationship becomes increasingly imbalanced. The predominant outcome of this, from the caregiver partner's perspective, is decreased marital satisfaction and poorer health (Kaiser & Panegyres, 2007; Clare et al., 2012). Caregivers experience losses in many areas of the relationship, including communication, closeness, reciprocity, intellectual stimulation, decision-making, and sexual intimacy (Mittelman et al., 2004).

Moving to a Dyadic View: Including Both Partners as the Focus of Research

Historically, there has been a gap in the literature, which has largely neglected a more holistic view of the shared couple experience (Ablitt et al., 2009). Until recently, only a few studies explored perceptions of relationship quality from the perspective of both the person with dementia and the caregiver (Clare et al., 2012; Spector et al., 2016; Wright, 1991). Daniels et al. (2007) underlined the importance of studying both partners together and acknowledging the voice of the individual with dementia. Clare et al. (2012) carried out a quantitative longitudinal study of 54 couples, examining

relationship quality over time for both partners. They found that caregiving partners in couples living with dementia showed significantly lower ratings of relationship quality than partners in couples without dementia. Notably, they found much greater discrepancies in ratings of relationship quality between partners in couples living with dementia (with the caregiving partners showing lower ratings) than in couples without dementia. These ratings declined even further over time. They argue that it's important to consider relationship quality when thinking about how to support couples where one partner has dementia.

A study by Rippon et al. (2019), also taking a dyadic view, further supports this point. They studied 1283 couples, investigating the impact of current relationship quality on life satisfaction and well-being. They found that the quality of the relationship between people with dementia and their caregivers is a key factor for life satisfaction and wellbeing for both partners. This study is the only large-scale quantitative investigation exploring relationship quality in caregiving couples and provides further evidence that the couple relationship is significant in dementia care. Relationship quality significantly impacts the life satisfaction and well-being of people with dementia and their caregivers.

Several studies confirm this finding, demonstrating that self-rated relationship quality is associated with life satisfaction and well-being for both caregiving and care-receiving partners. It also predicts lower depression and strain in the caregiving partner (Ablitt et al., 2009; Riley et al., 2018). Preserving the quality of the relationship is identified as a crucial determinant of the quality

of life and well-being of people with dementia (Clare et al., 2012; Clare et al., 2014) and their caregivers (Quinn et al., 2009). Furthermore, studies reveal that a lower quality of relationship is associated with higher levels of depression in the caregiver (Knop et al., 1998; Morris et al., 1988b), greater caregiver strain (Morris et al., 1988b), and lower perception of effectiveness as a caregiver (Townsend & Franks, 1997).

Burgener & Twigg (2002) found that the quality of the relationship, as reported by the caregiving partner, along with caregiving partner stress, predicted the psychological well-being of the partner with dementia, as well as several other aspects of their functional ability. Studies also show that the quality of the couple relationship is crucial for sustaining compassionate and effective care for the person with dementia (De Vugt et al., 2003) and is associated with lower depression and strain in the caregiver (Knop et al., 1998).

While it's clear that the progression of cognitive and functional impairment in the person with dementia presents massive challenges to the caregiver partner, for many years, the perspective of the partner with dementia was largely absent from research. More recent research, which embraces a dyadic view, indicates that the process of dementia affects both partners, whose capacities to adapt and change are tested as roles and identities must be negotiated and re-negotiated over the course of the illness.

Understanding not only the individual experiences of both the caregiver and person with dementia but also the way these individual perspectives interact

within the dyadic relationship to affect outcomes for the couple's relationship over the course of the illness is therefore crucial.

The Effect of the Pre-Morbid Quality of the Couple Relationship

It's no surprise that for many couples, the experience of dementia is coloured by the context of a relationship that has often spanned many years prior to the onset of dementia. Indeed, the quality of the relationship before the onset of dementia (premorbid quality) significantly influences how the disease is experienced (Ablitt et al., 2010). As Pozzebon et al. (2016, pp 549) highlight:

"Providing care and support to a partner takes place within the context of the pre-existing spousal relationship. This mutual familiarity supports established patterns of interaction, including preferred ways of expressing themselves within their relationship and underpins expectations for how each person will behave and react to one another."

Poor premorbid relationships are associated with significant caregiving challenges (Shim et al., 2012). Caregivers reporting lower premorbid relationship quality report higher levels of depression, distress (Gilleard et al., 1984; Knopp et al., 1998), strain (Morris et al., 1988b), and increased emotional reactivity to caregiving challenges (Steadman et al., 2007). Ablitt et al. (2009) in their review of quantitative studies found that the premorbid quality of the couple's relationship affected the bond between partners as dementia progressed. This decline in relationship quality had a detrimental effect on both partners as dementia worsened. Several other studies (Keady

and Nolan, 2003; Molyneaux et al., 2011) have also demonstrated that reflections on the premorbid relationship can influence how couples adjust to dementia. Notably, Winter et al. (2011) found that positive premorbid relationships significantly predicted continued home care, particularly for male caregivers.

In relationships that were strained prior to the onset of dementia, caregivers tended to perceive the behaviours of the person with dementia as a continuation of previous "bad behaviour", rather than symptoms of the disease itself (Balfour, 2014). Conversely, the positive quality of the premorbid relationship has been linked to resilience following a dementia diagnosis (Daniels et al., 2007; Davies, 2011).

Clearly, the couple's relationship is of paramount importance in terms of the clinical outcomes of dementia and the experience of the illness for both partners. It is, therefore, crucial to understand what enables the couple's resilience in the face of dementia's challenges. To this end, Rippon et al. (2019) highlight the importance of research considering both the perspective of the person with dementia and the caregiver. They found that maintaining positive perceptions of relationship quality can support life satisfaction and wellbeing for both partners. These authors stress the importance of this as a focus for interventions in dementia care, suggesting strategies that aim to preserve a sense of unity and involvement may be beneficial. This perspective is echoed by qualitative researchers such as Hellstrom et al., 2007; and Wadham et al., 2016, whose works will be discussed in the next section of this chapter.

The Qualitative Literature: How Does Dementia Affect the Couple's Relationship?

Recent years have seen an increase in exploring the lived experience of how couples respond to, manage, and negotiate the changes dementia brings to their relationships. A lot of this research has employed qualitative methodology, providing a deeper understanding of the changes couples go through during the disease process (Pozzebon et al., 2016). These qualitative studies, often dyadic in focus, offer more depth in exploring relational aspects than the quantitative literature, providing a more holistic understanding of the shared experience of dementia (Wadham et al., 2016). Data collection methods such as in-depth interviews allow caregivers to provide detailed descriptions of the everyday challenges they face with a partner with dementia.

This approach overcomes some limitations of quantitative studies, which often rely on scales and questionnaires, offering participants limited opportunities to explain the complexity of their experiences (Pozzebon et al., 2016). However, qualitative studies in this area employ a range of methodologies, making the task of synthesizing their findings a challenge due to the multiplicity of methodological approaches and philosophical perspectives (Lee et al., 2014). Despite these limitations, a reasonably consistent and coherent picture emerges from these studies, much like with the quantitative literature.

These studies specifically explore how dementia-related deficits affect the couple's relationship and the coping mechanisms of caregiving partners.

Perhaps the overarching theme is that dementia brings the experience of "loss of the partner" for the caregiver, with even subtle changes in the person with dementia's communication and behaviour posing a threat to the couple's cohesion. Reviews of both quantitative and qualitative research indicate that even the early, subtler changes of dementia can lead to feelings of distress, anxiety, and loneliness in caregiving partners (Pozzebon, 2016). A systematic review by Evans and Lee (2014) found that dementia impacted companionship, communication, reciprocity, and intimacy in couples' relationships.

Changes in roles between partners are another significant issue highlighted by researchers. As the person with dementia's capacity diminishes, a role change often ensues (Keady & Nolan, 2003). Several studies and reviews (Egilstrod et al., 2019; Evans & Lee, 2014) describe the gradual relinquishing of roles by the person with dementia. As the disease progresses, the partner without dementia is increasingly required to act as the caregiver in the relationship (Egilstrod et al., 2019; Boylstein & Hayes, 2012; Ducharme et al., 2013; Fjellstrom et al., 2014; Massimo et al, 2013; O'Shaughnessy et al, 2010; Quinn et al., 2009; Vikstrom et al, 2008).

Without a doubt, partners experience both emotional and practical impacts in their lives due to taking on increased responsibility and managing more tasks and concerns (Bergman et al., 2016). Male partners especially experience a shift in roles as they have to take on tasks that were previously unfamiliar, a situation that intensifies as dementia progresses (Balfour, 2014; Hellstrom et al, 2017). Day-to-day activities increasingly fall on the partner's

shoulders, leading to significant role changes (Boyle, 2013; Boylstein & Hayes, 2012; Lin et al, 2012; Quinn et al., 2008; Vikstrom et al., 2008). Cross et al (2018) in their meta-analysis highlight the challenges couples face moving from an equal relationship towards one of 'caregiver' and 'care recipient'.

A review by Evans & Lee (2014) of 19 studies reported shared experiences of changing roles and responsibilities, with one partner taking over the roles that their partner with dementia could no longer manage due to the disease's progressive nature. Many partners reported the role change from 'spouse' to 'caregiver' as frustrating, especially as the caregiver role became more dominant with the disease's progression (Boylstein & Hayes, 2012; Ducharme et al., 2013). These studies also show that, while partners reported spending more time together, they stated that dementia negatively affected their mutual engagement in everyday activities (Vikstrom et al., 2008). The emotional struggle of dealing with these relationship changes is a personal one for caregiver partners, with many feeling alone and isolated without a sense of marital closeness, potentially leading to higher levels of burden and depression (Pozzebon et al, 2016; Boylstein & Hayes, 2012).

It is unsurprising that such changes result in profound feelings of loss, with many couples reporting feelings of grief and uncertainty about their future life with the disease's progression (Evans & Lee, 2014). As Pozzebon et al (2016) highlight, for most couples, talking and sharing has been a natural and routine way of relating to each other. Dementia disrupts this capacity for emotional connection as it progressively reduces their verbal communication.

Many partners report struggling to maintain their identity as a husband or wife, often described as a crisis in self-identity, reflecting on their previously familiar couple partnership. Out of necessity, but often with resistance, partners begin to take on new roles and responsibilities (Massimo et al., 2013). The distressing transition from being a spouse to becoming the caregiver is often conveyed with deep emotion, as can be seen in the following quotation:

'All of a sudden, I went from wife to caregiver. And that label was placed on my chest that said 'caregiver now.' And then I accepted it for a while and then I realised that 'I don't want to be your caregiver.' I really don't want to do that' (Massimo et al., 2013).

The studies indicate that the caregiving partner is often grappling with their own feelings of loss, frustration, and anxiety, making it challenging for them to comprehend and emotionally support their partner with dementia (Balfour 2014). Dementia can put significant strain on the relationship, negatively impacting its quality (Baikie, 2002; Holdsworth & McCabe, 2017; Wadham et al., 2016). Despite many couples' attempts to preserve their bond (Clark et al, 2019; Davies, 2011), caregiving partners often report experiencing significant burden (Etters et al, 2008) and stress (Pinquart & Sörensen, 2003), stemming from the tension of meeting their partner's needs while managing their own (O'Shaughnessy et al, 2010).

Loss of Engagement/Emotional Connection

It appears that diminished engagement in everyday activities is linked to a corresponding emotional withdrawal between partners in couples where one individual is living with dementia. As Pozzebon et al. (2016) elucidate, a significant proportion of spouses in the qualitative studies reported changes in their dyadic interaction patterns. These changes contributed to feelings of increasing emotional disconnection from their partners. This finding aligns with quantitative dementia research that correlates the burden experienced by caregiving partners with changes in their partners' verbal communication and behaviour (de Vugt et al., 2003; Clare et al., 2012; de Vugt et al., 2012; Garand et al., 2007; Hsieh et al., 2013). Behavioural alterations, such as heightened apathy and diminished verbal communication, were associated with a reduced sense of emotional intimacy between partners. As Pozzebon et al. (2016) indicate, changes in modes of communication and interaction can undermine the spousal bond, given the central role of two-way conversations in sustaining emotional and intellectual intimacy.

Loss of intimacy in relationships is also reported in numerous studies (Massimo et al., 2013). As dementia progresses, maintaining meaningful communication between partners becomes increasingly challenging. The subject of sexual intimacy in late life, particularly in the context of dementia, has until recently been somewhat taboo. This reticence is reflected in the relative scarcity of research focused on this aspect of the couple's relationship. Nonetheless, several studies highlight a common decrease in physical intimacy reported by married couples (Harris, 2009; Hayes et al

2009; Sanders & Power, 2009). Interestingly, as physical intimacy diminishes, emotional intimacy may assume greater significance (Sanders & Power, 2009). In their review, Pozzebon et al. (2016) point to caregiving partners' reports of a shift from sexual intimacy towards other forms of physical contact, such as handholding, cuddling, and kissing (Davies et al., 2011; Harris et al., 2011; Gillies, 2012). These changes in intimacy and physical closeness were not universally viewed negatively, with other affectionate physical interactions often replacing sexual intimacy (Davies et al., 2011).

Individuals with dementia gradually lose interest and engagement in activities they once enjoyed with their partner. The overall consensus in the qualitative literature indicates that reciprocity between partners in couples living with dementia dwindles over time (Eloniemi-Sulkava et al., 2002; Murray et al., 1999). This reduction is coupled with declines in happiness (Eloniemi-Sulkava et al., 2002), communication, shared activities, and relationship quality. For caregiving partners, the quality of the relationship is demonstrated to significantly deteriorate over time (Clare et al 2012).

Sustaining the Relationship

The significance of our relationships in shaping and maintaining an individual's sense of self, and the implications of this for couples living with dementia, is a subject of interest for numerous researchers (Hellström et al, 2005; Johnston & Terp 2015). In relation to dementia, these authors underscore the necessity of studying "couplehood" among couples managing the disease. By "couplehood," they refer to the ways the couple relationship

can be sustained to potentially mitigate some negative outcomes, primarily by the process of engaging in shared activities (Hellström et al, 2005). As an illustration, they cite a case study where the dementia-affected partner encountered difficulties with cooking. The caregiving partner kept them company in the kitchen, offering subtle assistance (Hellström et al., 2005). These researchers propose "couplehood" as a pivotal factor fostering resilience, adjustment, and coping in couples living with dementia.

Forsund et al. (2014) indicate that 'couplehood' has emerged as an important construct in the literature, encapsulating the impact of dementia on the relationship, inclusive of the partners' experiences of intimacy, trust, and support. Their findings reveal that experiences of lost 'couplehood' were associated not only with feelings of separation and loneliness, but also with the loss of a shared past and future, especially in the later stages of the disease. Despite these losses, experiences of connection, reciprocity, and interdependence — contributing to a sense of 'couplehood' — ebbed and flowed. Intriguingly, even fleeting moments of such connectedness held great value for the spouses of those with dementia. The authors underscore the importance of recognising, understanding, and validating the shared, unique experiences of both partners in sustaining the sense of interconnectedness (or 'couplehood') in the relationship during the journey of dementia.

While the balance of power and responsibility within the relationship can shift over time for couples dealing with dementia, Wadham et al. (2016) observe that many couples managed to maintain a sense of connection and reciprocity. They navigated ways to uphold the involvement of the person

with dementia in shared activities within the relationship. Importantly, caregiving is not always an entirely negative experience (Hellstrom et al., 2005). Several qualitative studies have investigated how people with dementia and their caregivers strive to maintain a sense of 'couplehood' or 'togetherness', despite challenges posed by shifts in the relationship balance (Wadham et al, 2016). Wadham et al. (2016) sought insights from both partners in their meta-analysis of qualitative studies on dementia's impact on relationships and 'couplehood'. This led to the identification of four primary themes: concerted efforts to maintain togetherness; shifts in relationship balance and power (affecting both partners' identity); empathy and sensitive attunement between partners. They also identified several resilience strategies employed by couples amidst feelings of fear, uncertainty, and hopelessness. These included acceptance of the diagnosis, utilising humour to normalise their experiences, cultivating a positive life outlook, and fostering a greater appreciation of life's joys, as means of buffering emotional distress (Wadham et al., 2016).

Shared Involvement

Indeed, despite the multiple losses and changes reported in numerous studies, the qualitative literature underscores that feelings of belonging, reciprocity, and continuity can occasionally be maintained within intimate relationships for couples living with dementia (Hellstrom & Lund, 2007; Wadham et al 2016). This line of research suggests that the ability to perceive continuity with the past is a significant factor influencing caregivers' experiences of dementia. Moreover, the sustainment of meaning-making

processes, where partners devise novel ways of relating to each other within the dementia context, further impacts caregiving experiences (McGovern, 2012). As observed by Evans & Lee (2014), qualitative studies emphasise the continuities that can sometimes be maintained within the relationship, in addition to individual differences between couples in their responses to dementia. For some caregivers, it seems the caregiving role aligns with a theme of 'making sacrifices', reflecting their lifelong conceptualisation of their marital relationship (Cross et al., 2018). This alignment, they suggest, might indicate a sense of continuity amidst the shifting demands imposed by the disease on the couple's relationship.

In their review, Eligostrad (2019) describes how partners sought alternative strategies to cope. These included attempts to sustain 'couplehood' and reconstruct marital closeness (Bergman et al., 2016; Boylstein & Hayes, 2012; Hellstrom, Nolan, & Lundh, 2007; Lin et al., 2012). Some couples strived to preserve their marital relationship by enabling the partner with dementia to continue with social and household tasks (Boylstein & Hayes, 2012). Maintaining emotional closeness helped the caregiving partner contextualise their role, resulting in the acceptance of caregiving as a part of their relationship (Boylstein & Hayes, 2012). Despite considerable changes within the relationship, some partners attempt to maintain shared involvement or 'couplehood', and to hold onto a sense of closeness by focusing on former rituals and routines and continuing shared activities (Hellström et al., 2007).

Indeed, the significance of shared involvement within a couple, especially when one partner has dementia, has been recognized for several years. Hirschfeld (1983) found that sustaining a sense of shared involvement was the primary factor determining whether a person with dementia would continue to receive care at home or move into residential care. Moreover, maintaining a sense of mutuality was crucial in shaping the experiences of both the caregiver and the person with dementia throughout the illness stages. Pozzebon et al. (2016) highlighted that in some couples who were close and emotionally connected, the partner often adjusted their response and behaviour sensitively to minimize the impact of the challenges faced by the partner with dementia (Hellstrom et al., 2007; O'Shaughnessy et al., 2010; Harris et al., 2011; Shim et al., 2012). These partners devised several creative methods to maintain a sense of emotional intimacy with their partner. For instance, as reviewed by Pozzebon et al. (2016), caregiving partners often opted to perform tasks jointly with their partner with dementia. As discussed, one case study by Hellstrom et al. (2005) described a partner who proactively built on his wife's strengths, supporting her cooking skills by keeping her company in the kitchen and prompting her to verbalize the recipe, which helped her to remember it (Hellstrom et al 2005). This capacity to find ways of adjusting to the changes brought by dementia and to support the continued involvement of the partner with dementia have been cited as crucial factors by some researchers, such as Pozzebon et al (2016), who comment: '*There was a sense that the spouses were travelling a common journey ...which involved dealing with the massive changes in all aspects of their shared life together.*' Gillies (2012.)

'Being in the Atmosphere of Doing'

The concept of 'being in the atmosphere of doing' originated from Van't Leven & Jonsson's (2002) work, suggesting that for people with dementia, the experience of 'being' in an activity can be as valuable as the act of 'doing.' These researchers noted that both the person with dementia and the caregiving partner might describe themselves as engaged together in an activity, despite the person with dementia primarily existing in the 'atmosphere' or presence of 'doing', while the caregiver might be carrying out the activity. Thus, for the couple, the crucial aspect is not the act of doing the activity but the experience of 'being in the activity together'. Vikstrom (2008) emphasizes the significance of shared activities for maintaining closeness between partners, despite the progressive functional decline in dementia. The primary value of the activity lies in its function as a means for engagement and emotional connection between the partners. Thus, the activity's importance transcends the physical act and becomes a vehicle for shared engagement. Even if the partner with dementia is not wholly engaged in performing the task, their 'being in the atmosphere of doing' and sharing this experience with their partner fosters a sense of shared engagement that is critical for their relationship. This concept will be further explored in the context of intervention development.

Indeed, as Pozzebon et al (2016) highlight, some partners have been able to adapt to their significantly altered circumstances, including the reconstruction of their shared identity as a couple. The authors elaborate: "the findings suggest that when a spouse redirects their energies to preserving the

personhood of the partner, they also preserve their own identities as husbands and wives" (Perry and O'Connor, 2002). These individuals had a keen understanding of the value in maintaining their partner's abilities as a shared, social activity in its own right (Muller and Schrauf, 2014).

The Challenges of Sustaining 'Couplehood' in Dementia

It remains less clear what factors enable people to provide loving companionship to their partner. Pozzebon et al (2016) point out that some partners in the studies were unable to do this and that their inability to accept the burden dementia placed on their relationship led to feelings of resentment, frustration, despair, and emotional withdrawal towards their partner with dementia. Boylstein & Hayes (2012) found that, for partners who couldn't find a way to maintain a sense of closeness in the relationship, caregiving could become a harrowing experience.

While considering the potential to maintain a sense of 'couplehood' and emotional closeness, it's critical to remember the extent of personal loss for the caregiving partner and how painful it can be for them to witness the ongoing decline of their life partner. Gillies (2012) captures the emotional weight of these realities: "Well, you get very hurt about it but then I say, 'it's your husband,' and you've just got to shut yourself off, and just get on with it. . . . Your feelings are still there but you feel so sorry. At times you feel, 'why him, why has it happened to him?'" (Gillies, 2012).

Pozzebon et al (2016) argue that we need to deepen our understanding of how the quality of the partners' relationship influences their experience of

living with dementia. This knowledge could help inform therapeutic approaches to support partners in renegotiating a new way of relating to their life partners. The importance of this understanding lies not only in helping to maintain the quality of life for the person with dementia but also in supporting the caregiver's mental and emotional health.

Summary of Key Factors Which are Important for the Resilience of the Couple

Indeed, the research evidence collectively suggests that there are key elements within intimate relationships that can act as protective factors for couples, supporting their resilience in dealing with the challenges that dementia poses.

- **Continuity and Shared Involvement:** Maintaining a sense of connection and shared involvement between partners is essential. Encouraging togetherness, reciprocity, and the ability to maintain a sense of mutuality and 'couplehood' can serve as potent pillars of support (Hellstrom & Lund, 2007; Lewis et al, 2005; Wadham et al 2016).
- **Meaning-Making Processes:** The ongoing development of meaning-making processes through which partners construct new ways of relating to each other in the context of dementia is also crucial (McGovern, 2011).
- **Emotional Connectedness:** Preserving emotional connectedness with the partner who has dementia is another significant element. Many studies have discovered that some partners devise creative ways to maintain a sense of emotional intimacy and positive reciprocity with their

partner – generally involving joint participation in domestic tasks (Hellstrom, 2005).

- Engagement in Everyday Activities: Participating together in social or household activities is often expressed by spouses as a key factor in keeping their partner "present" and maintaining a sense of couple closeness (Pozzebon et al 2016; Boylstein & Hayes, 2012). Other researchers note that partners often adopt strategies to handle day-to-day challenges that preserve their sense of "couplehood," or mutual belonging within the relationship (Hellstrom et al., 2005; 2007; Molyneaux et al., 2011; Shim et al., 2012, 2013). It is apparent from this research that what's essential isn't just 'doing' things together – but the emotional connection that shared activities can facilitate.
- 'Being in the Atmosphere of Doing': The concept introduced by Van'T Leven & Jonsson (2002) expresses the idea that even though functional impairments increasingly limit the person with dementia's ability to directly engage in activities, they can still experience 'being in the atmosphere of doing' and derive benefit from being part of the activity, even if they cannot engage directly with it. The notion here is that both partners might perceive this as 'togetherness', as mutual involvement in the activity, even if it's predominantly the partner without dementia performing the task. This links to the concept of everyday domestic activities serving as vehicles for emotional engagement between partners living with dementia, where the interaction is with each other rather than the task itself.

Attachment and Dementia

The evidence reviewed thus far indicates several relationship factors that are vital for maintaining resilience in couples, such as cohesion and 'couplehood', which are maintained through mutual involvement in everyday life and activities. Even if the partner with dementia becomes less capable of participating in tasks, their mere involvement or presence might still be crucial. From a psychoanalytic perspective, this can be interpreted as the significance of maintaining an 'emotional connection' between partners. This theme's importance is also supported by attachment research, which contributes to our understanding of the psychological challenges couples facing dementia experience.

As adults, our need for security doesn't diminish, and the principles of attachment theory continue to be relevant in later life. As Browne & Shlosberg (2005, 2006) note, Bowlby (1969, 1979) emphasized that attachment behaviour becomes particularly noticeable during times of ill health or loss—circumstances that become more common with ageing. Attachment relationships are thought to serve as a protective resource in later life (Magai and Passman, 1997), and under conditions of threat, the need to seek closeness and proximity to attachment figures often re-emerges, leading to an increase in attachment behaviour (Bowlby, 1969).

There is a growing body of research exploring the role of attachment in caregiving relationships with older individuals (Bradley and Cafferty, 2001; Steele et al, 2004), and attachment theory provides valuable insights into the experiences of people with dementia. The progression of dementia is often

characterized by experiences of loss and separation from attachment figures (or the fear thereof) and feelings of insecurity. Involuntary separation and disruption of attachment bonds can often be a common part of the dementia experience (Browne and Shlosberg 2006). Thus, the principles of attachment theory can offer meaningful perspectives on the complex dynamics of couples navigating life with dementia.

The impact of dementia on individuals' 'attachment system' has been explored by researchers like Miesen (1992, 1993), who report a high incidence of 'attachment seeking' behaviour in people with dementia, including those in the later stages of the disease. Using an experimental situation analogous to the 'strange situation paradigm' from infant attachment research, Miesen observed that people with more advanced dementia manifested 'attachment seeking' in the form of 'parent fixation', while those in earlier stages showed more overt 'proximity seeking' behaviour.

Similar observations have been made by other researchers, who note 'attachment seeking' behaviour across the range of dementia, even in individuals with greater cognitive impairment. However, these studies, including Miesen's and the replication by Browne and Shlosberg (2005), have faced some methodological limitations, such as small sample sizes and the cross-sectional nature of the research.

Despite these challenges, there's a convergence of evidence suggesting that insecure attachment is related to higher levels of Behavioural and Psychiatric Symptoms in Dementia (BPSD), even when controlling for cognitive and general functioning (Perren et al 2007). Insecure attachment in caregivers is

associated with higher caregiving burden, negative appraisals, less satisfaction with perceived support, and higher levels of depression and anxiety (Van Assche et al 2013).

Studies have described why some carers adjust effectively to the changed circumstances associated with dementia and thus experience reduced challenging behaviour, while others do not (Feast et al, 2016). Anxiously attached individuals may panic and fail to accept the situation, while those exhibiting a pattern of compulsive self-sufficiency may engage in argument or withdraw from the partner. In contrast, secure attachment appears to facilitate a more accepting state of mind in relation to the losses and changes associated with dementia and to promote emotional connection with, and care for, the partner with dementia (Ingebretsen & Solem 1998).

Implications of developmental research for attachment in couples living with dementia

The importance of the 'meeting of minds'

The theoretical underpinnings outlined by Fonagy et al (2007) and Tronick (2004) emphasize the importance of a "primary inter-subjectivity," or shared understanding of the world, which is established through interactive 'dyadic states of consciousness' between an infant and their primary attachment figures. This interaction is critical to forming a coherent self-representation in the infant. When it is disrupted, infants are pushed towards states of emotional and cognitive disorganization, a phenomenon which is linked to severe depression.

The 'still-face' experiment by Tronick (2004) highlighted the distressing consequences of preventing the establishment of such dyadic states, which led to cognitive and emotional disintegration and withdrawal. This reaction mirrors observations made in dementia care settings, where patients, when left for long periods without personal interaction, exhibit similar patterns of disengagement and withdrawal (Davenhill et al, 2003). Partners of those with dementia also often express the impact of the loss of this inter-subjective contact or mutual communication within their relationship, an experience which is associated with depression (Braun et al, 2010).

Moving from these developmental considerations to their implications for adult relationships, the critical importance of reciprocal emotional exchange is highlighted. Moments of shared consciousness, where individuals 'match' or 'know' each other's states of mind, carry a potent sense of fulfilment (Beebe, 2015; Fonagy et al, 2007). This understanding from infancy research about the significance of the 'joining of minds' is highly relevant for couples living with dementia. They often face a loss of intimacy and mutual understanding, increased attachment needs, and cognitive and emotional disintegration due to progressive cognitive impairment. Yet, it's the loss of this shared understanding that is often the most challenging aspect of the condition. Carers have expressed this loss of communication as, "if only I knew what he/she was thinking" (Bull, 1998).

This insight is pertinent for both partners in the relationship and may offer critical insights into the emotional needs of individuals with dementia. As their capacity for language diminishes and opportunities for intimacy and mutual

understanding become constrained or lost, attachment relationships change, and the familiar social world becomes unsteady. The following chapter will explore interventions developed for couples living with dementia, considering these issues highlighted in this review. It emphasizes the importance of emotional connection, attunement, collaboration, and shared activities in order to regain, even if only temporarily, moments of 'connectedness' within couples living with dementia. These topics will also be revisited in Chapter 5, which focuses on the development of a new intervention for such couples, as these are fundamental components of our approach.

Chapter 3: Psychological Interventions for Dementia

Introduction

This chapter will review the literature on psychological treatments developed for couples living with dementia, detailing their strengths and limitations. This will then lead into a discussion of what is missing from the current intervention literature as well as an outline of areas for development. This review will set out the rationale for the proposed new intervention, which will be discussed in subsequent chapters.

Methods

Review Strategy

The literature review for this study was aimed at understanding the impact of dementia on couples' relationships and the influence of interventions in this context. To collate relevant articles, three database platforms - PubMed, OvidSP (including Embase, MEDLINE, global health, and APA PsychInfo), and Web of Science - were searched. The search strategy included the following terms: "Couple relationship" OR "marital" OR "spouse" OR "romantic relationship" AND "dementia" AND "intervention". The search was confined to articles published in English and peer-reviewed journals from 1990 to 2023.

Search Outcome

An initial search from EBSCO, PSYCHINFO, and PSYARTICLES databases yielded 161 papers published between 2000 and 2023. After screening, 139 articles were excluded for lack of relevance to the topic or the absence of intervention/couple relationship focus. The remaining 22 articles were subjected to a full-text review. Additional studies were identified by inspecting the reference lists and citation lists of the initial set of papers.

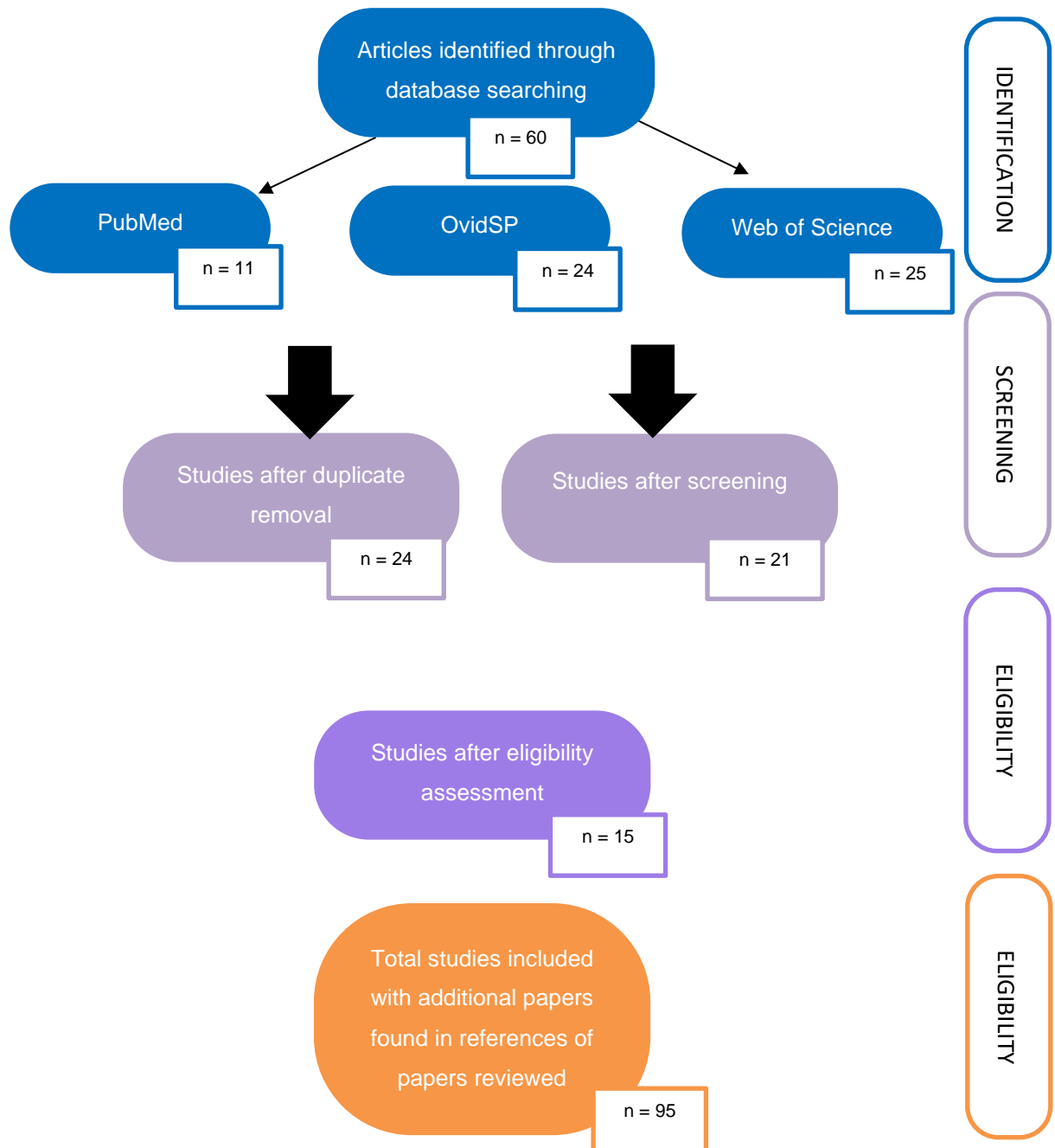
Inclusion and Exclusion Criteria

The research primarily examined the impact of dementia on couples' relationships. Therefore, the inclusion criteria involved studies focused on individuals with dementia (including Alzheimer's disease) or couples where one partner has dementia (including Alzheimer's disease). Exclusion criteria were set to exclude studies that involved participants with comorbid psychiatric conditions or physical diseases such as strokes, heart attacks, other degenerative diseases like multiple sclerosis, Parkinson's disease or Huntington's disease, or ambiguous diagnoses of dementia or Alzheimer's disease, such as "suspected Alzheimer's" or mild cognitive impairment. Early onset dementia diagnoses in individuals under the age of 60 were also excluded. Studies that concentrated on the risk dementia posed in other life areas, such as its contribution to other illnesses or mental health conditions, were not included.

Study Selection

A total of 60 articles were identified across the three databases - 11 from PubMed, 24 from OvidSP, and 25 from Web of Science. Twenty-four articles were discarded due to duplication, and 21 were excluded as they didn't meet the criteria. After screening titles and abstracts, a total of 15 articles remained for review - six from PubMed, three from OvidSP, and six from Web of Science. Figure 2 presents the AND intervention process in detail. In addition, a further 80 studies were identified by inspecting the reference lists and citation lists of the initial set of papers, yielding a total of 95 studies included.

Figure 2. Study selection process for the literature examining the effect dementia has on the couple relationship with the influence of intervention.



Evidence for the Effectiveness of Psychosocial Interventions in Dementia Care

The widespread early diagnosis of dementia, which is now more established due to international government policies, heightens the necessity for accessible evidence-based psychosocial interventions for individuals diagnosed with the disease. As De Vugt and Verhey (2013) argued, a gap remains between the growing capability to diagnose individuals at the pre-dementia stage and the limited knowledge on intervention effectiveness. Even a decade later, there has been little progress in this aspect, with no well-established, evidence-based psychosocial interventions available for couples living with dementia. Given the severe stress dementia imposes on a couple's relationship, which crucially influences outcomes such as quality of care and emotional wellbeing, the development of supportive interventions for couples dealing with dementia is essential (Gilbert et al., 2023).

In the broader dementia caregiver intervention literature, the strongest evidence points towards multi-component psycho-social interventions. These interventions have shown effectiveness in improving caregiver wellbeing and in delaying the transition to institutional care (De Vugt & Verhey, 2013). For instance, a meta-analytic review of randomized controlled trials exhibited promising effects of multi-component caregiver interventions on stalling institutionalization (Olazaran et al., 2010). The rate of institutionalization dropped by 33% after 6-12 months of intervention in cases of mild to moderately severe Alzheimer's Disease. The interventions employed in the

three Randomized Controlled Trials contributing to this effect (Lawton et al., 1989; Mittelman et al., 1993; Belle et al., 2006) were diverse.

Lawton et al. (1989) incorporated respite services over a twelve-month period, which effectively delayed the shift of the person with dementia to residential care. Belle et al. (2006) used a blend of informational provision, instructional training, role-playing, problem-solving skills, stress management techniques, and telephone support groups. Mittelman et al (1993) examined the effects of a combination of individual and family counselling, support group involvement, and on-call telephone counselling, in comparison to standard support provisions. The treatment group, after one year, had fewer nursing home placements than the control group. A long-term follow-up revealed a delay of approximately eighteen months in nursing home placement, attributed to enhancements in caregiver wellbeing post-intervention (Mittelman et al, 2004). This improvement in caregiver wellbeing allowed for the postponement of nursing home placement for the individual with dementia by a median time of 557 days (Mittelman et al., 2006), resulting in potentially substantial financial savings (Foldes et al., 2018; Long et al., 2014).

Limitations of Multi-Component Interventions to Date

From a brief overview of some of the most successful interventions thus far, it is clear that they are incredibly varied in their constituting components. A challenge associated with multi-component interventions is the complexity in reproducing their contents, clarifying the relative significance and effectiveness of their individual components, and determining the extent of

involvement from the person with dementia, their partner, or other family members (Belstein et al., 2019). Predominantly, these multi-component interventions target caregivers and largely focus on educational programmes, incorporating coping and support strategies and self-management support (Dam et al, 2016; Gilhooly et al., 2016; Veld et al, 2015; Jensen et al, 2015; Li et al, 2013).

What does the evidence suggest for these individual components? Education programmes have demonstrated a moderate reduction in caregiver burden and depression (Jensen et al, 2015; Parker et al, 2008). Coping strategy interventions have been successful in decreasing depression, but subsequent increases in dysfunctional coping have been observed after the interventions' conclusion (Li et al., 2013). A review of social support interventions showed no positive effects in quantitative studies; however, qualitative studies indicated that spouses felt more emotionally supported and less socially isolated (Dam et al., 2016). A reminiscence intervention offered to people with dementia and their caregivers showed no effects (Charlesworth et al, 2016).

Most multi-component interventions target only the caregiver and do not adopt a dyadic approach (Bielsten and Hellstrom, 2019; Clare et al, 2012; Gilhooly et al., 2016; Hellstrom, Nolan, & Lundh, 2007). Furthermore, the support they provide is typically practical, such as cleaning, cooking, shopping, and respite care (Alzheimer's Disease International, 2016; Gilhooly et al., 2016). While this type of support is crucial, these interventions often lack dyadic or relationship-based support (Bielsten and Hellstrom,

2019). This omission is significant, as dyadic interventions have proven to be more effective than those focusing solely on patients or carers (Schulz et al., 2008). For instance, Neely et al (2015) examined the effectiveness of a collaborative memory intervention for people with dementia and their spouse caregivers. The results showed superiority over an individually focused programme of the same intervention. Quayhagen and Quayhagen (2001) demonstrated the value of including the spouse caregiver as an active participant in cognitive rehabilitation for dementia using a dyadic-focused cognitive stimulation intervention. However, these interventions lack a specific focus on addressing relational issues in the couple relationship.

Dyadic Interventions for Caregiver and Person with Dementia

Smits et al (2007) evaluated the efficacy of combined interventions for both the person with dementia and the caregiver, noting that over half of the dyads in the studies they reviewed demonstrated positive mental health outcomes for both individuals. Most of these studies, however, implemented interventions for the caregiver and the person with dementia separately, rather than jointly, despite an emerging body of evidence emphasizing the significance of conjoint interventions (Townsend et al, 2001; Hausler et al, 2016). In their review, Pinquart and Sorensen (2006) observed a greater delay in residential care admissions in intervention studies with a higher percentage of participation from couple caregivers. This suggests that couples living with dementia could benefit from early diagnosis and interventions focused on both partners' involvement.

Interestingly, depression in individuals with dementia was found to decrease when the intervention targeted couples rather than the individual partners separately. Additionally, caregiver partners' anxiety was reduced when relationship issues were included in the intervention (Martire et al., 2004). The US Institute of Medicine called for dementia psychosocial interventions to involve both the person with dementia and their partner in 2008 (Johnston and Terp, 2015). Despite this call to action, the field still lacks couple-based interventions in dementia care. While evidence suggests an association between relationship quality and outcomes for both partners, existing studies on couple-focused interventions show little evidence of efficacy (Collins, Gilligan, & Poz, 2018; Eloniemi-Sulkava et al., 2009; Elvish et al, 2013). Rausch et al (2016), after reviewing seven couple-focused interventions, concluded, "None of the included studies showed clear, indisputable positive effects of any intervention" (p.8).

The seeming lack of clear positive effects of couple-focused interventions in dementia care may be explained in a number of ways. Bielsten & Hellstrom (2019) observed in their review of caregiving dyad intervention studies that few focused on relational issues and those that did often did not consistently target the couple. Furthermore, several studies reviewed by Rausch et al (2016) failed to distinguish between different caregiver-care recipient relationships (such as spousal or parental) in participant recruitment, intervention design, and data analysis. Bielsten and Hellstrom (2019) emphasized this point, noting that most studies they reviewed did not specifically select participant dyads based on the relationship type between the person with dementia and the caregiver. Rausch et al (2016) argued that

intervention development needs to consider research into the differential impacts of dementia on spousal and parent-child relationships to create effective psychosocial interventions tailored to the unique needs of these dyadic care relationships.

One crucial aspect of successful interventions appears to be a focus on the specific personal characteristics and resources of the participants. The effectiveness of interventions can be enhanced when they are individualized to meet the specific needs, skills, or characteristics of caregivers, such as gender, age, education, and relationship with the person with dementia (de Vugt et al., 2004). Moon & Adams (2012) and Van't Leven et al., (2014) found in their reviews of dyadic interventions that those involving joint sessions for people with dementia and their caregivers showed promising effects on the wellbeing of both parties. However, these reviews emphasized the need for a 'couplehood' approach - tailored support for couples focusing on relational issues. This lack of tailored support in dementia care was also noted by Belstein and Hellstom (2019a).

To provide effective tailored support, it's important to consider the nature of the relationship (parent-child or couple) and adapt the intervention to meet the specific needs of the dyad (Bielsten and Hellstrom 2019b). As Werner et al (2020) underscored, reviews of the intervention literature have consistently concluded that multicomponent psychosocial interventions that are individualized and sensitive to the unique needs and characteristics of individuals are the most successful in reducing caregiver distress (Dam, de Vugt, Klinkenberg, Verhey, & Van Boxtel, 2016; Gilhooly et al., 2016).

Unfortunately, according to Bielsten and Hellstrom (2019), most interventions fail to adopt this kind of tailored, holistic approach. These authors propose that interventions applying these criteria should have a greater potential to support close relationships, thus contributing to a sustained sense of personhood for the partner with dementia, and a sense of couplehood for spouses.

The Neglect of Interpersonal Issues in Dyadic Interventions.

Maintaining close emotional relationships is crucial for individuals with dementia to sustain their sense of personhood (Hellstrom et al., 2005; Phinney, 2002; Smebye & Kirkevold, 2013). However, according to Martire et al (2010), dyadic interventions vary greatly in the extent to which they address interpersonal issues. Bielsten & Hellstrom (2019a) found in their review that most dyadic approaches fail to focus on the couple relationship itself, indicating a lack of relational understanding. While dyadic interventions can provide opportunities for interaction and shared activity, promoting social inclusion, most do not consider relationship factors (Bielsten & Hellstrom, 2019a). Even when dyadic interventions primarily aim to reduce caregiver burden or address neuropsychiatric symptoms in people with dementia, relationship factors within the dyad often need to be addressed.

Several reviews of dyadic interventions have highlighted this lack of focus on relational issues (Moon & Adams, 2012; Van't Leven et al., 2014) and emphasized the importance of distinguishing between caregiver subgroups (Braun et al., 2009; Smits et al., 2007; Purkis & Ceci, 2015). Consistent calls in the literature argue for a stronger focus on relational understanding and

consideration of the nature of the relationship (couple or parental), which could enhance dyadic interventions in dementia (Merrick et al., 2016).

Thus, despite the importance of enhancing the resilience of the couple relationship in dementia, the research literature is diverse and many interventions, while including the couple in their design, do not specifically focus on relational factors (Bielsten & Hellstrom, 2019a, 2019b; Moon & Adams, 2013; Rausch et al, 2017; Gilbert et al, 2023). The inconsistency in the evidence can be attributed to problems in the design of these studies, including the failure to distinguish between types of relationships (parent-child or spousal), the lack of tailoring interventions to the specific needs of the dyad, or addressing relational issues. Moreover, Rausch et al (2016) and Gilbert et al (2023) noted that methods are not clearly described, systematic details of the interventions are often missing, and outcomes are not systematically reported in many dyadic intervention studies. These limitations hamper potential replication and make it difficult to assess the validity of the studies' claims.

Hence, there is a need for new approaches that adopt a more systemic, holistic focus, consider the nature of the relationships being addressed, and target relational issues. There is a clear imperative for the design and evaluation of interventions that are specifically aimed at couples, addressing relational and interpersonal issues for couples living with dementia. With these considerations in mind, interventions explicitly targeting the couple relationship and adopting a relational focus will now be discussed.

Relationally Focused Interventions with Couples

The importance of supporting the couple relationship in the context of dementia is well recognized. Researchers argue that this support can mitigate the negative impact of dementia (Ablitt et al., 2009; Hellstrom, Nolan, & Lundh, 2005; Hellstrom et al., 2007; McGovern, 2011), and might even contribute to slowing down the progression of the disease (Norton et al, 2009). However, when it comes to evidence supporting interventions that directly aim to improve the couple relationship, the literature shows a notable lack of intervention development and evaluation.

A review by Gilbert et al. (2023) identifies ten studies with a narrative focus, primarily involving activities that encourage couples to reflect on their lives together, such as reminiscence or creating life-story narratives (Dassa, 2018; Ha et al., 2021; Ingersoll-Dayton, 2013, 2016; Kindell et al, 2018, 2019; Kwak et al., 2018; Melunsky et al., 2015; Ryan et al, 2020; Sweeny et al. 2021).

Examples include the 'couples life story' interventions outlined by Scherrer et al (2014) and Ingersoll-Dayton et al (2013, 2016), which aim to foster meaningful engagement for both the individual with dementia and their caregiver partner. This intervention involves helping couples to narrate their shared life story, beginning with reminiscing about significant past events, and then co-creating a "life storybook" filled with meaningful mementos and designated space for future significant events. The intervention also provides training in communication skills to promote positive engagement between the partners. Qualitative analysis of post-intervention interviews suggested that

couples found the intervention beneficial, and practitioners observed increased expressions of affection. However, this study was limited by a small sample size and lacked comprehensive post-intervention data, including any systematic quantitative or qualitative outcome evaluations.

Such limitations are not uncommon in studies of relationally focused interventions involving couples, as Gilbert et al (2023) highlight. Only three of these studies used a randomized controlled design (Nordheim et al., 2019; Quayhagen et al., 2000; Quayhagen & Quayhagen, 2001), and none of them reported significant results. Quantitative measures were rarely used, and when they were, the data was often only descriptively reported without analysis. Systematic follow-up data was only collected in three studies, none of which reported significant results. While all the studies using a qualitative approach reported some benefits, most did not employ systematic methods of analysis, which makes their claims difficult to evaluate.

Overall, the methodological issues with studies aiming to improve relationships for couples living with dementia make it challenging to draw any conclusions about their effectiveness. There is a clear need for more rigorous methods of data collection and analysis, along with the use of control groups where possible, to account for the natural progression of dementia that complicates the interpretation of simple pre-post intervention designs.

There are indeed interventions that explicitly include the couple relationship in their approach, such as the Early Diagnosis Dyadic Intervention proposed by Whitlatch et al. (2006). This intervention focuses on couples where one

partner is in the early stages of dementia, aiming to help them collaboratively plan for future needs and develop positive communication patterns.

Another example is the model proposed by Baker et al. (2012), which uses music therapy to facilitate shared meaningful experiences within couples and reduce apathy and agitation in those with dementia. The goal is to improve communication and quality of life for both partners. Unadkat et al (2017) also reported beneficial effects from couples' participation in singing therapy. Two randomized controlled trials (RCTs) by Särkämö et al. (2014) and Davidson & Almeida (2014), along with a qualitative investigation by Unadkat et al (2017), found that singing therapy had beneficial effects for both partners in the couple, though these studies did not formally assess relationship quality.

A review by Gilbert et al. (2023) noted that most studies lacked a clear conceptual rationale explaining how the intervention could bring about improvements in the couple relationship. Two notable exceptions are the Living Together with Dementia program described by Balfour (2014) and an intervention study by Epstein et al (2007), which both applied principles of psychotherapy to dementia care and focused on the couple relationship.

Epstein et al (2007) and Auclair et al (2009) from New York University's Aging and Dementia Research Center (NYU-ADRC) described therapeutic interventions with couples where one partner has dementia. Epstein et al (2007) explored how the progression of dementia can complicate couples' therapy as partners may either blame dysfunctional patterns on dementia or deny its impact altogether. In a follow-up report, Auclair et al (2009) detailed their unique couples' therapy approach, which used concepts from Gestalt

Therapy and Transactional Analysis and treated both members of the couple as equal participants. They claimed this approach helped couples navigate the complex dynamics of blame and denial related to dementia.

In terms of outcomes, Auclair et al (2009) reported achieving shifts in couple dynamics with six sessions of therapeutic work. However, these studies were primarily qualitative and exploratory, offering only preliminary evidence to support the notion that couples therapy could help maintain the relationship and the sense of self for both partners when one has a diagnosis of dementia. The studies did utilize one quantitative tool, but data from this has not been published, limiting our understanding of the intervention's effectiveness.

In their review, Gilbert et al. (2023) identified a common limitation in many studies: they elicited expressions of negative emotions like loss, frustration, and conflict between partners (as seen in the studies by Dassa, 2018; Ingersoll-Dayton et al, 2013, 2016; Kindell et al, 2018, 2019; Kwak, et al, 2018; Ryan et al, 2020). Both the authors of the studies and the reviewers seem to assume that the optimal goal of interventions in this area is to encourage the expression of positive emotions.

However, these so-called "negative" emotions might not be mere limitations but rather crucial aspects of the experience of dementia for couples. As the research suggests, feelings of loss, sadness, distress, and conflict may be an inevitable part of the process as dementia impacts relationships. It will be argued below that interventions should explicitly address and work through these emotions rather than trying to avoid or suppress them. This topic will

be revisited in Chapter 5 in the discussion of the development of the Living Together with Dementia intervention.

Importantly, it seems that the majority of intervention studies to date lack a focus on processing these difficult emotions, as illustrated by the review by Gilbert et al (2023).

Additionally, when considering relational approaches to dementia, the field of attachment-focused studies presents another important area for consideration. Research on attachment and dementia, reviewed in Chapter 2, has significant implications for the development of interventions in this area.

Applications of Attachment Theory to Intervention in Dementia Care

Indeed, despite the relatively nascent stage of research in this domain, attachment theory offers promising insights into dementia care. As noted by Browne and Shlosberg (2005; 2006), attachment theory has relevance to caregiving relationships and can help in crafting supportive interventions for caregivers of individuals with dementia. This approach upholds the humanity and personhood of the person with dementia (Kitwood, 1997), and underscores the significance of a relational approach focused on attachment needs.

Innovative interventions addressing attachment needs in dementia patients have been developed. For example, Simulated Presence Therapy (SPT), proposed by Woods & Ashley (1995), attempts to simulate the presence of

an attachment figure through an audio recording of the figure's voice. This intervention aims to foster a sense of security and diminish separation anxiety in individuals with dementia. However, the effectiveness of this approach has shown mixed results. The initial study by Woods & Ashley (1995) provided preliminary evidence supporting SPT, showing a reduction in disruptive behaviour and/or an increase in communication in nursing home residents with dementia. But the study was small, lacked a robust control group, and the staff observing patient behaviour were not blind to the intervention.

Subsequent studies suggested that an individual's attachment style might influence the effectiveness of SPT (Cheston et al., 2007; Peak and Cheston, 2002). They found that those with secure attachment styles exhibited behavioural improvements with SPT, while those with insecure attachment did not. This finding, although intriguing, is based on a small case-study design and cannot be generalized.

Other attachment theory-based interventions include 'doll therapy,' as described by Browne & Shlosberg (2006). Evidence supporting this approach is limited, although a case study report by Bryant and Foster (2002) suggested that this approach could fulfil the need for attachment and provide a sense of purpose for individuals with dementia. The dolls can personify various roles such as a baby, spouse, or teacher, potentially evoking the positive emotions tied to the parent-child bond.

Interventions like SPT and 'doll therapy' typically target individuals with dementia living in residential care or nursing homes. However, as Cheston &

Bender (1999) note, supporting strong attachment relationships may be most effective through community-based interventions, helping individuals with dementia to stay with their existing attachment figures as long as possible. Van Assche et al. (2013) also highlight the need for more research in this area and the importance of linking this work to findings from attachment-based interventions for younger age groups, such as children and adolescents.

Attachment-Focussed Developmental Research: Implications for Dementia Care

Indeed, reflecting on attachment needs in dementia care, whether in a community or residential setting, necessitates considering insights from infant attachment research. As Ainsworth et al (1978) demonstrated, parental sensitivity and responsiveness to an infant's emotions are key determinants of secure attachment. The simulated presence therapy with taped voices (Woods and Ashley, 1995) or the 'doll therapy' (Bryant and Foster, 2002) cannot respond to the communication cues of individuals with dementia. These are material or mechanical objects offered as 'attachment objects,' intended to act as reminders or symbols of human attachment figures.

While these approaches might offer some comfort to the person with dementia, they lack the ability to respond or interact, which is reminiscent of Tronick's (2007) still-face experiment that illustrated the profound effect on infants when their caregiver ceases to respond to their cues. Such mechanical solutions to addressing attachment needs in dementia neglect the fundamental insight from developmental research: the critical role of the

caregiver's mind, the caregiver's 'mind-mindedness,' in the infant's cognitive and emotional development and in establishing a secure attachment. As Fonagy et al (1993) highlighted, "it is not gratification of need that is at the heart of bonding, rather, it is the caregiver's capacity to create in her mind the infant's mental state."

Transposing this understanding to the later stages of life underscores the importance of the relationship between a person with dementia and their caregiver. It suggests that a caregiver's sensitivity and continued mindfulness of their partner with dementia's experience, and their ability to convey this understanding, are essential. Fonagy et al (2007) noted that an infant 'finds and organizes his affect state through mirroring by someone who has the infant in mind...(but) the mirror display must have the Bionian function of containment as well as contingency in order to be effective.'

As dementia progresses and projective processes gradually replace language (Davenhill, 2007), these developmental research insights hold important clinical implications. Clinicians in the field have reported moments of enhanced cognitive and emotional coherence in individuals with dementia through establishing emotional contact (Balfour, 2007, 2014, 2018; Waddell, 2007).

Drawing on Bion's (1962) concept of 'containment,' this involves taking in, processing, and conveying understanding back to the person with dementia so that previously unmanageable experiences become more digestible and can be accepted in a modified form. Moments of clarity, or a temporarily

more integrated state, may be created for the person with dementia when emotional contact is made by conveying this understanding (Waddell, 2007).

Such clinical observations underline the importance of making emotional contact with a person with dementia. From an attachment perspective, it echoes the research emphasizing the significance of connecting with another mind (in developmental terms, mother and infant) to foster secure attachment. There's a convergence between these psychoanalytic and empirical attachment frameworks and the dementia research findings reviewed in chapter 2, all of which stress the value of emotional connection between partners and the profound impact of its loss on couples living with dementia (Hellstrom & Lund, 2007; Lewis et al, 2005; Wadham et al 2016).

Existing attachment-focused interventions in dementia care, such as Simulated Presence Therapy, do not adequately address the relationship dynamics of the couple itself, nor do they leverage the rich body of developmental research on attachment-based interventions used with children and adolescents, as highlighted by Van Assche et al (2013). An intervention designed to address the relationship difficulties and attachment issues in dementia is needed; one that synthesises research and clinical practices developed for relationships at earlier stages of life.

Indeed, while a multitude of interventions target the social and relational functioning of parents and children, including those with cognitive and other developmental disabilities (as per Fukkink et al 2008; Van Doesum et al 2008; Gutstein 2005, Rogoff et al, 1984), there is a conspicuous paucity of

interventions specifically designed for older couples grappling with dementia that have been adequately tested for efficacy.

This review of the literature on couple-focused interventions for dementia underscores the nascent stage of development in this field, highlighting the need for more robust studies dedicated to outcome evaluation and the assessment of efficacy. Most strikingly, the extant approaches are limited by a lack of conceptual grounding, with a general failure to focus on understanding relational and attachment issues, as indicated by Bielsten & Hellstrom (2019). As suggested by Wadham et al (2016), given the nuanced and differential effects of dementia on couple relationships, such interventions would need to be carefully tailored to each couple to account for these individual (or rather, couple) differences.

Critically, the interventions examined in this review do not sufficiently address the research-based evidence regarding the factors of importance in promoting couple and family resilience in dementia, as highlighted in Chapter 2. Namely, these approaches fail to incorporate an understanding of the significant ways in which dementia impacts couple relationships and the attachment needs of individuals with dementia. This failure to root these approaches in the evidence base represents a considerable gap in the development of interventions to date.

In light of these findings, the implications of research into the impact of dementia on couple relationships for the design of interventions are far-reaching. Carefully integrating these insights into intervention design is essential for improving the situation for couples navigating the difficult terrain

of dementia. As such, this dissertation will discuss the key elements for consideration when developing these much-needed interventions.

Implications of Research for Clinical Practice and Intervention Design

The call for interventions which align closely with research findings on the impact of dementia on couple relationships is clear and pressing (Gilbert et al, 2023), with the ultimate goal of providing more effective support for these couples. As highlighted in the preceding chapter, dementia often negatively impacts the quality of a couple's relationship, manifesting as decreased communication and companionship, empathy, and intimacy, as well as a reduced sense of emotional connection (Evans & Lee, 2014; Pozzebon et al, 2016; Wadham et al, 2016). This culminates in an overall increase in dissatisfaction, often linked to the perceived growing imbalance in the relationship as the individual with dementia experiences declining functional capacities.

The urgent need in this area lies in the development of interventions which specifically target the enhancement and strengthening of these relational factors for the couple. This will require systematic measurement, intervention design and evaluation of impacts. Moreover, this approach needs to be firmly rooted in a rigorous conceptual foundation, offering clear rationale for how the intervention techniques and methods will benefit the couple's relationship. The current literature falls short of such an approach. What is also notably missing is an acknowledgement of the importance of attachment and the implications of early infant attachment research for dementia care.

The present literature is further limited in its handling of 'negative' emotions, such as frustration, resentment, and grief. Such feelings, as Gilbert et al. (2023) illustrate, should be seen as an inherent part of the dementia experience and need to be incorporated within interventions aimed at benefiting the couple relationship.

The question then arises: how do the research findings on the impact of dementia on couples 'translate' into tangible implications for the development of interventions aimed at supporting and strengthening the couple relationship in dementia?

Key takeaways from the research, which should inform the direction of future intervention studies, include:

- Research supports the need for interventions that intentionally focus on the couple relationship, promoting a sense of unity as opposed to fostering 'separateness' (McGovern, 2011). This underscores the potential value of joint interventions that involve both partners, working towards improved relationship factors and fostering greater mutual understanding and collaboration.
- Several authors emphasise the importance of interventions that strive to alleviate the impact of the commonly observed shift in the balance of the relationship due to the progression of the disease, where the caregiving partner increasingly assumes responsibilities (Rippon et al 2019; Hellstrom et al., 2007; Wadham et al., 2016). Indeed, research highlights the significance of assisting couples in maintaining

continuity in their relationship both before and after the diagnosis of dementia (McGovern, 2011).

- Couples therapy can be beneficial if the therapeutic approach treats both partners equitably and respects the personhood of the individual with dementia (Epstein et al, 2006, AuClair et al, 2009). 'Radical acceptance' of the person with dementia's perspective during these shared experiences can foster "couplehood" and reinforce the co-created nature of long-term couple relationships (Johnston and Terp, 2015). Despite these findings, Gilbert et al (2023) found only two interventions that incorporate techniques from couple psychotherapy to improve relationships in dementia (Balfour, 2014; Epstein, et al, 2007), despite reports of such therapies being effective in improving relationships for those living with other neurodegenerative diseases (Beasley & Ager, 2019; Ghedin et al., 2017). Gilbert et al (2023) suggest this may be due to unjustified assumptions about the capacity of individuals with dementia to participate in such interventions. Yet, recent studies indicate that many people in the early stages of dementia remain aware of changes within their relationship (Alsawy et al, 2020; Wawrziczny et al., 2016).
- There is a clear need for interventions to shift their focus away from the cognitive decline associated with dementia, which traditionally garners the majority of healthcare professionals' attention, towards enabling better collaboration within the home setting for the couple (McGovern, 2011). This may entail emphasising existing strengths and encouraging the couple to consider creative possibilities for

shared activities (Johnston and Terp, 2015). Such an approach can help maintain a sense of "couplehood", the shared essence of the relationship, by continuing previously enjoyed activities whenever possible. Identifying new activities that both partners can partake in further affirms the 'personhood' of the individual with dementia— a task that might necessitate imaginative thinking (Johnston and Terp, 2015).

- As the functional capabilities of the individual with dementia decline, the notion of 'being in the presence of doing' becomes increasingly important. That is, for the individual with dementia, it's crucial to feel included as part of the activity, even if their capacity for active participation is significantly reduced. In this regard, employing strategies such as 'scaffolding' activities to support remaining capacities can be beneficial (Hellstrom et al, 2017).
- An essential ingredient in successful intervention programmes is the tailoring of the intervention to meet specific needs, competencies, or characteristics, such as gender, age, educational background, and the unique nature of the relationship with the person with dementia. This could entail addressing interventions to couples with their specific needs or to other relationships, such as parent-child relationships (de Vugt et al., 2004). As suggested by Pozzebon et al (2016), interventions should strive for a holistic focus and customise their approaches to support the unique needs of couples, understanding their relationship history, addressing past relationship issues, shared interests, and lifestyle to aid them in developing adaptive skills.

- It is vital to identify past dysfunctional relationship patterns and employ couples therapy to highlight new, functional coping skills (Johnston and Terp, 2015). These authors propose that future interventions should incorporate a needs assessment tool and a screening of the relationship quality prior to the intervention. The aim is to provide guidance on improving or maintaining the couple's relationship.
- Factors such as behavioural symptoms, depression, and stress are predictive of relationship quality as well as life satisfaction and well-being. Therefore, it's essential that interventions also take these factors into account (Clare et al., 2012).
- Early psychoeducation after a dementia diagnosis can be beneficial, provided it is attuned to the couple and offered in a way that is not overwhelming (Balfour, 2014). Johnston and Terp suggest that in the early stages of Alzheimer's Disease, couples need psychoeducation about the importance of maintaining both "personhood" and "couplehood" as long as possible (Johnston and Terp, 2015).
- There is a clear need for the development of interventions that offer psychological containment for couples living with dementia (Johnston and Terp, 2015). This idea aligns with psychoanalytic and developmental research on the fundamental human need for an emotional connection with another mind, which enables psychological containment. Secure attachment necessitates the child's experience of their feelings being understood (Ainsworth, 1978; Fonagy, et al, 1993), 'mirrored' and 'marked' by another mind (Fonagy et al, 2007).

This process imbues the child's feelings with psychological meaning and renders them emotionally 'digestible'; they are 'contained' (Bion, 1962). Balfour (2018) linked 'containment' in dementia with attachment-based developmental models, and several psychoanalytic writers, including Waddell (2007), Davenhill (2007), and Balfour (2006, 2007, 2014, 2018, 2023) have discussed the importance of containment in dementia. They highlight the significance for the person with dementia of their emotional states being recognised and processed by others, particularly those closest to them. As dementia induces an encroaching loss of meaning, a containing environment that seeks to assign meaning to emotional states becomes increasingly important.

- Dementia is likely to increase attachment insecurity for the partner with dementia (Miesen, 1993; Browne and Sholsberg, 2006). Attachment-focused developmental research underscores the importance for infants of emotional contact with their caregiver for establishing secure attachment (Ainsworth, 1978). This suggests that interventions aimed at strengthening emotional connections between partners in couples living with dementia may be important, as they could help to alleviate attachment insecurity. As the person with dementia progressively loses their bearings in time and space – alongside the threatened or actual experience of separation from key attachment figures, such as their partner – these interventions may become crucial.

- Studies consistently highlight the pervasive sense of loss and negative impacts on caregiving partners in dementia scenarios (Pozzebon et al, 2016; Lee & Evans, 2014), thus emphasizing the need to provide a safe space for these individuals to express their negative feelings (Balfour, 2014; 2023). It's essential that interventions don't merely urge caregiving partners to preserve the 'personhood' of the person with dementia, but instead, address the factors that might hinder the couple's 'togetherness' (Pozzebon et al, 2016). An intriguing observation is that many psychosocial interventions, despite intending to promote positive emotional outcomes, often regard conflict or the expression of feelings such as sadness and frustration as negative results (Gilbert et al 2023). This perspective indicates a shortfall in current approaches – their inability to acknowledge the inevitable negative impacts of dementia on couples and the importance of creating interventions that incorporate this reality. It's vital not to idealize what is achievable in dementia care: the caregiving partner may experience numerous negative emotions, such as resentment, anger, and frustration, towards the person with dementia, and interventions should provide a space to address these feelings. If these emotions are not given room for expression and reflection, they are more likely to manifest in negative actions. These concepts will be discussed further in Chapter 5, which outlines the development of the Living Together with Dementia intervention.
- Research highlights the significance of accessibility and the lack of readily available support for couples. Johnston and Terp (2015)

observe that the studies they reviewed required dyads to travel to community sites or clinics, emphasizing the importance of providing accessible interventions in couples' homes.

In conclusion, as indicated by researchers and authors in this field (McGovern 2011; Pozzebon et al, 2016), there is a need for healthcare interventions that are grounded in an understanding of the everyday lives of the caregiver and the person with dementia, and both partners' perceptions of their daily activities. In the following chapters, I will argue that this observation can be viewed in psychoanalytic terms as an acknowledgment of the importance of daily activities, not only for their practical uses but as a way of enabling couples to emotionally connect through the activity process - the activity serving as a mediator for emotional contact between the partners. Converging evidence from dementia, attachment, and developmental research underscores this as being fundamentally important. This concept will be further explored in relation to the development of a new intervention model for couples living with dementia, the Living Together with Dementia intervention, in chapter 5. But before that, chapter 4 will explore the pilot clinical work conducted over a 12-month period, funded by the Young Foundation, which informed the development of the Living Together with Dementia intervention.

Chapter 4: Qualitative Exploration of Cases: Evidence from the Clinical Situation

Introduction

How does the evidence from research translate to the experiences of couples living with dementia? This chapter presents a clinically focused qualitative investigation of themes that emerged during exploratory therapeutic work with six couples who were worked with clinically, as part of the initial phase of developing the intervention detailed in the next chapter. This initial work took place over a 12-month period in Redbridge, east London, in collaboration with the older adults' service of the NHS Trust (see Appendix 2). This phase of the project was funded by the Young Foundation over the twelve-month period. Couples participated in exploratory sessions, discussing their experiences and trialling techniques that would eventually become a key component of the intervention.

Themes from the exploratory work with couples, along with case studies, will be drawn upon to develop this thesis on the relevance of a psychodynamic approach to conceptualising the emotional and relational factors in dementia. This will be linked with the evidence from research reviewed in previous chapters. Collectively, this data forms the foundation for the development and design of the psychodynamic, attachment-based relationship intervention for couples living with dementia, which is discussed in the following chapter.

The couples were all in their eighties, were heterosexual, and the partners with dementia were in the early to moderate stages of the illness. Four of the couples were from working class backgrounds and two were highly educated and from a wealthier socioeconomic background. With all of them, the work went on for some months, on an intermittent basis and involved getting to know them and trying to understand their experiences, whilst trying out the elements of the intervention which was in development.

The Experience of the Dementia Diagnosis

Studies examining the experience of receiving and living with a diagnosis of dementia (Lee et al., 2014) underscore the importance of helping individuals make sense of and process the emotional impact. We found recurrent descriptions of the adverse effects due to the lack of adequate support at the point of diagnosis. The couples we worked with described a significant need for support, yet there was a common experience of being “left on their own” to process and cope with the emotional impact of the diagnosis.

What consistently emerged was the significant need for space for couples to reflect on their experience of the diagnosis, allowing both partners, including the one with dementia, to express their fears in words. One participant with dementia shared, "I went completely crazy. And started shouting and yelling and... I was very... very disturbed by it [dementia diagnosis]." Another participant with dementia noted, "Everyone had to put up with me screaming my head off at times and she [the doctor] never warned me that I might do this otherwise I would have cancelled the holiday."

Overall, participants conveyed a powerful sense of the trauma associated with receiving a dementia diagnosis, as highlighted by the following case example.

Case Example 1

Since the diagnosis, and in the period leading up to it, Brian had been very depressed. He said, "When the diagnosis was made, we cried every day and then every other day – and then you kind of get on with it... What is so difficult is the hatred that I have for what is happening... for the people that don't have this... the hatred that I feel in here (points to his head) ... I'm fucking angry... the hatred... it is so hard to have that inside you (then he became very distressed). I want understanding, but don't feel I get it... I can't manage the hatred and the rage. There was a painful period leading up to the diagnosis – first the doctors thought it was depression and then pseudo dementia and then when the diagnosis came, it was a relief... but the diagnosis is a terrible diagnosis – I feel normal and then it comes back in, I am reminded of it." At an outpatient appointment, he had encountered someone in the more advanced stages of dementia: "Who was all hunched over... a horrible picture... Will I be like that? What happens? Do you stop recognising people? How will it be? These are the kinds of thoughts I have." His wife added, "It is difficult for us to think about things like this... painful for me too."

Under such circumstances, having a mind available to help the couple think, process, or understand their feelings, as much as they can, seems crucial.

The experience of working with these couples suggested that, without such support, partners may withdraw further from one another, leading to the acting out of anger, frustration, or other feelings and anxieties. These themes will be discussed further below.

If we take seriously the trauma of the diagnosis for both partners, we need to recognise the importance of meeting them where they are emotionally and of offering a receptive state of mind to take in that experience. Several of the carer partners spoke of feeling 'bombarded' by well-meaning staff who visited them. One person said:

"These people keep coming and going, with their leaflets, their forms to fill in, saying I should apply for this or that. We don't know who they are or where they are coming from half the time... traipsing through here. They phone up and say it's so and so calling, and I don't know them and every time it's a different person. I got really cross with someone who came yesterday.

Hopefully I have stopped it for now. We need one person who we can build a relationship with. We just don't want any more information, leaflets, or forms – it's traumatic."

While the role of giving information is, of course, very important, there might be a pressure to act, to want to give something concrete like a leaflet or information when staff face helplessness and the limits of what can be done to make things better. We saw how this understandable reaction by care professionals can place the couple in a position where they must take in something they don't feel ready for, based on the staff's need to relieve their own anxiety. The point made here, about the couple's need for someone

they can build a relationship with, rather than having multiple professional staff coming into their home, echoes the findings of research that indicate the importance of the quality of relationships between the person with dementia, their caregiving partner, and health and social care professionals when receiving the diagnosis (Pointon, 2011).

The Emotional Challenge Facing the Carer Partner

Most of the carer partners we worked with reported feeling burdened by caregiving responsibilities and experiencing significant strain in their own lives. This strain manifested in feelings such as stress, exhaustion, anxiety, anger, depression, and being overwhelmed, as well as in physical ill-health. This aligns with the research literature discussed in previous chapters, which indicates that the need to adapt to the progressive changes brought by dementia is linked to stress, depression, and anxiety in the caregiving partner (Knop et al., 1998; de Vugt et al., 2003; Garand et al., 2007).

One carer partner shared, "My blood pressure shot up really high and as I said my weight. I was really stressed, so overbearing and umm I couldn't think of a way to help myself you know... umm but it was trying to hold down a full-time job and you know be a carer as well and all that involved and with a broken heart."

Another carer partner described, "I was psychologically and emotionally very weak. He or himself [partner], they're fine, they are looked after but it's not fine always as a carer, it's harder, exhausted... So much to do... Yeah... I am exhausted. Every time, every night before bed. Oh, I didn't do anything today

and the piling, half of the mountain is still there. The mountain doesn't go low at all."

A third carer partner reflected, "So you bump along with a little bit of CGT [cognitive group therapy] and uh or TLC [tender loving care] depending on where you go and uh... just slowly disintegrate."

Several of the carer partners spoke about increasingly struggling to manage their caregiving role and the anxiety that they would no longer be able to cope. One carer partner expressed, "I was worried about my health, and I did think with these sort of constant disturbances at night, you know, I was worried that I would have a bre- not a breakdown, I don't think I'm the breakdown kind but would physically get ill... I remember lying in bed, you know, having got up twice already and thinking you know how much more can I take of doing this, it's really, very hard...."

Another carer partner poignantly noted, "I am invisible, unless I break down... who knows when you're ready to break."

Impact of Dementia on the Couple Relationship

As discussed in Chapter 2, research indicates that dementia typically impacts the quality of a couple's relationship negatively, resulting in decreased communication, companionship, empathy, and intimacy, as well as a reduced sense of emotional connection (Evans & Lee, 2014; Pozzebon et al., 2016; Wadham et al., 2016). This culminates in an overall increase in dissatisfaction, often linked to the perceived growing imbalance in the relationship as the functional capacities of the individual with dementia

decline. As outlined in earlier chapters, research shows that there is a commonly observed shift in the balance of the relationship due to the progression of the disease, with the caregiving partner assuming increasing responsibilities (Clare et al., 2012; Rippon et al., 2019; Hellstrom et al., 2007; Wadham et al., 2016).

The couples we worked with conveyed how dementia affected their relationship in ways that converge with the findings of the research literature. They described how it pulled them apart in terms of shared activities and emotional connection. The carer partners also spoke of the difficulty of their role transforming from that of a partner to that of a 'carer', often adopting a more parental or teacher-like role with their partners, as the relationship took on a more parent-child-like quality:

[Directed to partner] "That is your napkin, wipe your mouth, then eat your cake!"

Carer partner

"Because I just couldn't deal with him [partner] sometimes and sometimes he just wouldn't do what I wanted him to do or I asked him to do or go where I wanted to go, sort of thing... so I'd just sort of leave it till about 10 minutes before I was going to go and then say well I'm going to art this morning so you can do this and give him some colouring to do or something or sometimes he'd just sit and I'd put something out for him in case he wanted to do it."

Carer partner

Most of the carer partners considered their role in protecting their partners with dementia, which is consistent with the idea that they felt they had to be parental guardians of their partners:

“I felt like I had to protect him and I wouldn't have thought that before....”

Carer partner

One carer partner compared looking after someone with dementia to looking after a baby, noting the sadness that accompanies their different trajectories:

“And you compare looking after somebody who is dying with somebody who is at the beginning of life, a baby, and the thing is the baby looking after, caring which people make a big hooaha about. After three or four years you're going to see real progress and get fulfilment out of that. What you have done will help create this being whereas when it is somebody who is going into decline it's more difficult and (pause) and more upsetting and you have to have a kind of commitment to it.”

Carer partner

All the participants commented on loss in some way, often perceiving a loss of some element of the previous relationship they shared, highlighting the transformation of the relationship:

“Well sex in dementia I'm not going to talk about because I haven't experienced it. We don't have any sexual relations at all my husband and I and um... so the next step is up to me really.”

Partner with dementia

“Wife and mother probably are certainly muddled up and actually now for my mother to have retreated from me because of the disease, well that’s a bit of a double whammy.”

Carer partner

“He gradually withdrew from things he used to do; he sort of seemed to realise he lost knowing how to do things.... lost habits of reading for example. Gradually it was a withdrawing from activity.”

Carer partner

These comments touch upon themes around daily life when dementia takes away previous functioning and shared activity for couples. This echoes the research evidence, indicating how difficult it can be for couples to lose these shared experiences. Withdrawing from activities and habits that were previously engaged with seems to be part of the experience of dementia, and we found there was often an avoidance of situations or activities that were felt to expose diminished capacities and associated feelings of shame. We also witnessed how carer partners at times intervened from their own anxiety, in ways that ‘took over’ their partner’s attempts to function, further displacing them from engagement in activities of daily living.

Case Example 2

A person living with dementia conveyed how holding onto her sense of self and her capabilities was easily lost in the face of the difficulties she faced while trying to manage ordinary activities. It was hard for her to keep struggling to remember, think, and recover what she could. She said that

thinking about it could sometimes make it worse. She remembered a lot but constantly saw evidence of what she was not remembering, of what had been lost. It seemed she was trying to hold onto her connection with the world, to a state of mind where she felt there were still things to enjoy. However, the difficulty with thinking and staying involved exposed her more to what she could not do, confronting her with the realities of her illness. All the time, she had thoughts like, "I should have known that" - reproachful thoughts. She would tell me about a schoolteacher who had always been so critical of her, whose voice was an internal figure in her mind, constantly criticising her. This seemed to be the challenge of her continued engagement with the world. Trying to do things confronted her with what she could no longer manage, with the reality of new limits in her capacity, which stimulated relentless self-criticism. While this may always have been part of her inner world, it seemed amplified now, when she was confronted by the impairment in her functioning. She was painfully aware of this, leading her to withdraw from her partner and from activities they had once shared.

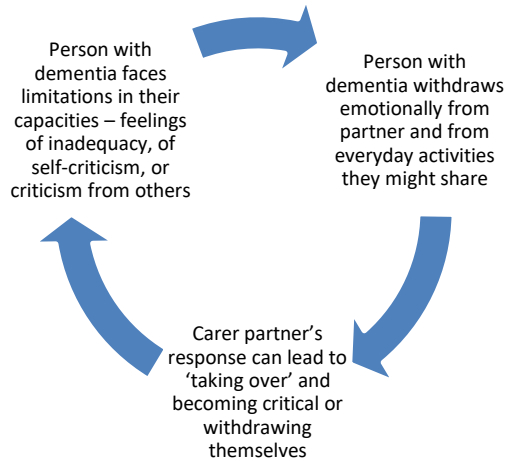
Case Example 3

At our first meeting, a carer partner in another couple was keen for me to understand how much her husband had withdrawn from her since dementia took hold. She told me that he spent nearly all his time reading. Even though he did not, she believed, follow the narrative in the text he read anymore, he was 'locked in' to the activity of reading. He would sit for hours on end in an armchair, with stacks of magazines and books in front of him, which she experienced as a kind of fortress protecting him from impingement from

outside, leaving her feeling shut out and unable to reach him. Strikingly, as we worked together over many weeks, she described him gradually emerging more and joining her again in activities that they had once shared.

Where withdrawal and loss of mutual involvement predominate, there can be a negative cycle of increasing withdrawal and 'secondary disablement' of the person with dementia, whose functional capacity then appears far worse than would simply be explained by the stage of progression of their illness. This is a familiar picture for clinicians working in the field and has been represented as a 'negative loop' of withdrawal, describing the interactional processes often at play in such situations (Balfour, 2014).

The 'negative loop of withdrawal' in dementia



Loss of 'Couplehood'

From these accounts, it is clear that dementia can progressively lead to the loss of 'couplehood', with couples becoming more disconnected from each other, and the relationship shifting to a more parental/child-like or guardian/dependent-like dyad. Research shows that the loss of intimacy is associated with carer partner depression, and that low levels of positive interaction between partners in marriages where one person has dementia predict a move to residential care and the death of the spouse with dementia within two years (Wright, 1991; 1994). Forsund et al. (2014) found that experiences of connection, reciprocity, and interdependence — contributing to a sense of 'couplehood' — ebbed and flowed. Intriguingly, even fleeting moments of recovered connectedness held great value for the partners of those with dementia. This is significant as it relates to the research literature (McGovern, 2012) indicating the importance of seeking to retain 'couplehood'

and underscores the need for interventions that address this, supporting couples to maintain or recover, as much as possible, their emotional connection.

Loss of Emotional Contact/Connectedness

The carer partner's experience of the loss of intimacy and understanding of their partner with dementia has been found to be a critical factor (Morris, Morris, & Britton, 1988a; Morris, Morris, & Britton, 1988b). Bull (1998) comments, "...the feeling of the loss of the partner is associated with the loss of sharing or interaction with the partner. Some carers expressed this loss of communication as: `...if only I knew what he/she was thinking`" (see also Lewis, 1998; Murray, Schneider, Banerjee, & Mann, 1999). This was evident in the accounts we heard, with carer partners often expressing the feeling that they did not understand what was happening in the mind of their partner with dementia. Many of them interpreted their partners' subjective state as characterised by a lack of awareness or cohesion of thought. This sense of the state of mind of their partner being incomprehensible to them seemed to be expressed in the view that their partner with dementia was 'crazy', or 'mad'.

"You're talking to a mad person; I mean it isn't rational. You can't have a rational discussion, so you don't try and argue about something."

Carer partner

“I don’t think he was aware of anything much outside himself really, I suppose... I think he had no idea of what it was like, what he was doing... I don’t think he understood very much, you know.”

Carer partner

What comes across is how difficult it is to maintain emotional contact with the fragmented experience of dementia and the new challenges this brings to the couple’s relationship. Most carers discussed the growing differences between themselves and their partners with dementia.

“Very sad really ‘cause I mean, going to concerts was something I liked doing and um I still do a lot and did a lot without him actually.”

Carer partner

Carer partners commonly discussed feelings of loneliness and the loss of emotional contact with their partners.

“I think I was beginning to feel at I was on my own because I couldn’t have a conversation with him.”

Carer partner

“Doesn’t matter how much I talks, how much I says, like this, nothin’ll change. Nothin’... I’m on me own. I’m on me own.”

Carer partner

Dementia as 'Contagious'

Carer partners pointed to concerns around their own memories and fears that they might be getting dementia in a 'contagious' way - being 'infected' so to speak, from close contact with their partner with dementia. Several of the carer partners talked about concerns around their memories and the sense that their cognitive abilities had decreased.

Every time you can't remember something you start to worry about whether you're starting to get Alzheimer's

Carer partner

I can see myself getting inefficient, I can't remember as I used to. I was better at remembering other things, now definitely slowed down...

Carer partner

I couldn't remember what I had said or thought and I got into a terrible depression about that. I'm getting a bit thick and my brain is definitely not working properly in the way that it used to... I introduced a lemma into my talking and my ideas and its actually thrown out my memory, how you say...So what was all that about? That was all about the difficulty of remembering and going gently gaga. It's not a big eh it's not a collapse... now I'm beginning to be a patient

Carer partner

I feel like I've not got dementia but I'm just waiting to be diagnosed as having dementia...I mean you look at the statistics most of the couples in

situations like that, one way or the other either follow into physical or psychological illness in the relating and caring situation. The high damage rate in caring with partners is quite high I thought... yeah, understandable.

Carer partner

There is a sense that the carer partners seem to feel they are moving into dementia in a 'contagious' way, infected by their partner, and this appeared to be a common anxiety of living at close quarters with dementia. To help us understand this phenomenon, we need to turn to the psychodynamic concepts of projection and projective identification

Projection, Identification, and Projective Identification

In understanding the phenomenon of the 'contagion' of dementia, the psychoanalytic concepts of projection, identification, and projective identification can help us to conceptualise how the psychic state of one partner may be felt to 'infect' the other. This process blurs the psychic boundaries between the couple and amplifies the anxieties of the 'healthy' partner, who may fear they are becoming 'infected' by the fragmented functioning of their partner. How is this formulated conceptually?

The term projective identification originally comes from Melanie Klein (1946) and was first described as a defence characteristic of the paranoid-schizoid position, whereby feelings or aspects of the self which are unacceptable are denied, split off, and projected into the object (i.e., the 'other') and then identified as properties of the object. This concept was later elaborated by Bion (1962), who added the idea that an unconscious aim of such projection

may be communication. This then becomes, in post-Kleinian theory and in wider psychoanalytic approaches (Sandler, 1987; Ogden, 1992), an account of how we act upon one another unconsciously to 'actualise' (Sandler, 1987) roles (or object relationships) that are part of our internal worlds. In our contemporary external lives, we may pass feelings or states of mind that we cannot encompass in our own psyche to the 'other', with one person's unconscious mind speaking directly to the other's.

As Bion (1962) describes, if the recipient of such projection can process and reflect upon how they are being made to feel, they might understand this as a 'primitive' communication of feelings and mental states. If these can be processed and re-communicated in words or in action, the now metabolised mental contents may be re-introjected by the other in what is known as the process of 'containment' (Bion, 1962). Where such a containing reflective state cannot be achieved, the experience of receiving such projection may be experienced as a 'numbing sense of reality' (Bion, 1962), as one mind 'invades' another, eliding the psychic barriers between two people, and transmitting feelings or states of mind directly from one to another. In the context of dementia, this situation may be experienced as a 'psychic infection' of the carer partner with the fragmented mental states of dementia, amplifying the anxieties of close emotional contact within the couple. This seemed to be a key area of anxiety that the carer partners expressed in our work with them.

As part of more sophisticated projective identification, a process held to be an aspect of normal adult mental functioning, projection followed by reality

testing – does the other really feel the emotion I am attributing to them – is the basis of empathy and understanding of our fellow human beings. To extend this model to the couple relationship, we may think of ‘projective systems’ operating within couples (Balfour & Morgan, 2018). According to this model, partners choose one another unconsciously, precisely because of their valency to receive the projections that each partner is predisposed to make. Thus, our relationships can serve a defensive function (our partner may carry aspects of ourselves which we struggle to encompass) as well as a communicative one (we may convey to our partner, at an unconscious level, aspects of ourselves which we cannot inhabit or acknowledge). Ultimately, this may have a developmental dimension – if our partner can ‘contain’ our feelings, we may be able to re-introject them, and thereby develop more mature mental functioning, integrating into ourselves what previously we could not. Thinking now about optimal couple functioning, one might say that couples who can maintain flexibility in their projective system – whereby the projections between partners can be processed, thought about, and taken back – are ‘healthier’, psychologically speaking, than those whose projective system is more rigid and fixed.

It is couples in the latter situation who are more likely to seek therapeutic help, feeling trapped in rigid roles within the relationship. Their conflicts and struggles will tend to be stuck in repetitive cycles of projection, denial, and splitting. As we have seen from the research, couples living with dementia are likely to have difficulty because they find themselves in more rigid roles of ‘carer’ and ‘cared for’, which become amplified and increasingly polarised as the illness progresses. In other words, in dementia, we might say that the

couple relationship will cease to function as a mutual container for both partners.

'Negative' Feelings and the Challenges of Emotional Contact in Dementia

The carer partner may find it hard to bear feelings such as anger and disappointment, particularly when their partner with dementia is more vulnerable. The present literature is limited in its handling of 'negative' emotions, such as frustration, resentment, and grief. These feelings, as Gilbert et al.'s (2023) approach illustrates, should be seen as an inherent part of the dementia experience. Carer partners expressed how difficult it is to look after someone with dementia and the toll it takes on their lives and emotional states. Anger permeates the carer partners' accounts, mostly implicitly, directed either towards their partners or at the dementia itself.

It is important to recognise the tremendous challenge facing the carer and not to gloss over this or idealise what is possible for them in looking after their partner with dementia. This draws our attention to the importance of the state of mind of the carer partner and their need for support and containment themselves. They may have all kinds of feelings towards the person with dementia in their care, apart from compassionate ones, such as resentment or hatred. These feelings can arouse tremendous guilt or anxiety, and there may be a great need for help and containment with this. Yet, approaches to interventions with carers generally do not address this more difficult area.

Carer partners talked about how much emotional strain they had to take on compared to their partner. Feelings of anger were expressed, with the carer partners feeling that they were having to bear a lot of the stress:

“I’m the one who’s going downhill... ‘cause it wears me, it do wear me out... I mean you’re a wreck and he’s standing there; everything bounces back off of him. He stands there as large as life, as healthy as can be and here you feel a wreck... I don’t know how much longer I can carry on...”

Carer partner

In the pilot work we undertook, one of the issues that we found to be important was the question of how the couple may be losing a relationship which can contain them, and in which they have provided containment for each other. As the research reviewed in Chapter 2 indicates, the partners of people with dementia may experience stress and burnout, and, at worst, unsupported carers in difficult and pressurised home situations can, in some cases, act out violently or neglectfully. Elder abuse is increasingly recognised as a major social problem. One carer partner said:

“There are all these images everywhere of rosy carers on all the leaflets – but it’s not like that... I hate her a lot of the time and it’s shit – and it’s like no one can tell the truth – how shit it is, and the resentment... What do I do with that?”

If we think about the concept of projective identification, we might recognise how difficult the task of sustaining emotional contact can be under such circumstances. Having emotional contact with fragmented experience is very

difficult, and it is understandable that carers with little support may be less able to tolerate emotional contact with the person with dementia and, like frontline staff, may become 'irradiated by distress' (Hinshelwood and Skogstad, 2002). In such circumstances, it is understandable that partners may withdraw from one another as a form of self-protection (defence) in the face of unmanageable feelings.

People often lack a way of thinking about or making sense of such emotions, particularly guilt and shame, and have no one to talk to about them. This highlights the importance of the carer partner having the opportunity to speak to someone non-judgementally, to have another person – such as a professional carer or therapist – to take them in. As we found in this phase of our clinical work with couples living with dementia, this may be a significant support: for them to be able to use the therapist in this way, as someone able to acknowledge, take in, and understand feelings that they may be very ashamed of having.

Case Example 4

One person we saw, whose husband was in the more advanced stages of dementia, spoke of how she felt that everyone expected her to be a saint and that they weren't interested in what she felt about how hard it was. "No one's interested, they don't know what it is like," she said. Her relationship with her husband had at times been violent, and in my contact with them, I felt I could see how important it was to understand their interaction.

For this couple, their marriage had always been difficult. Looking after him repeated, for her, a version of her experience as an only child when her

mother developed profound mental health problems after the death of her father. Then, as now, she felt left alone with a burden, with no one able to understand how difficult it was for her. In recent months, his dementia had progressed significantly, and increasingly he responded to the anxiety of not knowing what to do, moments when he was disorientated, by getting angry. For her, it was much like the angry exchanges they had had for years, and she retaliated with anger and criticism of him. This was worst at times when he was in a panic and feeling lost. I witnessed how she would tell him things that he couldn't understand or have the capacity to follow; he would respond by saying he didn't know what she was talking about, that she wasn't making any sense, and she would then get angry and critical of him. When she became critical or angry at the moments when he was most vulnerable, he became aggressive towards her. They showed me how quickly things could escalate between them. When he responded to her by saying, "You're not making sense" or, "Do it yourself then," she heard this as examples of his refusal to do things, his deliberately being difficult, and it took a lot of work for her to gradually begin to shift her perceptions of such episodes and to think about what might be happening in his mind, to put herself, to some extent, into his shoes. Crucial to this shift was the stance of listening and empathising with her feelings, so that she had the experience of someone taking her in and trying to understand how she felt and how she saw things. Once this process was established, when she started to feel 'taken in' emotionally, she began to be able to allow herself to think more about what his experience might be. This recalls Frieberg et al.'s (1975) observation that 'the mother whose cries are heard hears her infant's cries...'

Even if things up to now have been good enough, the couple living with dementia are losing a relationship in which they may have provided containment for each other. As I have said, in a relatively healthy adult relationship where projections are not too fixed, partners may be able to act as containers of difficult feelings for one another in a flexible way. In a relationship where one partner has dementia, the burden will increasingly shift to the partner without dementia to act as a container for their spouse. Carer partners, particularly men, often spoke of this as a 'reversal' of how things had been before. One man said:

"When we first got together, I used to be more shut off and my experience of being with her helped me change. She's always been so thoughtful... now she shuts down. It used to be me who was the one who was more shut down. Now it has switched around and she is the one who is more like I used to be.... now we are crossing over into opposite places."

"She looked after me, now I have to look after her, and I'm not good at it," was a comment we heard often.

Carer partner

The Importance of Emotional Contact between Partners: 'Containment'

As dementia progresses, the capacity for verbal communication diminishes, and projection may replace language. In this situation, the carer partner increasingly needs to be the container in the relationship. However, as research and clinical evidence show, they are also likely to be struggling with

their own difficult feelings, making it challenging for them to take in their partner's projections or state of mind. In this pilot work, it became clear how crucial it is to offer containment for the carer partner so that their capacity to be emotionally available to their partner with dementia is supported.

As I have already discussed, the original (Bion, 1962) model of containment entails the taking in and processing of experience (in the original developmental model, the mother is doing this for the infant) and conveying that understanding back so that unmanageable experience is rendered more digestible and can be taken in, in a modified form. Waddell (2007) points out how windows of clarity, a briefly more integrated state, may be opened for the person with dementia when emotional contact is made through finding some way, in words or action, of conveying that understanding to them. As described in Chapters 2 and 3, this links to attachment research, which shows the importance, in developmental terms, of contact with another mind in establishing secure attachment with the primary caregiver. This psychodynamic and attachment perspective allows us to understand in more depth the empirical finding reported in the literature of the importance of emotional contact between partners in sustaining the resilience of couples living together with dementia.

Drawing on psychodynamic theory, we can see why it is important for couples living with dementia that such a containing mind is available when a mind is being lost and when partners who may have contained each other are becoming less able to do so. Indeed, research suggests that containment at this point may set the stage for what happens later, with the finding that

providing carers with emotional support earlier on delays admission to residential care later in the illness (Brodaty et al., 1997).

Emotional Engagement in the Couple with Dementia

Despite the losses and negative changes highlighted by many studies, the qualitative literature presents case examples where feelings of belonging, reciprocity, and continuity within close relationships in couples living with dementia were sometimes possible to maintain (Hellstrom & Lund, 2007; Wadham et al., 2016). Forsund et al. (2014) found that couples' experiences fluctuated dynamically, with recovered moments of connectedness, reciprocity, and interdependence, which were reported as invaluable for the spouses of people with dementia. These authors emphasise the importance of identifying, understanding, and validating the shared experiences of both partners to support the sense of interconnectedness in the couple relationship in dementia.

This is crucial, as the research evidence indicates that the quality of the couple relationship affects carers' well-being and that a continued sense of connection between partners is linked to lower distress, lower burden, and higher caregiver competence (Lewis et al., 2005). Research underscores the importance of emotional connection, attunement, collaboration, and shared activities to regain, even if only temporarily, moments of 'connectedness' within couples living with dementia (Boylstein & Hayes, 2012; Forsund et al., 2014; Hellstrom et al., 2005, 2007; Pozzebon et al., 2016; Van't Leven & Jonsson, 2002).

In our work, we found that carer partners were often very sensitive to the fears and anxieties of the person with dementia. One carer partner shared an instance that illustrates this sensitivity:

“One thing that she does say which shows how she understands things and the real fear is what she said in the film (a video of the couple interacting, made as part of the intervention – which will be described in the next chapter), ‘the one thing that I’m most afraid of is that I would get to the point in which I won’t recognise my own children’.”

Carer partner

At this point, we should revisit the issue of how hard it can be to have close contact with diminished functioning and fragmented states of mind in dementia care.

Containment and ‘Containing the Container’

What emerged from our pilot work was the observation that, as dementia progresses, it may not simply be that dynamics within the couple’s relationship get reversed or amplified, but instead there may be a profound sea change. As the person with dementia deteriorates, they are not only unable to offer containment for their partner as they once did, but they may also project something persecutory into them. Thus, the situation may evolve into an experience where loss is not merely an absence but rather living in the presence of something persecutory. The carer partner increasingly needs to be the container in the relationship, yet they are likely filled with their own

feelings of loss, frustration, rage, fears, and anxieties, making it very difficult for them to take in their partner's projections or state of mind.

Offering containment for the healthy spouse becomes very important. The presence of a third containing figure, such as a therapist or counsellor, who the carer partner can talk to about the reality of their feelings without judgment, can be very powerful. This recognition has led us to the model of 'containing the container'. This concept is akin to a Russian doll: the person with dementia is contained by their partner, who is contained by the therapist, who in turn is supported through supervision. The crucial element is 'containing the container'.

As well as prior relationship quality, a protective factor for couples may be the carer's capacity to remain interested in what their partner may be feeling and to see potential meaning in their behaviour, even when this behaviour appears quite disturbed. According to the couples we worked with, a common experience of dementia involves dealing with concrete complaints that have a quality of perseveration, which, as they persist, can be wearing and feel meaningless—such as things going missing, being taken, or broken into.

Case Example 5

In one couple, the female partner complained repetitively about losing what she called 'her valuables', particularly her jewellery. Her husband found the relentless perseveration of the same complaint extremely frustrating and tended to withdraw and disengage in response. Part of the work with this

couple involved exploring whether, alongside the real frustration of losing these objects, there might be something else being communicated, possibly centred around the theme of the losses they were facing together.

Over time, there were shifts in their interactions. The female partner began talking about the loss of her dreams: "I miss my dreams. Since the dementia, I don't remember my dreams anymore. They used to be so vivid, and often I would write them down... but now I can't catch hold of them." This shift marked a lessening of her grip on the more concrete, repetitive complaints and a move towards a poignant expression of her feelings about the precious things she was losing. "I can be feeling normal, and then I lose my jewellery... and it's like the dementia crashing in... it's the loss of my mind that I am seeing," she said.

In parallel with this, her husband became more interested in thinking about what might be going on in her mind, becoming curious about the possible meaning behind what could seem, on the face of it, to be meaningless accusations and complaints. Previously, these almost always provoked anger and frustration in him, leading to a defensive response: "I've just got to block it out... she's driving me mad." However, he began to have more space to take in her distress and offer her reassurance. They began to cope with the complaints in various ways, such as setting a time limit for looking for the jewellery together, which had a calming effect, and finding Perspex boxes to help her see where her things were more clearly.

There was also more transparent communication about the loss of her capacities and the losses within the relationship. He spoke more of what he couldn't hold onto in her: "She is the most precious thing to me, and I'm

frightened that soon I won't be able to find her again, even for short times.” Being able to acknowledge his own loss and having someone to talk to about it allowed him to be more available to her experience of loss, to contain it better. “I can't say it'll be alright, but I'll be alongside you, we'll go through it together,” he said to her. She responded, “We are having a very open discussion now... this is the antithesis of the dementia, which makes me feel so hemmed in...” Interestingly, at this point in the work, she returned to reading novels, something she had not done since the diagnosis, but which had always been important to her.

This example reflects the couple's struggle with the loss of what is so precious: a sense of meaning in their actions and interactions. It conveys something of a recapturing of a meaningful narrative. In dementia, this may be fleeting and, as the illness progresses, the person with dementia will be less able to maintain this sense of meaning. However, keeping alive the potential meaning behind behaviour or interactions serves as a reminder of the humanity of the other. This may help the carer partner hold onto a sense of the personhood of their partner with dementia, which is important for the carer in the longer term, as research shows (Forsund et al., 2014).

Towards a Psychodynamic Model of How the Couple Relationship is Affected by Dementia

In summary, several interlinked elements of psychodynamic theory help us to understand how the dynamics of a couple's relationship are affected by dementia. Drawing together the themes emerging from the clinical work with couples described in this chapter, one way to conceptualise the situation is to

imagine how, in a relatively 'healthy' couple relationship, there is some flexibility in the projective system. With the pressures and changes brought by the progression of dementia, this flexibility shifts. As seen in both the research literature and clinical accounts, the dynamics of the relationship change as a function of the illness.

Although every relationship is unique, we can nevertheless extrapolate some general descriptions of the dynamics of couple relationships affected by dementia. Psychodynamic concepts help us synthesise the findings from the research and clinical data on the impact of dementia on the couple relationship.

Initially, in a healthy relationship, there is a balance where both partners can contain each other's projections and support each other's emotional states. However, as dementia progresses, the person with dementia increasingly loses the ability to offer containment for their partner, who, in turn, faces the challenge of managing their own difficult emotions while trying to contain their partner's anxieties and projections. This creates a significant imbalance and can lead to a rigidification of roles, with the carer partner becoming overwhelmed by the dual burden of their own emotional strain and the need to support their partner.

The dynamics may shift from a mutual, flexible containment to a scenario where the carer partner feels persecuted by the unmanageable projections of their partner with dementia. This can result in feelings of frustration, anger, and helplessness, which are compounded by the sense of loss and the grieving process. The carer partner's capacity to provide emotional support

and containment becomes strained, highlighting the need for external support systems, such as therapists or counsellors, to provide 'containment for the container'.

By acknowledging and addressing these dynamics, interventions can be designed to support both partners in maintaining a sense of connection and personhood, despite the challenges posed by dementia. This approach not only aids in the emotional well-being of both partners but also helps in sustaining the resilience of the couple's relationship over the course of the illness.

Psychodynamic Conceptualization of Changes to the Couple Relationship in Dementia:

The changes to the couple relationship in dementia can be understood through several linked elements of psychodynamic theory. Here are key points that help conceptualise these changes:

- **Pre-Morbid Quality of the Relationship:** The quality of the relationship before the onset of dementia profoundly influences how the couple experiences the intrusion of the illness.
- **Infectious Nature of Dementia:** Dementia can feel 'infectious', and the concept of projective identification is useful for understanding this phenomenon.
- **Couple Experience:** Dementia affects both partners, creating a couple experience with unconscious as well as conscious areas of experience that are held within the relationship.

- **Role of Projective Identification:** Everyone uses projective identification, which is also the basis of empathy and testing out one's understanding of the other's feelings.
- **Flexibility in Projective Systems:** Well-functioning relationships exhibit flexibility in their projective systems, allowing partners to take back projections and reality test their perceptions of one another.
- **Interchange of Projections:** In optimal relationships, there is a flexible interchange of projections, such as sharing the 'looking-after' role.
- **Impact of Dementia on Flexibility:** As dementia progresses, the flexibility of projections is lost. The couple can become increasingly separated as their roles diverge and become more fixed into 'carer' and 'cared for', leading to a loss of emotional contact and 'couplehood'.
- **Fears of Dependency:** Encroaching dependency and loss of capacity may evoke fears of returning to earlier traumatic states of dependency, akin to a breakdown experienced in infancy (Winnicott, 1974).
- **Loss of Anchoring:** As dementia advances, the person with dementia loses their anchorage in the world, leading to attachment insecurity and increased fear when the carer partner is absent (Miesen, 1993; Browne & Schlosberg, 2010).
- **Diminished Ego Functioning:** The partner with dementia's ego functioning—related to memory, perception, and judgement—is progressively diminished. This leads to a loss of the sense of time and

predictability, causing feelings of abandonment despite the carer's presence.

- **Impaired Object Constancy:** In developmental terms, as dementia advances, the person with dementia may suffer impairments in 'object constancy'. Like a young infant, they may be unable to hold a stable picture of the object in the face of separation or disappointment (A Freud, 1965; Edgumbe, 1973).
- **Pressure on Carer Partner:** The partner without dementia feels tremendous pressure when faced with their partner's vulnerability and need, especially when the reassurance of their return is forgotten within minutes.
- **Loss of Language and Increase in Projective Processes:** As language deteriorates, projective processes increasingly replace verbal communication.
- **- Burden on Carer Partner:** The burden shifts to the carer partner to provide a containing mind for the person with dementia, entailing a significant emotional burden.
- **Need to 'Contain the Container':** It is crucial to support the carer partner by helping them process their experiences so that they can remain emotionally available to their partner with dementia.

Case Example 6

The following case example illustrates the value of these psychoanalytic concepts in understanding the issues facing a couple living with dementia. Many themes discussed in this chapter are evident in the clinical material,

such as the 'infectiousness' of dementia, projective identification versus separateness in the couple, and the significance of containment in the recovery of emotional contact and resilience. Above all, this example shows how psychodynamic formulation can guide the clinician towards establishing a shared 'language of meaning' in working with a couple living with dementia.

A dilemma that couples of all ages can struggle with is the threat of losing individual identities within the relationship. For this couple, this longstanding difficulty was exacerbated by dementia. At the start of our work together, they described feeling like 'Siamese twins,' as they were 'thrown back upon themselves' by the dementia. This was a claustrophobic situation, and the dementia had robbed them of their established defences and previous 'escape routes,' such as spending time apart.

The husband was deeply immersed in his wife's world of dementia, expressing a desire to live through it alongside her but feeling as though he was struggling to keep his head above water. He felt submerged at times, strongly identifying with her experience. He described trying to keep his own mind alive through reading, though he struggled to write or engage in his creative work. He felt as though he no longer existed, his role gone, and at times, he perceived that she was coping better than he was. He felt anxious, cut off from people, and displaced from his old roles and from himself.

His health problems required treatment, and he was frightened of that. The struggle of managing their individual needs, which had previously threatened to negate each other, now appeared in a new guise: whose health would take priority. One row about whose needs should prevail left him feeling as

though she was 'putting the knife into him.' This image captures how her state of mind was projected into him, becoming 'infectious' as he put it. In one session, he reflected on his feelings of being overwhelmed and unable to manage or think clearly. He realised these were feelings one might expect her to have, and somehow, he was experiencing them. He recognised that while these feelings of losing his sense of identity and connection with the world were part of his own experience, they were also perhaps her feelings. This intense identification gave him an understanding of her experience.

As he recovered more of his sense of self and intellectual life, he started writing again. His previous identification with her maintained a lack of psychic separateness between them, perhaps avoiding the experience of loss but compounding the resentment and claustrophobia. With more internal and external support, he felt more anchored in his own mind and was able to engage with her without withdrawing in anger or frustration.

As more psychic separateness emerged between them, they became more in touch with the emotional pain of their losses. He spoke about the loss and changes they had to adjust to as a couple, and how it made him reflect on the past, particularly the impact of his decision to live away from her for so long. This time apart had caused losses and time that could not be regained. "I always thought that there would be more time, but some things are lost and that's it – they don't come back, and you don't get a second chance," he said.

He faced his guilt and the limits of reparation possible now that dementia was progressing. As he became more able to tolerate and articulate these

feelings, he expressed a wish to make it up to her for his previous unavailability. Although the clock could not be turned back, there was a sense of reparative processes beginning to emerge. He engaged more closely with her, allowing more emotional contact between them. She seemed to recognise this:

“The other night, we were going to sleep with our fingers linked together – touching our hands, and that hasn’t happened for a few weeks,” she said.

Her experience of emotional contact with him and with me in our joint discussions seemed to lead to a shift in her state of mind. At times, she felt more hopeful:

“There are things I look forward to – seeing people, family – walks,” she said, considering taking up music again. “There are things I can do to hold back the Alzheimer’s, not to give up. If I could find a teacher who would take someone like me, with my difficulties – what could be recovered and held on to?”

Our work seemed to help her feel that her mind was alive, enabling her to hold onto the music inside herself, so to speak. While such contact is very important, it will be increasingly difficult to sustain as dementia progresses. This raises the question of what the aim of psychological intervention should be. One answer might be to help support the couple to avoid the premature foreclosure of emotional involvement with one another, keeping alive, while they can, an imaginative engagement with their experience.

What seemed significant in our work was the couple’s experience of the therapist seeking to understand. It was the act of trying to understand, rather

than any special 'understanding,' that enabled an atmosphere of emotional contact and meaning making to emerge as part of a shared communicative endeavour. This reflects how Enid Balint, the founder of psychoanalytic couple psychotherapy in the UK, viewed psychotherapy as more akin to learning a language than a joint journey of explanation or research (Mitchell and Parsons, 1993).

This example shows how psychodynamic concepts helped to understand the issues facing the couple. The sense of the 'infectiousness' of dementia, which we heard often from the people we worked with, can be understood through projective and identificatory processes. In this case, difficulties with psychic separation between the partners persisted throughout their relationship. This highlights how psychological issues in couples living with dementia can be formulated using a psychodynamic understanding, providing a useful basis for psychotherapeutic work with the couple.

The Relevance of Psychodynamic Approaches for Intervention Development

The importance of psychodynamic concepts in understanding the research and clinical phenomena reviewed in these chapters is evident. We have seen the link between the psychodynamic concept of containment, the research finding of the importance of emotional contact for the person with dementia, and the understanding, from developmental research, of the importance of such 'meeting of minds' for addressing the attachment insecurity that dementia brings. In this way, psychodynamic theory has clear practical implications for dementia care. It augments our research-based

understanding of the importance of containment for the mental states of dementia by maintaining emotional contact with the person with dementia and highlights how the carer partner also needs containment to sustain their emotional engagement with their partner with dementia.

Additionally, the psychodynamic model enables us to see the importance of unconscious fears and anxieties and the ways in which difficulties in early life can underlie contemporary experiences. These factors will be central to the conceptualisation and development of the psychodynamic and attachment-based intervention for couples, which is discussed in detail in the next chapter. Overall, the evidence from clinical work links with the research literature, providing convergent sources of evidence to endorse the value of adopting an attachment-focused psychodynamic approach to understanding the couple with dementia and to inform intervention design in the post-diagnostic phase.

Conclusion

In summary, the couples worked with clinically in this pilot phase confirmed the findings of research reviewed in Chapter 2, indicating that dementia is associated with decreased marital satisfaction and poorer health (Kaiser & Panegyres, 2007; Clare et al., 2012; Fauth et al., 2012) and significant decline in relationship quality over time for caregiver partners (Marques et al., 2021). The clinical and interview material presented here also illustrates ways in which dementia negatively impacts the quality of a couple's relationship, manifesting in decreased communication, companionship, empathy, and intimacy, as well as reducing the emotional connection

between partners, all factors highlighted by research (Evans & Lee, 2014; Pozzebon et al., 2016; Wadham et al., 2016).

As we have seen in this chapter, the clinical evidence confirms that this is linked to dissatisfaction with the growing imbalance in the relationship as the individual with dementia experiences declining functional capacities, and their partner must take on what they can no longer manage. Additionally, there are areas that the research literature highlights, which have not been adequately addressed in psychosocial intervention design. For example, research studies consistently highlight the pervasive negative impacts on caregiving partners in dementia scenarios (Pozzebon et al., 2016; Lee & Evans, 2014), thus emphasising the need to provide a safe space for these individuals to express their negative feelings (Balfour, 2014; 2023).

Furthermore, dementia is likely to increase attachment insecurity for the partner with dementia (Miesen, 1993; Browne & Schlosberg, 2006), yet this area has also been under-acknowledged in intervention design.

There is a clear need for the development of interventions which seek to strengthen these relational factors. Indeed, research highlights the significance of assisting couples in maintaining continuity in their relationship both before and after the diagnosis of dementia (McGovern, 2011). As discussed, attachment-focused developmental research underscores the importance for infants of emotional contact with their caregiver for establishing secure attachment (Ainsworth, 1978). Transposed to the attachment-related anxieties of dementia (Miesen, 1993; Browne & Schlosberg, 2006), this suggests that interventions aimed at strengthening

emotional connections between partners in couples living with dementia are crucial. The threatened or actual experience of separation from attachment figures is a key area of difficulty. As we have seen, the negative consequences of 'emotional disconnection' in the couple living with dementia have significance for both partners and are linked to longer-term negative outcomes in mental and physical health as the disease progresses (Evans & Lee, 2014; Pozzebon et al., 2016).

To this end, we need to draw on what we know from research and clinical practice about the importance of emotional contact and containment in mitigating attachment insecurity and supporting the person with dementia's anchorage in the world of meaning and human relationships. The presence of another, understanding mind is vital as the mind is lost in dementia. This chapter, and the previous ones (Chapters 2 and 3), have reviewed the importance of the evidence of attachment research across the lifespan, linking this to the psychodynamic concept of containment in dementia care and the value of this for supporting couples and families living with dementia. These ideas will be further developed in the next chapter, which details the development of the Living Together with Dementia intervention – an approach that seeks to address these crucial areas in establishing an attachment-based and psychoanalytically informed intervention for couples living with dementia.

Chapter 5: Development of the Intervention Manual

Introduction

The previous chapter outlined key elements of psychodynamic and attachment issues pertinent to dementia. How can these be developed into an intervention for couples living with dementia? This chapter describes the development of such an intervention model, aiming to achieve 'face validity' and acceptability for a wide range of couples living with dementia, as well as for potential funders of such interventions. Consequently, the model has been designed with a 'pragmatic' focus, centring on everyday activities while maintaining a clear 'psychodynamic intent'. Case examples are provided to illustrate the practical application of this approach. These clinical vignettes are drawn from initial development work undertaken with couples living with dementia, focusing on the creation of the intervention manual.

Key Elements of the Intervention

How do we translate the psychodynamic conceptualisation of the couple relationship in dementia into an intervention that considers the empirical evidence on the impacts of dementia on couples, and the strengths and limitations of the current intervention literature? This section outlines the development of an intervention conceptually grounded in key elements of psychodynamic psychotherapy, while seeking a pragmatic and structured approach that incorporates key learnings from research, particularly from developmental studies of attachment.

Following the evidence detailed in the preceding chapters, the following issues have emerged from the research in dementia care, which are essential to the development of an intervention for couples:

Focusing on the Couple Relationship: Gilbert et al. (2023) identify only two interventions that incorporate techniques from couple psychotherapy to improve relationships in dementia (Balfour, 2014; Epstein et al., 2007), despite reports of such therapies being effective in improving relationships for those living with other neurodegenerative diseases (Beasley & Ager, 2019; Ghedin et al., 2017). There is a need for interventions that focus on the couple relationship, promoting a sense of unity rather than fostering 'separateness' (McGovern, 2011).

Continuity and Shared Involvement: Maintaining a sense of connection and shared involvement, encouraging reciprocity, and the ability to sustain a sense of mutuality and 'couplehood' (Hellstrom & Lund, 2007; Lewis et al., 2005; Wadham et al., 2016).

Treating Both Partners Equitably: Respecting the personhood of the individual with dementia has been shown to be an important factor in interventions (Epstein et al., 2006; AuClair et al., 2009).

Personalization: Interventions should be tailored to the specific dynamics and challenges in each couple's relationship. Pozzebon et al. (2016) emphasise that interventions should customise their approaches to support the unique needs of couples, focusing on understanding relationship history, addressing past relationship issues, shared interests, and lifestyle to aid in developing adaptive skills, and improving or maintaining the couple's relationship.

Attachment-Based Approaches: Interventions should address attachment needs by building upon existing research in infant and adolescent attachment (Miesen, 1993; Browne & Sholsberg, 2006; van Asche et al., 2013). Developmental research underscores the importance of emotional contact for establishing secure attachment (Ainsworth, 1978; Fonagy et al., 1993, 1997). This suggests that interventions aimed at strengthening emotional connections may enable psychological containment and help address attachment issues.

Psychological Containment. For couples living with dementia, psychological containment is crucial (Johnston & Terp, 2015). Several psychoanalytic writers, including Waddell (2007), Davenhill (2007), and Balfour (2006, 2007, 2014, 2018, 2023), have discussed the importance of containment in dementia. They highlight the significance for the person with dementia of having their emotional states recognised and processed by others, particularly those closest to them. The previous chapter details the need for containment for the carer partner, so they may be better able to contain their partner with dementia (Balfour, 2014, 2018, 2023).

Provision of a Safe Space: Interventions should provide a safe space to express negative feelings given the losses and negative impacts on caregiving partners (Pozzebon et al., 2016; Lee & Evans, 2014). Caregivers may experience numerous negative emotions, such as resentment, anger, and frustration, towards the person with dementia (Balfour, 2014; 2023). If these emotions are not given room for expression and reflection, they are more likely to manifest in negative actions. Many psychosocial interventions

regard conflict or the expression of such feelings as negative outcomes (Gilbert et al., 2023), indicating a shortfall in current approaches.

Accessibility: Johnston and Terp (2015) highlight the lack of readily available support for couples, emphasizing the importance of providing accessible interventions in couples' homes.

Engagement in Everyday Activities: There is a need for interventions grounded in an understanding of the everyday lives of the caregiver and the person with dementia (McGovern, 2011; Johnston & Terp, 2015; Pozzebon et al., 2016), enabling better collaboration within the home setting for the couple. Participating together in social or household activities is often expressed by partners as a key factor in maintaining a sense of couple closeness (Pozzebon et al., 2016; Boylstein & Hayes, 2012). The importance of daily activities may lie not only in their practical uses but as a way of enabling couples to connect emotionally, with the activity serving as a mediator for emotional contact between the partners (Hellstrom, 2005; Balfour, 2014, 2018, 2023).

Incorporating Resilience Factors: It is important to provide an approach that builds on existing strengths and encourages the couple to consider creative possibilities for shared activities (Johnston & Terp, 2015). Such an approach can help maintain a sense of "couplehood," the shared essence of the relationship, by continuing previously enjoyed activities and, whenever possible, identifying new activities.

Regular Assessment and Adaptation: Ongoing assessment of the couple's situation, as well as the effectiveness of the intervention, should be conducted to adapt and improve the intervention over time.

What follows in this chapter is an account of the key elements of the intervention and its development, linking these to their grounding in the research and theoretical issues outlined above. The aim has been to devise a psychodynamically-informed intervention that creates the conditions for emotional contact between partners. At the same time, the structure of the approach seeks to enable containment—for the person with dementia, the carer, and the worker who is supported in supervision to be emotionally engaged with the couple. The overarching principle of the model, which will now be detailed, is one of 'containing the container' (Balfour, 2014).

The intervention model aims to use practical ways of addressing key dynamic issues: articulating negative feelings, the importance of containment, and, above all, finding everyday ways of enabling emotional contact. These elements are integrated into an intervention focused on shared engagement in domestic activities. The behavioural focus on shared activity serves as a means of achieving emotional contact, which research and clinical evidence show to be vital.

In summary, the intervention has the following aims:

1. Preserve and strengthen the critically important relationship between the spouse carer and the person living with dementia, thereby reducing carer stress and breakdown.
2. Increase closeness in the couple relationship, enhance the capacity to

engage together in everyday activities, address negative cycles of interaction and withdrawal, and mitigate secondary disablement of the person with dementia. This involves enhancing understanding, sensitivity, and improving communication between the carer partner and the person with dementia.

3. Provide support and containment for both partners in coming to terms with the diagnosis, making optimal adjustments, maximising potential for engagement and activity, and addressing the challenge of social isolation and its adverse consequences on mental and physical health.
4. Develop strategies for both partners to become more interdependent, rather than the partner with dementia becoming dependent earlier and more completely than necessary.

Ultimately, the overarching goal is to develop an intervention that builds upon the implications of developmental research to strengthen existing attachment relationships by involving both partners in a joint intervention programme. This addresses the relational impacts identified by dementia research that are linked to negative outcomes for both partners. We have developed a manual (see Appendix p33) and a training programme, along with the piloting of our clinical approach (see Appendix p25).

Conceptual and Clinical Underpinning of the Intervention

The intervention is a structured programme, drawing upon several distinct conceptual and clinical areas. At its core is a psychoanalytic understanding

of the couple's relationship, developed from the field of couple psychoanalytic psychotherapy.

Working with the Couple's Relationship

The theoretical framework draws upon the model of couple psychotherapy developed at Tavistock Relationships (see Ludlum & Nyberg, 2007; Balfour et al., 2012; Morgan, 2018; Balfour & Morgan, 2018) to conceptualise how the partners in the couple may affect one another in conscious and unconscious ways, focusing on the interactional field of the relationship. As discussed in the manual for the intervention (see Appendix), while the partner with dementia may be the identified patient, this approach seeks to understand dementia also as a shared problem, experienced uniquely by each couple based on their shared histories and the underlying dynamics of their relationship. This interactional approach, examining both partners and how they work together, is central to the intervention, which is tailored to the unique situation of each couple (see Wadham et al., 2016).

It is important to note, however, that while research indicates the importance of the mutuality and interconnectedness of the couple, it also highlights the emotional challenges faced by the carer partner. The emotional demands of the situation raise questions about the supports needed to survive an experience that lacks the hope inherent in the carer/cared-for relationship early in life. Engaging emotionally with fragmented experiences is challenging, and it is understandable that carers who are themselves less contained may struggle to tolerate emotional contact with the person with dementia (Woods & Phipps, 2000). While there is substantial awareness of

the needs of mothers with newborn babies for support to combat post-natal depression, there is relatively little research or clinical interest in the needs of the caring relationship at the other end of the lifespan. As detailed in the previous chapter, pilot work in developing this model indicated the tremendous challenge that maintaining interest and emotional availability within the relationship presented to the carer partner (Balfour, 2014, 2015, 2023). This development highlighted the importance of considering not only the impact of dementia on couple attachment but also recognising the emotional challenges faced by the carer partner.

Clinically, an additional element has been crucial in developing the intervention model: the psychoanalytic understanding that it is difficult for someone—a carer partner in this example—to empathise with and understand another person's experience if they do not feel understood and supported themselves. Therefore, the approach includes separate space, outside the joint work, for the carer partner to have their feelings listened to by the therapist. This is based on the understanding from mother-infant psychotherapy that 'the mother whose cries are heard hears her infant's cries' (Fraiberg et al., 1975). This dimension is crucial in the clinical approach—not simply to urge the partner without dementia to understand better what is happening in their partner's mind, but for the clinician to think with them about their own feelings. This support enables them to understand their feelings and reactions better, thus enhancing their ability to empathise with their partner. Consequently, an important element of the intervention is providing space for each partner separately, as well as together, so that

more difficult feelings may be expressed freely, with less anxiety about hurting the other partner.

Reflecting on Feelings and Experiences: the Use of Video of Everyday Activities

Linking to the research evidence of the importance of 'mutuality' and shared involvement for couples (Hirschfeld, 1983; Uchino et al., 1994; McGovern, 2011; Wadham et al., 2016), the intervention draws upon approaches developed in working with parents and children, which emphasise the importance of observation and use of video as part of their intervention. These include Parent-Infant Psychotherapy (Baradon et al., 2005), Video Interaction Guidance (Kennedy et al., 2011), and the Relationship Development Intervention (Gutstein, 2005). I shall now describe these approaches and their relevance to dementia care in more detail.

The Relationship Development Intervention (RDI) (Gutstein, 2005) uses close observation and videoing to improve communication and patterns of interaction between parents and children with autism, with the aim of increasing sharing and reciprocal interaction. Two features of RDI are particularly important for our approach. One is 'Guided Participation,' which involves bringing out and highlighting the subjective experience of the participants when they are engaged together in a task—slowing actions down, sharing, and doing it together. The other is 'Scaffolding,' where the child with autism is supported to be an active participant. Importantly, this practical approach seeks to create the conditions for meaningful emotional contact through shared experiences. RDI techniques of focusing on shared

engagement in domestic tasks are used in the current intervention to structure increased opportunities for emotional contact between partners. This aspect of RDI utilised in our intervention focuses on the emotional meaning and potential of everyday activities, using these to create conditions for inter-dependency between partners. The aim is to enable partners to maintain emotional contact with one another and counteract the pressure towards withdrawal and loss of connection often associated with dementia.

Video Interaction Guidance (Kennedy et al., 2011) aims to enhance communication within relationships, using video clips of adult-child interactions that focus on the positive features of the interaction. In shared video review sessions, the family and the professional review micro-analyses of successful moments in the interaction, focusing on non-verbal as well as verbal cues. These reflections move from analysis of behaviour to the exploration of feelings and thoughts about the relationship, which is a central part of the current intervention. The use of video clips of shared activities serves as a springboard for reflections on thoughts about the relationship between partners in couples living with dementia.

Parent-Infant Psychotherapy (Baradon et al., 2005; Golub, 2016) emphasises 'reflective self-function' in attachment theory, supporting mothers in observing their interaction with their infants, thereby enhancing their capacity to think about and reflect upon their and their baby's feelings.

These video approaches have been found to be very powerful in work with parents and children, promoting change and new understanding. They have the advantage, given the cognitive deficits of dementia, of not relying on

linguistic and symbolic communication. As Woodhead (2006) discusses, video uniquely captures aspects of the relationship that take place in the procedural domain of 'implicit relational knowing.' We have found that through the use of video, it is possible to work with couples with dementia across a range of illness stages to reflect upon relational patterns and promote change through shifts of awareness, thereby improving the intersubjective experience between people with dementia and their partners. An important dimension is video-based observation of the person with dementia's (as well as the caregiver partner's) engagement, responsiveness, and pleasure in dyadic interactions, which can be captured visually. This will be described in more detail in the case examples below.

Drawing on these approaches, the intervention aims to support and enhance the reflective functioning, sensitivity, and attunement of the carer partner to the state of mind of the partner with dementia, as well as helping the couple to reflect upon their relationship. We have found video to be a powerful tool in helping couples reflect on their interactions, supporting them in finding a state of mind in which they can become interested in why things happen between them in particular ways. This capacity to observe and pick up meaningful communications when they occur is a focus of our use of video.

The aim of using video in this intervention is to help the couple become observers of themselves, focusing on finding meaning in everyday activities. The idea is that if the couple can be helped to begin to think about their everyday activities as opportunities for increased involvement before the dementia becomes too advanced, this may be protective and provide

strategies and understanding that can be helpful later as the dementia progresses. Whether we work with the couple together in reviewing the video or with the carer partner alone varies case by case. For individuals where the dementia is more advanced, we may be more likely to do this with the carer partner alone. The activities we video may seem mundane and everyday, but finding new meaning and new ways of thinking grounded in the couple's daily living is very important. Relationships can easily become calcified, with partners seeing each other as unchanging, but the video allows something to be noticed and seen afresh, which can support change and new ways of thinking.

The Process of the Intervention

I will now outline the process of the intervention, drawing on case examples to describe some important themes that have emerged in the piloting phase. As developed, it is an eight-session intervention with the possibility of further follow-up. We have found that intermittent sessions at roughly two- to four-week intervals work well, so the initial phase of the intervention tends to run over a six-month period, with the possibility of additional work. The essential focus of the intervention is to use shared activities as a way of structuring conditions for emotional involvement around a joint focus (what Uchino et al., 1994, called 'cohesion') to create conditions for supporting dyadic emotional contact and mutuality, using everyday domestic activities as opportunities for joint endeavour and involvement.

i. Beginning the intervention

Remembering the factors identified as important for intervention, the first principle is Personalisation. In the initial phase of the work, the structured focus of assessment is on individual (and couple) differences, and the intervention is tailored according to the specific dynamics and challenges in each couple's relationship. As detailed in the Intervention Manual (see Appendix), the therapeutic task is to explore the main issues facing the couple. One key aspect we have found important is what happens to containment within the couple relationship. For many couples, the partners may have fulfilled this function for each other until the illness interfered with it. The therapist needs to ask, how are the couple functioning now? What are the points of maximum pressure, and what kind of support will help them? What aspects of the couple's relationship provide resilience?

A focus of the assessment is identifying the issues that feel important in the relationship. Although someone trained as a couple therapist will have a model for thinking about this, our piloting of training in the intervention (to be described in the next chapter) has shown that a range of professionals can apply this approach in their own settings using the manual for the intervention, along with training and supervision. The aim is not to train people to become couple therapists or to make 'expert' formulations; the important thing is for the therapist to model a position of curiosity and an interest in thinking about what behaviour or feelings may mean. It is this act of showing curiosity and interest that we see as the central element of the intervention, modelling for the couple the idea that there is something to think about, and that both partners' experiences are meaningful and worthy of attention. In summary, the initial emphasis of assessment and intervention

should be on engaging the couple, exploring their experiences, and focusing on the containment of their feelings.

The assessment is a consultative process that can involve several meetings with the couple, depending on their capacities and presentation. There is an opportunity to discuss and reflect on this process in supervision and to establish a focus for the work.

We have developed a 10-point Assessment Guide (see Manual in Appendix for more details). The instructions to clinicians indicate that these headings are a guide—they do not need to (and cannot) cover everything, and these issues may not all be equally appropriate for all couples. Above all, the 'assessment' is about trying to make an emotional connection with the couple and to engage them in the process of the work.

The ten-point assessment guide covers:

1. Individual histories of both partners
2. History of the couple's relationship
3. Changes in the relationship
4. Experience of the diagnosis
5. Current situation
6. What is going well/strengths
7. Difficult areas
8. Assessment of time the carer partner has for themselves
9. Sexuality
10. Need to instil hope

Additionally:

- Video assessment exercise
- Assessing the couple interaction (in discussion with supervision group)

This structured approach aims to create a comprehensive understanding of the couple's dynamics and needs, fostering an environment where both partners feel understood and supported. By focusing on personalisation and emotional containment, the intervention seeks to strengthen the couple's relationship and enhance their capacity to cope with the challenges of dementia.

ii. Setting-up the video work with the couple

At the end of the assessment, a short video-assessment exercise is conducted. The essence of the approach involves inviting the couple to engage in a typical household task together, for example:

"We want you to work together as a team. Can you think of something that needs to be done around the house, like cleaning the fridge, something that feels natural?"

How the couple responds to this request can be very revealing of the core underlying dynamics in their relationship. At this stage, the practitioner provides minimal guidance, allowing the couple to undertake the exercise with as little interference as possible to elicit their characteristic dynamics. This interaction is videoed, and the video extract is subsequently discussed in the supervision group to formulate an understanding of the key dynamics

within the couple. These spontaneously undertaken activities yield significant information about the couple's baseline functioning together and often reveal core dynamic issues to be addressed.

Case Example: Henry and Jane

Jane has noticed Henry's withdrawal and wants to prevent it from worsening. However, the problem lies in her approach—fearful of taking over, she either leaves him to do things himself and stays away or stands on the sidelines, instructing him. This lack of interactive engagement will not help as his capacities diminish. Instead, as his functioning deteriorates, his current independence is likely to flip over into dependence, and the couple may miss the opportunity to develop a more interdependent approach while there is still time.

The practitioner discussed with Jane approaches that might help preserve Henry's agency and active involvement, countering the tendency towards withdrawal. The emphasis was on the importance of not simply leaving tasks to him and refraining from any involvement herself, but rather finding ways to be involved together. At present, their interaction was framed in dichotomous terms—either she takes over or leaves it entirely to him—resulting in a parallel interaction.

When viewing the interaction with Henry on the video, Jane immediately understood the formulation. She spontaneously commented, "I am hovering, I don't have a role—he is doing it entirely on his own. We tend to do things in parallel." Although they felt 'in sync' with each other, the challenge for this

couple was to find ways of doing things more interactively, fostering shared involvement and emotional contact.

In summary, this initial video assessment exercise not only provides a practical demonstration of the couple's current dynamic but also serves as a powerful tool for facilitating immediate understanding and reflection. This process enables the couple to recognize and address their interaction patterns, fostering a more interdependent and emotionally connected relationship.

iii. What happens after the assessment?

In the ongoing work of the intervention, the practitioner supports the couple in planning and structuring the activities they do together. Techniques of 'scaffolding' and 'guided participation' (Gutstein, 2005) are essential in this phase. Each activity is slowed down, with the person with dementia given a clear role, enabling them to be an active participant. The focus is on each partner's experience of the interaction.

The video work is manualised, with step-by-step instructions for the practitioner to follow (see appendix). The approach is structured, focusing on techniques to enable greater contact around everyday activities, while also encouraging the couple to think about their feelings. The process involves filming interactions between the participants and selecting clips to show the couple, focusing on the transactions between them. There is a 'video feedback' element to the subsequent session, where the couple and the practitioner review the film clip together. This review particularly focuses on moments when the carer partner has responded in an attuned way to the

partner with dementia's actions or initiatives, using a combination of verbal and non-verbal responses.

The practitioner examines the video interactions, looking at moments of contact between the partners, as well as points of frustration or difficulty. The aim is to work alongside the couple, engaging them in working together on carefully selected everyday activities that highlight and support moments of emotional contact. The activities are structured to be broken down into manageable tasks, with the carer partner learning to function as a guide, enabling their partner to be as involved as possible. The intention is to maximise shared activities rather than having the healthy partner take over. The process of the shared activity, rather than the end goal, is what is important, focusing on mutuality and emotional engagement.

This approach can be very powerful, helping the couple, or the carer partner, become an observer of the relationship and fostering a self-reflective state of mind where they can think about their interaction with their partner. The practitioner and couple reflect collaboratively on what is successful and formulate further goals for change. These reflections quickly move from analysis of behaviour to the exploration of feelings, thoughts, wishes, and intentions, helping the carer partner become more mindful and understanding of the feelings underlying the partner with dementia's behaviours.

The approach needs to convey respect for strengths and capacities and avoid drawing too much attention to difficulties. Helping the couple think about their everyday activities as opportunities for greater involvement and

mutual interdependence before the dementia becomes too advanced can be protective, providing strategies and understanding that will be helpful later in the illness. It is also important to spend time with each partner individually to allow for the expression and consideration of feelings and thoughts stirred up by the activities. This can be done with the couple together or separately, with the aim of helping partners feel more contained and reducing the need for defensive withdrawal or acting out of anger and frustration.

The principles underpinning these approaches make them very suitable for working with the couple relationship in the context of dementia. Carer partners are helped, through the filming and feedback sessions, to become more sensitive to the communicative attempts of their partner with dementia and to develop greater awareness of how to respond in an attuned way. By 'standing back' and looking at themselves on screen, partners can examine and think about what they were doing when things were going better than usual and consider how they might behave differently in more problematic situations.

It is important to note that the use of video is only part of the intervention. Discussion of the video clips serves as a springboard for reflections on the relationship, and for exploring the feelings of each partner and the dynamics between them.

Case Example: Ray and Barbara

Before the visit, the carer spouse, Barbara, had said on the telephone that there was no point in going ahead with the intervention as her partner, Ray,

did not really do anything—his memory loss was too severe, and he had totally withdrawn. However, once the therapist showed her the video and highlighted examples of her partner’s competence, she was very taken with what she saw. She recognised Ray's capacities that she had previously overlooked and her own capacity to learn from the work done so far. Specifically, she moved away from her familiar, memory-testing interaction with him (where she tended to question him in a rather schoolmistress-like manner) to using declarative comments.

For example, on the video, instead of testing him with questions about what he remembers, she shows him a picture and says, “These are old buildings that were near your parents’ house.” She supplies the context and her personal memory. Ray then supplies an association to it and a memory of his own, and they are both in more emotional contact with one another. This was something the therapist had been working on with her, and using the video clip, the therapist was able to show Barbara how effectively she was putting it into practice and how much Ray was responding to her.

This facilitated Barbara in changing her mind; she re-engaged and became very interested in the process, seeing the intervention through to its end, some months later. While focusing on the positive aspect, it is also important to explore more negative feelings. Another video, this time of their clearing the fridge together, captured a moment where she expressed frustration. In one part of the activity, things became more difficult when Ray's role was to put things back into the fridge. Watching the video, one can see Barbara's tension from the outset. The therapist is careful to show Barbara the positive

interaction first and then shows her a moment of frustration: in the corner of the screen, she can be observed putting her hands to her head in a manner suggesting rage and frustration. She is asked, "What were you feeling?" The ensuing discussion is helpful and links to mourning the man she used to have, but there is also a discussion of her ability to focus on what she does have with her husband and what is possible now.

She described her frustration about the fridge and other things, such as his complaints about his tinnitus. Her frustration with him felt, at times, like a terrible noise between them. However, the opportunity to think about it and to help her seemed to lead to a softening between them and evident shifts in their relationship. Ray, whom she had described as often being hidden behind a book, shut off and withdrawn, was described by her as emerging more. She noticed that he now comes out into the kitchen and says to her, "Is there anything I can do?" She thought he was making a link with the work they had been doing. He had never done this before. This seemed to help her tolerate the difficulties and her frustrations with him. Towards the end of the therapy, Ray spoke in a way that seemed linked to a restoration of greater intimacy and a sense of being more contained by her and the therapeutic work. Here, Ray seems to be communicating something about this:

"I have moods—particularly when my tinnitus is bad. She treads softly around me—she doesn't say anything—she is quietly responsive. I am a lucky man. My memory is not so good. She helps me; she's my rock. I do fear the couple being broken...not staying...that it will come to that."

With many couples, depending upon the severity of the dementia, it will be possible to work with both partners together to review video recordings of their carrying out activities. This can be very powerful, particularly if each partner can be asked at critical points in the video what they think their partner was feeling. This can enable an 'imaginative leap' where an empathic identification can be made with the other partner, sometimes leading to significant shifts in feeling and understanding. At other times, particularly with couples where the dementia is more advanced, it may be more helpful to look at the video with each partner separately.

In our focus on these everyday things, our efforts have been to create the conditions for emotional contact between people, grounding this in the domestic detail of life, and using video to provide a vantage point from which people can reflect upon their relating. The focus is on containment, curiosity, and the act of seeking to understand—a condition where, while anchorage in personal relationships and attachments may be more vital than ever, the couple are faced with profound emotional challenges.

iv. Working with the Couple

Discussion of the shared activities leads into broader conversations where the practitioner helps the couple think about their feelings, explore, and understand the dynamics of their relationship. As part of this, the therapist uses three sources of information (detailed in the Manual):

1. What each partner says about the relationship.
2. What can be observed about the interaction between the partners.
3. What can be noticed about the practitioner's own emotional

experience as they engage with the couple (countertransference).

Although the partner with dementia is the identified 'patient', this approach seeks to understand dementia as a shared problem, experienced uniquely by each couple based on their underlying relationship dynamics and shared histories. This 'interactional approach' focuses on both partners and how they work together, including the difficulties they experience in being together.

The practitioner examines how the partners behave towards each other and tries to understand their experiences—what they think they are doing and how they feel their partner is responding to them. For couples in the earlier stages of dementia, both partners may be able to express much through verbal interaction. Later in the disease process, the therapist will need to rely more on behavioural and other aspects of communication between them. Technically, the practitioner needs to shift attention between partners—empathising and seeking to understand one partner's experience, then the other's, and ultimately linking the two perspectives. This process involves moving between vantage points, clarifying with the partners as they go along, and attempting to understand (or formulate) the relationship dynamics and key areas of focus.

This requires the practitioner to hold in mind multiple perspectives, to be subjectively involved with both individuals, but also to be able to stand outside the relationship and observe it. The capacity to understand the dynamics of a couple and arrive at a formulation of the areas of difficulty is

fundamental to a couple approach and necessitates supervised work within the context of training to develop this skill.

Overall, the task for the practitioner is to work alongside the couple, highlighting and supporting moments of emotional contact between the partners and engaging the person with dementia in activities they can still manage. The practitioner maintains a position of curiosity, interested in what behaviour or feelings may mean, modelling for the couple that there is something to think about, and that both partners' experiences are meaningful and worthy of attention.

The following example highlights how focusing on the video of a shared activity can create conditions for a discussion with deep emotional significance for the couple, enabling significant emotional issues to emerge, be thought about, and be reflected upon.

Case Example: Jack and Mavis

Jack and Mavis were watching a film of their attempt to sort out the videos in a display cabinet. Soon after the video clip began, both partners laughed, and the therapist stopped the tape to ask them about this. Jack responded, saying that he thought Mavis was 'peeved' because he wasn't sticking with the task. The therapist then asked Mavis what she thought Jack had been feeling. Mavis said that she thought he felt parts of his life were being thrown away. The therapist picked up on this comment and repeated it, asking Jack if this was right, if that was how he felt. He said, "It feels like that... yeah..." and then talked about how he used to go to the cinema every Saturday

morning as a boy. Mavis chipped in, reminding him of the name of the cinema when he struggled to recall it. He had seen all these people—Laurel and Hardy—all the old classics, the ones on the videos.

After a few more minutes, Jack took the initiative and asked Mavis what she was feeling. She said, "I thought you are not going to give in, no matter how I tried to help you, you were fighting me... That's what it was, a fight... a quiet fight, but still a fight." He agreed with this and went on to describe how the mess in the cabinet was what in Yiddish they call a 'bouja'. The therapist asked what this meant. "A big mix-up," he said. Mavis commented, "That's what your mind is sometimes, isn't it?" Jack agreed and then there was a discussion of how what was happening was a good example of the difficulty of helping each other with the 'bouja', the difficulty and confusion of his memory loss, and how it could turn into a battle.

Mavis went on to say that it didn't use to be like that. "Everything used to be organised but now we keep not being able to find things. If anything happened to Jack, I wouldn't know where to start, to sort it all out. My mind, now, is quite tidy... but this morning I had such a shock. I lost my purse."

Mavis then described how she had become very angry with him. "I felt such an idiot myself and then I let him have it full blast—two guns... which is a shame and I do feel sorry."

It was possible for the therapist to explore this with them—how it seemed that Mavis could try to keep her mind 'tidy', but when she lost her purse, it felt as though she were becoming forgetful too, that the dementia was overtaking both of them. This was frightening for her, and she became angry and

attacking of Jack. Mavis said: "It is like a precipice, and I can't afford to lose my mind or my memory because I am fighting for the two of us—and that is what it boils down to, because I have no one to rely on, you know, if I go down."

This example highlights how focusing on the video of a shared activity can create conditions for a discussion with deep emotional significance for the couple. By examining their interactions, the couple can better understand the underlying emotions and dynamics of their relationship, leading to meaningful conversations and reflections that can help them navigate the challenges of dementia together.

Summary

As demonstrated in the case example, a seemingly pragmatic focus on behaviour and interaction around shared activities can provide a structured opportunity for couples to engage with deeper underlying emotions. This account of the intervention captures its approach, distilling the essential features identified by research as key to the resilience of couples living with dementia, which were highlighted at the outset of this chapter.

Referring to the main issues emerging from research identified at the beginning of this chapter, the intervention addresses each of these in the following ways: A highly personalised, tailored understanding of the couple is achieved through a focus on assessment that encompasses the couple's dynamics in a relational context, engaging both partners. Additionally, the intervention employs a pragmatic structure, providing face validity and a

concrete shape to the intervention. Shared activities and videoing serve as a means of structuring the conditions for shared emotional experiences between the partners. Within this structure, videotaped clips act as a springboard for self-observation and reflection, offering a vantage point from which to explore the dynamics of their relationship with the practitioner.

The emphasis on emotional contact between the partners, and with the practitioner, highlights the importance of containing feelings—crucial in relationships with key attachment figures. This includes providing space to express negative emotions, which is vital in dementia care. Ultimately, the intervention model is akin to a Russian doll: the practitioner provides containment for the carer partner so that they can better support their partner with dementia. Ongoing supervision of the practitioner is crucial to ensure they are sufficiently contained in the work. The intervention is best delivered in the couple's home, ensuring accessibility and providing a meaningful context for the everyday activities that are the focus of the work. Additionally, assessment of the couple's interaction is an ongoing element of the intervention, along with the evaluation of the intervention itself, with psychometric measures enabling ongoing review and refinement.

In conclusion, the Living Together with Dementia intervention aims to support the sense of self-efficacy of the person with dementia, the sensitivity and understanding of their partner, and the mutuality and interpersonal engagement of the couple. This chapter has outlined the key elements of the intervention, tracing their grounding in both dementia studies and psychodynamic and attachment-based theory and research. Brief case

vignettes have illustrated how this framework translates into the clinical situation of therapeutic intervention with couples. The next chapter will outline the development and implementation of the training programme for practitioners to enable them to deliver the intervention.

Chapter 6: Development and Evaluation of the Training Programme

This chapter details the development and evaluation of the training programme. It is divided into Study 1: which describes the development and quantitative evaluation of the training programme, and Study 2 which details its qualitative evaluation.

Study 1

This study gives an account of the development and quantitative evaluation of the Training Programme.

Introduction to Studies 1 & 2

An important key to improving dementia services is to strengthen the emotional and psychological support for staff working with people with dementia. Stress and burnout are recognised as common occupational hazards, which have negative consequences for both staff and the people with dementia in their care. Kokkonen et al. (2013) highlight the need to address burnout among dementia care staff to improve their well-being as well as the quality of care for people with dementia. Research indicates that stress and burnout negatively impact staff behaviour towards their patients with dementia, and are associated with less empathy, less willingness to help, and negative responses to their behaviour (Astrom et al., 1991; Todd & Watts, 2005).

The importance of this area has been recognised by policymakers and other stakeholders in the field for some time. For example, a government report on improving dementia services in England raises urgent concerns about high staff turnover and vacancies in dementia care (Committee of Public Accounts, 2010). High staff turnover in dementia care is linked to stress, burnout, and low job satisfaction, with the UK having one of the highest rates of staff reporting 'burnout' in Europe (Health Education England, 2014). What do we know about how to reduce stress and support the emotional and psychological capacities of staff? Here, we can draw upon our psychodynamic understanding of the relationship dynamics of dementia and the impacts on family caregivers, which have been discussed in previous chapters in terms of the couple relationship. This understanding also has implications for the challenges facing staff working with people with dementia (Morgan et al., 2002; Pitfield et al., 2011).

As we have seen in our discussion of the relationship difficulties that can ensue when the carer partner is anxious and unsupported, this is a dynamic process whereby the person with dementia may respond to negative interactions with increased anxiety or agitation, which in turn leads to further stress in the caregiver (Woods, 2001). People with dementia are progressively less able to communicate with language, and those in contact with them are faced with patients whose inner states are increasingly conveyed through projective processes. Considering the level of anxiety that may be felt by such patients, and projected onto the professionals involved, we can see how it may lead to fragmentation of thinking in staff, with negative feelings towards those in their care (Balfour, 2006). If this is not

contained, if professionals do not have a forum for thinking about such feelings, then there is a danger that these emotions may be acted out by staff, with all the associated risks. As Obholzer (2000) puts it, in such settings, staff go about their daily work “irradiated with distress.” Without containment and support, they can find themselves acting in ways that echo the difficulties of their patients. In this way, the emotional world of older people with dementia can “infect” those around them, creating a parallel emotional process that, particularly in less contained settings, may be mirrored and enacted by staff.

Those working in the caring professions may be drawn to this work partly due to an internal, unconscious motivation to repair damage. In situations where there is no hope of cure, and where the situation involves progressive deterioration, as in dementia, the failure of such reparative wishes may be hard for staff to bear. The anxieties that can be felt in such circumstances can be very powerful and may be projected around the system. Anxieties and defences can be expressed at the institutional level (Menzies, 1988a, 1988b) within groups of staff across the dementia care setting. Defences and ways of managing anxieties arising from the difficult work of caring for people with dementia are, of course, necessary. However, if staff working in dementia care are not helped to process the feelings arising from their work, there is a danger that these emotions will be expressed in ways that negatively affect the quality of care, as research indicates (Astrom et al., 1991; Todd & Watts, 2005; Kokkonen et al., 2013).

The importance and value of psychodynamic approaches to interventions with staff working with people with dementia are highlighted in several studies. Arden et al. (1998) describe the value of psychodynamic input to the old age psychiatry team, as do Stern and Lovestone (2000). Holman and Jackson (2001) describe reflective practice groups for staff on a continuing care ward based on a psychodynamic approach. Ashburner et al. (2004) describe an action research project aimed at supporting staff in a continuing care setting using a psychotherapeutically informed approach. Davenhill (1998) employs a psychodynamic approach to understand the difficulties arising in the provision of long-term care for people with dementia and the institutional and service-level response. In addition, several authors have described the use of psychodynamic observational methods and psychodynamic models to understand issues arising at an institutional level in dementia care settings (Davenhill et al., 2003; Mackenzie-Smith, 1992). Terry (1997) describes work with care staff and service managers based on psychodynamic principles. The work of Kitwood (1997) and Kitwood and Bredin (1994) has profoundly influenced establishing person-centred care based on psychodynamic approaches.

The research in this area shows that staff training and supervision are vital elements in reducing stress and supporting staff's emotional resilience and engagement in their work (Islam et al., 2017; Costello et al., 2019). For staff to be receptive to the emotional states of people with dementia, they need access to supervision and support that addresses the emotional impact of their work on them (Berg, Hansson, & Hallberg, 1994; Islam et al., 2017; Costello et al., 2019). This supports the World Health Organisation's

recommendation for enhanced workforce education and training programmes on dementia and long-term care [WHO, 2012], and the Care Quality Commission (CQC, 2014) regulation proposing that staff must receive training, support, supervision, and professional development to fulfil their roles.

Interestingly, the literature in this area suggests that staff training on the role of attachment in dementia care is important, with evidence that incorporating attachment theory into staff training programmes is helpful (Kokkonen et al., 2013). Mills et al. (1999) designed a teaching package that encouraged greater awareness of attachment relationships across the lifespan and delivered it to care staff in three residential homes. As a result of the training, the caregivers reported feeling closer to clients, with increased knowledge of the clients' pasts leading to a greater understanding of their behaviour. Furthermore, numerous studies have reported that positive interpersonal relations between supervisors and staff can minimise job-related stress and be a meaningful source of job satisfaction (McGilton et al., 2007). Greater awareness of their own attachment style, and of attachment theory, may play a role in reducing levels of burnout in staff and lead to better quality relationships between staff and people with dementia (Kokkonen et al., 2013).

Drawing on the link between attachment theory and containment detailed in previous chapters, from a psychodynamic point of view it can be argued that, in addition to understanding attachment from a theoretical standpoint, the containment of staff is crucial in supporting them emotionally in their role.

Vital to this is providing staff with opportunities to express difficult emotions arising from their work. In some organisations, this approach can feel counter to the prevailing culture, and resistance to it can be encountered at both individual and organisational levels. This is understandable, as such an approach may disrupt the established modes of defence within the organisation (Menzies, 1988a, 1988b). While staff may intellectually agree that this is beneficial, there may be considerable anxieties about it at another level. Both clinical experience and research indicate the importance of seeking to understand the unconscious anxieties and defences that arise in the dementia care setting (Hinshelwood & Skogstad, 2000; Balfour, 2006). As discussed, frontline staff are subject to powerful and disturbing projections. Given this, it is important that they are given the opportunity to process and discuss the feelings engendered in them by working in close contact with the frailty and diminished functioning of people with dementia. Support and containment for staff are of vital importance in helping them to be alongside and emotionally engaged with the people with dementia in their care.

The Living Together with Dementia training programme seeks to incorporate these issues identified as important by the research and the psychodynamic literature. The programme emphasises understanding the implications of attachment theory and research for dementia care (Kokkonen et al., 2013). In addition, it encompasses consistent supervisory input to provide emotional support and containment for staff in their work with people with dementia, following the evidence from both researchers (Astrom et al., 1991; Todd & Watts, 2005; Berg, Hansson, & Hallberg, 1994; Islam et al., 2017; Costello et

al., 2019) and clinically focused psychodynamic literature (Davenhill, 2007) that this component is crucial for staff development and resilience and, ultimately, for the people with dementia for whom they are caring..

Development and Implementation of the Training Programme

The training programme was developed through initial piloting. Two clinical workshops, which extensively utilised video clips taken during the pilot year of intervention work with couples with dementia (as described in Chapter 4), were held at the Royal College of Psychiatrists' annual conference.

Additionally, a presentation and discussion occurred at the British Psychological Society annual conference on neuropsychology. Furthermore, the content of the teaching programme was refined through the initial trialling of the ideas and key elements of the training programme during a series of one-day workshops conducted nationally with Admiral Nurses in London, Birmingham, Leeds, Manchester, and Nottingham.

Following this development phase, the structure of the training was established as a two-consecutive-day programme focusing on content, comprising theory and clinical discussions. This was followed by a third day dedicated to the clinical delivery of the Living Together with Dementia intervention. Upon completing the three-day training, participants joined a fortnightly group supervision (90 minutes each fortnight) to support them in delivering the intervention to couples living with dementia. Teaching methods employed a blended learning approach, incorporating theory presentations, discussions, role plays, and filmed vignettes from couples participating in the intervention. Clinical and theoretical papers, along with the Living Together

with Dementia Training Handbook (see Appendix, p25), were used as the foundation for the training.

The Content of the Programme

The programme content covered three areas: couple psychotherapy, attachment theory and research, and video-based approaches to clinical intervention. The training begins with an overview of the research on the couple relationship in dementia and includes a detailed presentation and examination of the intervention using video clips, role plays, and group discussions.

The target learning outcomes for each of the three content areas—couple psychotherapy, attachment theory, and video-based approaches—were as follows:

1. **Couple Psychotherapy:** Participants will gain an understanding of the dynamics of couple relationships affected by dementia, develop skills in facilitating therapeutic conversations between partners, and learn techniques for addressing emotional and psychological challenges within these relationships.
2. **Attachment Theory and Research:** Participants will explore the relevance of attachment theory to dementia care, understand how attachment patterns influence the behaviour and emotional responses of both people with dementia and their partners, and learn to apply attachment-based interventions to support and strengthen couple relationships.

3. Video-Based Approaches: Participants will learn how to use video as a tool for clinical intervention, including recording and reviewing interactions between couples, using video to facilitate reflective practice and supervision, and employing video feedback techniques to enhance therapeutic outcomes.

The training programme aimed to equip professionals with the necessary knowledge and skills to effectively support couples living with dementia, fostering stronger and more resilient relationships through evidence-based interventions and ongoing professional development.

Method

Recruitment of Trainees

Trainees were recruited in three geographic locations: Camden and City & Hackney in London, and Bristol. We obtained both NHS research ethics approval and site-specific R&D approval for each organisation from which we recruited trainees and couples within each location (see Appendix).

Camden Training

The recruitment of interested trainees in Camden began with a free half-day conference where the ideas and pilot work were presented. This event attracted around 70 attendees from adult social care, the NHS, and various third sector organisations in Camden. Following this event, and through liaison work with the Local Authority commissioner and senior NHS Trust

staff, we recruited participants from within Camden for two cycles of the three-day training.

The first training cycle recruited 11 participants with the following professional backgrounds:

- 4 counsellors from Third Sector organisations working with older people
- 1 systemic family therapist from a Third Sector organisation
- 2 clinical psychologists (one a researcher in old age, the other from the Memory Service)
- 2 psychotherapists
- 1 Activities Coordinator working with older adults in the voluntary sector
- 1 Adviser from a Third Sector organisation

The second training cycle also recruited 11 participants with these backgrounds:

- 2 psychotherapists
- 5 counsellors
- 1 counsellor/prof doctorate trainer
- 1 family therapist
- 2 support workers in the Third Sector

In total, 22 people were trained across the two three-day training cycles in Camden. From this initial group, 16 began in supervision groups, and 13 completed both the three-day training and the supervised casework.

Bristol – Harbour and Older Adults’ Wellbeing Service Training

Interest from local clinicians in Bristol was elicited through presentations to Bristol Older Adults’ services on two occasions, each a half-day introductory training to large groups of staff and managers. These sessions also helped establish referral networks. Following this, three clinicians, including two psychotherapists and one counsellor working in the NHS Trust Older Adults’ Services, joined the three-day training. They all joined a supervision group and sustained their commitment, taking on cases referred by the NHS Older Adults’ Wellbeing Service.

City and Hackney Training

Recruitment of trainees in City and Hackney was achieved through publicity, marketing, and local meetings held at the One City Dementia Alliance Meeting, Alzheimer’s Society, and the Older Adults’ CMHT, as well as through telephone and email networking. This required negotiation with senior managers to allow staff to undertake the training. Three cycles of the three-day training were run, training a total of 24 staff. These trainees came from the following backgrounds and settings:

- 12 staff from the Older Adults’ Community Mental Health Team
- 4 from Hackney Mind
- 2 from the Alzheimer’s Society
- 5 from the NHS Dementia Care Team (two Social Workers, one Community Psychiatric Nurse, one Consultant Psychiatrist, and one Occupational Therapist)

- 1 Family Counsellor from the local hospice

Some staff were clear they wanted to attend the training for CPD rather than undertake clinical case work. Those who joined the supervision groups often found the pressure of their regular work too great to continue. Additionally, 2 trainees left their posts, and 2 others withdrew due to sickness. Overall, 3 supervision groups were established, and out of the 24 staff initially trained, 10 engaged further with the project and joined the supervision groups.

Overall Recruitment and Engagement

Across the different sites, 49 staff were trained, 22 in Camden, 24 in City & Hackney, and 3 in Bristol. Of these, 29 went on to join fortnightly supervision groups. The main reason cited by those who did not join or sustain their commitment to the supervision groups was a lack of time due to other work pressures. Some trainees indicated that they had attended the three-day training for general CPD purposes but could not commit to the clinical component of the training.

Evaluation of the Training

Pre- and post-training measures (see appendix for the measures used) were collected from staff attending the training through four questions asked at the start and upon completion of the three-day training. These questions aimed to assess the impact of the training on key areas of professional competence in working with couples with dementia, thereby operationalising the learning aims and outcomes of the training. Each supervision session was rated anonymously by trainees at the end of each session. Additionally, a sub-

sample of trainees were interviewed at the end of the training. These interviews were transcribed and analysed qualitatively, and these are evaluated in Study 2, below.

Results

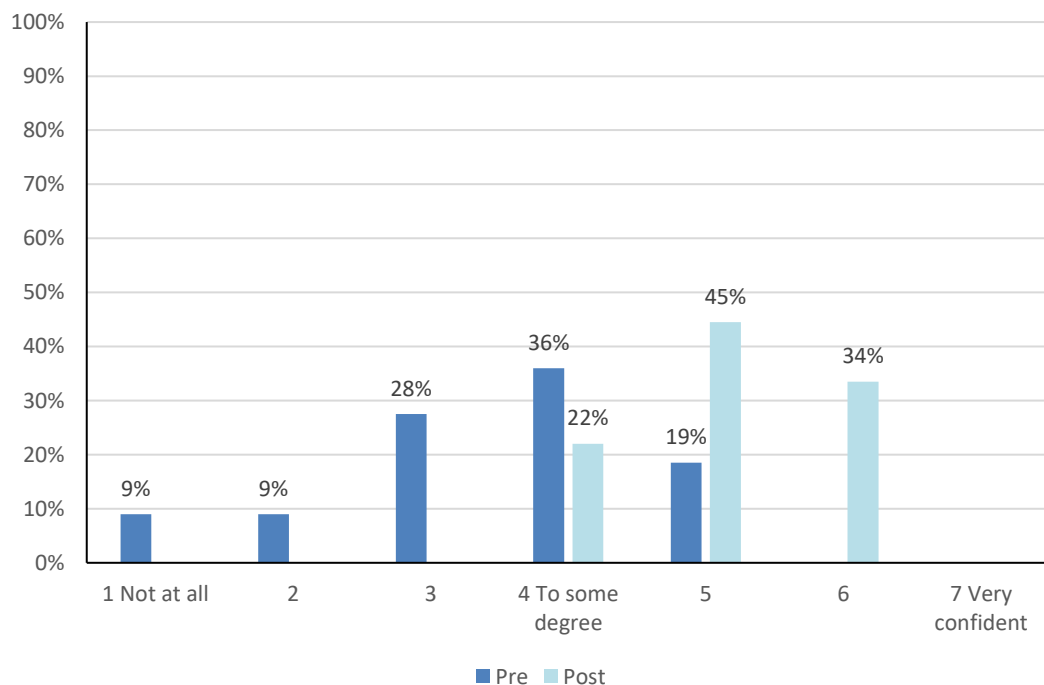
Evaluation of Three-Day Trainings

The graphs below illustrate the positive shift towards greater confidence in each of the key areas of learning outcomes, as reported by participants.

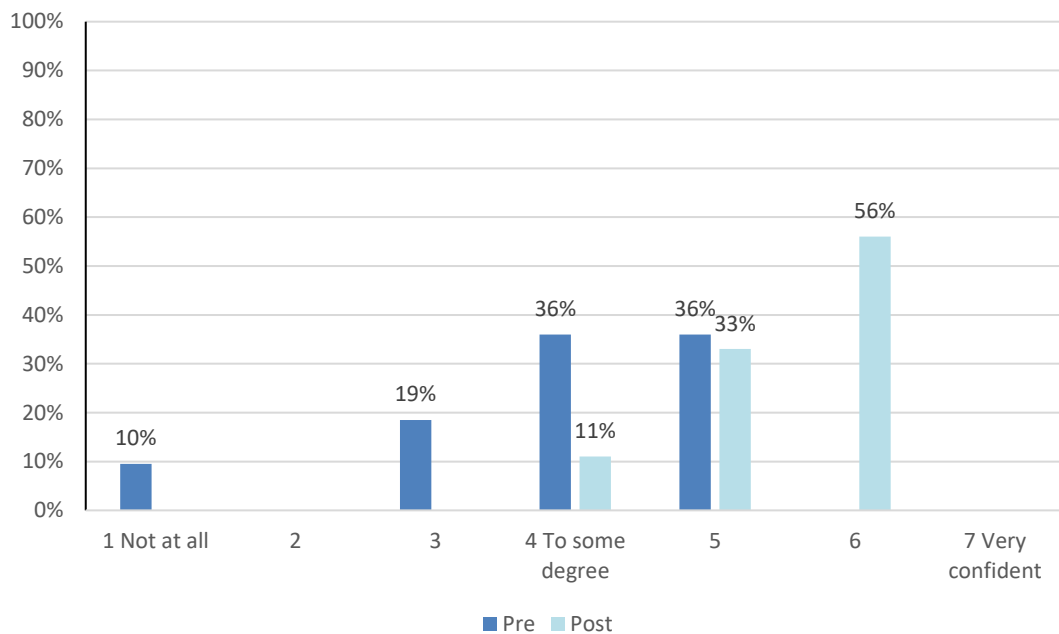
These graphs compare self-ratings on these dimensions before and after the training, demonstrating enhanced competence as a result of the programme.

Camden and Bristol (Combined)

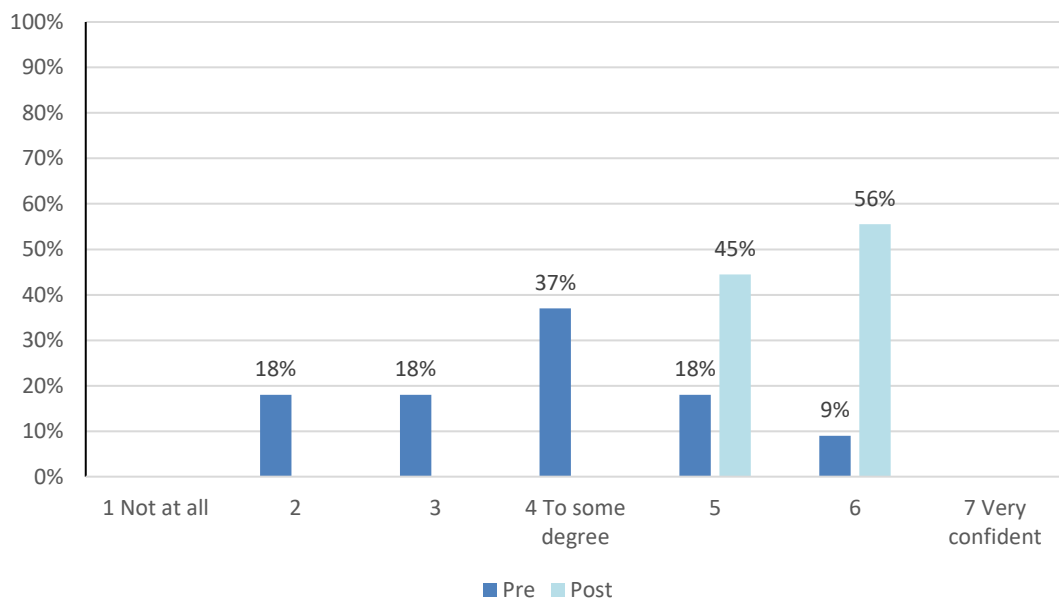
Q1: How confident do you feel about working with couples with dementia?



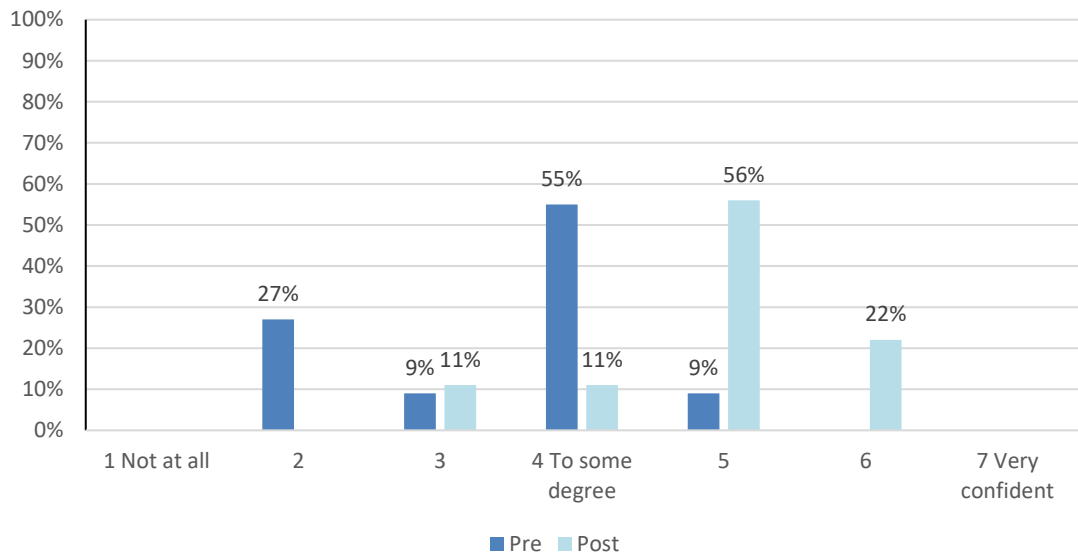
Q2: How confident do you feel about your knowledge and understanding of the impact of dementia on the couple with relationship?



Q3: How confident do you feel about your knowledge and understanding of attachment issues in couples with dementia?

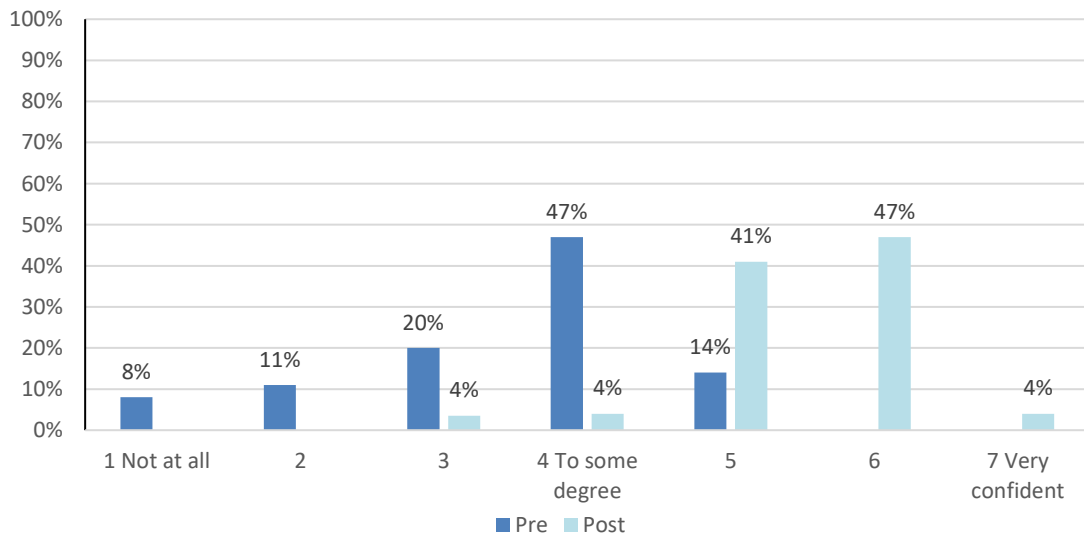


Q4: How confident do you feel about intervening with partners to promote communication?

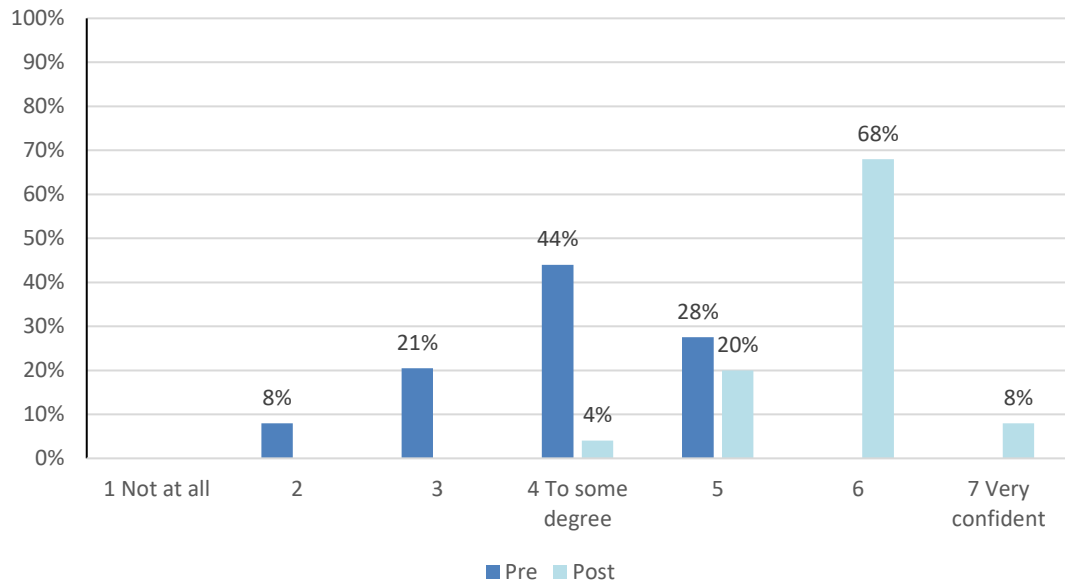


City & Hackney

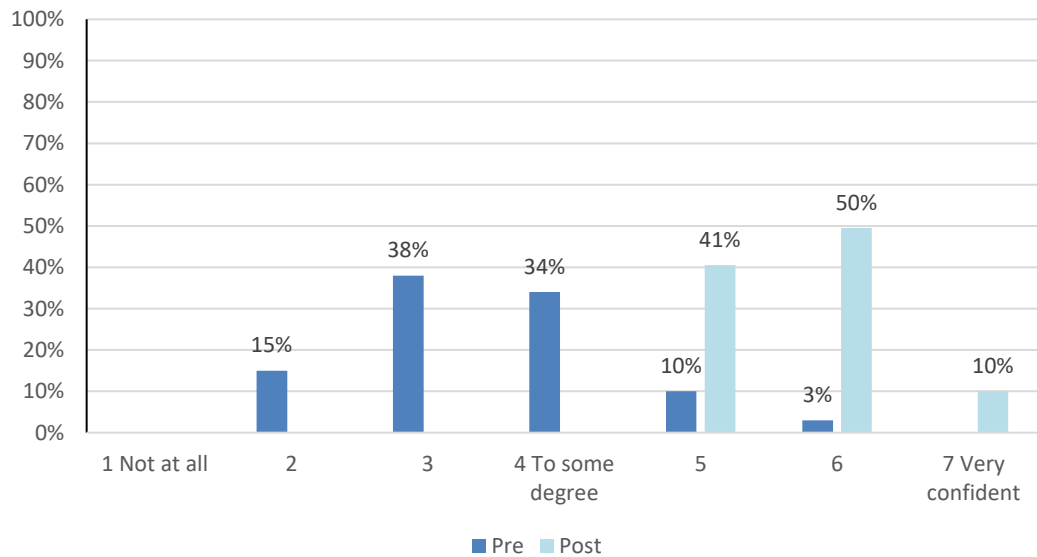
Q1: How confident do you feel about working with couples with dementia?



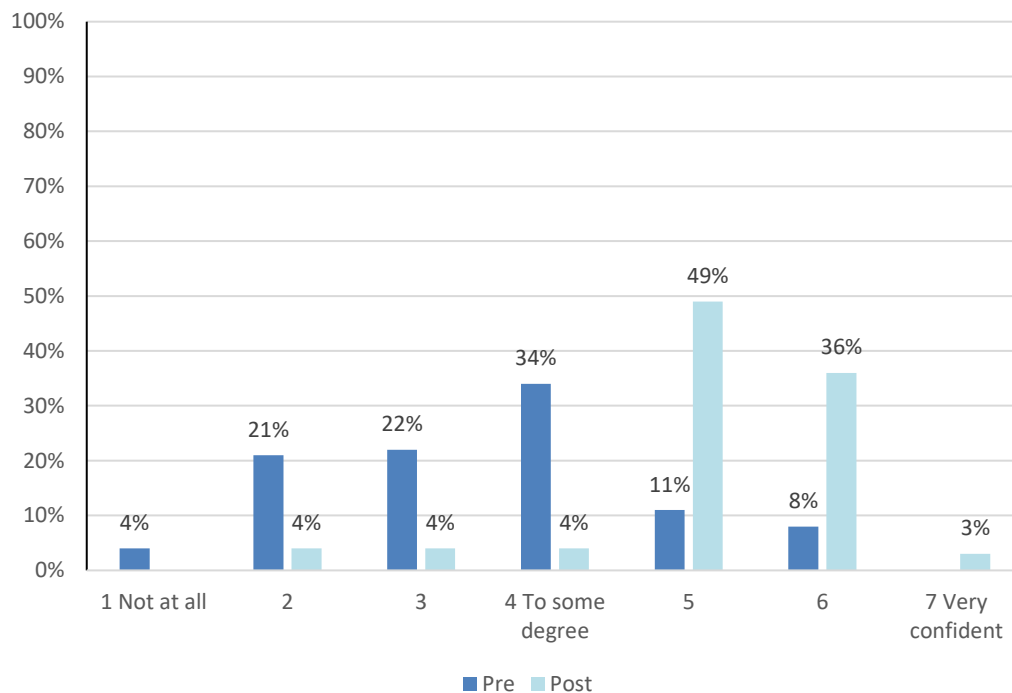
Q2: How confident do you feel about your knowledge and understanding of the impact of dementia on the couple relationship?



Q3: How confident do you feel about your knowledge and understanding of attachment issues in couples with dementia?



Q4: How confident do you feel about intervening with partners in order to promote their communication?



In the combined results for Camden and Bristol (due to the small number of participants in Bristol and the similar time period of the training), and in City & Hackney, there is a clear indication of a trend toward improvement in professional confidence and competence among the trainees. This positive trend reflects the efficacy of the training programme in meeting its objectives and supporting the development of skills necessary for effective intervention with couples living with dementia.

Data Analysis

Nonparametric Wilcoxon signed ranks tests were performed due to the type of data, the low number of observations and because the data did not constitute a normal distribution. These analyses found no statistically

significant differences between pre and post training scores on any of the questions. However, the data shows that scores on the questions increased from pre-post training in most cases (with two instances where there were marginal reductions in scores). Therefore, although there is clear evidence of improved competence on nearly all the outcomes, this was not found to be statistically significant. In summary:

- Question 1 (How confident do you feel about working with couples with dementia?) and question 2 (How confident do you feel about your knowledge and understanding of the impact of dementia on the couple relationship?) saw increases in both Camden & Bristol and City & Hackney cohorts.
- Question 3 (How confident do you feel about your knowledge and understanding of attachment issues in couples with dementia?) saw increases in the Camden & Bristol cohort but a slight decrease in the City & Hackney Cohort.
- The opposite was observed on question 4 (How confident do you feel about intervening with partners to promote their communication?); there was a small decrease in the Camden & Bristol cohort but an increase in the City & Hackney cohort.

Table 1. Analysis of pre/post training ratings per borough and per question

	Q1		Q2		Q3		Q4	
	Camden & Bristol	Hackney & City	Camden & Bristol	Hackney & City	Camden & Bristol	Hackney & City	Camden & Bristol	Hackney & City
Pre	2.75	3.75	2.5	3.25	2.5	3.67	2.75	2.88
Post	5	4.33	5	4	3.75	3.33	2.25	4.75
Outcome	↑	↑	↑	↑	↑	↓	↓	↑
Z	-0.105	-0.674	-0.135	-0.135	-0.338	-0.734	-0.105	-0.169
p value	0.916	0.5	0.892	0.893	0.735	0.463	0.917	0.866

Note: pre and post values are the mean ranks.

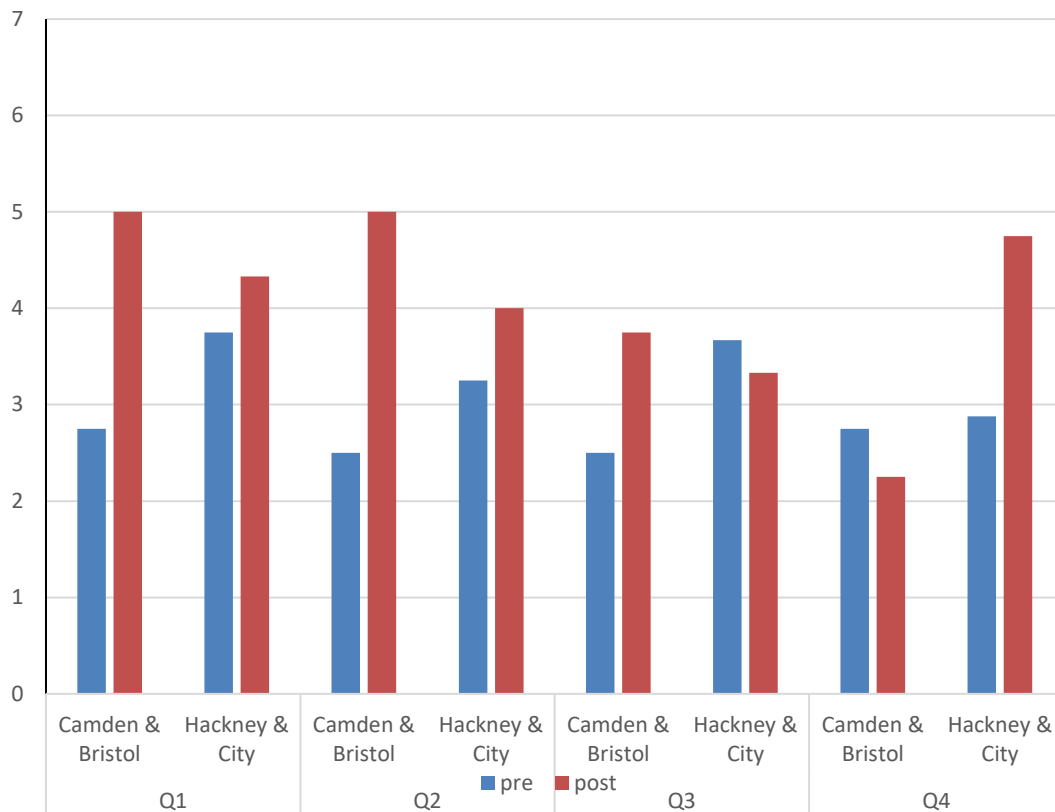
Q1: How confident do you feel about working with couples with dementia?;

Q2: How confident do you feel about your knowledge and understanding of the impact of dementia on the couple relationship?;

Q3: How confident do you feel about your knowledge and understanding of attachment issues in couples with dementia?;

Q4: How confident do you feel about intervening with partners in order to promote their communication?

Figure 3. Pre and post (total).



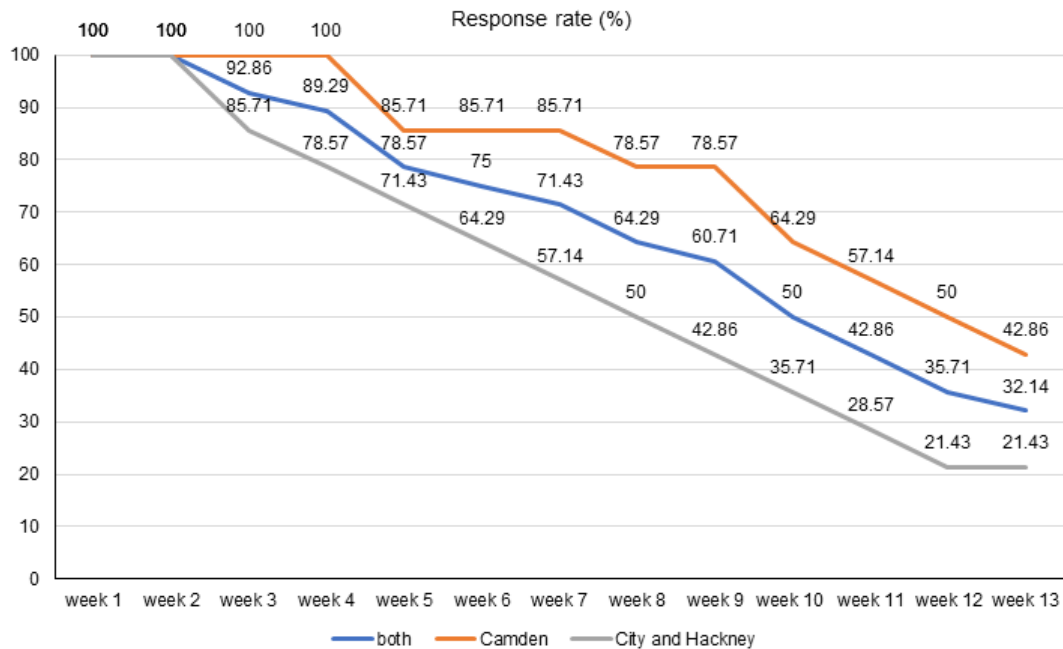
Evaluation of Supervision Groups

The trainees attended fortnightly supervision sessions and anonymously completed a five-item supervision rating scale after each session to assess their experiences. The questions were rated on a seven-point scale, where 1 = 'Not at all,' 4 = 'To some degree,' and 7 = 'A great deal,' and asked trainees how well they felt a particular supervision session helped them in various areas. Although data was collected up to 15 weeks, the quantity of returned questionnaires diminished towards the end; therefore, the last time point with a significant number of the questionnaires returned was used (week 12).

- Q1. To what extent do you feel that today's supervision group helped you to feel supported in your clinical work with couples with dementia?
- Q2. To what extent do you feel that today's supervision group helped you to increase your knowledge of the psychological issues and experiences of couples living with dementia?
- Q3. To what extent do you feel that today's supervision group helped you to understand and work more effectively in the LTwD model?
- Q4. To what extent do you feel that today's supervision group helped you to share concerns and talk openly about your experience of the clinical work?
- Q5. How confident do you feel in working with couples with dementia?
(See appendix for rating scale)

The aim was to evaluate the effects of supervision on individuals' confidence in their clinical work with couples with dementia. Due to the nature of the data and the large number of missing values, non-parametric Friedman tests were conducted on a sample of 28 therapists over the course of 12 weeks, by the end of which there was a 35.71% response rate for all participants. Additionally, the results were examined within individual cohorts, combining Camden and Bristol participants and City and Hackney participants. By the end, Camden and Bristol participants had a response rate of 42.86%, while City and Hackney had a response rate of 21.43%, and, throughout, the response rates were much higher for Camden & Bristol. Figure 4 (below) illustrates the weekly responses for the cohorts.

Figure 4. Response rates across the weeks in which supervision groups ran comparing Camden (incorporating Bristol) and City & Hackney.



Results

The data show consistently high ratings of supervision (>5 score) on the scale. Friedman tests showed one significant difference on question 3 (To what extent do you feel that today's supervision group helped you to understand and work more effectively in the LTWD model?) indicating a significant increase in scores for this question from the beginning to the end of the period of supervision. Overall, the highest total mean score was for question four (To what extent do you feel that today's supervision group helped you to share concerns and talk openly about your experience of the clinical work?). The highest mean scores as separated into Camden and Bristol and City Hackney showed highest mean scores are for question four.

Figure 5. Showing mean scores and SD per site, per question.

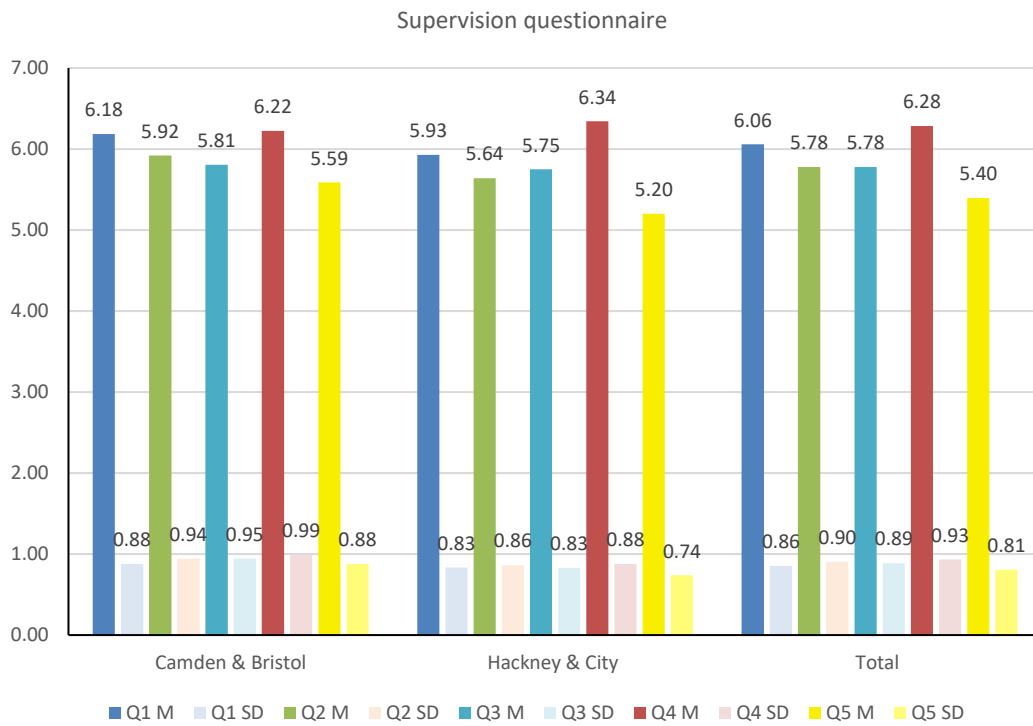


Table 2. Showing means and SDs per question and per week

	Q1		Q2		Q3		Q4		Q5	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Camden	6.1	0.8	5.9	0.9	5.8	0.9	6.2	0.9	5.5	0.8
& Bristol	8	8	2	4	1	5	2	9	9	8
	5.9	0.8	5.5	0.9	5.2	1.0	5.7	1.0	5.5	1.0
week1	3	3	7	4	9	7	1	7	7	2
	6.2	0.8	5.8	1.0	5.7	0.8		1.2	5.4	0.8
week2	1	9	6	3	9	9	6	4	3	5
	6.5	0.8		0.9	5.6	1.1	6.4	0.9	5.3	0.7
week3	7	5	6	6	4	5	3	4	6	5
	6.1	1.2	5.8	1.1	5.5	1.2	6.1	1.4	5.6	0.7
week4	4	9	6	7	7	2	4	1	4	5
	6.3	0.6		0.8	5.8	0.9		0.6		0.5
week5	3	5	6	5	3	4	6.5	7	5.5	2
	6.1	0.9	5.9		6.0	0.7	6.3	0.7	5.5	0.5
week6	7	4	2	0.9	8	9	3	8	8	2
	6.0	0.6	5.8	0.8	5.8	0.8	6.1	1.1	5.6	0.7
week7	8	7	3	4	3	4	7	2	7	8
	6.0	0.8	6.0	0.8		0.7	5.9		5.7	1.0
week8	9	3	9	3	6	8	1	1.3	3	1

	6.3	0.8	6.1	0.7	6.2	0.6	6.4	0.6	5.7	1.0
week9	6	1	8	6	7	5	5	9	3	1
	6.3	0.7		0.8	5.6	0.7	6.3		5.6	
week10	3	1	6	7	7	1	3	1	7	1
	6.1	0.8		1.0		0.9	6.1	1.1	5.7	1.0
week11	3	4	6	7	6	3	3	3	5	4
	5.8	1.2	5.7	1.1	5.7	1.3	6.5	0.5	5.4	1.2
week12	6	2	1	1	1	8	7	4	3	7
City &	5.9	0.8	5.6	0.8	5.7	0.8	6.3	0.8	5.2	0.7
Hackney	3	3	4	6	5	3	4	8	0	4
	5.9	1.0		1.1	5.7	0.9		0.8	5.2	0.8
week1	3	0	5.5	6	9	8	6.5	6	1	9
	6.0	0.9	5.6	0.9	5.5	1.0	6.4	0.9	5.4	0.9
week2	0	6	4	3	7	2	3	4	3	4
	6.0	0.7	5.5	1.0	5.9			0.6	5.2	0.7
week3	8	9	8	8	2	0.9	6.5	7	5	5
	5.9	0.5	5.7	0.9	5.4	1.1	6.1	0.8	5.0	
week4	1	4	3	1	5	3	8	7	9	0.7
	5.9	1.2		0.8		0.9				0.8
week5	0	0	6	2	5.9	9	6.4	0.7	5.4	4

	5.8	0.7	5.4	0.8	5.6	0.8	6.2	0.6	5.1	0.7
week6	9	8	4	8	7	7	2	8	1	8
	6.0	0.7	5.7	1.1	6.1	0.8	6.1	0.9	5.3	0.7
week7	0	6	5	7	3	4	3	9	8	4
	6.0	0.8	5.8	0.9	5.5	0.5	6.2	1.1	5.2	0.9
week8	0	2	6	0	7	4	9	1	9	5
	5.6	1.0	5.6	0.5	6.3	0.8	6.1	1.1		0.5
week9	7	3	7	2	3	2	7	7	5.5	5
	5.6	0.5		0.7		0.8		0.5		0.5
week10	0	5	5	1	5.4	9	6.6	5	4.6	5
	5.5	1.0		1.2	5.2	0.9		1.4		0.5
week11	0	0	5.5	9	5	6	6	1	4.5	8
	6.6	0.5		0.0			6.6	0.5	5.6	0.5
week12	7	8	6	0	6	0	7	8	7	8
	6.0	0.8	5.7	0.9	5.7	0.8	6.2	0.9	5.4	0.8
Total	6	6	8	0	8	9	8	3	0	1

Table 3. Showing means, SD and Freidman’s tests assessing week 1 through to week 12

	Q1		Q2		Q3		Q4		Q5	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Camden	6.1	0.8		0.9	5.8	0.9	6.2	0.9	5.5	0.8
& Bristol	8	8	5.92	4	1	5	2	9	9	8
Hackney	5.9	0.8		0.8	5.7	0.8	6.3	0.8	5.2	0.7
& City	3	3	5.64	6	5	3	4	8	0	4
	6.0	0.8		0.9	5.7	0.8	6.2	0.9	5.4	0.8
Total	6	6	5.78	0	8	9	8	3	0	1

Statistical tests Week 1 - week 12

Friedman

χ^2	12.384	10.623	23.383	11.919	8.293
(p-value)	(p=0.335)	(p=0.475)	(p=0.016)	(p=0.370)	(p=0.687)

Note: Q1= To what extent do you feel that today’s supervision group helped you to feel supported in your clinical work with couples with dementia?;

Q2= To what extent do you feel that today’s supervision group helped you to increase your knowledge of the psychological issues and experiences of couples living with dementia?;

Q3= To what extent do you feel that today’s supervision group helped you to understand and work more effectively in the LTWD model?;

Q4= To what extent do you feel that today’s supervision group helped you to share concerns and talk openly about your experience of the clinical work?;

Q5= How confident do you feel in working with couples with dementia

Discussion of Study 1: Quantitative Evaluation of the Components of the Training Programme

Three-Day Training Programme

While there was no statistically significant difference between pre- and post-training scores, the data shows a clear trend towards improvement in professional confidence and competence among the trainees. This suggests that the training programme was, to some degree, successful in meeting its objectives of developing participants' skills for the effective delivery of the intervention. Overall, although not statistically significant, the improvement in self-rated competence on the 'before' and 'after' measures indicates that the three-day trainings were successful in meeting their aims and learning objectives.

The Supervision Groups

The findings indicate that supervision did not result in significant differences across the weeks that the supervision groups were attended, except for trainees' ratings of their being helped to understand and work more effectively in the LTwD model (question 3). Participants began with high confidence scores on all questions, suggesting that the supervision was consistently helpful. This stability in high scores may indicate the effectiveness of the supervision in maintaining participant confidence. The significant improvement in participants' confidence in working within the Living Together with Dementia model (question 3) indicates that, while ratings of other aspects of supervision remained consistently high without

changing, the participants' experience of working in the intervention model showed development over time. This indicates that participants could see themselves developing more skills in delivering the intervention within the supervision groups as time went on.

These findings make conceptual sense: one would expect that, with good quality supervision, ratings of supervisory functions may remain high without changing significantly, whereas skills in working effectively in the new model would be expected to show development over time. These data, therefore, indicate that the participants valued their experience of supervision highly throughout, and that they also felt they had significantly developed in their capacity to deliver the Living Together with Dementia intervention effectively over the course of the supervisory period of the training.

Limitations

The increasing reduction in response rates for the supervision questionnaire undermines a clear understanding of the effects of the supervision across the weeks. The supervision groups began with 28 individuals, but by week 13, only 9 participants had recorded their answers to the questionnaire. It is notable that the response rates for self-ratings of supervision were significantly lower for the City & Hackney trainees. The attrition from the three-day training into supervision groups and subsequent commitment to sustain the clinical work was much lower for the City & Hackney group, reflecting differences between the two groups of participants. The Camden & Bristol group comprised more therapists, counsellors, and other professionals who undertook the training in their own time and had made a

more explicit commitment to the work from the outset. In contrast, the City & Hackney participants were mostly from the Older Adults' mental health team and undertook the training during their work time. Consequently, this group faced more pressure within their roles and struggled to protect time for the training. Their motivation was often more equivocal, and the higher dropout rate reflected this. This high drop-out and low response rate for time 2 means that data from a large number of participants is not reported here. Consequently, this constrains the generalisability of the data and the claims that can be made for the effectiveness of the training programme.

Study II: Qualitative Evaluation of the Training Programme

The Experience of Training and Supervision

Qualitative interviews were conducted with a sample of five trainees (four from Camden, one from Bristol) to gain a deeper understanding of their experiences of the training and supervision, providing a qualitative, experiential dimension to the training outcome data.

Methods

Interview Schedule

A semi-structured interview format was used (see Appendix), allowing flexibility in exploring different views and enabling participants to elaborate on their thoughts and direct the interview in meaningful directions. The aim was to obtain detailed and authentic accounts of their experiences.

Interviews were audio-recorded and transcribed verbatim (Braun and Clarke,

2013). Identifiable information was anonymised during transcription. The audio-recorded data was initially stored on an encrypted USB stick and then transferred to a secure, password-protected platform, after which the original recordings were deleted. The transcriptions were encrypted and saved, with the plan to delete them once the research was completed.

Participants' Demographics

Five participants took part in the interviews:

1. Female participant in her late 50s, trained as a psychotherapist. White, originally from a central European country.
2. Female participant in her late 20s, working as a support worker. White British.
3. Female participant in her late 40s, trained as a counsellor. Black British.
4. Female participant in her late 20s, in training as a counsellor. White Irish.
5. Female participant in her early 60s, trained as a systemic psychotherapist. White British.

Thematic Analysis

The interviews were anonymised and then analysed using thematic analysis (TA), following Braun and Clarke's (2006) guidelines. The six phases of conducting thematic analysis include familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and collating themes into a report.

These semi-structured interviews were conducted in the latter part of the participants' training. The questions (see Appendix for details) focused on exploring their experiences of the three-day training and the supervision groups, as well as understanding their motivations for joining the project.

Results

The thematic analysis explored several key themes related to the trainees' experiences associated with the training programme, and within these, thematic analysis also revealed several sub-themes:

THEME 1: Challenges and Barriers: 'It's so hard' – Emotional

Challenges of Working with Dementia

- i) Shift from external to internal: recognition of difficult feelings in self
- ii) Wider impact of dementia: society and self

THEME 2: Peer Support and Shared Learning: 'Can I do it?' – Anxiety and Uncertainty around Training

- i) Unsure what to expect
- ii) Training is anxiety-provoking
- iii) The place of difference in training and supervision

THEME 3: Enhanced Professional Confidence: Containing and Contained

- i) Supervision group offering containment
- ii) Containing the container
- iii) Training environment as a place of safety

THEME 4: Practical Application of Theoretical Knowledge

- i) **Connecting things up** – linking theory, clinical practice, and self-experience

The Thematic Analytic Data

THEME 1: Challenges and Barriers: 'It's so hard' – Emotional Challenges of Working with Dementia

Participants conveyed powerfully the emotional demands of working with people with dementia and the barriers to engaging with dementia. They explored their thoughts about the impact of dementia on the self as well as on society. Some participants mentioned other challenges such as balancing training with work commitments.

Shift from External to Internal: Recognition of Difficult Feelings in Oneself

A strong theme that emerged was the shift participants experienced from attributing difficult feelings about dementia to external factors—to society, policymakers, or others—to recognising their own anxieties and fears. The group and the training supported them in becoming more emotionally in touch with their experience. One participant reflected, "I thought they were neglecting people with dementia. But actually, recognising just how, oneself, one's own bad feelings about it." Another shared, "Talking to people whose partner has got dementia, then a light would flash, and I'd say 'ooh.' You know, it's helpful for me in my work as well, and my personal life of course."

The work and the learning process were seen as personal endeavours. Participants spoke of bringing themselves into the clinical work and recognising shifts in themselves, leading to greater openness and less defensiveness in relation to the emotional experience of working with people with dementia. A participant noted, "I think there were some of the things in the training that did make me think about... the effect on other people, your (own) relationships as well, it's a sort of ripple effect around." Others described how the clinical work deeply touched them emotionally, raising personal and existential questions. One participant reflected, "It made me...think about, what if that happened to me or to people I'm close to, and what is the core of a person, how can we lose our personality? I mean, it's a strange thing... we lose what we consider to be our personality, we're kind of lost in space, or caught in a space we don't know. It opened up questions for me, who are we as human beings." Another participant shared, "I think...to look at (dementia) as a change as if it's all of the person. Their emotional life, their physical life. It is like the impact of a disability." This sentiment was echoed by another, who stated, "It's not always very helpful to talk about memory and dementia, really, because that's what everyone thinks about... But it actually isn't about memory, it's more profound than that."

Some participants movingly described how deeply the clinical work had touched them emotionally. One said, "It was so deep, sadness...I had two experiences... of one of the (partners having gone) to a home...and it's just so hard, so moving, and just difficult...when I see people...towards the end, the person's gone in their home and they're just managing the best way they can... managing with loss, it's a difficult struggle or whatever, but it's towards

the end of the process." This depth of emotional connection was linked to a motivation to help, particularly the idea of intervening at an early stage in the disease process. One participant reflected, "This experience made me feel more encouraged in terms of working at an earlier stage...the beginning or the middle at least, to try to do some work before the loss is so unbearable." Alongside the difficulty, there was also hope that working in this area could make a difference. Another participant noted, "It's an earlier stage and we can hopefully intervene rather than people being left with a lot of very difficult emotions, which I think is what happens at the moment, really, that people are left with a lot of...information (after a) diagnosis, but actually there's not very much help to process all that. People are told, 'Just go away and look at a leaflet or have a conversation about what's happening in somebody's brain,' but it's not quite the same as actually being able to process that and deal with it emotionally. I think that's the difference."

There was a sense of optimism and hope engendered in the training. One participant expressed, "Personally, I would say [pause] that it (the experience of the training) makes me feel there is life in dementia, life after dementia. It felt actually just different, that's all. It didn't scare me. In fact, it did the opposite, in a sense. Dementia wasn't something that particularly scared me. I think it can be incredibly sad, and I can see people being scared."

Nevertheless, many comments highlighted how challenging the work is, particularly around the experience of working with couples where one partner has dementia and focusing on the emotional aspects of the situation. One participant shared, "I've also heard horrific, awful stories.... of what it's like to work with people and how their families react...And dealing with distressed

relatives." Another participant noted the difficulty in working with a partner as opposed to a parent: "I suppose with the couple (I'm) working with as well, that there's a sort of wishing for help, but it's such a difficult thing working with a partner, as opposed to a parent. It's something that isn't in the deal when you get together, so it's perhaps much more difficult."

Participants also noted that the emotional side of dementia care is often neglected in favour of medication or practical issues. One reflected, "There's a lot of flurry and attention around either the medication side or the practical side, but actually not the emotional side, and perhaps what is neglected is...in terms of couples, how do you manage this, one person is perhaps less able, and working out those different things around pace and understanding. It's tricky."

ii) ***The Wider Impact of Dementia: The Care Setting, Society, and Self***

The context of dementia care is fraught with resistances and challenges, as voiced by the participants. One noted, "I think one of the main things is how...constrained you can sometimes feel by providers of services, who expect you to behave in a certain way...how difficult it is to negotiate a way around the system, I think, and how it can feel very punitive at times."

The training's focus on institutional dynamics and issues in dementia care was found to be particularly helpful in addressing these challenges. One participant reflected, "I think one of the things that was actually very helpful was looking at things like institutional care and the impact on workers and carers in those situations...it made me think about that in a different sort of way... How a lot of people, workers in those circumstances, and that

includes us as well, deal with dementia and the awfulness of it, [pause] in a way that isn't particularly helpful, but you can understand, perhaps, how that might happen."

Participants were also stimulated to think more broadly about the impact of dementia. This included considerations of the individual and their immediate context, such as couple and family relationships, as well as broader community and societal impacts. Recognising one's own feelings was seen as an essential part of this broader understanding. One participant shared, "I really begin to think about the impact it has on people and on society, extended family, families, people, society, neighbourhoods...you have to convince not only society and the world but oneself that it is worth working with and taking a look at that."

This wider perspective underscores the multifaceted impact of dementia, highlighting the importance of addressing not only the immediate care needs but also the broader social and emotional dimensions. The training's emphasis on these aspects helped participants to contextualise their work within a larger framework, fostering a more comprehensive approach to dementia care.

THEME 2: Peer Support and Shared Learning

The supervision groups also provided a valuable space for participants to bring anxieties where they could be thought about and processed, as well as a place for peer support and shared learning. Participants highlighted the importance of discussing cases and receiving feedback from colleagues.

j) 'Can I do it?' - Anxiety and Uncertainty Around Training

Unsure of What to Expect

The trainees expressed significant uncertainties about joining the project and their initial anxieties and uncertainties about what to expect. One participant shared, "I wasn't sure at all... I remember not feeling sure...I wasn't sure, and I would have liked a bit more of an idea. Maybe you did give us an idea, but I didn't get it... I wasn't sure exactly what it would look like or be like."

Even at the end of the three-day training period, some of these anxieties persisted. One trainee noted, "I think perhaps at the end I was left thinking, how will I do it with a couple, how will that work? That still felt like an unknown to me."

When asked to reflect on what had brought them into the training, participants were often unclear about their expectations, although they mentioned their interest in the project. One remarked, "I didn't think it through properly, or I didn't have [inaudible] the real expectations. But I thought it was a very interesting project in terms of working with couples, and working with couples when one of the members has got dementia." These anxieties extended to the anticipation of joining the supervision groups, with participants conveying similar uncertainties about how the supervision groups would function.

Initial anxieties were often focused on practical issues, such as the size of the groups. One participant questioned, "I wasn't sure how many people, I thought about four or five people...And I wasn't sure how it would work, but I sort of imagined we would all be having the space to talk about mainly the

clinical work, I suppose..." Another participant reflected, "I suppose I thought it would be fairly practically based... I knew about the videoing quite early on, so I think I was more focused on that as part of the training. In fact, now thinking about it, I thought that might be where the whole focus was going to be...didn't know what to expect." There was also confusion about the group composition, as one participant explained, "I didn't really know how many, until recently, I hadn't understood that it wasn't going to be different groups of people... I don't think I'd quite understood it was just going to be us, if you like, this small number today, originally. So, I was thinking there'd be fifteen people or something."

Despite the pervasive uncertainty about what to expect, some elements of the training were perceived as containing, particularly the structure and course materials. One participant appreciated, "I wasn't sure what would be involved and included, and I thought it was all very clear, actually. I liked having the handbook. I felt it all felt quite organised and contained, so I knew where I was."

In summary, the sub-theme of uncertainty about the training was prominent among the trainees. Their initial apprehensions were partly alleviated by the structured elements of the training, yet the lingering doubts about practical and clinical application persisted throughout the early stages of their involvement.

ii) Training Can Be Anxiety-Provoking

There was considerable anxiety expressed by the trainees regarding the responsibilities they were taking on and concerns about their ability to

manage the tasks. One participant articulated this, saying, "[sigh] It was quite intense, I thought, and I thought that there was enormous trust placed in me and the other people, that we would be able to... I felt there was enormous trust, actually, towards me, that I could manage and understand and do it."

The trainees' anxieties often centred on the technical aspects of the training, particularly the use of video technology. One participant noted, "The technical side of it. Yeah, that frightened me [laughter]. It made me think, oh God no, will I be able to do this, maybe I shouldn't be doing this." Another shared a similar sentiment: "I didn't like doing all the technical stuff... I was terrified that I'd lost that recording somewhere. And despite charging up the batteries, and various things. I didn't enjoy the technical side, but it was reasonably painless."

There was a recognition that these technical anxieties might be displacements of deeper feelings of anxiety about the work itself and fears of becoming overwhelmed by it. One participant reflected, "I think it was probably my state of mind, perhaps, feeling a little bit lost in it, but aware that there seemed a clear structure. That's why I thought, is it me, am I not fully engaging? So, there was talk about couple work and about videoing and then I think in one of the trainings I had to do the videoing, and that bit was really quite perplexing for me."

Importantly, trainees also commented on their sense of development, recognising that they were learning and understanding more about their own anxieties related to the work. One participant observed, "I'm learning and there's some anxiety about it, and things (are) working." Another added, "...

it's a sort of anxiety, and I wonder what, it's not just around the couple, it's also around us and our role, and how do we do it and manage it, and I've understood a bit more ... This morning I thought, I get it now..."

Although the trainees frequently expressed the emotional difficulty of the work, they also highlighted the role of the supervision group in helping them engage with their own feelings about working with dementia. One participant remarked, "The supervision group made me think about my own fear (about dementia) and how difficult that is for everybody."

In summary, the training in working with couples with dementia was anxiety-provoking for many trainees, with significant concerns about the responsibilities involved and the technical aspects of the work. However, through the training, participants began to recognise and understand their anxieties, finding the supervision groups to be a place where their anxieties could be understood and contained, and seeing their development and growth in managing these challenges.

iii) The Place of Difference in the Training/Supervision

There was considerable heterogeneity in the supervision groups, encompassing professional backgrounds, levels of experience, and ages of participants. Some participants were clinicians nearing the end of their professional careers, while others were early in their careers, including two young support workers/advisers. Participants were primarily selected based on their personal aptitude for the work, determined through an interview process. Consequently, differences between group members, particularly in terms of professional background, became a significant theme. Additionally,

the psychodynamic orientation of the intervention and the organisation where the training was situated contrasted with the diverse clinical backgrounds and orientations of the participants, some of whom had no formal clinical training. This theoretical orientation became a key locus of anxiety about differences within the training.

Participants expressed anxiety about fitting in before the start of the training. One participant mentioned, "I think I'd been reassured when I met you for the interview that actually, people came from a variety of backgrounds. And actually, I did feel very comfortable with, I liked the group, I liked the people." Another participant shared their concerns about fitting in due to their mixed professional background: "One other thing is, I think I worried because I have a psychodynamic supervisor...but I work in an integrated way, and... for me it's because I straddle two cultures, I straddle things a lot, in the way I think, and it did worry me that I wasn't going to fit in. So that was a worry for me."

There were also preconceptions about the organisation hosting the training and anxieties about how clinicians of different orientations would be received. One participant stated, "I think maybe there's this kind of fantasy of places like Tavistock having all the ideas and the right ideas because you get the kudos for them. I trained in Transactional Analysis at Metanoia, and it felt the culture was different... and I guess I come here and I'm thinking, ooh, I feel a bit like an outsider with different thoughts." Another shared similar concerns: "I was aware, I suppose, of your orientation, from the Tavistock, can be more psychodynamic. So, I was a bit concerned about that and how

that would be, because my background's systemic. But I thought, let's see how we go."

Despite the welcoming of plurality in backgrounds and orientations, participants consistently voiced anxiety about whether they fit in and what their role was. One participant noted, "It's nice to have different perspectives as well, I think. But it can be difficult to know, how are we going to pitch this, what is my role here?" Some participants commented on the use of 'psychodynamic language' in the supervision groups, which they found alienating. One participant remarked, "I sort of translate the mechanisms you talk about. The countertransference, I wouldn't particularly talk about countertransference. I don't know how I'd talk about it, but it's something that's there, I just wouldn't." Another shared their experience of feeling on the edge of the group due to language barriers: "(I felt) on the edge of the group in a way, I think, because of my background, perhaps, around language and stuff like that. When we come out with words like countertransference? Yeah. I'm used to countertransference, but [laughter] some of the ones that you've flung at me. And I don't ask, and I think, what?"

One participant highlighted the expectation for participants to be prepared to discuss difficult areas of their experience, viewing this as a 'psychodynamic assumption.' This comment underscored the emotional challenge of the training and suggested that not everyone might be suited for this aspect of the work. "The assumption is that we are all psychodynamically trained, and therefore we are up for discussion and being able to address difficulties. I mean, it's part of our training and our way of being, I guess."

Despite these anxieties, the main position reached by the participants was that the differences within the groups were ultimately productive. Fears about the anticipated rigidity of the training approach were allayed by the actual experience of being part of the training and supervision group. One participant reflected, "I think (people in the group) are very open to discuss things. So, I think personalities that, for whatever reason, are in this supervision, are very open and up for it, I think." Another noted, "(My fears about the institution have) been disabused a bit by coming here ... I've always felt that the Tavistock is quite posh, not for the likes of me, sort of thing [laughter]. Whereas this isn't quite the same...because of the mix of people, it doesn't feel like that."

Overall, the overarching sentiment was an appreciation for the differences within the groups, which were seen as a creative and positive feature of the supervision. One participant remarked, "I felt in some ways, because it was a different perspective, that was something I could learn from as well, different ideas. And also seeing how I can fit those ideas into my approaches. I think that was interesting. And I did enjoy it." Another added, "... we are coming from very different perspectives and it's fascinating, because when there's feedback... I'll think, goodness, that's just such a different take on my take of it."

iv) Training Environment as a Place of Safety

The theme of the training environment as a safe base for exploration and thinking was a recurring aspect in all accounts. One participant noted, "(Supervision is a place to) get support and... (where difficulties in the work

are) going to be talked about, and you'll gain an understanding of what's going on... And it may not be easy in terms of cases or whatever, but that you can come out here (to the supervision group) and this is an open space, where you feel safe."

The role of the supervisors was seen as crucial in setting the culture of the group. There were two supervisors for each of the supervision groups. One participant commented, "...both of you (supervisors) were very inclusive, that even if people sometimes got a bit anxious, that it was facilitated in such a nice way, and in such a kind way, that was inclusive. I appreciated that and I thought that it's really useful to make it an open space, an inclusive space also. I thought that was very nice." Another participant echoed this sentiment, "I did feel it was, it felt quite comfortable, and felt able to share things and able to share difficulties... it felt fairly non-judgmental. Didn't feel too worried about saying the right thing or the wrong thing..."

The importance of peers within the group in setting the culture was also recognised. One participant noted, "I mean just lovely people in the group, or even in our training, just really lovely, the people that were taking part. And you (supervisors) are very facilitating and very inclusive, so I never feel I'm an idiot when (supervisors) are there, and that I think is quite helpful, so you're not frightened."

In summary, the differences within the training and supervision groups, although initially a source of anxiety, were ultimately seen as enriching and beneficial, fostering a diverse and inclusive learning environment. The training provided a safe and supportive space for exploration and reflection.

The inclusive and non-judgemental atmosphere fostered by both supervisors and peers was crucial in enabling participants to engage fully with the material and their experiences.

THEME 3: Enhanced Professional Confidence Participants reported an increase in confidence in working with couples living with dementia, attributing this to the comprehensive nature of the training and the supportive supervision sessions.

'Containing and Contained'

i) Supervision Group Offering Containment

The primary function of the supervision groups was to provide a containing environment for trainees as they embarked on this new area of work, learning how to work with couples and, for many, entering the field of dementia care for the first time. The emotional demands were significant, emphasising the importance of the groups' ability to contain their feelings, create conditions for reflection, and process difficult emotions while thinking about their work experiences.

Overall, participants' comments endorsed this aspect of the supervision groups' functioning. This containment was something the trainees had hoped to gain, providing the freedom to bring their fears and struggles to supervision. Their comments expressed anxieties about feeling safe within the groups and fears of being judged. One participant stated, "I hoped it would be supportive, and that was the main thing, just some space, and to feel comfortable and not to feel things like judged. To feel free enough to talk

about worries about things. I sometimes do feel slightly on the edge, and maybe other people feel that as well." Another added, "Space for learning, for discussing difficult things as well as the work we're doing. A group in which you are able to really rest and open up and draw things to help you...And it was with the group that I was able to digest, and therefore helpful to be a base, a receptacle where I could get these things."

Trainees' comments conveyed how supervision enabled a vantage point, a place to identify and reflect on feelings, observe their own reactions, process emotions, and understand difficult dynamics in their work. One noted, "It's difficult sometimes to observe and to know... my own reactions at the time in the place. And when you bring that to supervision and an observation or a dynamic is picked up, and the group explain it or whatever, you're able to digest, and been able to help to digest." There was a strong sense of valuing a non-judgemental space in supervision, albeit with some implied anxiety that the supervision might not turn out to be supportive. Another participant reflected, "I think... in the supervisions, I see things closer and better, I feel more grounded. And I think that just to have the ability to really have been able to talk in the group about it... with an open understanding that it's all supportive and...even though in rough bumps and difficulties, that we can talk about it."

The importance of learning from peers within the group was also highly valued. Participants appreciated the shared experience and the opportunity to learn from each other. One participant noted, "... you have the supervisors, but it's also a shared experience in a way, that we can learn

from each other, I think that's really important." Another echoed this sentiment, "...I related to other people's experiences and made meaning of it. It was very good in doing that." The enthusiasm for learning from others was evident: "...And having other people's observations, I really was excited, somebody else was bringing something, because I want to hear what they felt and what they thought."

ii) Containing the Container

A key element of the model is the importance of 'containing the container.' This concept refers to the idea of 'layers of containment'—the practitioner working with the couple needs containment themselves to provide this for their clients. Participants in the training indicated that the groups had successfully provided this containing function for them. One participant remarked, "Yeah. I feel that I can go out and work and come back to supervision and things will be better, or I'll be helped, or be able to explore things in a benign way. And it may not be easy in terms of cases or whatever, but that you can come out here and you'll get support and it's going to be talked about, and you'll gain an understanding of what's going on, that this is an open space, where you feel safe."

There was also a recognition that their own experience of containment in the group enabled them to contain the couples they were working with. Another participant noted, "So if you feel supported, if you feel contained, in a containing environment that the group may provide, then you are containing as well. Containing, contained. Containing the container - supervision as container enabling practitioner to contain."

Importantly, the feelings that the trainees felt able to bring to the group included 'negative' ones such as hostility and anger. One participant shared, "It was in the group that I was able to express that and be angry, my own hostility. And the group wanted to help me in being able to digest... And that changed, that gave me the ability to be able to talk about it. This solved a lot of the very negative feelings (in response to the hostility she encountered in the clinical situation)." Another added, "I'm not really sure what I'm doing, but it's alright, just sit with it, and as long as, I think, I make sure I'm working in an ethical way, that's the bottom line. It was with the group that I was able to digest, and therefore helpful to be a base, a receptacle where I could get these things."

The importance of being able to express these 'negative' feelings and not to hide or cover them up was also understood by some of the participants. One commented, "I think it's pointless hiding something, there's no gain in it. And I don't want to go into shame, I feel embarrassed, I don't want to go into a very shameful place. Because then I think I would withdraw and leave if I did that. But I think I find things become bearable once you say what you feel."

Crucially, there was recognition of the valuable role of supervision in supporting the participants to face difficult feelings and anxieties about uncertainty and not knowing, which were evoked by the clinical work. The following comment refers to the importance of not responding defensively by retreating into action, thereby avoiding emotional contact in the work. In supporting the reflection process, the supervision group could help the trainee avoid such a defensive response. One participant articulated this

well, "(Being in the group enabled me to) sit with (difficult feelings) and I'm aware that if I feel uncomfortable and I want to impose a plan that actually, it's sitting with that discomfort and uncertainty, that's what supervision enables you to do, to tolerate that, I think. Not to jump into action, that's one thing."

In summary, the concept of 'containing the container' was pivotal in the training model. It appears that the supervision groups provided crucial support, allowing trainees to process their own difficult feelings and enabling them to offer containment to the couples they worked with. The ability to express and work through negative emotions within a supportive environment was perhaps fundamental to their professional development and effectiveness in their clinical roles.

THEME 4: Practical Application of Theoretical Knowledge

The trainees appreciated the blend of theoretical knowledge and practical skills, which enabled them to apply what they learned directly to their clinical practice.

i) Connecting Things Up – Linking Theory, Clinical Practice, and Self-Experience

The supervision groups were seen as instrumental in integrating and embedding elements of the three-day training. One participant remarked, "I'm talking about how the various modules of the training helped me to begin to connect things and to be much more [inaudible] in terms of what I am here to do and what the challenges are, what's the difficulties."

Overall, the feedback for the training and supervision, and the linkage between the two, was positive. One participant noted, "It was great, I think it was very helpful... I mean, I couldn't have expected something better. I think it was well-paced, it was the material that we needed. Now in supervision, I can think about bits of the training that help me to link up things and pose questions about the elements of the couple that would have been hidden in supervision, for instance. So, I think the training was very helpful and it was very complete..."

In summary, the integration of theory, clinical practice, and self-experience within the supervision groups further enhanced the trainees' learning and professional development.

Discussion

This small-scale, qualitative study met its aims of augmenting our understanding of the quantitative measures of the effectiveness of the training and supervision. Participants' accounts indicate that the supervision groups offered both a crucial context for embedding the learning from the three-day training over time and, most importantly, provided a vital containing function for the trainees over an extended period as they undertook the clinical implementation of the intervention programme.

The thematic analysis of the qualitative interviews indicates that, over the course of the supervisory period of the training, participants shifted towards an orientation to their own internal emotional responses to the work. They reported moving from a focus on external factors to becoming more in touch

with their own experience, expressing and exploring their anxieties about the work within the supervision. This endorses the success of our approach to training, which emphasised the central importance of trainees processing the emotional experience of their clinical work and sought to enable this within the supervision groups.

This element of emotional containment for the participants clearly emerges as being of central importance, and participants rated the containing function of the supervision groups highly throughout. The qualitative interview data indicates how important this function was for them, as they describe high levels of anxiety at the outset of the training. The participants were apprehensive about the training itself, as well as the clinical work with people with dementia. Their responses suggest that they found the supervision helped them to process these anxieties, think about their experiences of the work, and consequently be more emotionally available to engage with the couples with dementia in implementing the intervention.

As part of this, the participants needed to be able to express their anxieties and negative feelings arising in the work, and to be able to think about and explore these within a safe and non-judgemental setting. From their responses, it seems that the supervision groups served these functions well and, in doing so, supported the trainees to become more confident in delivering the LTWd model effectively. The significant increase in self-rated confidence in their capacity to deliver the intervention over the course of the weeks of supervision is testimony to the value of the supervision groups as an addition to the initial three-day training. This evidence links to the

research literature, which consistently highlights the function of staff training in enabling and supporting engagement in emotionally challenging clinical work (Berg et al., 1994; Islam et al., 2017; Costello et al., 2019).

In addition to placing central importance on internal factors, the training and supervisory focus also included an emphasis on understanding the psychodynamics of the context of dementia care. This element of the training was valued by participants, as their responses demonstrated their appreciation of the importance of understanding how anxieties arising in the work can give rise to organisational defences which, as well as having a protective function, can compound the stress and difficulties of the staff and interfere with their capacity to have an emotional engagement in their work (Menzies, 1988a, 1988b; Hinshelwood & Skogstadt, 2000). The interviews with participants indicate that this focus on the anxieties and resistances that can be evoked at the level of the team and care setting, as well as in the self, helped them to understand the dynamics of dementia care as expressed in the wider contextual setting. Their comments highlight that this was helpful in containing the participants, helping them to be in touch with, and to process and understand, these dynamics both in their immediate clinical setting and in the wider context of the organisation and society.

Overall, these results, which indicate that the anxieties raised for the participants by working with people with dementia were contained by the training programme, are important. They support the findings of the research literature, which shows that staff training and supervision are vital elements in reducing stress and supporting staff's emotional resilience and emotional

engagement in their work (Islam et al., 2017; Costello et al., 2019).

Specifically, the results of these studies of this training programme indicate the success of its containing function, particularly during the extended supervisory phase, which was vital for working through the participants' anxieties and enabling them to make significant development in their sense of competence to deliver the intervention model. These findings are congruent with the research in this area, which was reviewed earlier, indicating that for staff to be receptive to the emotional states of people with dementia, they need access to supervision and support in which the emotional impact of their work on them is addressed (Berg, Hansson, & Hallberg, 1994; Islam et al., 2017; Costello et al., 2019).

The motivations for joining the project varied, with some participants seeking professional development and others driven by a personal interest in dementia care. The level of commitment appeared to correlate with the perceived value of the training and supervision. As described in the manual for the intervention, the main tenet of the Living Together with Dementia approach is to accompany the couples and model the stance of 'seeking to understand,' rather than acting as an oracle of special understanding. The intervention process is a shared endeavour of conjoint meaning-making. This approach, however, would not suit all trainees. Our experience confirmed this, with participants in Camden and Bristol being, for the most part, well-suited. These trainees often came from psychotherapy or counselling backgrounds or worked in the voluntary sector alongside people with dementia, possessing the personal capacity to build relationships and engage authentically emotionally. This links to a significant limitation in our

approach, in so far as this focus on the emotional aspects of the work would not suit all trainees. This was particularly evident in our City & Hackney cohort, where initially we had less control over which trainees came into the training, and some were effectively co-opted by the consultant psychiatrist of the team, who was an enthusiastic proponent of the project.

Limitations

This small-scale study comprised five interviews. A further limitation is that the qualitative data comes from interviews with Camden and Bristol trainees only, and the quantitative data is also chiefly from this group as well (their return rates of self-report questionnaires were around double the number received from City & Hackney). This introduces a significant omission in our results, with the 'voice' of City and Hackney trainees absent from the interviews, and far less represented in the quantitative data reported here. At the same time, this fact may be interpreted as indicative of some key issues, which may be understood by drawing on the research and clinical literature outlined at the beginning of the chapter.

As a group, City & Hackney staff were initially recruited from the NHS mental health team, and they brought many of the team dynamics into the groups. The consultant psychiatrist, initially an enthusiastic supporter, brought most of her MDT team into the training with her. This turned out to be a mixed blessing, as team politics initially played out within the training groups. Many participants from this training left, citing the demands of their roles as the reason. They were more stressed, had less 'space' for undertaking the training and the subsequent clinical work in the model. As a group, they were

holding considerable anxiety and work pressure. Consequently, many felt that they did not have the resource to take on more commitments, in the form of the ongoing clinical component of the LTWD training.

The literature indicates that staff at the front line of dementia care delivery are likely to be experiencing considerable stress and anxiety (Obholzer, 2000) and the defensive response to this, at the level of the team and the individual (Terry, 1997; Davenhill et al., 2003; Balfour, 2006; 2024 in press) may underlie resistances to emotional engagement with their patients (Todd & Watts, 2005; Kokkonen et al., 2013). Intervening in such a staff team in a way that threatens to change the emotional dynamics of the situation is analogous to the process of therapy itself, whereby changing defensive structures releases more anxiety into the system, in the short term at least, until new adaptations are in place. This requires considerable resources and support at a senior level within the organisation to release time for staff and provide managerial authority to support change (Hinshelwood & Skogstad, 2000; Balfour, 2006). The constraints of the resources of this study limited our capacity to provide such support and containment for what amounted to a significant intervention with the community multi-disciplinary team in City & Hackney. However, although these issues introduced difficulty, limiting this cohort of participants' capacity to retain their commitment to the training, a number of these staff did sustain their involvement and the indications are that those who did stay had a personal aptitude for the work and valued their experience of the supervision and training highly.

For future research, it would be useful to evaluate whether the training programme had longer-term impacts on the participants' work with people with dementia, and on their resilience in their roles.

Overall Conclusions

Taken together, the findings of the evaluations of the training programme, both quantitative and qualitative aspects, endorse the evidence of the research and the psychodynamic literature cited earlier, which indicate the importance of two elements of staff training in particular: theory-practice learning as well as supervisory support to enable the emotional processing of experience (Rodriguez-Monforte, 2020; Davenhill et al., 2003; Balfour, 2006). The quantitative and qualitative results as presented in these two studies indicate the overlapping, mutually supporting elements of these two dimensions of the training programme.

Trainees' scores on the measures used demonstrate progress in learning on key outcome variables, indicating that the training equipped them to begin working with couples to implement the intervention. While they did not show significant shifts over the training period, except for trainees' ratings of their confidence in delivering the intervention, they consistently received high ratings on key supervision measures, and the pre-post training ratings showed positive impacts although these did not reach significance. Additionally, the qualitative data augments these quantitative findings, showing that the training impacted trainees' ways of thinking about themselves in working with dementia, just as intended.

The training was ambitious. It targeted a diverse group of individuals, mostly with some therapeutic training, although not exclusively, all working in mental health, with many specialising in old age. The aim was to train these individuals to work with couples in the context of dementia, utilising the technical approach of incorporating video into clinical work. In selecting such a broad group of clinicians, we emphasised judging personal capacity and the therapeutic stance of working alongside couples living with dementia, rather than training 'experts.'

Ultimately, the key to creating a successful intervention within NHS and Social Care is its capacity to be delivered at scale. While most of the trainees were already skilled and experienced clinicians, this was not uniformly the case. Our experience showed that even those without formal psychotherapy training could be supported to deliver the intervention. Despite the small sample size and the caution required in making generalising claims about the results, these data suggest that our approach may be translatable at scale. This could be tested on a much larger cohort of trainees, selected based on personal suitability, potentially reaching a significant number of trainees able to work with couples living with dementia. This scalability affords the possibility of larger, more rigorous, controlled evaluations of the training and intervention programme.

In summary, while the broad and inclusive approach of the training programme presented challenges, particularly with the City & Hackney cohort, it was largely successful in Camden and Bristol. The emphasis on personal capacity and emotional engagement proved effective in selecting

suitable trainees, underscoring the importance of these qualities in working with couples affected by dementia.

The implementation and evaluation of the intervention are the subjects of the following two chapters.

Chapter 7: Implementation and Quantitative Evaluation of the Intervention Programme

This chapter details the implementation, methods and quantitative results of the Living Together with Dementia intervention with couples.

Introduction

As dementia progresses, the couple's relationship becomes increasingly negatively impacted, with reduced communication, closeness, reciprocity, intellectual stimulation, and sexual intimacy, as detailed in the research reviewed in Chapter 2. These issues heighten the burden experienced by the caregiving partner, which emerges from the literature as a critical factor in determining the outcomes of both partners living with dementia. Carer burden is defined as the extent to which caregivers perceive their emotional or physical health, social life, and financial status as being negatively impacted by their role in looking after the person with dementia (Zarit et al., 1986; George & Gwyther, 1986). Thompson and Doll (1982) distinguish the objective events and activities associated with caregiving from the experience of carer burden—that is, from the subjective feelings of burden aroused in caregivers because of their role.

Across numerous studies, a consistent picture emerges of the caregiving partner assuming increasing responsibility, which is linked to heightened burden and decreased relationship satisfaction (Mittelman et al., 2004; Wright, 1991; de Vugt et al., 2003; van Vliet et al., 2011; Garand et al., 2007). These factors are associated with poorer physical health (Kaiser &

Panegyres, 2007; Clare et al., 2012) and mental health (de Vugt & Verhey, 2013; de Vugt et al., 2003). The carer's experience of burden is also linked to relationship factors such as the loss of shared meaning and connection to their partner with dementia (Massimo et al., 2013; Riley et al., 2018) and poorer relationship quality (Rippon et al., 2019).

Importantly, although carer burden is a construct of the emotional state of one partner in the dyad, it is associated with negative outcomes for both partners in the couple. For example, several studies find that carer burden is more strongly associated with nursing home placement of the partner with dementia than are objective indicators of the severity of dementia (Zarit et al., 1986; Umberson et al., 2006; AIHW, 2014). Indeed, carer burden even correlates with mortality rates: caregivers who reported distress and burden in their role had 63% higher mortality risks than those caring for a spouse or partner with dementia who did not experience significant burden (Schulz & Beach, 1999). Brown et al. (1990) demonstrated that caregiver burden has significant implications for outcomes and, potentially, costs, finding it to be the most important factor in determining who would use formal services. These authors suggest that burden should be evaluated as part of routine assessment in dementia care.

It is frequently assumed that the caregiver's burden is strongly related to the severity of the partner with dementia's disabilities, but research indicates otherwise (Zarit, 1980, 1986). These studies found that, among variables such as the extent of cognitive impairment, memory and behaviour problems, functional abilities, and the duration of illness, only the frequency of family visits had a significant effect on caregivers' feelings of burden. In cases

where more visits were made to the person with dementia by family members other than the primary caregiver, the carer burden was reduced. This research (Zarit, 1980, 1986) suggests that external support is most strongly linked to improved carer burden.

The focus of the study in this chapter is the implementation and quantitative evaluation of the Living Together with Dementia intervention, which aims to strengthen support by improving the emotional connection between partners and enhancing the sense of internal support through the containing function of the intervention. The aim is that a strengthened relationship and greater containment will leave the caregiving partner feeling more resilient and able to cope with the demands of their role—resulting in less subjective burden.

In summary, evidence suggests that as dementia progresses, the burden on caregiving partners increases, while relationship satisfaction and communication between partners decline. Additionally, other health-related factors deteriorate due to the increased stress experienced by caregiving partners as their partner's dementia progresses (Kaiser & Panegyres, 2007; Clare et al., 2012; Fauth et al., 2012; Knop et al., 1998; de Vugt et al., 2003; Garand et al., 2007; Rippon et al., 2019).

This study aimed to examine the potential impacts of the relationship intervention for couples, Living Together with Dementia (LTwD), on the following variables: reduction in the burden of the caregiver role (our primary outcome), improved relationship satisfaction for both partners, improved health-related outcomes for the caregiving partner, improved communication between partners, and enhanced caregiver coping.

Furthermore, qualitative interviews with a sub-sample of participants explored both partners' subjective experiences of these areas and of the intervention itself. These findings will be reported as a separate study in Chapter 8.

Methods

Participating Sites

Camden

The work in Camden was funded by a grant from the Local Authority's Innovation Fund. The project was presented and discussed in various settings, including two public events for older people within the London Borough of Camden. At the final stage of the funding application process, the Living Together with Dementia project was presented to an invited audience that included service users, carers, other members of the public, professionals in the field, and Camden Council officers. Their endorsement was crucial in securing the funding. Subsequently, the project's design and aims were discussed with members of the Alzheimer's Society and other local stakeholders such as Age UK Camden. This consultation process was vital for refining the design and processes, as well as for enhancing the conceptual foundation of the work. Upon completion of the study, the results were presented to patients, service users, and members of the public, and disseminated through publications in professional journals (Balfour, 2023). Three sites within Camden participated in the project, each obtaining site-specific approval from the NHS ethics committee (IRAS – see appendix).

The participating sites were Camden Memory Service, Age UK Camden, and Tavistock Relationships.

Bristol – Harbour and Older Adults’ Wellbeing Service

Site-specific ethical approval was obtained for The Harbour, a non-NHS site in Bristol specialising in psychotherapy for older adults suffering from ill health and terminal illness (see appendix). The project was presented and discussed with key stakeholders in Bristol during a half-day event with the NHS Older Adults’ Wellbeing Service, and a day of discussion and training involving key individuals, commissioners, service leads, and clinicians from the voluntary sector, as well as Local NHS Older Adults’ Services.

City & Hackney

The work in City & Hackney was funded by a one-year grant from the Clinical Commissioning Group. The local participating sites where clinical work was conducted, and for which IRAS approval was obtained (see appendix for details) along with East London Foundation Trust R&D approval, were:

Alzheimer’s Society, East London Foundation Trust, St Joseph’s Hospice, and Hackney Mind.

Training and Supervision Across All Locations

The process of inducting and training practitioners was consistent across all locations, as detailed in the previous chapter. All LTWD practitioners underwent a three-day training programme and received supervision while delivering the intervention. The supervision leaders (the author and a close colleague) were experienced supervisors. Sessions from a randomly

selected subgroup of practitioners, which were audio-recorded, were monitored for adherence, and some co-working was undertaken, along with reviews of video work with the participant couples. Additionally, the high frequency of small group supervision (maximum of four practitioners per group) facilitated ongoing auditing of the quality and consistency of the intervention delivered. All sessions selected adhered to the intervention model as outlined in the treatment manual.

Recruitment of Participants

Participants were recruited through older people's mental health services, particularly memory services, which could refer couples in the early stages of dementia, as well as local voluntary sector and social service settings. Local teams and voluntary sector staff, such as those from community teams within local memory services, clinicians, and other voluntary sector staff from Age UK counselling service, St Joseph's Hospice, Camden Carers, and Jewish Care, played a crucial role in identifying couples who might benefit from the intervention and met the research criteria. Their knowledge of their clients and patients meant that researchers did not need access to medical records or other privileged information about the participants.

The initial approach to potential participants was through the mental health team, clinicians already known to them, or other staff in local settings such as day centres, or voluntary sector settings like Camden Carers or Age UK (particularly their clinical services). Staff in these settings were informed about the aims of the study, the intervention involved, and the inclusion and exclusion criteria. They used their knowledge of their patients or service

users to decide who might be interested in participating in the project and who might benefit from it. This personal approach was important for providing a sensitive and non-coercive initial contact. Some participants also discovered the project through literature and self-referred.

If individuals expressed interest in participating, they were contacted and given an explanatory letter. Upon indicating continued interest, an introductory visit was arranged at their home, meeting both the person with dementia and their partner. Meeting both partners together was crucial not only because the project aimed to recruit couples but also because the caregiving partner provided additional support and maximised the confidence and understanding of the person with dementia regarding the project. A written explanation of the project was provided alongside the verbal explanation given at the meeting. The issue of capacity to give informed consent, which is of major importance here, is addressed below. See the appendix for all information provided to participants.

Inclusion/Exclusion Criteria

Inclusion Criteria:

- 1. Residing within one of the funding areas:** Camden, City & Hackney, or Bristol. Couples who were married, in a civil partnership, or in a long-term relationship, where both partners were prepared to be involved in the study and one partner had a diagnosis of dementia.
- 2. Informed consent:** Participants needed to be able to give informed consent or have a suitable person available to act as a consultee who could give assent on their behalf (see below for further details).

3. Range of dementia severity: We were interested in exploring the experiences of individuals across the range of dementia and did not impose any a priori limit on the degree of impairment of those included in the study. Indeed, a strength of the pilot work was finding that some individuals with very low scores on measures of cognitive functioning could still participate.

4. Clinical judgement: A clinical judgement was made with the help of formal and informal carers regarding the inclusion of individuals at the more impaired end of the spectrum, which also depended upon the issue of consent (see below).

5. Severe impairment: For couples interested in the intervention but with more severe impairment, we discussed their situation with the referrer. If appropriate, we met with the couple to explore their suitability for the intervention. The decision to include them was based on clinical judgement, input from carers and professionals, and adherence to Good Clinical Practice Guidelines.

Exclusion Criteria

1. Concurrent diagnoses: Major psychiatric disorder or other significant physical illness.

2. Age restriction: People below the age of 65. While including individuals with younger-onset dementia is possible, our focus was on the experience of older couples with dementia within the context of their relationship and evaluating the utility and acceptability of our approach for this older population.

3. Non-discrimination: We did not exclude individuals from the study based on physical disability, race, religion, or sexual orientation.

Informed Consent

Informed consent is a crucial issue in dementia research, as participants may lack the capacity to give informed consent or may lose that capacity during the research process. We obtained IRAS NHS approval for our approach to this issue (see Appendix p8), which will now be detailed.

Clear written and verbal information about the study and the intervention was provided in a form that potential participants could understand (see 'information sheets' and 'consent forms' in Appendix, p91). Depending on the participants' capacity to assimilate the information, this was repeated as necessary at the start of each session. Where appropriate, the carer partner assisted in imparting information to the partner with dementia. Time was allowed for participants to understand and retain the information, and their understanding and retention were checked at intervals during the study. We were guided by clinical judgement regarding the participants' wishes and feelings. For example, if they appeared distressed or unhappy at any point, we responded appropriately, seeking help from their carer to understand their wishes and feelings and endeavoured to be as sensitive as possible throughout the research.

Determining Capacity for Informed Consent

Best practice literature was used to determine whether participants could give informed consent, and this was monitored over the course of the intervention (Warner et al., 2008). All such decisions were made on a

consensual basis, with the Chief Investigator being advised and guided by the NHS care team, including the Consultant Psychiatrist, Psychologist, and Care Coordinator. We discussed the case of every participant carefully and were guided by best practice in this area (Warner et al., 2008).

Fluctuating Capacity for Consent

The capacity of participants inevitably fluctuated during the research. This was managed in several ways. Firstly, consent was not considered a once-and-for-all process. Given that dementia is a progressive illness, capacity diminished over the course of the study. We continuously monitored and reassessed the capacity to consent by regularly re-presenting information about the study, allowing time for participants to understand and retain it, testing retention and understanding, and finally assessing their ability to comprehend the information with input from carers and staff involved in their care. In situations where participants were judged unable to give informed consent, an alternative approach was adopted.

For participants unable to consent to inclusion in the research, we included them only if a suitable person could be identified to act as a consultee to advise on whether the individual would want to be involved in the project. The carer partner was not used as a consultee due to potential lack of objectivity; instead, friends, other professionals, or relatives were chosen. We maintained ongoing discussions with participants' key workers and other members of the multidisciplinary team involved in their care.

To assist the consultee in making the best decision, we enabled them to consider factors such as whether the person with dementia would be content

to take part or whether participation would upset them; what their past wishes and feelings about participating in the study might have been, and their current preferences. The consultee was thoroughly informed about the aims of the study and what it entailed. They were also made aware that they could advise us at any point if the person who lacked capacity would not wish to continue. Furthermore, they had access to information about whom to contact for independent advice about their role. Each consultee was asked to give their written assent to the participation of the person with dementia who was unable to consent for themselves.

Throughout the project, we maintained ongoing contact with the consultees and others who could keep us informed about how the participants were faring, their experiences of the research, and any issues that needed consideration regarding their continued participation. We were also in regular contact with the clinical team involved in their care. The lead collaborators for the participating sites were, in each case, the lead clinicians within their clinical teams. Additionally, due to the nature of the research design, we maintained ongoing contact with the partners of the participants with dementia, ensuring multiple sources of contact with named consultees and others who could provide monitoring and advice regarding the participants in the study.

Criteria for Withdrawal of Participants

While it was not anticipated that the content or manner of the sessions would cause distress to participants, we aimed to be sensitive and use our clinical skills and judgement to support people if any distress did arise. If participants

showed signs of distress during the intervention, we were prepared to stop the intervention and attend to their needs. If necessary, we referred them to appropriate services for additional support. Every effort was made to minimize any inconvenience, distress, or discomfort during the study. We were attentive to signs of fatigue, distress, and other feelings, adjusting our approach accordingly. For instance, we would halt a session or defer measures to a later meeting if needed.

We also liaised with other care professionals involved to ensure participants received appropriate care, support, and follow-up from statutory services.

The aim of the intervention was to provide therapeutic benefits to participants, offering a space for their experiences to be considered and understood, even if these experiences touched upon potentially painful and sensitive areas. If the intervention was not beneficial for some participants, we exercised care and respect, taking appropriate clinical responsibility to refer them for further help elsewhere.

Recruitment and Retention of Participants

Overall, 87 couples were referred to the programme and screened for eligibility (see CONSORT diagrams). Forty-eight couples were accepted into the programme: 38 couples from London and 10 from Bristol. Participants were residents of London (n=76) and Bristol (n=20), referred through memory services, carer associations, and professionals in older people's services. Thirty-two couples (64 participants) completed the intervention, with residents from London (n=48) and Bristol (n=14) (see CONSORT flow diagram).

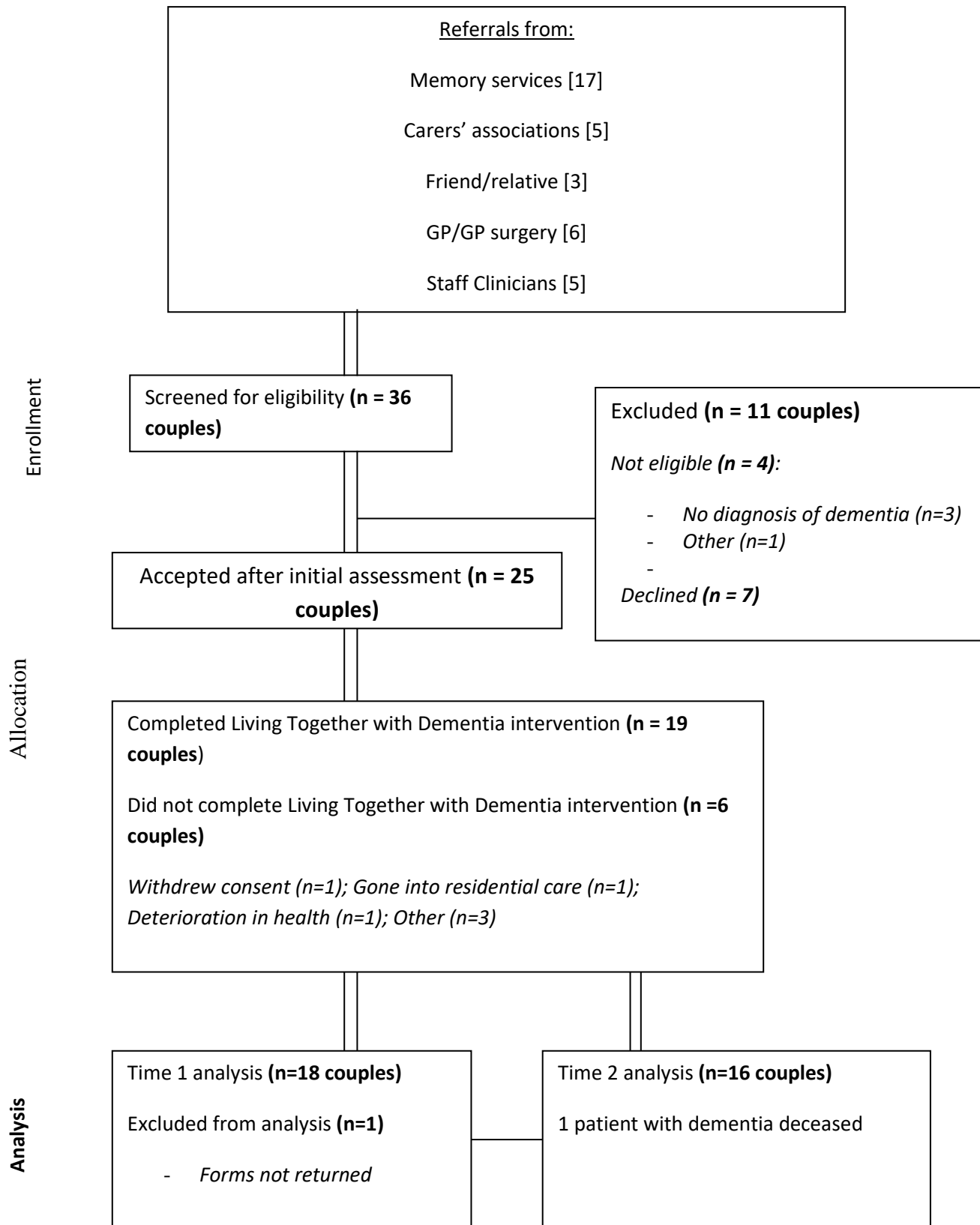
Participants were in established couple relationships where one partner had a diagnosis of dementia, lived in the community, and were able to speak English. Data were collected at intake and post-intervention. One couple was excluded from the analysis due to the death of the partner with dementia. Most of the partners with dementia (nearly 75%) were male. At the time of their referral into the project, clients' ages ranged from 66 to 90, with a mean age of 73.62 years (SD=7.19); on average, the partners with dementia were older (mean age=77.32) than the partners without dementia (mean age=74.91).

The process of eliciting referrals involved sustained liaison with local agencies in each area where the project was run. This included marketing efforts such as distributing flyers at GP surgeries and placing slides on surgeries' electronic billboards. Information was sent out, and telephone conversations were held with many potentially interested couples. As detailed in the CONSORT diagrams, there were significant numbers of couples who did not receive an initial assessment appointment.

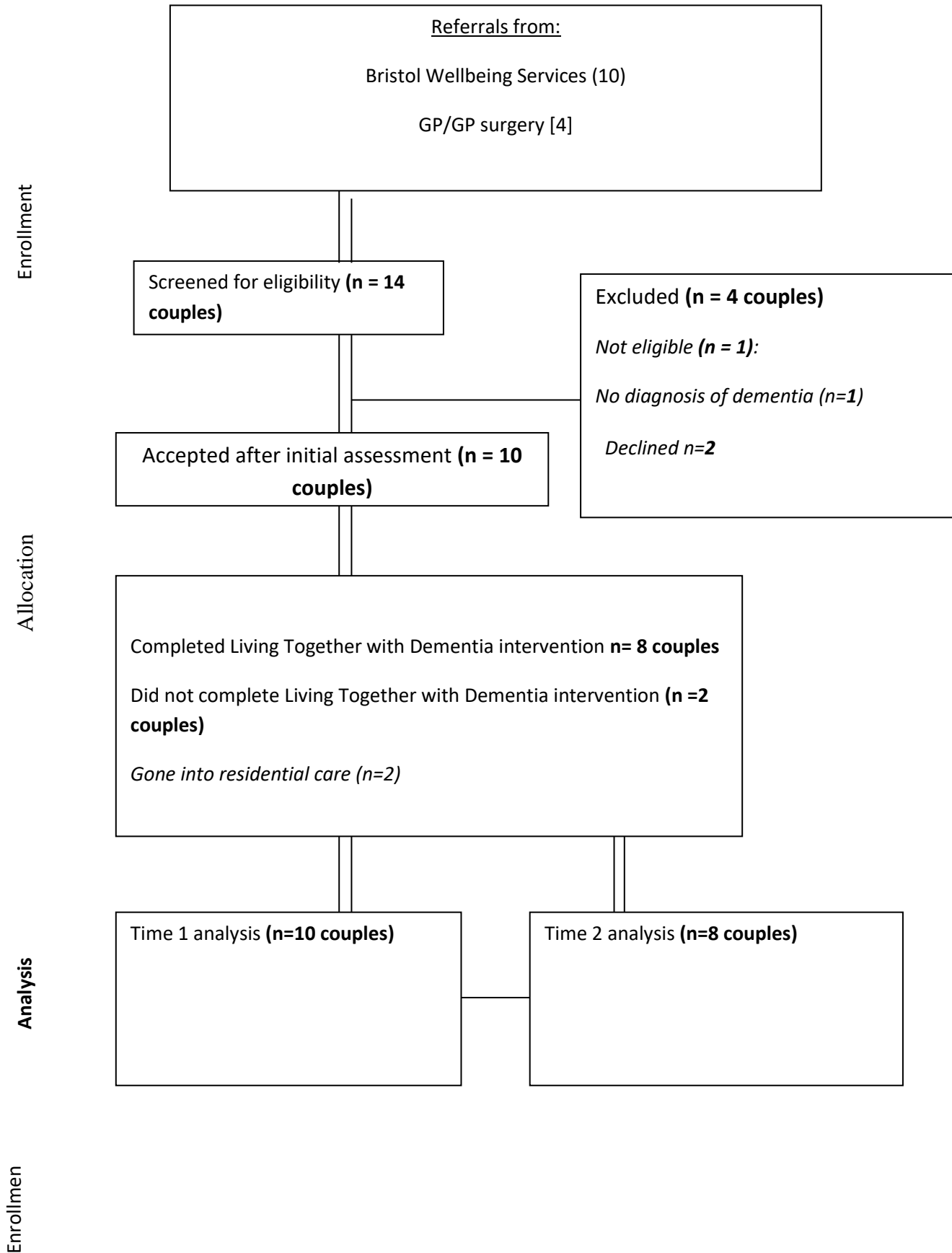
The key reasons for this are recorded in the CONSORT diagrams. In the early stages of the intervention, partly due to receiving many referrals from Mental Healthcare of Older People Services, a lot of the referred couples had multiple comorbidities and were at the later stages of dementia. Although the programme accepted a range of dementia severity levels, many of these referrals were not suitable for trainees taking on the intervention for the first time.

Local Memory Services, where dementia was diagnosed, were identified as a key gateway for referrals into the project. Staff from local Memory Services were contacted, and in each area, at least one staff member was recruited from the Memory Service into the project and received training in the intervention. This helped to enhance the flow of suitable referrals into the project and highlighted the importance of targeting recruitment and ensuring referrals into the project shortly after diagnosis or relatively early in the dementia process.

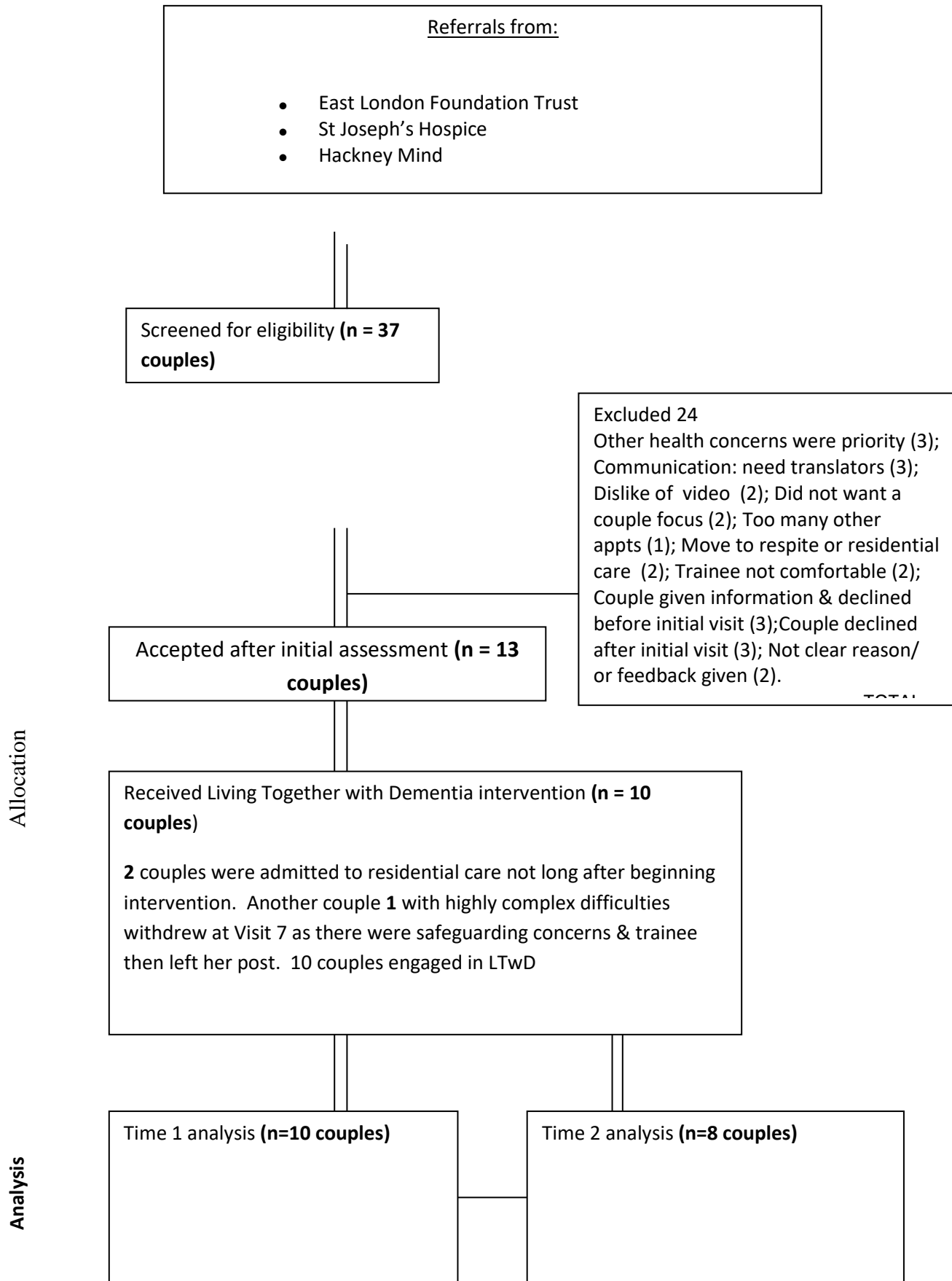
Camden referrals: CONSORT



Bristol referrals: CONSORT



City & Hackney referrals: CONSORT



Measures

Measures Completed by the Carer Partner (Partner A)

1. Perceived burden: Zarit Burden Interview (Zarit, Todd, and Zarit, 1986).

The primary outcome measure, the Zarit Burden Interview (ZBI), is a subjectively worded 22-item instrument that measures the level of burden perceived by caregivers of people with dementia. Items are scored using a five-point scale, ranging from 0 (never) to 4 (always). Some researchers group the items in the questionnaire into five domains: Burden in the Relationship, Emotional Well-being, Social and Family Life, Finances, and Loss of Control over One's Life. Scores range from 0 to 88, with higher scores indicating greater levels of perceived caregiver burden. Caregivers' scores can indicate little or no burden (0 to 21), mild to moderate burden (21 to 40), moderate to severe burden (41 to 60), or severe burden (61 to 88). The ZBI is the most used measure of caregiver burden. Responses to the ZBI have been found to be reliable across populations of caregivers and patients, with studies finding that the ZBI shows good internal consistency and reliability, with a Cronbach's alpha coefficient of .92, which was not significantly improved by the removal of any of the 22 items (Hérbert et al., 2000; Bachner & O'Rourke, 2007). In terms of its validity, these authors found that the measure is appropriate for use with a variety of populations, and that scores were strongly positively correlated with behavioural problems in older adult patients and depression scores of caregivers. Only versions of the ZBI with 22 items reflect both statistical and meaningful differences in

reliability, and hence researchers recommend that the 22-item version of the ZBI be used in research and clinical practice (Bachner & O'Rourke, 2007). Hence, the long form of the measure, the 22-item version, is used in this study.

2. Quality of relationship: The DAS-7, a short form of the Dyadic Adjustment Scale (Spanier and Thompson, 1982).

The DAS-7 is developed from the 32-item Dyadic Adjustment Scale, which assesses relationship adjustment in married or cohabiting couples. Total scores on the DAS-7 can range from 0 to 36, with higher scores indicating greater relationship adjustment. Sharpley & Rogers (1984) and Hunsley et al. (2001) found the DAS-7 to possess good internal consistency and, according to these studies, the reliability of the DAS-7 ranged from 0.75 to 0.80. The concurrent validity of the DAS-7 appeared to be unaffected by whether the scale was administered as an independent measure or obtained by items extracted from the long form of the DAS itself, and the brief measure retains the strong reliability and validity of the longer-form DAS (Hunsley et al., 2001). The original 32-item scale (Spanier & Thompson, 1976) shows high construct and criterion validity and a total scale reliability of 0.96.

3. Health Status Questionnaire (HSQ-12): Radosevich and Pruitt, 1995.

The Health Status Questionnaire (HSQ) measures an individual's subjective health, well-being, and level of functioning in both healthy and ill individuals. In the current project, it was used only with the partner without dementia. There are fifteen items on the measure, but only twelve measure perceived health status. The last three questions are used as a depression screen; if

the client answers 'yes' to one or more of these questions, they should be followed up with a diagnostic measure. The measure has eight subscales: Health Perception, Physical Functioning, Role Limitations Attributable to Physical Health, Role Limitations Attributable to Mental Health, Bodily Pain, Energy/Fatigue, Social Functioning, and Mental Health. The internal consistency reliability was .88. Two factors were found: physical and mental health, and the HSQ-12 is a reliable, valid, and low-cost measure of health status (Barry et al., 2007).

4. The Thomas Assessment of Communication Inadequacy (TACI) (Done and Thomas, 2001).

This is a twenty-item measure assessing the level of problems related to a carer's everyday communication with their partner affected by dementia, as well as the degree to which these problems distress carers. It yields a standardized factor score describing the levels of difficulties in communication (the higher the score, the greater the dissatisfaction) and an impact score describing the degree to which these problems distress carers (the higher the score, the more these problems affect them). The authors (Done and Thomas, 2001) developed the TACI because there were no other validated questionnaires for measuring communication problems with people with dementia. Although there are no published reliability and validity data for the scale, it was used successfully to measure significant reductions in communication problems following skills training for carers of people with dementia (Done and Thomas, 2001).

5. The Brief COPE Inventory (Carver, 1997).

The Brief COPE Inventory is a short form of the 60-item COPE Inventory (Carver, Scheier & Weintaub, 1989), which is a 60-item instrument with 4 items per scale. The Brief COPE omits two scales of the full COPE and includes 28 items which measure 14 differentiated coping reactions. Carver (1997) reports the psychometric properties of the measure in a study of the process of recovery of adults from a natural disaster (Hurricane Andrew). This shows that although the subscales of the measure include only 2 items each, their reliabilities all exceed 0.50, which is in accord with minimally acceptable levels. Other studies have supported its psychometric properties with different populations (Garcia et al., 2018), and it has proved to be a widely used measure of coping, which has the advantage of reducing impatience found in participants using the longer form of the measure. This factor was important in selecting the measure for the participants in this study.

Measures Completed by the Partner with Dementia (Partner B)

1. Cognitive functioning: Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975).

The MMSE is an eleven-item measure that tests cognitive functioning and is a commonly used, brief measure of impairment level in dementia. The first section of the questionnaire, covering memory, attention, and orientation, is administered by the clinician but requires vocal responses from the participant. The second part of the questionnaire, completed by the participant, tests the ability to follow written and verbal instructions, spontaneous sentence formation, and visuospatial skills. Along with other

tools, the MMSE can be used to formulate a diagnosis of dementia. The maximum available score on the MMSE is 30, with higher scores indicating healthier cognitive functioning. Previous studies using the MMSE report mean scores of 18.1 for people with dementia who can complete the MMSE, compared to a mean score of 4.1 for those who cannot; individuals with normal cognitive function have scores of 27.6. Those with scores below 17 are classified as having severe cognitive impairment. The MMSE is a very widely used measure, with excellent discriminative validity (distinguishing different patient groups) and concurrent validity, as well as good reliability, with Cronbach's alpha scores of 0.82 in test-retest reliability (Folstein et al., 1975).

2. Quality of relationship: The DAS-7.

The DAS-7, described above, was initially used only with the partner without dementia but was later added to the partner with dementia's booklet of measures. This measure assesses relationship adjustment in married or cohabiting couples. Total scores on the DAS-7 can range from 0 to 36, with higher scores indicating greater relationship adjustment. It retains strong reliability and validity, with internal consistency and concurrent validity unaffected by the method of administration (Hunsley et al., 2001).

See Appendix, p74-91, for the 'Partner A & Partner B Booklet of Measures.'

Procedure

With informed consent obtained (see Appendix p91 for examples of information sheets and consent forms), participants completed quantitative

measures prior to and following the eight-session Living Together with Dementia (LTwD) intervention. At one-year follow-up, clients were invited to opt-in for a qualitative interview (this is described in the next chapter).

The initial meeting with participants involved discussing the study and seeking consent. This was conducted by the Chief Investigator or a clinically qualified research assistant under supervision. Interviews took place in participants' homes, ensuring privacy and confidentiality throughout. Baseline measures were taken, including the assessment of cognitive functioning and marital satisfaction for participants with dementia. For carer partners, baseline measures included perceived burden, coping orientation, depression, quality of life, and health. Additionally, both partners were videotaped engaging in an everyday activity together. All measures and the videotaping were administered by the Chief Investigator or a clinically qualified research assistant under supervision.

Evaluation/Assessment

These measures were administered to all participants at the beginning of the intervention and repeated at the end. Assessments often spanned two meetings at each point, considering the attention difficulties and fatigue of people with dementia and the importance of pacing the work suitably for all participants. The measures were given to the couples in the form of two booklets, one for each partner, with the measures described above contained in the relevant booklet (see appendix for Partner A and Partner B booklets of measures).

The Intervention

Once couples were consented into the programme, they were discussed within the supervision groups and therapists were allocated to each case. Each couple was contacted by telephone, and the first session with the therapist was arranged at the couple's home. All subsequent sessions also took place in the couples' homes. Chapter 5 describes the intervention (and the Manual for the intervention can be viewed in the appendix).

The initial session with the therapist involved helping the couples fill out the Time 1 measures. In general, the carer partners were able to undertake this themselves, allowing the therapist to focus on working with the partner with dementia to administer their measures. Once these were completed, the therapist worked with the couple to undertake the initial clinical assessment (see Chapter 5 and the Manual for an account of the 10-point assessment guide developed for the intervention). Following this, the therapist made the initial assessment video with the couple. In all cases, this involved a video of the couple spending 15 minutes on an everyday activity together. At this stage, they were asked to choose an activity that they would like to do and to work together as a team. This is an initial diagnostic tool, highlighting couple functioning and interaction. This video was then viewed in supervision, and the discussion with the supervision group formed the basis for the psychodynamic formulation of key issues in the couple's dynamic. As described in Chapter 5, this, along with the clinical assessment, served as the basis for ongoing work with the couple.

The couples were then seen for six further sessions, with an additional session after the six sessions as a final session. Sessions were scheduled at two to three-week intervals. The six sessions of the intervention following the assessment phase combined both individual and couple psychotherapeutic discussions, alongside a review of video recordings of the couple carrying out everyday activities together. The pattern was to record the couple doing an activity in one session and then review this together in the next session, following an AB/AB pattern: videoed activity at one session, review of the video at the next. Each session lasted 90 minutes, allowing time for psychotherapeutic discussions with the couple together and with one or other partner separately.

At the final session, the couple was videoed doing the same task that they had done during the initial assessment video. After this, there was space for the couple to discuss their experience and to reflect with the therapist about the ending of the intervention. At this point, they also completed the Time 2 psychometric measures.

Results

Main analyses

Table 4. All Analyses

<i>Quantitative Results</i>					
	Time 1	Time 2	t/Z statistic	Outcome	p-value
	Mean (SD)	Mean (SD)	(df)		
ZBI (ALL)					
total	41.66 (16.23)	39.22 (15.66)	1.039 (31)	↓	0.307
burden	12.5 (4.75)	11.28 (4.78)	1.518 (31)	↓	0.139
social	7.6 (4.16)	7.07 (3.54)	1.332 (29)	↓	0.193
finances	1.38 (1.47)	1.14 (1.19)	1.097 (28)	↓	0.282
loss	7.41 (3.46)	7.97 (3.41)	-1.041 (31)	↑	0.306
personal strain	21.97 (8.38)	21.19 (7.89)	0.574 (31)	↓	0.570
role strain	11.7 (6.36)	11.2 (5.13)	0.720 (29)	↓	0.477

ZBI (HIGH)

total	55.38	46.44		-2.665	↓	0.008	
	(9.29)	(15.15)					
burden	15.63	12.69	(2.31)	-2.364	↓	0.018	
	(3.44)						
social	10.93	9.40	(2.97)	-2.458	↓	0.014	
	(2.31)						
finances	1.73	(1.75)	1.40	(1.30)	-1.025	↓	0.305
loss	10.31	9.44	(3.20)	-1.601	↓	0.109	
	(1.82)						
personal	28.81	24.25	(7.79)	-2.451	↓	0.014	
strain	(5.34)						
role strain	16.53	14.20	(4.60)	-2.170	↓	0.030	
	(3.89)						

MMSE 18 (7.27) 16.64 (8.21) 1.547 (24) ↓ 0.135
Score

DAS

Partner A	17.21 (6.84)	16.45 (6.38)	0.628 (28)	↓	0.535
Partner B	18.88 (6.98)	20.50 (6.62)	-0.756 (15)	↑	0.461

TACI*Communication problems*

	0.02 (2.22)	0.08 (2.40)	-0.124 (23)	↑	0.902
Partner A					

Impact

	0.03 (3.06)	0.03 (3.06)		=	.
Partner A					
Partner B					

BRIEFCOP**E**

Partner A	0.99 (0.35)	0.96 (0.40)	0.301 (18)	↓	0.767
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Partner B

HSQ

Partner A	56.18	58.55	-0.883	↑	0.384
	(22.36)	(16.44)	(31)		

Note: ALL= all observations; HIGH= observations scoring >40; Partner A= Partner carer;
Partner B= Partner with dementia

The number of cases included in each analysis varied due to item omissions; thus, the number of observations in each analysis is reported separately.

Primary Outcome Variable: Carer Burden (ZBI)

Paired samples t-tests were performed on the ZBI items. For all carers, there was a slight decrease in total carer burden scores from 41.66 at intake to 39.22 at Time 2 (n=32, p=.307), but this was not statistically significant.

Further analyses (t-tests) on each of the individual sub-scales of the ZBI also showed no significant differences: burden (p=.139), social (p=.193), financial (p=.282), loss (p=.306), personal strain (p=.570), and care role strain (p=.477). See Table 4.

Separate analyses of the results for those carer partners whose level of burden was in the range from moderate to severe at the start of the intervention (scoring 41-88 on the ZBI at intake (n=16)) were conducted, utilizing nonparametric Wilcoxon signed ranks tests (because the data were skewed, not conforming to a normal distribution). These analyses found

there was a significant reduction in total carer burden for this group, $Z=-2.665$, $p=.008$, with mean burden scores dropping from 55.38 to 46.44. As separated into the individual sub-scales of the measure, these analyses indicated significant decreases in burden ($Z=-2.364$, $p=.018$), social strain ($Z=-2.458$, $p=.014$), personal strain ($Z=-2.451$, $p=.014$), and carer role strain ($Z=-2.170$, $p=.030$). There were no significant changes for finances ($Z=-1.025$, $p=.305$) and loss ($Z=-1.601$, $p=.109$) – though the mean scores did indicate some, non-significant, reduction in these variables. See Table 5.

Further analysis indicated an additional dimension to this finding.

Nonparametric analysis was undertaken on categorical variables derived from a median split (low versus high burden) of continuous variables corresponding to the Zarit Interview scores at intake and Time 2. This showed that 38% (6 out of 16) of those carers who were in the high-burden group at intake moved to a low-burden group at Time 2. The proportion of “improvers” was significantly higher than the proportion of those who reported higher burden at Time 2 ($n=30$, $\chi^2(1) = 4.57$, $p=.03$).

Table 5. Carer burden ZBI

<i>Primary Outcome Variable: Carer Burden (ZBI)</i>				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean (SD)		
ZBI (ALL)				
total	41.66 (16.23)	39.22 (15.66)	↓	0.307

burden	12.5 (4.75)	11.28 (4.78)	↓	0.139
social	7.6 (4.16)	7.07 (3.54)	↓	0.193
finances	1.38 (1.47)	1.14 (1.19)	↓	0.282
loss	7.41 (3.46)	7.97 (3.41)	↑	0.306
personal	21.97 (8.38)	21.19 (7.89)	↓	0.570
strain				
role strain	11.7 (6.36)	11.2 (5.13)	↓	0.477

ZBI (HIGH)

total	55.38 (9.29)	46.44 (15.15)	↓	0.008
burden	15.63 (3.44)	12.69 (2.31)	↓	0.018
social	10.93 (2.31)	9.40 (2.97)	↓	0.014
finances	1.73 (1.75)	1.40 (1.30)	↓	0.305
loss	10.31 (1.82)	9.44 (3.20)	↓	0.109
personal	28.81 (5.34)	24.25 (7.79)	↓	0.014
strain				
role strain	16.53 (3.89)	14.20 (4.60)	↓	0.030

Note: ALL= all observations; HIGH= observations scoring >40

Marital Satisfaction (DAS7)

Paired samples t-tests were carried out on the DAS-7, assessing marital satisfaction. There was a slight decrease in scores for carer partners from a mean of 17.21 at intake to 16.45 at Time 2 (n=29, p=.535), which was not statistically significant. There was a slight increase in scores for partners with dementia, from a mean of 18.88 at intake to 20.5 at Time 2 (n=16, p=.461), which was also not statistically significant. Overall, these results suggest that there was no significant change in marital satisfaction for either partner from intake to Time 2. See Table 6.

Table 6. Marital satisfaction (DAS)

Marital satisfaction				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean (SD)		
Partner A	17.21 (6.84)	16.45 (6.38)	↓	0.535
Partner B	18.88 (6.98)	20.50 (6.62)	↑	0.461

Note: Partner A= Partner carer; Partner B= Partner with dementia

Communication Between the Partners (TACI)

Paired samples t-tests were performed to assess the level of communication problems experienced by carer partners. The scores slightly increased from a TACI mean of 0.02 at intake to 0.08 at Time 2 (note that these scores were standardised, hence the initial value), however, this was not statistically significant ($t(23)=-0.124$, $p=.902$). The impact of these problems remained the same at intake (mean of 0.03) and at Time 2 (mean of 0.03). Thus, there was no evidence of change in communication problems or in how these problems affected carers. See Table 7.

Table 7. Communication between the partners (TACI)

Communication between partners				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean SD)		
<i>Communication problems</i>				
Partner A	0.02 (2.22)	0.08 (2.40)	↑	0.902
Partner B	Measure only administered to carer partners			
<i>Impact</i>				
Partner A	0.03 (3.06)	0.03 (3.06)	=	.
Partner B	Measure only administered to adult partners			

Note: Partner A= Partner carer; Partner B= Partner with dementia

Carer Partners' Coping (BRIEFCOPE)

Carer partners' levels of coping decreased from a mean of 6.13 at intake to a mean of 5.69 at Time 2 (n=23, p=.554), which was not statistically significant. Paired sample t-test on the BRIEFCOPE of carers showed a nonsignificant decrease in score (t(18)=0.301, p=.767).

Table 8. BRIEFCOPE

BRIEFCOPE				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean (SD)		
Partner A	0.99 (0.35)	0.96 (0.40)	↓	0.767

Note: Partner A= Carer Partner

Carer Partner's Health Status (HSQ)

Paired sample's t-test showed that there was an increase in carer partners' scores indicating their health status, from a mean of 56.18 at intake to a mean of 58.55 at Time 2 ($t(31)=-0.883$, $p=.384$), which was not statistically significant. Therefore, the health status of carer partners remained unchanged from intake to Time 2. See Table 9.

Table 9. Carer partners' health status (HSQ)

Health status questionnaire				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean (SD)		
Partner A	56.18 (22.36)	58.55 (16.44)	↑	0.384

Note: Partner A= Partner carer;

Cognitive Functioning of Partners with Dementia (MMSE)

The cognitive functioning of partners with dementia at intake ranged from normal (27.6 or above, n=2) to very low (0-4, n=1), with just over half of the sample scoring within the severe range of 0-17 points (52% of the sample). A paired samples t-test showed that there was a decline in cognitive functioning of partners with dementia, from an MMSE mean score of 18 at intake to 16.64 at Time 2 (n=25, p=.135), which was not statistically significant. See Table 10.

Table 10. Cognitive functioning of partners with dementia

Mini mental state evaluation				
	Time 1	Time 2	Outcome	p-value
	Mean (SD)	Mean (SD)		
MMSE Score	18 (7.27)	16.64 (8.21)	↓	0.135

Discussion

This chapter reports on a study evaluating the quantitative outcomes of the relationship intervention for couples living together with dementia (LTwD). Although this is a small-scale pre-post study, it presents interesting and encouraging results, demonstrating positive impacts on our primary outcome variable: the reduction in carer burden. Significant reductions in carer burden were observed for those carer partners who began the intervention

experiencing moderate to severe burden. Additionally, a significant number of those initially experiencing 'high-burden' transitioned to 'low-burden' by the end of the intervention.

The findings reported here, of high levels of burden in our carer group, with half scoring in a 'moderate - severe burden' range, concur with the findings of research in this area, which shows that dementia is often associated with increased stress and anxiety in the caregiving role (Knop et al., 1998; de Vugt et al., 2003; Garand et al., 2007). As described in Chapter 2, a recurring theme across numerous studies is the association between high levels of distress and burden and the caregiving role, with as many as 80% of spouse caregivers reportedly reaching their maximum limits of burden during the dementia disease process (de Vugt & Verhey, 2013). These negative effects of living with a partner with dementia have been identified as critical factors in the partner's decision to transition the individual with dementia into residential care (Zarit et al., 1986; Umberson et al., 2006; AIHW, 2014). Furthermore, these negative impacts of severe burden can extend to the risk of death for those caring for a partner with dementia (Schulz & Beach, 1999).

Such research underscores the importance of reducing carer burden, highlighting the significance of our finding that half our sample began the intervention experiencing 'high burden' and that this group of carer partners showed a statistically significant reduction in subjective burden at the end of the intervention.

The results also indicate that this shift was clinically meaningful, as there was a significant improvement in participants' self-rated burden. A significant

number of these participants, who were initially classified as experiencing high burden, had moved into the low burden category by the end of the intervention. The proportion of "improvers" was significantly higher than the number of individuals moving from lower to higher burden, which would be expected as the normal trajectory of carer burden increases with the progression of their partner's dementia.

Data Analytic Strategy for our Primary Outcome: Carer Burden

In analyzing the outcomes of those participants experiencing significant levels of burden at the outset of the intervention separately, our aim was to examine the effects of the intervention on those carer partners who were more distressed and experiencing moderate to severe burden. Whitlach et al. (1991) point out that one of the difficulties with intervention studies in this area is the high degree of variability in caregivers' scores on dependent measures, with some scoring relatively low on measures of burden—reflecting differences in their response to caregiving demands. These authors highlight that if some caregivers initially report few problems or symptoms on dependent measures, there is little opportunity to demonstrate improvement for the more highly distressed portion of the sample, potentially leading to the underestimation of the positive impact of the intervention.

This supports our data analytic strategy, which focused on those participants who, at the beginning of the intervention, were scoring in the moderate to severe burden range—half of all carer partners in our sample. Those with relatively low burden scores are unlikely to improve significantly, particularly in a brief intervention, and in a small sample this potentially obscures the

intervention effects on those participants who are more clearly experiencing problematic levels of burden. Examining intervention effects on this subgroup of half our participants revealed significant improvement for these carer partners on carer burden overall, as well as on most of the sub-scales of the Zarit Burden Scale, including social burden, personal strain, and role strain.

Relationship satisfaction did not show improvement but remained stable, indicating no positive evidence of improvement in relationship satisfaction. The stability of relationship scores is significant for two reasons: Firstly, it is important to set this finding in the context of research evidence, which consistently indicates a significant decline in relationship quality over time for caregiver partners (Marques et al., 2021; Clare et al., 2012; Fauth et al., 2012). Secondly, maintaining stable scores is noteworthy given the difficulties faced by couples coping with dementia and the negative impact of dementia on their relationship. Studies analyzing relationship adjustment have found mean scores of 23.2 for married couples, 22.5 for the general population, and 15.2 for divorced couples. This indicates that participants in the LTWD programme had poorer relationship adjustment than the general population at each time point, with carer partners scoring just above the mean score for divorced couples.

In addition, there is a well-recognized finding in general couple therapy outcome research that untreated control groups of distressed couples tend to show no improvement and often get worse (Baucom et al., 2003). Taken together, this literature provides some grounds for viewing our results as

indicative evidence of the value of the finding that relationship satisfaction did not show the expected worsening over time that research would predict for couples living with dementia.

Carer Partner Coping (BRIEF COPE), Health Status (Health Status Questionnaire), and Communication (TACI) Levels of coping and health status of carer partners remained unchanged from intake to Time 2, indicating no change on these variables. Given the evidence from the literature reviewed in Chapter 2, which shows negative impacts on health and coping (de Vugt et al., 2003; Kaiser & Panegyres, 2007; Fauth et al., 2012; Schneider et al., 1999), detecting positive intervention effects would likely necessitate a no-treatment control. This would allow us to test whether the stability we found on these variables represented a significant improvement, given the negative impact of dementia on these factors in participants who were not receiving treatment. Similarly, there was no evidence of change in communication problems or in how these problems affected carer partners. This may be viewed positively, considering the negative impacts on communication between partners living with dementia, as evidenced in many research studies (de Vugt et al., 2003; Clare et al., 2012; Garand et al., 2007). However, again, it would be necessary to have a non-intervention control group to test this.

The cognitive functioning of the partners with dementia declined over the period of the intervention, although this was not statistically significant. The level of impact of dementia on the cognitive functioning of our participants is indicated in their low scores on the MMSE, with just over half of the sample

scoring in the 'severe' range. As a group, their mean scores moved from being above the cut-off indicating 'severe' to below it by the end of the intervention—so that at Time 2, the average score of our participants with dementia was within the 'severe' range of cognitive impairment.

In summary, the research literature indicates that over time, carer burden typically increases, marital satisfaction diminishes, and health-related outcomes for carer partners worsen. The fact that these factors did not show the expected worsening during the intervention, and that carer burden reversed this trend, is an encouraging result. This finding is interesting and potentially important, suggesting the intervention's effectiveness in reversing the expected trajectory of increased burden, diminished relationship satisfaction, and health decline. Encouragingly, these results were not achieved solely by experienced therapists, potentially attributable to general therapeutic factors, but by a range of different practitioners who were trained and supported through regular supervision. This raises the possibility that the LTWD intervention could be delivered by a wider workforce, at greater scale, with an economically viable model—crucial factors for achieving long-term dissemination and sustainability.

In summary, results indicate that the intervention at least partially met its main goals, indicating that, following the intervention, there was evidence of:

- Significantly reduced burden for carer partners who began the intervention experiencing moderate to severe burden.
- Stable relationship satisfaction despite the expected decline associated with dementia.

- Stable health for carer partners.
- Stable communication problems between partners, which would typically worsen as part of the illness's normal trajectory.

However, the analyses reported here should be interpreted with caution due to the small sample size and the lack of a control group. Future research could test these results on a larger scale through a controlled trial with a randomized design to evaluate overall impacts and establish a causal link with the intervention. The limitations of this study are discussed in more detail in the next section below.

Limitations of the Study

In addition to being small in scale, this study lacked a control group, which is a significant limitation when studying the outcomes of intervening in a condition such as dementia, where the trajectory of the illness brings progressive worsening in all the domains of interest: carer burden, marital satisfaction, communication, and health-related outcomes. Therefore, these results must be treated with caution. Without a randomised controlled design, we cannot infer a causal link between the relationship intervention and the reduction in carer burden. Additionally, the small scale of this study means that we do not know if the lack of change found in the other variables we studied, apart from carer burden, was due to the study being underpowered.

We also need to consider the types of changes that can reasonably occur in a brief intervention, as well as the goals caregivers have for themselves and their initial levels of distress. The chronicity of the stressors caregivers

experience and the short-term nature of this intervention may help explain why we did not find more evidence of positive outcomes.

Given the limits of the available resources, a randomised controlled trial was not possible in this study. However, the next step for researching the LTWd intervention's effectiveness would be to undertake an efficacy study to examine whether the promising finding of reduction in carer burden is sustained and amplified with a larger group randomised to this condition, as compared with a no-treatment control group. Additionally, testing the variables that were stable on repeated measures in this study against a non-intervention control group would be important in determining whether such stability found in this study on relationship satisfaction, communication, and health-related outcomes represents a positive improvement compared with the normal trajectory of dementia's impact on these variables in couples who do not have the relationship intervention.

Furthermore, there are limitations regarding the variables measured in this study. A future study would optimally control for factors such as depression in both partners, and other issues would also be important to measure, such as assessing the amount of time the carer partners spent in the caregiving role. For example, Schneider et al. (1999) found that family caregivers providing more substantial care—over 20 hours per week—were more than twice as likely to experience mental health problems as those family carers providing less intensive care. Given that all the participants were living together as couples, we can assume that they were giving 'significant care'. However, an assessment of the amount of other support they could draw

upon and how much time they spent caring for their partner would be an important dimension to measure, to examine in greater detail the link between the caregiving role and carer burden.

Conclusion

The starting point for this study was the idea that an attachment-focused relationship intervention could reduce the stress and burden of the carer partner and support the resilience of the couple living with dementia. This study provides some preliminary evidence to support this, as post-intervention results showed some improvement in carer burden. Additionally, our measures of relationship satisfaction, communication, and health status remained stable, despite the normal trajectory of dementia, which would be expected to bring a commensurate decline in all these variables. Therefore, these results provide some indication that this attachment-focused intervention, which seeks to remediate the negative impacts of the relationship dynamics of dementia, can engage such couples and potentially improve the situation for both partners.

However, the limitations of the design of this study, notably its small scale and lack of a control condition, constrain the claims that can be made. The next steps would be to test the feasibility of a larger scale, randomised controlled study of this intervention for couples living with dementia and its training programme for staff, assessing both the efficacy of this approach and the feasibility of delivering it at scale. Future research is needed to build on the foundation begun in this study, moving us toward the goal of developing an evidence-based relationship intervention for dementia.

In the next chapter, the qualitative data from this study will be reviewed to explore the participating couples' experience of the intervention and the evidence for the hypothesis that Living Together with Dementia enhances the internal support that participants feel. To this end, the next chapter evaluates the qualitative data for impacts of the intervention on the couple's relationship itself.

Chapter 8: Qualitative Evaluation of the Intervention Programme

Introduction

This chapter presents the qualitative evaluation of the intervention programme, aiming to provide a deeper understanding of the quantitative outcomes detailed in the previous chapter and to contribute to the growing body of qualitative research in dementia care. Qualitative studies offer an advantage over quantitative ones by providing a more nuanced understanding of the changes couples undergo during the progression of the disease (Pozzebon et al., 2016). These studies, often focusing on dyadic interactions, offer a holistic perspective on the shared experience of dementia (Wadham et al., 2016). Specifically, qualitative research in dementia care explores how illness-related deficits affect the couple's relationship and the coping mechanisms of caregiving partners.

As reviewed in Chapter 2, a central theme in the qualitative literature on this topic is that dementia leads to the experience of "loss of the partner" for the caregiver. Changes in the communication and behaviour of the partner with dementia pose a threat to the couple's cohesion, companionship, communication, reciprocity, and intimacy (Evans & Lee, 2014; Pozzebon et al., 2016). As the cognitive and functional capacities of the person with dementia decline, there is a gradual shift in roles, with the person with dementia progressively relinquishing their roles (Egilstrod et al., 2019; Evans & Lee, 2014; Keady & Nolan, 2003). As the disease advances, the partner without dementia increasingly takes on the role of caregiver within the

relationship (Egilstrod et al., 2019; Boylstein & Hayes, 2012; Ducharme et al., 2013; Fjellstrom et al., 2014; Massimo et al., 2013).

Caregiving partners experience both emotional and practical impacts due to the growing responsibility placed upon them (Bergman et al., 2016), with day-to-day activities increasingly becoming their responsibility (Boyle, 2013; Boylstein & Hayes, 2012; Lin et al., 2012; Quinn et al., 2008; Vikstrom et al., 2008; Quinn et al., 2009). Many partners report that the shift from 'spouse' to 'caregiver' becomes increasingly frustrating as their partner's dementia progresses. These studies show that, although partners may spend more time together, dementia adversely affects their mutual engagement in everyday activities (Boylstein & Hayes, 2012; Ducharme et al., 2013; Vikstrom et al., 2008). The emotional challenge of managing these changes in the relationship can be profoundly difficult, with many caregiving partners feeling isolated and without a sense of closeness in their relationship, leading to higher levels of burden and depression (Pozzebon et al., 2016; Boylstein & Hayes, 2012). It appears that reduced engagement in everyday activities is associated with a corresponding emotional withdrawal between partners, which contributes to feelings of increasing emotional disconnection within the couple (Pozzebon et al., 2016).

How might these negative impacts be remediated? As discussed in Chapter 2, researchers highlight the importance of studying "couplehood" as a pivotal factor in finding ways to support the couple relationship to mitigate negative outcomes, primarily through engaging in shared activities (Forsund et al., 2014; Hellström et al., 2005; Johnston & Terp, 2015). Research in this area suggests that reconstructing relationship closeness by developing new

coping strategies and sustaining shared activities can help build resilience in couples living with dementia (McGovern, 2012; Eligostrad, 2019; Bergman et al., 2016; Boylstein & Hayes, 2012; Hellström et al., 2007; Lin et al., 2012). However, it is clear from this research that what is essential is not merely 'doing' things together but rather the emotional connection that shared activities can foster.

The concept of "Being in the Atmosphere of Doing," introduced by Van'T Leven & Jonsson (2002), conveys the idea that even though functional impairments increasingly limit the person with dementia's ability to directly engage in activities, they can still experience 'being in the atmosphere of doing.' This concept underscores the idea that everyday domestic activities can serve as mediators of emotional engagement between partners, where the interaction is centred on each other rather than the task itself. The notion that interaction around an activity can serve as a vehicle for emotional contact is a central premise of the Living Together with Dementia intervention. As discussed in Chapter 4, this intervention seeks to improve outcomes for both partners and reduce the burden on caregiving partners by alleviating the negative impacts of dementia on relationships, which often diminishes closeness and emotional contact between partners. The intervention aims to achieve this by creating conditions that support emotional contact between partners, using shared activities as a vehicle for mutual involvement.

To what extent did the intervention succeed in its aims of enhancing 'couplehood' by supporting mutuality and shared emotional engagement within the participating couples?

Aims of the Study

This qualitative study aimed to explore the experiences of couples who participated in the intervention and to understand which elements, according to the participants' subjective reports, may have influenced its outcomes. The goal of this study is to gain a deeper understanding of the aspects of the intervention that participants found helpful and those that were less so. It also seeks to explore the extent to which the elements of the intervention that were salient to the participants align with its conceptual foundation, as operationalised through its aims and methods.

A substantial amendment to the original NHS ethics was approved for this study by the Health Research Authority, London-Camberwell St Giles Research Ethics Committee (IRAS project ID: 137317 Living Together with Dementia REC reference: 14/LO/0112 27). (See Appendix p20.)

Methods

Procedure

Approximately 12 months after the completion of the intervention, LTWd practitioners contacted clients with whom they had worked in delivering the intervention to gauge their interest in participating in this follow-up study. Individuals who expressed interest were then contacted to discuss the study in more detail and to arrange interview dates. In total, nine interviews were conducted: six with couples and three with only the carer partner present.

Capacity, Consent, and Ethical Considerations

Potential participants were provided with a written Participant Information Sheet two weeks prior to initial contact by phone, explaining what participation in the study would entail. Written consent was obtained from all participants on the day of the interview.

Participants were required to have the mental capacity to provide informed consent and to have insight into their own experiences. Capacity was assessed by the practitioner who had previously worked with each couple and had access to the person with dementia's MMSE scores obtained at the conclusion of the LTWD intervention. The practitioner also conducted preliminary discussions with both the carer and the person with dementia over the phone. Capacity was assessed initially via phone and again in person before the interview. Careful attention was given to any signs of fluctuation or change in capacity throughout the interview process.

There were some risks associated with this research, particularly given the vulnerability of the participant group. Asking couples to engage with sensitive material could potentially elicit distress. The aim throughout the research was to minimise distress, and efforts were made to remain sensitive to participants' situations, proceeding at the couple's pace and using clinical judgment to determine whether the interview was becoming too upsetting.

Participants were informed that:

- They had the right to withdraw or suspend their participation in the research at any time without providing a reason.
- They had the right to refuse to answer any questions.

- They could request a debriefing session after the interview.
- They could be directed to further support if needed.

Participants were able to withdraw from the study by contacting the lead researcher. This information was provided to them prior to their consent to participate in this phase of the research.

Inclusion Criteria for Follow-Up Interviews

- One partner in the couple had been diagnosed with dementia.
- The couple had lived together for at least two years.
- The couple had undergone the LTWd intervention.
- Participants had sufficient language abilities to engage in the study.
- Participants had the capacity to consent (as assessed by the practitioner and interviewer).

Exclusion Criteria

Participants were excluded if they were deemed to be emotionally vulnerable, physically frail, experiencing significant distress, or facing difficult family circumstances that would render participation inadvisable.

Nine interviews were conducted in total. Six couples were recruited and interviewed, and three additional interviews were conducted with only the carer partner. In these cases, the partner with dementia was either deceased (1 person), living in a care home and unable to participate (1 person), or physically present in the house but too frail to participate (1 person). Two other partners with dementia were living in care homes at the time of the interviews but were able to participate.

Participants' Demographics and Relevant Information (using pseudonyms)

1. Montse (82), carer partner, female, White British. Her partner, who had Alzheimer's disease, had died shortly after the intervention finished, so this interview was conducted with the carer partner only.
2. Melissa (74), carer partner, female, White British. The interview was conducted with her alone, as her partner, Arthur (79, male, White British), who had a diagnosis of Alzheimer's disease, had recently moved into a care home.
3. Jane (80), carer partner, and Bob (79), partner with dementia, both White British. Bob had a diagnosis of Alzheimer's disease, and both partners were present for the interview.
4. Abi (81), carer partner, and Albert (82), partner with dementia, both White British. Albert had a diagnosis of Lewy Body dementia, and both partners were present for the interview.
5. James (89), carer partner, and Carrie (90), partner with dementia. James was originally from Guyana, and Carrie from Jamaica—both Black British. She had a diagnosis of mixed dementia (Alzheimer's and Vascular). Both partners were present for the interview.
6. Andy (91), carer partner, and Matilda (87), partner with dementia, both White British. Matilda had been diagnosed with Lewy Body dementia, and both were present for the interview.
7. Martin (84), carer partner, and Ilse (82), partner with dementia, both White British. Ilse had been diagnosed with Posterior Cortical Atrophy (PCA). Although she was physically present in the house, her

deterioration was very advanced, so the interview included only the carer partner.

8. Philippa (68), carer partner, and Edward (Ted, 77), person with dementia, both White British. Both were present for the interview, which took place in a care home.
9. Kumiko (78), carer partner, and Robbie (80), partner with dementia (Alzheimer's Disease). Kumiko was Japanese, and Robbie was White British; both were present for the interview, which also took place in a care home.

Written consent was obtained from all participating couples on the day of the interview, after assessing their capacity to consent. Face-to-face, semi-structured interviews were conducted in participants' homes or, in two cases, in a private room in the care home where the partner with dementia resided. Participants were asked to reflect on their experience of the intervention, as well as their current perceptions of their difficulties.

Interview Schedule

A semi-structured interview format was used, providing flexibility to explore different perspectives and allowing space for unanticipated issues to emerge (Braun and Clarke, 2013). Face-to-face interviews created a context for emotions to surface, enabling the researcher to observe inflections, silences, facial expressions, and the couples' body language.

The semi-structured interview schedule was developed to address the research question: "How did the couples experience the intervention?" (see Appendix p73). Participants were asked open-ended questions to elicit

detailed accounts of their experiences. Interviews were audio-recorded and transcribed verbatim (Braun and Clarke, 2013). Both partners were encouraged to contribute as equally as felt natural, with the aim of fostering a flowing dialogue that ensured one partner's voice was not prioritised over the other's.

All identifiable information was anonymised during transcription by using pseudonyms. Audio-recorded data were initially stored on an encrypted USB stick and subsequently deleted after being transferred onto a secure, password-protected platform at Tavistock Relationships. The encrypted transcriptions were saved and will be deleted once the research is completed.

Thematic Analysis

Face-to-face interviews were audio-recorded and transcribed using the notation system suggested by Braun and Clarke (2013). The dialogue from the interviews was then cut and pasted into Microsoft Word files, and the original recordings were destroyed. All interviews were anonymised before being analysed using thematic analysis (TA).

Thematic analysis is a qualitative approach that involves "identifying, analysing, and reporting patterns within data" (Braun and Clarke, 2006). At the core of TA is the iterative process of developing and refining thematic maps, which represent a comprehensive understanding of the dataset through interconnected themes and sub-themes. Thematic analysis of the interviews was conducted following Braun and Clarke's (2006) guidelines, which outline six phases: familiarisation with the data, generating initial

codes, searching for themes, reviewing themes, defining and naming themes, and collating themes into a report. Adhering to these guidelines helped to establish the credibility and trustworthiness of the analysis.

To begin with, the author familiarised themselves with the data by listening to the interviews and reading the transcriptions multiple times. This initial step also involved generating a preliminary long list of codes. The list was then reviewed to identify potential themes worthy of further exploration. The next phase involved a thorough review of the identified themes, which included revisiting the original data to ensure the themes were coherent, consistent, and adequately reflected the source material. During this phase, all interviews were reread with these criteria in mind, and text relevant to the emerging themes was highlighted. Each highlighted text was then scrutinised to assess its relevance to the theme and to determine whether there was sufficient data to support it.

The internal consistency of the themes was reviewed to minimise overlap between them and to assess the coherence of the thematic segmentation. This review process helped determine whether the themes needed further refinement. In the final phase of the analysis, each theme was further defined and refined by returning to the collated data extracts and organising them into a coherent narrative, examining the linkages between them. A key aim of this process was to include a broad range of extracts within each theme to capture the full spectrum of participants' perspectives.

The analysis sought to balance descriptive statements about specific extracts with summative statements within themes that were more

conceptual in nature (Braun and Clarke, 2006). Connections between the themes themselves and with the research questions were identified, leading to the formulation of the resulting conclusions.

Results of Qualitative Analysis

Four themes emerged from the data, each linked to the central research question of how the intervention was experienced by participants. The four themes identified were: 'Experience of the Sessions'; 'Containing the Container'; 'Reconnecting: The Sense of Couplehood'; and 'Wanting More'. Each of these themes contained several sub-themes, which will now be detailed as the participants' accounts are examined. In discussing these results, the themes are linked back to the research question, exploring the extent to which participants' accounts validate the conceptual approach of the intervention, as reflected in its aims and methods. The overarching goal was to explore how the LTWd intervention was experienced by the participants.

Themes Identified

1. Experience of the Sessions

Participants' Experience of the LTWd Practitioner

Space to Express Feelings within the Sessions

Focus on the Couple's Relationship: Use of Video

2. Containment and Containing the Container

The Containing Function of the Relationship (for the partner with dementia;
for the carer partner)

The Intervention as Container for the Carer Partner.

3. Reconnecting: The Sense of Couplehood

Reconnecting Between Partners

Modelling Curiosity: Towards Recovering a Meaningful Narrative

4. Wanting More

Not enough time – the intervention not long enough

Experience of the Sessions

Participants' Experience of the LTWd Practitioner

Many participants focused on their sense of connection with the LTWd practitioner. In most interviews, carer partners expressed a positive emotional connection with the practitioner, highlighting the value of the therapeutic alliance and the ways in which they felt understood and that their feelings were "taken in." The therapeutic relationship was frequently mentioned, along with the value of being able to talk with the practitioner and connect with them emotionally.

For example, one individual conveyed very positive feelings about the intervention and his relationship with the practitioner:

"Yeah, it was very, very pleasant indeed, you know... and um, we dealt with all manner of things really, yes... it just happened to click with her [LTWd

practitioner]. She had a very nice manner and uh so on. The whole thing was most satisfactory, I, we found. Very, very helpful.” (George, carer partner).

Other carer partners expressed similar sentiments, combining positive feedback about their experience of the intervention with strong positive feelings about the practitioner:

“Yeah, well it [LTwD] was such a lovely experience... I thought [LTwD practitioner] was excellent, she just ‘got’ us.” (Philippa, carer partner).

It is striking that, in many accounts, the intervention was described as helpful for both partners, including the person with dementia. This was evident in comments from several participants with dementia who described themselves as enjoying conversations with the LTwD practitioner.

“She was down-to-earth... she was good... Visits, people coming to talk to you... Well, she listens to you... It was good, somebody being able to come out and talk with you.” (Bob, partner with dementia).

Other comments by partners with dementia underscored the importance of the relationship with the practitioner:

“I think... positively... of your ... effort... your attention... I don’t know exactly how to put things because my memory is not good enough for that.” (Robbie, partner with dementia).

Partners with dementia often remarked on the quality of the practitioner’s personality and personal attributes:

“She makes you feel quite relaxed. And she is good company... I think a lot of it was her personality. She made people feel at ease.” (Bob, partner with dementia).

Indeed, the comments conveyed the significance of the relationship with the LTWd practitioner for both partners in the couple:

“She (the practitioner who had visited the couple) ... related to me, and I related to her and at the same time (she was) building up the relationship with my wife in the latter part of her dementia.” (James, carer partner).

Carer partners expressed gratitude for the practitioner’s understanding of their feelings, emphasising how important this was to them and valuing the practitioner as an impartial listener, a "third party" who sought to understand the context of dementia and its impact on them:

“It does help, it’s nice to have someone to chat to, have, you know, not sympathy, just understanding of what you’ve got to put up with...” (Jane, carer partner).

There was a consensus among the carer partners interviewed, conveying how helpful they found the visits from the LTWd practitioner:

“She is very good at her job. She’s good at making you feel um, easy, which is nice She had a very nice manner and...the visits were...very helpful. And I remember saying to her, I hope you have found it as helpful as we have [laughs] on her last visit here.” (Albert, carer partner).

In summary, numerous comments from participants indicated their sense of being helped by the LTWd practitioner. Participants consistently conveyed

how valued their relationship with the practitioner had been, and what was striking was that this sentiment was shared by both carer partners and the partners with dementia. One person summed up the couple's feelings about the intervention by stating:

"I think we were both happy to have been included in it, so I think it was a, it was a good thing." (Montse, carer partner).

Space to Express Feelings

Carer partners described how they were able to express their feelings with the LTWd practitioner, particularly when voicing more difficult or 'negative' emotions, such as frustration, anger, and sadness. Participants highlighted how crucial it was to be honest about what they were thinking and feeling during the intervention:

"I was very frank at the sessions we used to have... I was, I get to know her [LTWd practitioner] and we spend many an hour here, and we were able to be frank with each other and I thought she was helpful..." (James, carer partner).

Several participants indicated the importance of having a non-judgemental practitioner—someone they could speak to freely about their feelings.

"I felt free to just to say, do whatever, I wanted—to cry, be angry'... All the emotions of life that were very much there and just needed to come out... I think being able to be honest about how I felt, and you know how he was, how lost I felt a lot of the time, it was just, it was an amazing thing to be able to do that." (Philippa, carer partner).

Some carer partners described how self-critical they could be about feelings and behaviours that made them feel guilty, and how much they were helped by the non-critical response of the LTWd practitioner:

“And I said, feeling really guilty ‘I do drink more’ and the [LTWd practitioner’s] response, I don’t know the exact words, but she just put it in such a way that I felt anything but judged... I think my physical health has improved as well.”

(Philippa, carer partner).

An important element of the intervention is its aim to provide space for both partners to express their feelings. From participants’ accounts, it appeared that the sessions did create space for both partners. In the next comment, a carer partner speaks of the importance of their partner with dementia having their feelings of frustration and anger—being ‘fed up’—acknowledged:

“He needs to, I think he needs to talk... to a professional like (practitioner) about what he’s feeling himself in his mind. (Speaking to her partner with dementia, she said:) Quite often you said I feel fed up with everything, you quite often said to me... when you are in a low mood and just fed up with everything.” (Kumiko, carer partner).

Indeed, it is noticeable that in several interviews, the need to ‘open up’ and honestly express feelings was seen by carer partners as important for the person with dementia:

“I suspect that he might’ve opened up to her [LTWd practitioner] more about his real feelings than he was able to me.” (Montse, carer partner).

This idea, highlighting the importance of providing space for partners with dementia to express their own feelings and anxieties, was echoed by several other participants. The following quotation, for example, describes the value of the partner with dementia being able to talk to a skilled listener:

“...those fears that a lot of dementia patients have that they don't want to talk about that things are going wrong in their bodies to the doctor and don't even want to complain about it to anybody but somebody with a really good empathetic view of things, and trained empathetic views would be able to notice and so on. That's what's needed.” (Andy, carer partner).

In summary, the opportunity to freely express their feelings in the sessions was seen by participants as very important. They expressed how they were helped by the practitioner's non-judgemental response to feelings they felt guilty about, such as anger and frustration. Normalising these feelings, and thereby reducing the self-criticism and guilt that carer partners often felt, emerged as a key element of the practitioner's approach. Participants strongly endorsed how helpful they found this aspect of the intervention.

Focus on the Couple Relationship - Dementia as a Shared

Problem

The experience of the intervention highlighted the importance of providing both shared time with the practitioner for the couple and individual time for each partner alone with the practitioner:

“Sometimes we explored things together and sometimes it was on my own, the times where [LTwD practitioner] had Toby on his own too, so that was

important as well that we could be together, and apart.” (Philippa, carer partner).

Most couples spoke about living with dementia as a shared experience and emphasised the significance of the intervention's focus on their couple relationship, which included both partners. They also noted the value of having time apart to speak with the practitioner separately:

“I needed desperately to have a very professional listener, together especially, the good thing is it's not only with me, but together with Robbie.” (Kumiko, carer partner).

“[Talking about the intervention] sometimes we explored things together and sometimes it was on my own, the times where [LTwD practitioner] had Ted on his own too, so that was important as well that we could be together, and apart.” (Philippa, carer partner).

Participants with dementia also expressed a need for their experiences to be understood and their personhood validated:

“But it's nice to think that someone's remembered that you have got this. You do feel quite lonely... This is a sort of a mysterious illness, isn't it?” (Bob, partner with dementia).

This appreciation of being "remembered" by the LTwD practitioner indicates the importance for the person with dementia of being held in mind. It was particularly moving to note that some individuals with dementia, whose memories were often severely compromised, nevertheless retained a memory of the practitioners' visits for many months afterward. It seemed that

the emotional contact with the practitioner formed a lasting emotional memory that could be consciously recalled long after the visit. Although anecdotal, this observation suggests the profound importance of establishing emotional connections with people whose memories are impaired but who can still create and maintain a bond with another person, with the strength of the connection perhaps evidenced by the conscious recall of the memory of the practitioner's visits.

In summary, participants emphasised how important it was to be seen together, as a couple. At the same time, it was evident that they valued having time with the practitioner individually—this was particularly noted by the carer partners, who needed space away from their partner with dementia. The interviews conveyed a strong sense of emotional connection with the practitioner, a sentiment that was echoed in the comments of both partners in the couple.

Observing the Relationship and the Use of Video

Carer partners reflected on how the intervention captured a sense of closeness within their relationship that could be observed, and they highlighted the value of the video technique used to facilitate this.

“The sessions together showed, gave a recording, of how we lived. And it showed our relationship, what we enjoy, going for a little walk around the park and things like that. And we always tried to keep the relationship fresh.”
(James, carer partner).

Some comments underscored the value of the video component in providing couples with a perspective on their couplehood in action. Carer partners

appreciated the intervention's ability to capture moments of closeness within their relationship that might otherwise have gone undocumented:

“We were still managing to laugh when she [LTwD practitioner] came, yes, and she caught that on the video which was very good actually.” (Montse, carer partner).

Several carer partners conveyed how much they valued the video recordings in documenting a period of their lives that was otherwise largely unrecorded. Many noted that they had very few photos of this period. One carer partner specifically mentioned how the video captured the essence of her partner with dementia and how important this was to her, as she had no other photos of her husband during his long illness. This highlighted a broader reality—that the long duration of a dementing illness, which might constitute the last decade or so of life, is often a period that is undocumented:

“She did a little video and that was quite amusing, you know, one of the best bits and she sent me some stills from it. It’s actually one of the best photos I’ve ever had of him...but he’s really laughing, you know, he was still, he was quite a jokey, sociable, jokey sort of person.” (Montse, carer partner).

Overall, the use of video was a technical element that fitted within the broader context of the practitioner’s stance of curiosity about the couple, aiming to understand them from an external vantage point. This approach seemed to help some carer partners adopt an "observing position," allowing them to reflect more deeply on themselves and their relationship with their partner:

“The other thing about [the intervention] was reminding me about being curious about things because when I was in the midst of all sorts of feelings and emotions sometimes, I wasn't able or I forgot to stand back and be curious, to ask myself the question, I wonder why, I wonder why I'm feeling upset about something I'll wonder why this feels so difficult. Standing back, reflecting on myself – observing myself and thinking about my feelings.”

(Philippa, carer partner).

In summary, the use of video was helpful to couples by providing a vantage point from which they could observe and reflect on their relationship. Carer partners specifically commented on this aspect of the intervention and how powerful it was to see something essential about their relationship captured on video. This facilitated their ability to cultivate an internal capacity for observing and being curious about their own feelings within the relationship.

Containing the Container

The Containing Function of the Relationship

The Partner with Dementia

The following quotations illustrate how a person with dementia can feel reassured by their partner and how the carer partner can have a containing function when they are feeling frightened or anxious. Since the voices of people with dementia are often missing from research, several quotations on this theme from the partners with dementia are included here.

One individual, who suffered frequent hallucinations due to her dementia (a common symptom in some dementias, such as Lewy Body dementia),

describes how crucial her husband's containing presence was when she was frightened by her hallucinations:

"...On the whole he is the one person who can calm me down, if I see or hear anything horrible...And he doesn't say 'oh well you're a silly idiot for imagining all these things'if it hadn't been for (him), telling me that I was seeing things, I would've been terrified. So, I owe him a debt of gratitude..."

"He [partner] rescued me. I could hear him coming up the stairs and I wasn't afraid that it was a burglar or anything. I knew, I could tell it was him... And if you've got dementia, you don't want pity, you want help like (partner) has given me. You need that." (Matilda, partner with dementia).

Another participant with dementia spoke about the strength of their relationship:

"We are very good together, yeah." (Edward (Ted), partner with dementia, speaking about his relationship with his partner).

Another partner with dementia expressed both his deep love and appreciation for his wife and his anxiety about losing her:

"I loves her dearly, I don't want to lose her, she been, she's a good wife to me, ain't changed, she is." (Bob, partner with dementia).

Another participant described how, despite some communication difficulties due to his dementia, he and his partner still maintained a good relationship and were able to share moments of humour:

“We still have a good relationship with each other, and we get on well together apart from the occasional bark and bite... there's a language difficulty, that kind of thing, but not saying that it stops us from having a good laugh together if something funny happens.” (Rory, person with dementia).

Carer partners were often acutely aware of their role as a containing presence for their partners with dementia and described their sensitivity to this need:

“Because if I said to him look it's alright, calm down, just hold my hand, it's alright he would calm down, he would let things be done, you know in a way that, um, if I wasn't around, he wouldn't.” (Montse, carer partner).

In summary, many participants with dementia were able to articulate their feelings about the importance of their relationship with their partner, sometimes expressing anxieties about losing them. It was striking how powerfully they conveyed their partner's unique capacity to help contain their disturbing feelings and states of mind, manage symptoms of dementia (such as hallucinations), and provide vital reassurance during times of high anxiety.

The Carer Partner

For the carer partners, one of the consequences of dementia was the loss of a relationship that could provide containment for them, as their partner's cognitive and emotional functioning declined. One carer partner described how everything had changed since his wife's dementia, and how he had to assume all the caregiving responsibilities within the relationship:

“Her dementia...you know, it was a big, big change. A big, big change. I had to make that adjustment.” (James, carer partner).

However, there were nuances to this experience, as expressed by some participants. The following quotation shows a carer partner shifting her perception of her partner with dementia and regaining a sense that he could still, at times, provide some containment for her:

“That for me was a huge turning point (during the intervention) where I realised you know it’s OK Ted is my partner. I can share my stress with him, and he can still contain some of that and still help me a bit...noticing if I’m struggling... saying how I feel and Ted being able to pick up on the emotions and give me sustenance in a very good way.” (Philippa, carer partner).

This comment highlights that the person living with dementia may still access aspects of themselves that the carer partner finds important. In this example, the partner with dementia may still provide some containment for the carer partner’s anxieties.

One carer partner pointed out that, despite the ‘chasms’ created by dementia, emotional closeness could still be achieved:

“So that when you come to look at how things work out between two people in a situation like this, those chasms are there but they are bridgeable. They’re bridgeable with care.” (Andy, carer partner).

Some comments from the carer partners conveyed the ongoing significance of the relationship for both partners:

“I think you, Ted, show people very much that we are a couple when I arrive if you see across the room you shout ‘hello this is my lovely woman’...Ted laughs... and then you come running over and you know you hug me so tight, you hold me so tight that you shake and its such. It’s so full of love. And that’s another communication...that we have and that I feel...I feel very loved.” (Philippa, carer partner).

In summary, while the carer partners expressed the loss of a relationship that could provide containment and the significant adjustments they had to make in becoming the ‘carer’ partner, there was evidence that emotional closeness could still be retained for some. At times, even the partner with dementia could provide a containing function. Overall, there was a continued sense of the importance of the relationship for both the carer partners and the partners with dementia. This observation will be further developed in the discussion of subsequent themes, particularly in ‘Recovery of Connection Between Partners’.

The Containing Function of the Intervention

Many carer partners entered the LTWd intervention at a point when they were experiencing high levels of stress and burden. One carer partner described her experience of feeling overwhelmed:

“...I think at that time... I was just feeling really burdened...” (Philippa, carer partner).

Another reflected on how challenging things had become, noting the significance of the intervention during a particularly difficult period:

“I look back to how tough it was.... I see that as being really significant that we had the intervention at a time when my blood pressure had shot up really high.” (Philippa, carer partner).

The caring role could be an isolating one, as reflected in one person’s account of the lack of communication with her partner with dementia:

“I was beginning to sort of feel at that time I was more or less on my own because I couldn’t have a conversation with him...” (Melissa, carer partner).

She went on to indicate that the intervention was helpful when she was struggling with feelings of isolation and loneliness in her role:

“...and I felt it was just me really against the world in a sense, so it [LTWd] did help in that regard.” (Melissa, carer partner).

Indeed, many participants’ accounts conveyed that the intervention helped them manage their feelings of stress and burden. They highlighted how the practitioner’s efforts to listen and understand them were fundamental to this support:

“...and (the LTWd practitioner) helped, supporting us to talk together more and what I realised was that it wasn’t the end of conversations. It was just, it was just a change, it was a change in how we... could cohabit... I have got my life back – within my relationship.” (Philippa, carer partner).

Participants noted that being able to express feelings they felt guilty about was particularly helpful. Receiving a non-judgemental, thoughtful response from the practitioner allowed them to feel understood, which in turn helped contain their feelings and reduce their stress and anxiety:

“... (I was) feeling really guilty and the [LTwD practitioner’s] response... was just so valuable to me because I was often critical of myself at that time...”

(Philippa, carer partner).

There was a strong sense that carer partners valued being "contained" in this way—having a safe space to express difficult feelings and have them acknowledged and understood by the practitioner:

“Uh, just somebody I could talk to, I think and understands, understands it, understands what you’re sort of goin’ through ‘cause it ain’t easy it ain’t easy at all. Because um, your life’s gone. Your life’s gone... she [LTwD practitioner] caught me, as soon as I said what I calls a bad time and then she’d chat like you’ve [interviewer] done, and I’d sort of cool down sort of thing.” (Jane, carer partner).

Carer partners spoke of the importance of being able to bring "negative" feelings of frustration, anger, and hostility to the sessions. These feelings were often associated with considerable guilt and anxiety, and being able to express them was clearly vital. For example, some carer partners voiced anxieties about their frustration and anger towards their partner with dementia:

“He was just getting so, difficult, and I was getting quite impatient with him because I just couldn’t deal with him sometimes, and sometimes he just wouldn’t do what I wanted him to do or I asked him to do, or go where I wanted to go, sort of thing, so I ended up getting quite ratty with him really [laughter] which I now feel guilty about [intake of breath] because I knew it

was his illness and everything but I still couldn't help getting ratty..."

(Melissa, carer partner).

Another participant expressed such feelings more intensely, describing anxieties about extreme thoughts and states of mind arising from the stress of caregiving:

"...they are going...into Alzheimer's disease and the strain then for the healthy one, comparatively healthy one could easily erupt in the sort of madness that leads to them killing their wives." (Martin, carer partner).

These feelings were accompanied by guilt and shame, adding to the emotional burden experienced by carer partners. The extent of the burden they felt was evident in these interviews, and the listening function of the practitioner was reported to be crucial in containing such states of mind. Participants vividly conveyed how important this aspect of the intervention was:

"... It's the... how do I put it? ...uh hopelessness... and I was psychologically and emotionally very weak and uh, I needed desperately to have a very professional listener... it's helped a lot... hmm... because every day sometimes I be in a harsh mood towards him, I hated myself but sometimes I couldn't stop it." (Kumiko, carer partner).

The intervention was clearly perceived as helpful in addressing feelings of guilt and self-blame, with many carer partners commenting on its therapeutic nature. Initially, many were very aware of the research aspects of the intervention, possibly because of the process of inducting each couple into

the project. However, over time, their perception shifted, and the therapeutic aspects became more apparent to them.

"I found that what was a research procedure started to become a therapy."

(Andy, carer partner).

"It was very comforting because it was supportive and...we could have rambling thoughts like as I am doing now and you responded to them, I mean that's a bit like, a kind of, it's a bit of psychotherapy, isn't it?" (Martin, carer partner).

Overall, the intervention appeared to help all the carer partners who participated in this study by providing space to talk openly and honestly about how they were feeling. They conveyed how they felt that the practitioner was 'there' for them, containing some of their emotional burden:

"But of course, in that sort of research, a bit like being a psychotherapist, you're not really offering stuff, you're taking in, and adding it all together ..."

(Montse, carer partner).

Some carer partners conveyed their disturbed states of mind and the value of the practitioner being open to thinking with them about such emotional states:

"You can see when the partner is going crazy or wants to kill himself or herself. You know, you monitor that as well, you don't just look at the subject (person with dementia) ... You can help by helping to talk to carers..." (Andy, carer partner).

These accounts underscore the importance of the practitioner as an emotional resource, capable of taking in and processing such feelings and validating these aspects of the carer partners' experiences:

“The fact is that the help that is needed for situations like this as you can see is professional help that is focused on an understanding of the real/unreal life that people with dementia or Alzheimer's live. Of huge reality next to an unreality.” (Andy, carer partner).

In some cases, participants noted how the challenges and traumatic aspects of their current experiences could re-evoked earlier childhood disturbances and difficulties. One participant, for instance, recalled early trauma—his mother's death during World War II—and being "left screaming" without any attention from the adults around him at the time. He remembered this experience—his own unattended screams—when he described trying to respond to his wife, who often screamed at night as her dementia advanced. This provides evidence for the psychodynamic concept that current trauma can re-stimulate early traumatic experiences. The participant reflected on how important it was for him to be able to discuss these feelings with the practitioner, which led to him expressing his thoughts about his own impending death and his wife's:

“Sort of being able to look at dying without getting upset by the thoughts I think is an essential. Is essential for anybody. On the other hand, ... It's difficult to talk about it...and many friends who are on the verge of dying don't want to talk about it...” (Martin, carer partner).

This conveys how, through forming an emotional connection with the practitioner, this participant was able to express feelings of loss, as well as deeper fears and anxieties about death and mortality. It was important for the practitioner to be open to exploring participants' feelings about death and dying, which, as this quote suggests, they felt others did not want to discuss. Demonstrating an openness to discussing fears of death emerged as a crucial aspect of the work.

In summary, the carer partners valued the intervention as a space to express their feelings, and there was moving testimony from many participants indicating that the intervention had served a containing function for them. This enabled them to express feelings that they felt they had no one to talk to—feelings of guilt or shame, such as anger and frustration with their partner with dementia, or fears about dying, which they felt others did not want to hear about. The open, non-judgemental stance of the practitioner was seen as highly important by the participants we interviewed.

Reconnecting: The Sense of Couplehood

Reconnecting Between Partners

The theme of partners reconnecting and regaining a sense of their "couplehood" is central in the narratives of the interviews. Participants often described how the intervention facilitated this reconnection, allowing them to rediscover emotional bonds and intimacy with their partners.

"We [he and his partner] got closer together, there was an emotional bond... I feel feelings here, when Marie [partner] is needing support which are

fulfilling, I mean they are... supportive as well for me... I take comfort from feeling those feelings.” (Martin, carer partner).

Many participants expressed how vital their relationship with their partner was to them and the importance of finding ways to maintain it despite the challenges posed by dementia:

“We always had a really close relationship and it’s very important that continues. I always repeat what I said from the beginning if you’re having dementia Ted that I will stay with you on the journey through thick and thin. Because we are strong together.” (Philippa, carer partner).

Carer partners indicated that, through the intervention, they discovered new approaches to understanding and connecting with their partners with dementia:

“I found new ways of looking at things and new ways of understanding Ted, and we communicate better.” (Philippa, carer partner).

They also felt supported by the practitioner’s practical focus, which included techniques such as modelling or scaffolding, to help them find new ways of connecting with their partner with dementia. For example:

“When I said about not facing each other he [LTwD practitioner] suggested we face each other and that we hold hands or touch each other to sort of well to reassure him really that I was there for him in a way. Things like that, I think that did help.” (Melissa, carer partner).

Other carer partners agreed that the sessions were beneficial in enhancing their relationship by increasing contact between them. They described how

the practical aspects of the intervention and the suggestions offered by the practitioner for improving their relationship made a tangible difference:

“Yeah, I mean for me it was very good I think because it was nice to talk to them... to talk through things and they had suggestions.... I think it seemed a bit better for a few days afterwards, you know, and if they'd have given me suggestions then that would help.” (Melissa, carer partner).

Several participants mentioned a sense of reconnecting with their partners and experiencing more positive feelings towards them, which they directly attributed to the intervention. One participant described how her partner with dementia started engaging more during the sessions, which continued afterward, leading to improved communication and revived warmer feelings in the carer partner:

“I found it's always a warm feeling, straight away...straight away it [LTwD intervention] was helpful. Before your coming, he was really quiet in the back (laughter) but to talk before and afterwards, it's no exception, I always feel warm subtle feeling towards him. I still remember... it spontaneously happened. Yes, I still feel this, so it works!” (Kumiko, carer partner).

This process of reconnecting was sometimes evident within the research interview itself. During one discussion, a carer partner, speaking to her partner with dementia, expressed:

“I see some really lovely things about you and some of the things that would make me warm to you even more than normally, are how much you need me on this journey and I'm just so willing to be on it with you, that it makes me

feel good and fulfilled, in a very different way than before, but good.”

(Philippa, carer partner).

Sometimes, these moments of connection were brief, but they were still perceived as valuable by the carer partner:

“I mean now and again, you know the way he was, now and again that person emerges, briefly and then, ‘Polly’ (daughter) says suddenly dad appears, and then he’s gone again.” (Melissa, carer partner).

Another carer partner described finding ways to communicate with his partner even in the advanced stages of her dementia, where emotional warmth was expressed physically when words were no longer possible:

“...(I) hold her wrist and squeeze it gently... I feel that a communication is taking place ...there is a kind of warm flesh to flesh sort of grasping of her wrist and her hands ... there’s a lot of emotion in what she’s doing with her hands and those movements.” (Martin, carer partner).

These quotations illustrate many examples of how the intervention helped couples reconnect by fostering greater understanding and emotional contact:

“(In the LTwd sessions) I think we got to understand each other ... I’m always in her life, she knows me...” (James, carer partner).

Additionally, some comments highlighted the significance of the couple relationship for partners with dementia, who were sometimes able to express feelings about their relationship even in the advanced stages of the illness:

“We manage quite well; I think we have managed quite well to have a reasonable or quite good or very good relationship with each other or... connection with each other... because... we ... we ... we do not speak each other's language... I had the idea in my head that I should learn Japanese, extending my... my... my options.” (Robbie, partner with dementia).

An important aspect of this theme was the quality of the loving aspects of the relationship that the couples were able to maintain. For some, there was a strong sense of the bond they were able to hold onto between them:

“... I still love him... we do still have a ‘something’. Love, I think it's called.” (Abi, partner with dementia).

Such loving feelings and assertions of the crucial importance of the couple relationship were also articulated by many of the carer partners. One person expressed it movingly:

“The relationship's alright because she [partner] knows me for my, for my entire life. I told her social worker, I said this woman is part of me, my entire life and don't try to break the relationship...” (James, carer partner).

Another carer partner conveyed loving feelings and the difficulty of separation, reflecting on the comings and goings of visits to her partner in residential care:

“When I come and see you ... we have a lovely time and you tell me how much you love me and I tell you how much I love you ...it's hard to separate it's hard to um leave each other when we are having a nice time... but the

times that we do have together umm we talk a lot and we have a lot of fun together.” (Philippa, carer partner).

Overall, references to the struggles that partners faced in managing dementia recurred in their accounts, often coupled with positive comments about the relationship and their importance to one another:

“We had one really rough spell, um, we were just barely hanging on in there, like. We had absolutely nothing. ... You do learn from each other, don't you? Definitely... I think in a way we comp- can't think of the word I want to say. Complemented each other.” (Abi, partner with dementia).

Participants also spoke about how, during the intervention sessions, discussions sometimes focused on what their relationship was like before the onset of dementia. They reflected on how they had managed difficult periods in the past, navigated previous challenges and losses, and recalled positive memories. Contemporary struggles were often linked to reminiscing about historic challenges as well as the good times earlier in their lives together. Many carer partners mentioned that they were engaging in reminiscence during the intervention:

“It was a, a reflection on happier times.... we had some rough passage at the beginning.... I enjoy reviewing the years, the decades going by.” (James, carer partner).

Some partners with dementia also described the intervention as an opportunity to reminisce about their life together:

“We started off going through our wedding photographs and talking about things that have come and gone since.” (Albert, partner with dementia).

Couples' narratives suggest several factors contributed to this reflective process: the practitioner's ability to establish an atmosphere of curiosity and interest in them and their history, encouraging the couple to explore their shared past, and in doing so, rekindling feelings of "couplehood." There were many examples of this. One person evocatively described how, during the intervention, he and his partner:

“... (we) got to understand each other and... memories I had, well for me it took me back to decades when... we developed the relationship and how we enjoyed it. In the Tavistock sessions, we were rekindling.” (James, carer partner).

Describing how the intervention helped her to recover her sense of connection with her partner with dementia, one person recounted a particular memory. This account is quoted in full because it seems emblematic of her experience of the intervention and its impact on her thinking about her relationship:

“(I was driving us in our van) ... it feels dangerous, it's windy and on top of this big bridge it was really scary and I was just describing this (to the LTWd practitioner)... I was saying I was trying really hard to keep hold of the wheel and keep hold of my stress so I wouldn't upset Ted and (the LTWd practitioner) said why do you worry about upsetting Ted? And I said, well... I felt like I had to protect him and I wouldn't have thought that before dementia... I could feel myself being frightened underneath but also irritated

you know 'just a minute Ted I've got to concentrate' and actually I didn't need to do that I could just say I'm really scared of this wind, it's moving the van around and you know it's worrying for me... this really wonderful relationship that we have had since the time I met Ted and I thought dementia was ending that but it hasn't ended it, it's changed it." (Philippa, carer partner).

This quotation could be seen as a metaphorical account of the dementia 'journey,' where the turbulence of the experience brings significant anxiety and, for the carer partner, a sense of being "alone at the wheel." Her account illustrates how the intervention helped her to recognise her underlying anger and frustration and to alleviate some of her anxieties about needing to protect her husband from her feelings of stress. This allowed for some recovery of emotional honesty and connection in the couple's relationship.

In summary, many participants' accounts indicate that they felt the intervention had increased the closeness between them. For some, there was a recovery of emotional connection in their relationship. Participants conveyed very movingly the experience of "bridging the emotional chasm" that dementia had brought to their relationship, showing a revival of warmer and more loving feelings. This comment seemed to capture this sentiment:

"I always feel warm subtle feeling towards him (after the practitioner's visit). I still remember... it spontaneously happened."

Recovering a Meaningful Narrative

Another important element of the intervention is the practitioner's modelling of interest in, and curiosity about, the experiences of the couple, including the partner with dementia. The aim is to help the couple recover a

meaningful narrative of their lives, as this is often lost or fragmented due to dementia. This approach was found to be important for both partners, as the following comments suggest:

“And there’s something about curiosity that’s... umm... vital in this kind of journey.” (Philippa, carer partner).

This theme of the practitioner’s curiosity about the experiences of both partners is closely linked to another significant aspect—the focus on seeking to understand and find potential meaning in their behaviour and feelings.

Participants highlighted how valuable this approach was for them:

“It was tremendously helpful... especially your approach of trying to understand what’s going on in his head - it’s helped a lot... if we have a very high standard professional listener, therapist with us, to understand what’s going on in his mind and if possible, in my mind - as well from the more logical, the third person’s eyes. Especially to understand him but also to understand myself.” (Kumiko, carer partner).

There was also evidence that partners with dementia valued the intervention, both from their own accounts and from the observations of carer partners who noticed the positive effect of the intervention on their partners:

“It [the intervention] worked very well indeed because she (partner with dementia) felt she had someone she could focus on and could focus on her.” (Andy, carer partner).

Partners with dementia also expressed appreciation for the intervention:

"I've always had a good impression of your effort..." (Robbie, partner with dementia).

Overall, most participants described the intervention as valued and helpful. There was evidence that both partners with dementia and carer partners felt understood and validated, both as individuals and as a couple. Several carer partners discussed the intervention as a space where they could try to make sense of events and feelings. This underscores the perceived helpfulness of the intervention, and it is unsurprising that more than half of the carer partners commented that the intervention was not long enough.

In summary, the practitioner's approach of demonstrating curiosity and seeking to understand both partners' experiences was seen as crucial in helping them recover a meaningful narrative of their lives. The intervention provided a space where both partners could feel understood and validated, which was highly valued by the participants.

4. Wanting More

The theme of "Wanting More" highlights the importance of the consistency and regularity of the sessions within the intervention, as well as the lack of any similar support provision once the intervention ended. This sentiment was strongly reflected in the participants' comments:

"He (person with dementia) really liked... and actually looked forward to it... and that's why it was, you know, helpful to have somebody to touch base with and it's, so it was a stability factor for him." (Montse, carer partner).

The reference to the intervention as a "stability factor" is striking, suggesting that the regularity of the visits helped both partners feel a sense of continuity and helped establish a reliable therapeutic alliance. This is a central aim of the intervention—to foster a stable therapeutic relationship with the couple, involving both the person with dementia and the carer partner.

The importance of the regular sessions and home visits was expressed by several other participants, who pointed out that they would have liked more sessions and felt that the intervention ended too soon:

"...If it's a free choice, then it could have been another one year, it was very short but also visiting us, that's also very helpful." (Kumiko, carer partner).

"We were quite upset when it finished. And tried to extend it for a bit... I hope you get more funding and can do it for longer than eight sessions." (Montse, carer partner).

The gap left in the couples' lives after the intervention ended was poignantly expressed by many participants, indicating the lack of other similar interventions that could take its place. One participant reflected:

"In a program like this, you vanish... There is no other organisation to take over with enough expertise to be able to handle it [talking about carer burden] ... So, you see the gap that your procedure, your research procedure leaves..." (Andy, carer partner).

Another participant expressed a similar sentiment:

“It [the LTwD intervention] was like finding a port in a storm for me at that time and what I have gained from it has sustained me... even though I wanted more.” (Philippa, carer partner).

In summary, the participants expressed a strong desire for more sessions and an extension of the intervention, highlighting the significant impact it had on their lives and the lack of comparable alternatives. The intervention appeared to provide a sense of stability, support, and continuity, and its ending left a noticeable void in the lives of the couples. The comments reflect the value placed on the intervention and speaks to a need for more sustained support for couples living with dementia.

Discussion

The qualitative data provide valuable insights into the experiences of couples participating in the LTwD intervention, adding context and depth to the quantitative results. This discussion explores the links between the participants' accounts and the key elements of the intervention, assessing how these align with the conceptual and clinical foundation of the approach while drawing on the existing research literature.

Participant interviews support the findings from quantitative measures, indicating that many carer partners entered the LTwD intervention at a point when they were experiencing high levels of stress and burden. Comments such as *“...I think at that time... I was just feeling really burdened; I look back to how tough it was... we had the intervention at a time when my blood pressure had shot up really high; I felt it was just me really against the world.”* illustrate the intensity of their experiences. As reflected in their accounts,

carer partners talked about the relief of being able to express their feelings: *“all of the emotions of life that were very much there and just needed to come out”* and the importance of not feeling judged by the practitioner: *“she was anything but judgemental...”*

These participant narratives are consistent with the research literature, which shows that as the illness progresses, the carer partner must take on increasing responsibility for their partner with dementia (Ducharme et al., 2013; Vikstrom et al., 2008). Consequently, carer partners experience heightened burden, which is associated with negative physical and mental health impacts (Boyle, 2013; Boylstein & Hayes, 2012; Lin et al., 2012; Quinn et al., 2008; Vikstrom et al., 2008a, 2010; Quinn et al., 2009; Vikstrom et al., 2008).

From a psychoanalytic perspective, this situation can be conceptualised as a need for the carer partner to become the "container" for their partner with dementia's increasingly fragmented states of mind, beyond the practical demands of the caregiving role (Balfour, 2014; 2023). The interview data underscore the emotional challenges of this role change for the carer partner: *“(I felt) hopelessness... and I was psychologically and emotionally very weak,”* and highlight the importance of their containing function for the partner with dementia: *“he is the one person who can calm me down.”*

Furthermore, some carer partners' comments reflect the potential rewards of this caregiving role and how crucial it was for them to sustain the relationship with their partner: *“how much you need me on this journey and I'm just so willing to be on it with you, that it makes me feel good and fulfilled.”*

However, the interviews show that becoming a 'carer' partner was often a profoundly challenging situation for participants and was frequently linked to difficult feelings of frustration, anger, loss, and resentment towards their partner with dementia. Comments such as *"I (was often) in a harsh mood towards him, I hated myself but sometimes I couldn't stop it; I ended up getting quite ratty with him, (even though) I knew it was his illness; you can see when the healthy partner is going crazy or wants to kill himself"* highlight the intensity of these emotions. This qualitative data echoes existing research findings about the significant emotional challenges associated with becoming a carer partner (Pozzebon et al, 2016; Boylstein & Hayes, 2012).

The role of being the container for the emotional distress of the person with dementia is invariably an emotionally exhausting one, as reflected in the accounts of the carer partners in this study: *"it ain't easy, it ain't easy at all. Because um, your life's gone. Your life's gone; one could easily erupt in the sort of madness that leads to them killing their wives."* Carer partners need substantial emotional resources to sustain this role. This requires that their own feelings and emotional states are "contained" to provide them with sufficient internal support to maintain an emotional link with, and offer containment to, their partner with dementia.

This concept is discussed throughout the theme of "containing the container," which is explicitly addressed in the aims of the Living Together with Dementia (LTwD) intervention. The intervention emphasises the crucial importance of a third containing figure—a practitioner—to whom the carer partner can talk openly about the reality of their feelings without fear of judgement, and who will listen and provide support. The interviews

demonstrate that the emotional connection with the practitioner was vital in this regard, with carer partners expressing how the practitioners helped to contain their feelings, reducing stress and improving well-being:

"...she (the practitioner) talked to me about these feelings – and I cooled down."

Overall, the carer partners experienced their relationship with the LTWd practitioner as being like *"somebody I could talk to, who understands what you're going through,"* helping them make sense of their feelings.

As previously discussed, the concept of "containing the container" can be visualised as a "layering of containment," akin to a Russian doll: the person with dementia is contained by their partner, who is, in turn, contained by the therapist, who themselves has the containment of supervision (Balfour, 2014). With such containment, carer partners may be better able to provide emotional containment for their partners with dementia over time. Some carer partners' comments provide evidence for this outcome, with the benefits of the intervention being sustained even after it ended: *"What I have gained from (the intervention) has sustained me,"* as one carer partner noted at the twelve-month follow-up. From the participants' accounts, the LTWd practitioners appear to have been successful in "containing the container," one of the key aims of the intervention.

Without such containment for carer partners, "negative" feelings of frustration, stress, and anger—which cannot be expressed and processed—may be enacted in harmful ways, either through acts of commission or omission. This could manifest as overt criticism, hostility, or abuse directed at

the partner with dementia. Alternatively, such feelings may be perceived as damaging and disturbing, leading the carer partner to withdraw into anxiety and depression, amplifying their burden. While the idea that uncontained feelings are likely to be discharged in action is central to a psychodynamic understanding, it is notable that other approaches to intervention in this area do not recognise the importance of containing "negative" feelings.

In their review, Gilbert et al. (2023) identified that many studies found expressions of negative emotions like loss, frustration, and conflict between partners (Dassa, 2018; Ingersoll-Dayton et al., 2013, 2016; Kindell et al., 2018, 2019; Kwak et al., 2018; Ryan et al., 2020). Yet, the authors of these studies—and indeed, the reviewers too—viewed the expression of such "negative" emotions as problematic. However, such feelings are often crucial aspects of the experience of dementia for couples. The evidence from this qualitative study suggests that if these emotions are explicitly addressed, rather than suppressed or ignored, they may be worked through and contained, as was achieved for some participants in the LTWd intervention.

Modelling Interest and Curiosity

Interest in, and curiosity about, the experience of the partner with dementia has historically been a neglected perspective in research. Froggatt (1988) comments that it is difficult to give credence to "*fragmented thought*," but this difficulty has resulted in the experience of dementia becoming an "*invisible*" one, largely overlooked by research. One aim of the intervention is to model a valuing of both partners' experiences, including those of the partner with

dementia. By doing so, the intervention seeks to help the couple maintain or recover a meaningful narrative, which is often lost as dementia progresses.

The interviews show that participants appreciated being seen as a couple, with the practitioner taking an interest in the experiences of both partners.

Their comments supported the research evidence that a lack of communication in the couple's relationship was part of the stress and burden experienced by the carer partners. Carer partners described their partners with dementia as having become withdrawn before the intervention began: *"Before your coming, he was really quiet... but to talk... afterwards, it's no exception, I always feel warm subtle feeling towards him."* This withdrawal by the partner with dementia was significantly improved by the intervention's focus on exploring and seeking to understand their experience. This approach seemed to enhance the emotional connection and communication between the partners:

"I found new ways of looking at things and new ways of understanding Ted, and we communicate better." (Philippa, carer partner).

This was a key aim of the intervention: to enhance emotional contact and understanding between the partners in the couple. By modelling a position of curiosity about each partner's experience, and about the couple as a whole, the practitioner's goal was to encourage the couple to develop their own curiosity. The findings suggest that this was important in sustaining emotional contact between the partners. As one carer partner noted:

"thinking about the other person's mind... it's still there." (Carer partner).

Supporting the carer partner's ongoing ability to remain interested in their partner's internal world and feelings is a crucial element of the intervention. Participants' comments underscored the importance of this focus in supporting emotional connection within their relationship. The practitioner's modelling of curiosity and genuine interest provided a framework for the couple to explore and understand each other's perspectives, which, in turn, fostered greater empathy and connection. This approach helped to counteract the withdrawal and loss of meaningful communication that can accompany dementia, thereby enhancing the quality of the couple's relationship and their ability to navigate the challenges of the dementia journey together.

Videoing the Couple Doing Everyday Activities

Central to the intervention's approach to fostering emotional contact between partners is the technique of videoing them while they are engaged together in everyday activities. Research evidence suggests that participating in shared activities is a powerful means of establishing greater mutuality within couples. Supporting new coping strategies and maintaining shared activities can help build resilience in couples living with dementia (Eligostrad, 2019; Bergman et al., 2016; Boylstein & Hayes, 2012; Hellstrom et al., 2007). However, the essential element is not merely 'doing' things together but rather the emotional connection that these shared activities can facilitate.

To enable the couple to find new ways of being together and communicating, the practitioner facilitated their engagement in shared activities, at times intervening practically to model and scaffold ways of connecting through the

activity. This approach helped partners use shared activities as a vehicle for emotional connection.

As described in chapter 5, the activities were videoed and then watched back with the couple. This element of the intervention served as a means of helping the couple gain a fresh vantage point to see themselves and their couplehood in action. The role of the practitioner was to support this process, helping the couple reflect upon the dynamics of their relationship as captured on the video. As part of this, the practitioner sought to hold a "couple state of mind" (Morgan, 2019), attempting to maintain, at least some of the time, a "third position" (Britton, 1989) in relation to the couple. This involves the therapist being subjectively involved, in turn, with each individual partner and with the couple as a unit, while also finding the psychic space to move to a different vantage point—to stand outside these relationships and observe.

Participants' comments conveyed their perception of this approach: "*the therapist with us... to understand what's going on in his mind and if possible, in my mind as well,*" and the use of the video, combined with the practitioner's position of curiosity about the couple, seemed to help some carer partners to observe themselves and their relationship from an "observing position."

Carer partners' comments highlighted this aspect of the intervention, noting that it helped them "*to understand... from the more logical, the third person's eyes,*" and supported reflection on their relationship with their partner and themselves: "*Standing back, reflecting on myself – observing... and thinking about my feelings.*" The videotaped vignettes of the couples' interactions

proved to be a powerful way of creating conditions for such self-reflection and capturing the dynamics of their relationship. This had considerable face validity for the couples, who engaged in this aspect of the intervention with enthusiasm.

An unanticipated benefit of this approach was the ability to produce still photos from the videos, which captured moments of closeness between the partners. These photos proved to be very important for the couples involved, often moving them deeply by capturing their interaction during this period in their lives together. In several cases, by the time of follow-up, the partner with dementia had died or moved into residential care, and the photos of the couple engaged with one another became of great emotional significance.

Overall, the use of video in the intervention provided a unique and valuable tool for enhancing self-reflection, fostering emotional connection, and creating lasting memories that held meaning for the couples, especially in the context of their dementia journey.

Recovering a Sense of Couplehood

An overarching aim of the intervention is the recovery of a sense of "couplehood," which encompasses the theme of enhanced emotional contact within the couple. Qualitative research in this field identifies "couplehood" as a pivotal factor in understanding how couple relationships can be supported to mitigate the negative relationship outcomes of dementia (Forsund et al., 2014; Hellström et al., 2005; Johnston & Terp, 2015). The qualitative data from this study suggest that the intervention helped many couples maintain or recover the emotional closeness in their relationships that was being

eroded due to dementia. The data indicate that the intervention succeeded in helping couples to reconnect by enabling more emotional contact between them:

“We [he and his partner] got closer together, there was an emotional bond.”

Indeed, many participants’ accounts suggest that they felt the intervention increased the closeness between them:

“Those chasms are there but they are bridgeable.”

These findings support the idea that emotional disconnection is a significant source of difficulty for couples dealing with dementia and that increased connection can alleviate this situation. Carer partners’ comments about how much this reconnection helped them reinforce this thesis:

“We could still share things; bridge the chasm; I could still get some containment from him.”

To enhance emotional contact between the partners, the intervention also focused on exploring what the relationship was like before the dementia, how the couple managed through difficult periods in the past, previous challenges, and losses, as well as recalling positive memories. Many participants noted that they engaged in reminiscing during the intervention. One participant evocatively described how, during the intervention, he and his partner *“were rekindling.”*

Overall, the interview data suggest that subjective "burden" for carer partners was reduced and couple resilience was strengthened as a result of increased emotional contact between partners, enhanced understanding, and an

increased sense of "togetherness" and "couplehood." This recovery of couplehood not only supports the emotional well-being of both partners but perhaps also enhances their ability to face together the challenges posed by dementia.

‘The Intervention Was Too Short’

Many participants commented that the intervention did not last long enough. This feedback aligns with our observations that an acute, brief model of intervention is not optimal for a long-term, progressive illness like dementia, with which couples may live for many years. The experience of the intervention underscored the need for long-term support for people living with dementia. Overall, couples conveyed that they needed the practitioner to be alongside them in a more ongoing capacity, aligning with the protracted timescale of the illness. Future research should explore extending the timeframe of the intervention to better match the long-term nature of dementia care.

Limitations of the Study

This study is limited by its small sample size, warranting caution when discussing the results and extrapolating from them. It is also notable that the participants’ comments were almost entirely positive, with no direct criticisms of the intervention or comments about its limitations—except for its brevity and the expressed desire for more sessions. This could suggest ‘demand effects,’ given that the study’s aims—to improve the relationship of the couples involved—would have been apparent to the participants.

Additionally, the interviewer was known to the participants and closely

identified with the project, which might have constrained participants from voicing criticisms, even though they were encouraged to discuss aspects that had not worked well. The sample was a small, self-selecting group of participants who may have been predisposed to view the intervention positively.

In future research, conducting follow-up interviews anonymously, with interviewers who are clearly independent of the project and its aims, would be crucial to create conditions where participants feel free to provide honest feedback.

Regarding the participants, it is important to note that most were of "White British" ethnicity, with only two participants from non-white, non-British backgrounds. This limits the study's insight into the lived experience of people from other ethnic backgrounds and its applicability in different cultural contexts. Additionally, all participating couples were married and had been together for several years, even though some were in second marriages, which limits the understanding of experiences in "new" couples. As divorce rates rise, the demographics of couples facing dementia may change in the coming years. Furthermore, all couples were heterosexual and older than 65, with six out of the nine couples interviewed coming from upper-middle-class backgrounds.

Not all partners with dementia were able to participate in the interviews, resulting in more carer accounts and a greater number of carer quotes used in the analysis.

Despite these limitations, this study successfully recruited a primary sample, engaged with both partners in most cases, and gained a rich understanding of their subjective experiences. Future research could focus on process studies, including recording therapeutic sessions and analysing these transcripts, to provide a more in-depth understanding of the intervention's effects on the elements of the couple's relationship that it aims to improve. This would help determine whether the proposed mechanisms of action of the intervention—namely, greater containment of both partners, enhanced emotional contact, and a strengthened sense of couplehood—are indeed the active ingredients that serve to bolster resilience, reduce the burden on carer partners, and improve outcomes for both partners.

Conclusion

Despite the limitations regarding the claims that can be made, this small-scale qualitative study of participants' accounts suggests that the intervention effectively addressed the issues it sought to tackle. Specifically, it appears to have ameliorated factors associated with the negative effects of dementia on relationships, such as the loss of emotional connection, shared involvement, and "couplehood." The intervention was designed to help partners observe and reflect on their relationship, enabling them to consider the impact of dementia on their way of being with one another. Participants reported feeling supported by the intervention's techniques for enhancing emotional contact through engagement in shared activities, which helped them establish greater "mutuality" and "couplehood"—factors that research identifies as crucial for resilience (Hirschfeld, 1983; Uchino et al., 1994; McGovern, 2011; Wadham et al., 2016).

The themes emerging from the participant interviews support the conceptual foundation of the intervention, which is rooted in key principles of a psychodynamic approach. Most notably, the importance of containment was highlighted, with participants frequently mentioning the value of being able to express their feelings and have them understood, as well as the benefits of increased contact and understanding between partners. The intervention appears to have helped many couples reconnect emotionally, feel closer, and find new ways of being together while living with dementia.

Overall, this study contributes to the growing body of literature supporting the value of a relational approach to dementia care, where the "unit of care" is not the person with dementia in isolation, but rather their relationship with their partner and family, as well as their wider community.

Chapter 9: Discussion and Overall Conclusions

This PhD study has investigated the implications of psychoanalytic models and attachment research in establishing an intervention aimed at improving relationship factors in dementia, thereby reducing carer burden and enhancing outcomes for both partners in a couple. A central component of this approach has been to extend the concept that, at the beginning of life, the relationship with primary attachment figures is crucial for the development of the mind, to the end of life when cognitive function is being lost in the "reverse ontogenesis" of dementia (Reisberg, 2002). As this study has sought to demonstrate, for couples living with dementia, the quality of their relationship becomes increasingly significant, with profound implications for the mental and physical health of both partners as the disease progresses.

The empirical and theoretical literature underpinning these claims has been reviewed, highlighting the evidence for the lack of empirically based, conceptually grounded relationship interventions for couples living with dementia. It is within this context that the present study has sought to establish a foundation for developing a relationship intervention for couples who, in increasing numbers worldwide, are living with dementia. Additionally, the study has explored the development of a training programme in this intervention for healthcare staff.

This chapter will review the conclusions drawn from this work and consider the next steps for research and development in this field.

Reviewing the Approach to Intervention Presented in this Study

A crucial factor in evidence-based arguments in psychosocial intervention research is the conceptual foundation of the work (Bringmann et al., 2022). This aspect has often been overlooked in the design of interventions in dementia care (Gilbert et al., 2023). For example, as described in chapter 3, Multi-Component Interventions that comprise diverse elements without cohesive conceptual models may show statistical evidence of effectiveness. However, if it is not clear what the "it" is that is effective—and why we would predict it would positively address the problem—then claims of purported "efficacy" are difficult to substantiate meaningfully (Belstein et al., 2019). In other words, intervention design should be grounded in robust conceptual and clinical models, which are then empirically tested.

As detailed in earlier chapters, the approach of this study is informed by attachment research, psychoanalytic thinking, and dementia research, providing a foundation for modelling the relationship dynamics of dementia. The aim has been to create a conceptually grounded intervention that leverages what is known from attachment studies about factors likely to mitigate the insecurity and anxiety that dementia introduces into the attachment system. The intervention also draws on psychodynamic clinical thinking to ameliorate the relationship impacts of dementia, which research has shown to be highly detrimental to the mental and physical health of both partners in a couple living with dementia.

On the surface, couples engaging in everyday tasks together—such as washing up, looking at photo albums, or clearing a cupboard or fridge—and recording these activities on video might not appear particularly psychoanalytic. However, this study has aimed to "translate" key psychoanalytic and attachment concepts into a pragmatic intervention, seeking ways to remediate the negative relationship impacts of dementia that are well-documented in the research, as discussed in detail in chapter 2. In essence, the Living Together with Dementia (LTwD) intervention provides practical methods for addressing key dynamic issues: enabling the expression of negative feelings, finding everyday ways to enhance emotional contact, using shared domestic activities as mediators of emotional connection between partners, and above all, offering containment for the couple.

The intervention also draws upon approaches developed in work with parents and children, which emphasise the importance of observation and incorporate video as part of the method. This model of videotaping shared everyday activities with the couple, alongside therapeutic discussions, is designed to enhance closeness and "couplehood." These elements have been combined into an intervention with a practical focus on shared engagement in everyday tasks, where the behavioural focus serves as a means to achieve emotional contact between the couple. As discussed in previous chapters, research indicates that emotional contact is a key factor in the quality of life for couples and, ultimately, their resilience (Balfour, 2014, 2018; Boylstein & Hayes, 2012; Hellstrom, 2005, 2023; Pozzebon et al., 2016).

How Far Did this Study Succeed?

One of the primary aims of this study was to assess whether its results would justify advancing to a larger-scale testing of this approach. As discussed, this study has provided preliminary evidence for the effectiveness of the intervention: it significantly reduced carer burden for participants who experienced moderate or severe levels of burden at the study's outset, with other variables, such as relationship satisfaction, communication, and coping, remaining stable. This stability is notable, given the expected decline in these areas due to the progression of dementia. Additionally, the qualitative data illustrate the perceived helpfulness of the intervention in mitigating the negative relational impacts of dementia. Participants' accounts supported its effects in the specific areas it aimed to address, offering containment, enhancing the couple's resilience through improved emotional contact and understanding, and supporting mutuality and "couplehood."

Further evidence also supports the effectiveness of the training programme. Data show that the training and supervisory model significantly improved participants' confidence in delivering the intervention to couples living with dementia. The study highlighted the importance of staff training in this area: how it can enhance morale, reduce burnout, and thereby improve outcomes for patients with dementia in their care. Importantly, the study found that it was feasible to train a range of staff from diverse backgrounds, provided they were assessed for personal suitability. This finding suggests that training in this intervention model may be scalable.

While acknowledging that this was a small, naturalistic, and therefore limited study, the results support a positive answer to the question posed at the outset: the study data indicate the value of conducting a randomised controlled trial (RCT) of the intervention and training programme as a next step. An RCT would allow for testing the efficacy of the intervention at scale and more rigorously examining its benefits for couples living with dementia, as well as for staff implementing the intervention. Additionally, incorporating a more extensive qualitative component into the trial would help elucidate the potential mechanisms of action of the intervention and better understand the mediators of the effects found. Moving forward, the current study provides evidence for the value and feasibility of establishing effective and meaningful relationship support for couples living with dementia—a crucial first step towards launching an RCT to evaluate the efficacy of this approach.

To envision change in which such relationship support for couples with dementia is achievable at scale, it is necessary to consider wider systemic aspects and the context of implementation. These considerations include the resistances that dementia can evoke at the organisational level, within staff teams, and among professionals such as psychotherapists, who currently offer very little to this population. Additionally, a re-evaluation of dementia care pathways and post-diagnostic treatment for people with dementia is required. As discussed, this shift must move beyond the current atomised focus on the individual patient with dementia to include the couple, family, and wider community and social context.

As this study has discussed, reframing our approaches to dementia in this way necessitates clarity about the "negative" feelings it evokes. It is insufficient to simply encourage family carers, partners, and workers in the field to "embrace" a positive view of dementia, as much of the literature in this area tends to do (Killick, 2013). Instead, as this study has demonstrated, psychological support and understanding must be integrated to create a context where resentments, frustrations, anger, and, above all, anxieties about close emotional contact with fragmented minds can be expressed and, to the extent possible, worked through. In the words of Tom Main, founder of the Cassell Hospital, from his address to the British Psychological Society in 1957: *"If at any time you are impelled to instruct others to be less hostile and more loving than they can truly be—don't!"* As he argues, this would only drive such feelings underground, where they would be expressed in less conscious and more destructive ways.

As discussed, the current literature and existing psychosocial models of intervention are limited in their handling of "negative" emotions. As the findings of the Gilbert et al. (2023) review illustrate, such emotions should be seen as an inherent part of the dementia experience. Recognising this is essential for interventions aimed at benefiting the couple relationship. Therefore, it is critically important to enhance our understanding of the resistances among practitioners, family members, and wider society to engaging with dementia at the emotional level. Addressing these factors is crucial to developing effective psychotherapeutic interventions and services.

Taking Account of Resistances to Psychotherapeutic Work in Dementia Care

Why has psychotherapy research taken so long to consider the couple relationship in dementia care? In exploring this question, it is essential to recognise the resistances to offering psychotherapeutic help to people living with dementia. Psychotherapy is rarely provided for individuals with dementia, and it is often assumed that they lack the cognitive capabilities or willingness to engage with such an approach (Watts et al., 2014; Gilbert et al., 2023). However, as discussed in this study, understanding the internal experiences of people with dementia and their partners is vital, as the anxieties felt at both conscious and unconscious levels can be substantial as the illness progresses and dependency increases.

From a psychoanalytic perspective, as the ego's resources and defences are progressively diminished in dementia, unresolved psychological difficulties may resurface, influencing how losses and changes are experienced. For some, the growing dependency associated with dementia may trigger fears and anxieties that replay issues from infancy in the experience of "becoming dependent again" (Martindale, 1989). Earlier problematic emotional constellations do not "grow old" in the sense of diminishing or fading away; rather, they may persist and become more powerful as dependency increases and adult coping mechanisms erode, "...because the unconscious does not participate in the process of growing older" (Grotjahn, 1940). In this way, contemporary experiences may be shaped and coloured by earlier

times, and even the unremembered past may now make its presence felt as "ghosts" in the care setting (after Fraiberg et al., 1975).

Psychological care for the person with dementia is crucial throughout the illness, irrespective of whether conscious insight or awareness is retained. Anxieties are experienced at both conscious and unconscious levels, and research shows varying levels of awareness, with evidence for unconscious awareness even in advanced stages of dementia (Phinney, 2002; Balfour, 2006). Despite this, psychological interventions for people with dementia are poorly developed, and there has been a notable lack of sustained interest in this area from the psychotherapy profession.

'Double-Discrimination'

If people with dementia are rarely offered psychotherapeutic help, this is even more pronounced when considering psychotherapeutic interventions developed specifically for couples living with dementia. As described in chapter 3, there is a notable scarcity of interventions focusing on the relationship dynamics of couples dealing with dementia (Gilbert, 2023). Many psychotherapists are hesitant to work with older couples when dementia is present, reflecting negative assumptions about the capacity of such couples to engage in these interventions and a lack of specialised training among therapists to work with this population. This lack of training and the limited development of interventions in this area are striking, especially given the evidence of the profound psychological challenges faced by couples living with dementia. Furthermore, therapeutic approaches have been shown to improve relationships for those living with other neurodegenerative diseases

(Beasley & Ager, 2019; Ghedin et al., 2017), and studies indicate that people in the early stages of dementia retain an awareness of changes within their relationship (Alsawy et al., 2020). The testimony of the participants in this study reinforces this, highlighting the vital importance of the couple relationship in their lives (see chapter 8).

The lack of existing models from psychoanalysis and psychotherapy focusing on relationships in dementia, and the dearth of interventions to support such couples, is stark. This neglect, alongside the historical marginalisation of individuals with dementia in psychotherapeutic contexts, may be considered a form of "double discrimination." Not only is there a general oversight of the psychological needs of people with dementia, but there is also a specific neglect of the relational dimension of their care.

In response to this situation, a central aim of this study has been to deepen our understanding of the psychological needs of couples living with dementia and to develop a nascent model of "the dynamics of dementia" (see chapter 4). This involves operationalising a proposed model of relationship dynamics in dementia, linked to the research literature reviewed in chapters 2 and 3. These chapters detail what is known about couples living with dementia and what has been found effective in supporting them. Building on this foundation, the study has sought to design a relationship-based intervention tailored to the unique needs of these couples (see chapter 5).

Understanding the Relationship Dynamics of Dementia and Engaging Practitioners

Understanding the experiences of couples and developing models of the relationship dynamics of dementia may help enhance the capacity and competence of practitioners and increase their willingness to work psychotherapeutically with this population. As described in chapter 6, the development of models for understanding and intervening in the relational issues of couples living with dementia successfully engaged psychotherapists and other mental health staff in a Training Programme. These practitioners, drawn from a range of backgrounds, were engaged and, through the training and supervision provided, developed their clinical practice in working with couples living with dementia.

The Concept of 'Relationship Reserve'

This study suggests that relationship quality and effective dyadic coping could be conceptualised as a "relationship reserve," akin to the concept of 'cognitive reserve' (Robertson, 2014). The notion here is that this "relationship reserve" may serve as a resilience factor in dementia. If this reserve can be strengthened early in the illness, it could provide essential resources for the couple that would benefit them later as the dementia progresses. Effective relationship interventions could enhance this "relationship reserve," helping to reduce carer burden, depression, and burnout (Coyne et al., 1996) and improve the psychological and physical well-being of both partners (Riley, 2019; Riley et al., 2018).

This concept has been central to the approach explored in this study, which has aimed to enable the couple to become more interdependent earlier in the illness trajectory. By fostering this interdependence, the intervention seeks to provide couples with strategies and ways of being together that may help delay the partner with dementia from becoming dependent sooner than necessary. This, in turn, can help the couple avoid becoming ensnared in the "negative loop" of dementia (see chapter 4). As will be discussed further, this approach is immensely important for the quality of life and resilience of couples living with dementia. It also has wider economic benefits, potentially reducing family breakdown and reliance on residential care. The question then arises: what are the implications of such an approach for treatment pathways and social policy?

The Social Policy Context and Treatment Pathways

Globally, government policies are increasingly focused on achieving widespread early diagnosis of dementia, which, in turn, heightens the need for psychosocial interventions to accompany this diagnosis (De Vugt and Verhey, 2013). The research reviewed in chapters 2 and 3, alongside the data reported in this study (chapters 4, 7, and 8), illustrates that dementia imposes severe stress on a couple's relationship. Yet, the quality of their relationship and the resilience they can maintain are of immense significance for the physical and mental health of both partners (Ablitt et al., 2009; Hellstrom, Nolan, & Lundh, 2005; Hellstrom et al., 2007; McGovern, 2011; Norton et al., 2009). However, despite repeated calls in the literature for a stronger focus on relational understanding and dyadic interventions in

dementia (Merrick et al., 2016), there remains a notable lack of intervention development and evaluation that directly aims to improve the couple relationship.

Given that care for people with dementia is predominantly provided within the home by family members—husbands, wives, or partners who take on new responsibilities as carers—the need for couple support in dementia treatment and support pathways is critical. It is essential, therefore, that the Government increases its support for these so-called "informal carers," as living with dementia within the couple context is the lived reality for most people worldwide. Currently, the NICE-recommended post-diagnostic support pathway for people with dementia involves diagnosis by a specialist, usually a memory assessment service, which may also provide immediate support post-diagnosis. Following this, individuals are discharged from the memory assessment service to their GP, who takes over their ongoing care and support (NICE, 2018).

However, there is a concerning lack of guidance and support surrounding this stage of the pathway, often resulting in a postcode lottery regarding access to effective care and support. The complexity of dementia requires a "multidisciplinary and holistic approach to support, which is frequently lacking in primary care" (Arblaster & Brennan, 2022).

What Needs to Change?

Even without a 'postcode lottery,' the evidence reviewed here indicates that there are currently no established, evidence-based relationship interventions

to support couples living with dementia. Unsurprisingly, in terms of post-diagnostic psychosocial intervention, the NICE guidance states: "it was not possible to make specific recommendations in this area due to the lack of evidence" (NICE, 2018). Despite substantial research indicating the impact of dementia on relationships, current practice and treatment largely focus on managing the individual's physical and cognitive decline. There has been insufficient investment in developing evidence-based psychological interventions to provide emotional support and containment post-diagnosis. This PhD thesis demonstrates that such interventions are most needed to help couples living with a diagnosis of dementia, helping to sustain their resilience and mitigate the profoundly negative effects of the illness on their relationship. This is critical, as it is often the relationship itself that is at the "front-line" of dementia care.

The evidence of this study supports the view that it is possible to design relationship support interventions for dementia, offering a model with face validity and acceptability for couples, alongside preliminary evidence for effectiveness. Crucially, the findings endorse the perspective emerging from the research literature that a broader, systemic, or 'relational' lens is urgently needed in approaches to dementia care—and that achieving this is indeed possible. Overall, the evidence from this study aligns with that of other researchers (Wadham et al., 2016; Ablitt et al., 2010; Forsund et al., 2014; Evans & Lee, 2014; McGovern, 2011), who argue for a more comprehensive view of dementia treatment that places greater emphasis on relationship support within dementia care.

The research discussed in Chapter 3 demonstrates the positive impact of maintaining a sense of 'we-ness' in couples affected by dementia (Garand et al., 2007; Hellstrom et al., 2005). In 'Moving Beyond the Deficit Model,' McGovern (2011) suggests recontextualising the experience of dementia as an illness affecting relationships rather than only individuals. This conceptual shift supports the development of services and policies geared towards relationships, recognising that the strengths inherent in couplehood can enhance physical and mental health and overall well-being. In this context, the need for services that support couples in achieving this becomes more pronounced. Pozzebon et al. (2016, pp. 553-554) argue that: 'Because sustaining robust relationships is central to the human experience, efforts need to be invested in 'couple sensitive' approaches to prevent or at least reduce caregiver burden'. What stands out from this research is that relationships are crucial for both quality of life and clinical outcomes. The need for dementia services to acknowledge couples as an interdependent and dyadic unit is highlighted by many researchers (see Wadham et al., 2016; Ablitt et al., 2010; Forsund et al., 2014; Evans & Lee, 2014).

However, these studies from the qualitative literature, which advocate for a 'paradigm shift' towards a more 'positive psychology' of dementia grounded in a relational focus, must be balanced with a recognition of how difficult this can be. Any intervention designed to support the resilience of couples living with dementia needs to recognise the findings from research showing, across a convergence of studies worldwide from both the quantitative and

qualitative literature, the tremendous psychological challenges that living with a partner with dementia presents. While this literature underscores the importance of the couple relationship in determining the quality of life and outcomes for both partners and offers insights into resilience and which relationship factors are crucial for securing optimal outcomes, a balanced perspective is essential. We need to account for the considerable challenges that couples face in their journey through dementia.

These issues have been woven throughout this study, and our model for intervention with couples living with dementia aims to address the emotional challenges of their situation. It also seeks ways to promote emotional connection and 'couplehood,' which, as the research suggests, can be highly valuable for couples if it can be maintained amidst the difficulties posed by dementia.

Final Conclusions

In summary, this PhD thesis has reviewed the research and demonstrated that there is now a 'critical mass' of evidence supporting the need to 'recontextualise' dementia as an illness that affects relationships rather than just individuals. This shift in perspective supports the development of services and policies geared towards fostering togetherness rather than separateness, focusing on family systems rather than solely on individuals. This thesis aligns with calls for a more 'relationship-focused' approach (McGovern, 2011), which 'offers more hope than focusing exclusively on cognitive decline, which is of crucial importance given the intense distress, despair and hopelessness that such couples can face' (Wadham et al.,

2016). Moving forward, it is essential to build the evidence base needed to expand the scope of the dementia support pathway, ensuring that the psychological, emotional, and relational issues accompanying a dementia diagnosis are treated alongside the physical and cognitive responses to the disease. Researchers and policymakers need to collaborate to ensure that decision-making is driven by this emerging evidence base, which shows that the treatment of dementia must become more couple focused.

A couple-focused approach to dementia treatment will benefit not only the carer partners—who are often isolated, vulnerable, and in desperate need of support—but also the physical and mental health of people with dementia, as the research reviewed in this study shows (see Chapter 2). Beyond the significant personal and relational value of this approach, there are substantial economic benefits to introducing a couple-focused approach in dementia care. The role of partners in providing ‘care’ in couples living with dementia will become increasingly indispensable as the country seeks ways to manage the social costs of dementia (Wimo et al., 2015). The cost of dementia to the UK is currently £34.7 billion a year, which equates to an average annual cost of £32,250 per person with dementia (The Alzheimer’s Society). Government investment in relationship interventions that provide the tools and support needed to help couples live optimally with dementia has the potential to yield significant financial benefits by reducing hospital and care home admissions.

To address the current NHS crisis seriously, the Government must therefore prioritise a relational approach to dementia care. For dementia care to be

most effective, it must not only focus on managing the individual's physical and cognitive decline but also adopt a broader, holistic approach that targets the relationship, the carer partner's well-being, and the wider family environment. This study has aimed to make a significant contribution towards developing an understanding of relationship dynamics in dementia, providing the conceptual basis for the development of the Living Together with Dementia relationship intervention to support such couples. While the results are preliminary, they are encouraging, showing face validity for couples who were engaged in the approach and found it helpful in sustaining them through the challenges they faced. For the high proportion of partners experiencing moderate to severe levels of burden in our study, we demonstrated a significant reduction in burden, and the testimony of the couples themselves indicates that our intervention benefited them in the ways it was intended to. There is an urgent need for further research and development in this area, which is one of the most pressing social concerns of our time. The couples and families who are increasingly faced with the immense challenges of dementia demand and deserve that we take this up as a matter of urgency. This PhD thesis has contributed towards this goal, bringing us one step closer to developing a meaningful, evidence-based relationship intervention to support couples living together with dementia.

75,419 words excluding references and appendices.

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