Experiences of living and dying with Lewy body dementia: A longitudinal narrative study

Allison Bentley

RGN, BA (Hons), MSc

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules with the blended PhD programme

January 2023

Faculty of Health and Medicine

Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of higher degree elsewhere.

Word count 39,895

Acknowledgements

I would like to thank the participants who kindly took part in this study and gave their time to tell me their experiences, and those who gave up their time to form part of the patient and public involvement group who provided invaluable direction, guidance, and support.

I would also like to thank my supervisors Professor Catherine Walshe and Dr Yakubu Salifu who through their experience and knowledge have guided me through this PhD. Also, a sincere thanks to Dr Steve Wright for his extensive knowledge and patience in supporting me with data analysis software advice.

I am extremely grateful to the following scholarship and funding awards, without which this PhD would not have been possible:

- Florence Nightingale Foundation Research Scholarship 2017–2018
- Cambridgeshire and Peterborough NHS Foundation Trust research grant 2017–2019
- Lewy Body Society research grant 2021–2022

Finally, I would like to thank my friends, family, and work colleagues for their support, encouragement, and belief in me throughout the PhD programme.

Abstract

Lewy body dementia is a life-limiting condition with multiple, complex symptoms. As the condition progresses much of the caring and nursing duties fall to families. However, little is known about how people with Lewy body dementia and their families are affected by the condition. The overall aim of this thesis was to explore the experiences of people living with Lewy body dementia, and their family carers over time. An integrative systematic review of the literature was conducted. A convergent integrated design was applied to facilitate the synthesis of published research exploring the experiences of people living with Lewy body dementia and family carers. There was scarce qualitative evidence identified on the lived experience, with a predominant biomedical focus and cross-sectional designs.

Methodology

In order to gain unique insights into people's experiences of living with Lewy body dementia a narrative methodology was chosen. A social constructionist approach influenced the research conducted, drawing from the psycho-social discipline and experience-centred narrative theory. The underpinning perspective was that knowledge and reality are socially produced, and humans' understanding, and interpretations of their world occurs through stories.

Method

A longitudinal narrative study using three sequential interviews and life story work was completed to gain unique insights into five couples' experiences of living with Lewy body dementia. Participants were recruited from memory clinics and the 'Join Dementia Research' database within the east of England. Narrative data were collected using dyadic narrative interviews with each couple over a six-month period (August 2019 – Februrary 2020). The analysis of the stories was conducted using Murray's levels of narrative analysis in health psychology. Murray's anaytical framework enabled stories to be analysed at the personal, interpersonal, positional, and societal level.

Findings

The main finding from this study was that the overarching narrative of ‘social connectedness’ was found to be important, and this continued over time. In this study, social connectedness represents a stepwise description of how a person is actively involved with others and their surroundings, leading to a sense of comfort and wellbeing. Seven stages of social connectedness were identified: maintaining social connections, developing new connections together, social disconnection, support from adult children, marital disconnection, connecting to health and social care, and emotionally separated but living together. Lack of social connectedness leads to social disconnection. Repeated losses over time resulted in difficulty in maintaining social connections giving rise to a reduced sense of agency. Loss of continence, energy, and independence, together with difficulty managing medications, significantly impacted on couples’ quality of life and ability to remain connected through all stages.

Conclusion

Maintaining a social life and support network was important for both people living with Lewy body dementia and family carers. The findings contribute to the methodological literature that gives voice to those living with dementia over time. They highlight how physical and personality changes, communication challenges, and behavioural difficulties, undermine established social connections. The stepwise diagrammatic representation of social connectedness provides guidance for more targeted healthcare interventions and management of Lewy body dementia.

Published peer reviewed papers from this research

The peer-reviewed papers below are published based on the research reported in the thesis. Full texts of the articles can be found in appendix 1 and 14.

Bentley, A., Morgan, T., Salifu, Y., Walshe, C., 2021. Exploring the experiences of living with Lewy body dementia: An integrative review. J. Adv. Nurs. jan.14932. https://doi.org/10.1111/jan.14932 (Appendix 1)

Bentley A, Salifu Y, Walshe C. Applying an Analytical Process to Longitudinal Narrative Interviews With Couples Living and Dying With Lewy Body Dementia. *International Journal of Qualitative Methods*. January 2021. doi:10.1177/16094069211060653 (Appendix 14)

Conference posters

Bentley A, Salifu Y, Walshe C. Narrative methodology: Analysing the personal experience of couples living and dying with Lewy body dementia. Poster presented at: International Mental Health Nursing Research Conference. 2021 June 09-10; Royal College of Nursing, London, England: Online.

Bentley A, Salifu Y, Walshe C. Experiences of living and dying with Lewy body dementia: a longitudinal narrative study. Poster presented at: International Lewy body dementia conference. 2022 June 15-17; Newcastle, England: In person.

Contents

List of Tables

List of Figures

List of Boxes

Chapter 1: Background

The overall aim of this research study is to explore the experience of everyday life of people living with Lewy body dementia and their family carers. Dementia is a syndrome which causes deterioration in memory, thinking, and behaviour. The condition can affect people's ability to perform daily living activities and is a leading cause of disability and dependence (WHO, 2021). Dementia is said to affect around 55 million people worldwide, with an estimated increase to 150 million cases in 2050 (Nichols et al., 2022). The term dementia is referred to as a 'major neurocognitive disorder' in the revised Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and encompasses a range of conditions (American Psychiatric Association, 2013). Alzheimer's disease is considered the most common form of dementia, affecting 60 – 70% of people with dementia. Other common types are vascular dementia, fronto-temporal dementia, and Lewy body dementia (WHO, 2021).

Lewy body dementia is an umbrella term that includes both Parkinson's disease dementia and dementia with Lewy bodies. Pathology studies report it to be the second most common cause of neurodegenerative dementia after Alzheimer's disease (Barker et al., 2002). Epidemiological and neuropathological studies estimate dementia with Lewy bodies to account for 7.5% of all people with a dementia diagnosis (Vann Jones and O'Brien, 2014), with the prevalence of Parkinson's disease dementia said to be between 24 – 31% for those with Parkinson's disease (Aarsland et al., 2005). Clinical numbers are often reported to be lower than pathological studies as people with Lewy body dementia are often under- or misdiagnosed (Surendranathan et al., 2020). This is likely to have a negative effect on their experiences of healthcare, and limit their support options (Kane et al., 2018). Dementia with Lewy bodies and Parkinson's disease dementia share many clinical and neuropathological similarities, and are considered subtypes of the Lewy body disease spectrum (Jellinger and Korczyn, 2018). However, the difference for diagnostic purposes is related to the timing of the major symptoms. Parkinson’s disease dementia is classified as a dementia that develops at least one year after the onset of motor symptoms. If cognitive symptoms develop initially or at the same time as the motor symptoms this is considered to be dementia with Lewy bodies (McKeith et al., 2017).

People with Lewy body dementia often live with an array of symptoms such as cognitive fluctuations, visual hallucinations, falls, and motor features of Parkinsonism. Other prominent features include disability, recurrent behavioural and emotional problems, rapid eye movement (REM) sleep behaviour disorder, and autonomic dysfunction (Dubois et al., 2007; McKeith et al., 2017). In addition to the complex overlapping symptoms it is said that Lewy body dementia may be associated with differing prognoses and shorter life-expectancy compared to other forms of dementia (Mueller et al., 2017). These apparent differences to other forms of dementia highlight the importance of considering wider clinical, care, and social perspectives for people living with Lewy body dementia.

1.1 The medical history of Lewy body dementia

In 1817 James Parkinson first described ‘paralysis agitans’ (now referred to as idiopathic Parkinson’s disease) in his classic text, An *Essay on the Shaking Palsy*. Parkinson described the condition as an ‘Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from walking to a running pace: the senses and intellects being uninjured’ (Parkinson, 1817 p.1). It was over 60 years later that cognitive impairment and dementia was recognised as part of Parkinson’s disease by the French neurologist Jean-Martin Charcot. Eventually, in 2007 the Movement Disorder Society developed a task force to define and develop diagnostic guidelines for Parkinson’s disease dementia (Dubois et al., 2007; Goetz et al., 2009).

In 1912, the neurologist Friedrich Lewy first described aggregates in the cytoplasm of neurones of the substantia nigra of the brain of people with Parkinson's disease at autopsy. Named 'Lewy bodies' these are now regarded as the histological hallmark found in Parkinson's conditions (Rodrigues e Silva et al., 2010). It was not until the 1970s that researchers started to note widespread cortical Lewy bodies in patients with progressive dementia and concomitant Parkinsonian features at autopsy. Findings were eventually consolidated with the 1995 first consensus report on dementia with Lewy bodies (McKeith et al., 1996). The report outlined that these patients should be considered to have a separate disease from both Alzheimer's disease and Parkinson's disease. The consensus report has been subsequently updated with the most recent being in 2017 (McKeith et al., 2017).

There has been some difficulty and controversy around the separation of dementia with Lewy bodies from Parkinson's disease dementia. Many people with Parkinson's disease develop cognitive changes and dementia as the disease progresses, and many of the pathological features may overlap (Outeiro et al., 2019). In addition, the discovery in the 1990s that the main component of Lewy bodies is the protein alpha-synuclein means that dementia with Lewy bodies may also be considered within a spectrum of disorders. The Parkinson's plus syndromes, which include multiple system atrophy, progressive supranuclear palsy, and corticobasal degeneration, are considered to have some pathological overlap. Currently there are no disease-modifying therapies for any of these disorders (Olfati et al., 2019). This highlights the difficulties in clinically diagnosing and treating theses conditions and differentiating the conditions for research purposes.

The pathological similarities between dementia with Lewy bodies and Parkinson's disease dementia are acknowledged, but difficulties differentiating clinically have resulted in the umbrella term Lewy body dementia to encompass both subgroups

(Galvin et al., 2010a). I will therefore refer to Lewy body dementia within this PhD thesis, although differentiation between the two subgroups may be required at times, such as within the literature review.

1.2 Lewy body dementia: a life-limiting illness

Compared to Alzheimer's dementia, it is said people with Lewy body dementia have shorter survival time (Liang et al., 2021; Mueller et al., 2019; Price et al., 2017). The differences in time from diagnosis to death varies, but is reported as an average of 6.9 years for people with a diagnosis of Alzheimer's compared to 4.4 years for Lewy body dementia (Oesterhus et al., 2014). In addition there is increased disease burden, complex symptom management, and higher health care cost across the Lewy body dementia trajectory compared to other forms of dementia (Mueller et al., 2018). The difference in the disease progression between Alzheimer's disease and Lewy body dementia may be partially explained by a greater likelihood of falls, injuries, and hospitalisation, with the presence of severe autonomic symptoms in those with Lewy body dementia (Stubendorff et al., 2012). It is also considered that a combination of Alzheimer's and Lewy body pathology may be a factor in accelerated decline (Outeiro et al., 2019). Accelerated cognitive decline, more comorbid conditions and having complex symptoms can lead to poor quality of life (Lee et al., 2018). With no specific disease-modification therapies, the focus is supporting the complex combination of cognitive, motor, autonomic, and psychiatric symptoms encountered. However, treatment of one symptom can exacerbate another which makes clinical management difficult (Taylor et al., 2020). This requires a careful, negotiated balance of symptom management with the quality-of-life priorities of the person living with Lewy body dementia and their family carers. This, together with a lack of knowledge by clinicians about disease trajectory and prognosis, can make it difficult to instigate support, long-term management, and care at end of life (Armstrong et al., 2019a).

As healthcare costs continue to rise and availability of community services decrease, families are often called upon to manage and coordinate many aspects of dementia care including physical, social, and medical needs (WHO, 2021). This poses many challenges for people with Lewy body dementia and family members providing for their care. Family make substantial contributions to the support of people with dementia, which comes at a considerable financial cost (Wittenberg et al., 2019). There is also the physical, emotional and social impact on family caregivers which can affect their own psychological well-being (Park et al., 2019). It is therefore important to consider if people with Lewy body dementia and their families may be better supported by a palliative care approach. However, how a palliative care approach may be applied to Lewy body dementia is yet to be explored.

1.3 Palliative care and dementia

Within the UK, palliative care services developed from within the hospice movement in the 1980s. The emphasis on cessation of curative treatment for cancer, and ‘diagnosing dying’, was key to the original palliative care transition and service design. Nonetheless, since then an array of complex models have developed within the delivery of palliative care services. Palliative care can be seen as an approach to care, a system of care, and a way of delivering services (Jerant et al., 2004). To enable palliative care delivery, all health and social care professionals should have core palliative care knowledge (generalist palliative care). Specialists usually work in separate units and have additional training to manage complex and difficult cases (specialist palliative care services). Terminology may be confusing when the term end-of-life-care, which is considered to be the last year of life (DOH, 2018), is interchanged with palliative care (Gove et al., 2017a). The term supportive care is also used with a variety of definitions and meanings in the context of palliative care (Berman et al., 2020). This has resulted in misperceptions and confusion for patients, members of the public, and healthcare professionals (Enguidanos et al., 2022; McIlfatrick et al., 2014; Ryan et al., 2020). Therefore it can be challenging to define what palliative care needs are, or may look like to those with non-malignant illness such as dementia (van der Steen et al., 2017).

Improving palliative care for people with dementia has been identified as an international priority (Kluger et al., 2017). Scientific advancement has resulted in an ageing population. Living longer into older age has resulted in people living, and dying with multiple long-term conditions, such as dementia. Deaths due to dementia have more than doubled between 2000 and 2019, with an estimated 1.62 million deaths globally due to dementia in 2019 (GBD 2019 Collaborators et al., 2021). It is said to be the seventh leading cause of death worldwide in all ages, and fourth among individuals aged 70 and older (GBD 2019 Collaborators et al., 2021). Research within dementia has improved knowledge of the underlying pathology of dementia, which has resulted in disease-modifying therapies becoming more widely used (NICE, 2018). However, there have been relatively few new drug advancements, and it is not known when, or if, a cure may be discovered. Multiple complex symptoms and a progressive course of functional decline has resulted in a reframing of dementia as a ‘life-limiting’ illness within the context of palliative care (Fox et al., 2018).

Recent UK government policy and guidelines suggest that health and social care professionals should adopt a 'palliative care' approach from the time of diagnosis for conditions such as Lewy body dementia. It is recognised that planning, intervention, and support earlier on are essential for people living with dementia (Middleton-Green et al., 2017). It is even suggested ‘From diagnosis, [healthcare professionals should] offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be’ (NICE, 2018 p.30).

However, palliative care policy, research, and funding in dementia has mainly focused on the end stages of life (Mataqi and Aslanpour, 2020). This may be because dementia has an unpredictable, multifactorial form of progression which is based on a ‘slow dwindling’ with acute episodes followed by some recovery (Murray et al., 2005). The traditional focus is on functional change and deterioration, though this is quite variable amongst different types of illness trajectory (Lunney, 2003). This proves challenging for a traditional palliative care approach. Attempts to stage dementia often focus on the progression of memory loss and decline in function. Scales such as the Functional Assessment Staging Tool (FAST) examine in more depth the overarching stages of mild, moderate, and advanced stages of dementia (Sclan and Reisberg, 1992). In contrast to the ‘slow dwindling’ end stage of Alzheimer’s Disease, people with Lewy body dementia often experience acute episodes of ill health followed by recovery (Alzheimer’s Australia, 2012). Viewed clinically it seems that those with Lewy body dementia are likely to have episodes more in keeping with pattern of long-term neurological conditions. Indeed, early work on Parkinson’s disease progression identified four stages: diagnosis; maintenance; complex; and palliative. Within this model the palliative stage was considered to last around 2.2 years (MacMahon et al., 1999). This stage is characterised by a reduced response to dopaminergic therapy, increased visual hallucinations, falls, and cognitive impairment. However, over the past decades the palliative phase for those with Parkinson’s disease is considered to have extended mainly due to advances in Parkinson’s therapies, with the recognition that palliative care approaches should be considered earlier in the disease trajectory (Senderovich and Jimenez Lopez, 2021).

Whilst a palliative care approach is considered appropriate for people with dementia and Parkinson’s, few people living with the condition, or their families, have access to such care (van der Steen et al., 2019). However, the foundation of palliative care is one of holistic attention to physical, psychosocial, and spiritual needs. Palliative care aims to achieve the ‘best quality of life of patients and their families’ facing any life-threatening illness:

> *‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual’* (WHO, 2020).

The underlying person-centred philosophy of palliative care resonates with that of dementia which is also framed as a bio-psycho-social condition (Revolta et al., 2016). There is a need to probe further into how a palliative care approach can improve the lives of people living with Lewy body dementia. The main issues arise from the complex symptoms, shorter life expectancy, poor quality of life experienced by patients, and long term physical and psychological effects on family carers. The problem I noticed clinically and academically is that there is no consistent follow-up, which can lead to patients and their carers having unmet physical, psychological, social, and support needs. This also denies them opportunity for forward planning of affairs and anticipatory consideration for complex symptom management (Harrison Dening et al., 2019).

An additional challenge for healthcare professionals is involving the person with dementia more in the care process. This may be because of a lack of time, or of training in communication skills, with the understanding that different forms of dementia may require a more individualised approach to communicating. For example, people with Alzheimer’s disease have progressive degradation of language in the area of verbal expression, understanding, and fluency. In the advanced stages non-verbal communication is mostly preserved. Language disturbance in Lewy body dementia is characterised by difficulty naming common objects, and by reduction in verbal fluency and perseveration during conversation (Reilly et al., 2010).

1.4 My perspective as a researcher

My interest and focus on Lewy body dementia stem from a multitude of different perspectives, roles, and experiences within clinical and research nursing. For 25 years I have worked as a community nurse in a variety of roles, which has enabled me to work with a large number, and a wide variety, of palliative patients, often with complex problems and comorbidity issues. I started to develop a special interest in dementia, frailty, and end-of-life care. To gain further experience I worked as a palliative care specialist nurse, and then as a community matron, focusing on older people with complex needs, many of whom had end-stage dementia. I then took the opportunity to become a study co-ordinator on a National Institute for Health Care Research-funded project, with the aim of improving the diagnosis and management of Lewy body dementia in the clinical setting (O'Brien et al., 2021). I noticed the wide range of symptoms being reported, and the effect this was having on people's day to day living. I considered whether the complex symptoms and shorter life expectancy compared to other types of dementia may have a relationship to unmet palliative care needs. As a nurse researcher within the area of Lewy body dementia I continued to explore options which could combine research and clinical work to improve end-of-life care for people with dementia and frailty. This led me to a role as an Admiral Nurse within a hospice setting. Admiral Nurses provide specialist dementia nursing to families across a range of areas, such as hospitals, community, GP practices, care homes, and mental health services (Dementia UK, 2018). Admiral Nursing is relatively new to the hospice setting, but there has been increasing numbers since the publication of guidance for hospices on how to review and audit current services and strategic planning for dementia care (Hospice UK, 2015). Many Admiral Nurses are now involved with developing and implementing dementia specific services, providing case management, training, and support to hospices across the UK (Harrison Dening et al., 2017) A recent return to community nursing as a Parkinson’s nurse has enabled me to focus on research into clinical practice.

I therefore approach the research professionally and academically from a variety of stances. These include the medical model of dementia as a progressive neurodegenerative disease, specialist palliative care, and a community nursing perspective, where the ultimate aim of the nursing interaction is to provide tangible assistance to the patient. The process of reflexivity is central to this research, with the need to constantly reflect and challenge assumptions. To aide in the reflective process I also explored ways to plan and embed meaningful patient and public involvement within this Lewy body dementia research study (Burton et al., 2019).

1.5 Development of research aim, objectives, and approach

Current research within Lewy body dementia remains focused on carers and professionals, with less involvement from people with Lewy body dementia themselves. It is also mainly constructed around traditional prognosis-based disease ‘events’, and pharmacological management of symptoms (Lane and Conroy, 2022; Stinton et al., 2015; Watts et al., 2022). There is clear evidence of complex symptom burden for the person with dementia, and caregiver burden and grief associated with disease manifestations (Galvin et al., 2010b; Huang et al., 2022; Zweig and Galvin, 2014). A holistic palliative care approach could address the complex physical and psychosocial symptoms experienced for both people with Lewy body dementia and their family carers.

1.5.1 Aims and objectives

The overall aim of this research study is to explore the experience of everyday life of people living with Lewy body dementia and their family carers. The key objectives are:

- Examine physical, psychological, social, and spiritual aspects of everyday life with Lewy body dementia.
- Understand similarities and differences between the experiences of people with Lewy body dementia and those of their family carer.
- Explore if stories allow insight and depth to our understanding of palliative care in Lewy body dementia.

1.6 Overview of the thesis

To provide an overview of the thesis I have provided an outline of the chapters to follow.

Chapter 1:

Within Chapter 1 I provide the background and rationale for the focus of the thesis, by describing one type of dementia, Lewy body dementia, within the context of a life limiting illness. I reflect on how my career background and perspectives influenced the overall aims and objectives and research questions.

Chapter 2:

Within Chapter 2 I provide an overview of previous literature conducted around the experiences of living with Lewy body dementia. An integrative approach to reviewing the literature is presented and the general themes are discussed. Four main themes were identified from the literature: living with an uncertain diagnosis and prognosis; fear of the now, worry for the future; living with behavioural and psychiatric symptoms; and maintaining a social and emotional life. The findings identify the need for wider, more in-depth perspectives on what day-to-day living is like for people living with Lewy body dementia and their family carer.

Chapter 3:

In this chapter I lay out the study design and conceptual framework underpinning the empirical research by examining how the aims and questions interrelate. I discuss my interpretivist and social constructionist epistemological and ontological perspectives in relation to narrative research. The underpinning philosophical theories of narrative as situated within self and personhood, and psychosocial models of dementia are explained. I explore the methodological narrative-based approach to health and illness, and the relevance of an experience centred approach to answer the research questions. Finally, I consider the importance of the analysis process and examine validity within narrative research.

Chapter 4:

In Chapter 4 I further introduce the research methods taken by exploring the use of narratives and storytelling in social science research, and how different aspects of narrative inquiry relate to the study's methods of data collection and analysis. Ethical considerations, inclusion criteria, sampling, and recruitment strategy are set out within the research design. I explain how the design links to the dyadic, longitudinal, narrative interview methods used in this study, and discuss the practical aspects of collecting three dyadic longitudinal narrative interviews over time. The role of reflexivity and patient and public engagement are expanded.

Chapter 5:

Within Chapter 5, I provide an in-depth explanation of the narrative analysis process and its relevance in contributing to methodological rigor and validity within narrative research. To provide transparency of the analytical process, data from one couple is provided as an example of how Murray's (2000) four levels of narrative analysis was applied to longitudinal narrative interviews. There follows a description of how connections between the four levels were identified, and how these were articulated across different interview time points.

Chapter 6:

Within Chapter 6 I present the findings of the empirical work. The narratives of being social, looking for answers, self-sufficiency, communication, and conflict, all contribute to the overarching narrative of social connectedness. Physical changes such as tiredness and incontinence, communication challenges, and personality changes undermined the established social connections for people living with Lewy body dementia and their family carers. This is further explained as a stepwise representation of social connectedness.

Chapter 7:

In Chapter 7 I discuss the findings in relation to previous literature and theoretical perspectives. I then relate the findings to the insights of narrative theorists who investigate how people use stories to make sense of, and identify with, the world, and how this may change when memory is interrupted. I examine how new insights into grief, loss, and liminality may affect the experience of living with Lewy body dementia.

Chapter 8:

Within Chapter 8 I draw together the main points of the thesis and review the strengths and limitations of the study. I reflect on the importance and significance of the patient and public involvement during the study. The potential contribution of this research to theory and Lewy body dementia care is expanded. Recommendations are made for clinical practice, and considerations for further research are discussed.

Chapter 2: An integrative review of the literature: the experiences of people with Lewy body dementia and family carers

2.1 Introduction

In this chapter I describe a systematically conducted review of the literature regarding the experiences of people living with Lewy body dementia and their family carers. The rationale for conducting an integrative review of the literature is explored, and the four key themes that were identified are discussed. A published version: ‘Exploring the experiences of living with Lewy body dementia: An integrative review’ (Bentley et al., 2021a) is included in Appendix 1. I conclude by highlighting the research gaps identified within the literature review and discuss how these provided the focus for the research described in this thesis.

2.2 Review aim and questions

The aim of this review was to identify and understand what is currently known about the experiences of people living with Lewy body dementia and family carers. The review aimed to address the following questions:

1. What are the day-to-day experiences of people living with Lewy body dementia (dementia with Lewy bodies and Parkinson’s disease dementia)?
2. What is it like to be a family carer of someone living with Lewy body dementia?
3. How does the person with Lewy body dementia describe experiences around their health and social care?
4. How do families describe and experience interactions with healthcare professionals?

2.3 Review design

In designing a literature review the questions posed at the outset inform the choice of method and the synthesis, which should be in alignment with the research paradigm. To understand the literature around experiences generally requires a qualitative perspective. Within the Lewy body dementia literature some experiences are documented through quantitative measures such as quality of life and caregiver burden, but these are unable to capture the wider psychosocial perspective of experiences that are socially constructed. Despite the paucity of qualitative, experience focused literature, it was likely that important insights may be gleaned from previous quantitative research. Therefore, the review design required a systematic review which incorporates mixed methods. Systematic reviews of quantitative and qualitative studies come in a variety of approaches, and can include those that summarise the selected literature, and those that synthesise (Aveyard et al., 2021). A narrative review summarises selected literature on a specific topic, and is often used in healthcare to provide a snapshot of a specific clinical issue (Toronto and Remington, 2020). However, given the wide-ranging focus and methodologies in the Lewy body dementia literature, a design which looks more broadly at a phenomenon of interest (such as experiences) with the ability to synthesise was deemed important. Examples of systematic reviews of qualitative and quantitative studies with an interpretive focus include the critical interpretive synthesis, with a focus on generating new theories and concepts, and the integrative review (Aveyard et al., 2021; Dixon-Woods et al., 2006).

A systematic integrative literature review based on Whittemore and Knafl's (2005) method was selected to review current literature. First, this method was selected over other knowledge synthesis methods as it allowed for synthesis of heterogeneous evidence and paradigms from research across 'a fragmented field' (Cronin and George, 2020 p.1). An integrative review can accommodate differing ontological and epistemological assumptions, where no shared paradigm or theoretical framework exists. Second, integrative reviews also provide new insight into a topic by using a unique methodology with specific stages. These stages include: problem identification; literature search; data evaluation; data analysis and synthesis; and presentation stage (Whittemore and Knafl, 2005). The synthesis stage is the main area which identifies the integrative review from other methods, in that it can generate new knowledge, with the aim to 'produce fuller understanding of a phenomenon through the unique perspectives gained by using different research strategies' (Cronin and George, 2020 p.3). To demonstrate robustness and strengthen the interpretation and synthesis stage, a convergent integrated design was applied to facilitate synthesis process (Noyes et al., 2019). With there being little qualitative research in the field of Lewy body dementia, gaining new insights was deemed important, as such insights can provide background to support or dispute findings from the empirical research.

A systematic review of the literature should demonstrate methodological thoroughness and rigour, with consistent reporting (Snyder, 2019). The Enhancing Transparency in Reporting the Synthesis of Quality Research guidelines (ENTREQ; Tong et al., 2012); and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines (PRISMA; Moher et al., 2009) were used to guide reporting. Currently there is no specific reporting guidance for integrative reviews (Toronto & Remington, 2020).

2.4 Review methods

Inclusion and exclusion criteria

Papers were included if they were published in peer-reviewed journals and discussed the experiences of people living with Lewy body dementia and/or of family carers, and where experiences can be disaggregated from other forms of dementia. Box 2.1 presents detailed inclusion and exclusion criteria.

Box 2.1: Literature review inclusion and exclusion criteria

Inclusion criteria

Population:

- People with a diagnosis of Lewy body dementia (dementia with Lewy bodies, Parkinson's disease dementia) and/or
- Family carers, as defined by WHO (2015 p.1):

  'Family caregivers can be defined by the relationship (spouse, adult children, daughters and sons-in-law, friends, neighbours), living arrangements (co-resident with the care recipient or living separately), and care input (regular, occasional or routine)'

- Experience of living with or caring for Lewy body dementia.
- Adults (aged 18 years and over).

Type of studies:

- All subtypes of dementia, where the perspectives of those with Lewy body dementia or their family carers can be disaggregated.
- Studies published between 1995 and 2020.
- Full text in English.

Type of data:

- Published, peer-reviewed studies.
- Quantitative and/or qualitative studies.
- Case studies.

Exclusion criteria

Population:

- NO diagnosis of Lewy body dementia (dementia with Lewy bodies, Parkinson's disease dementia).
- Formal and paid carers who are not defined as 'family carers.'
- Professional views and experiences.

Type of studies:

- Prevalence/incidence, genetics, pathology, scanning, treatments and/or symptom- measurement-only studies.
- Carers' perceptions of what it is like for the person with Lewy body dementia.
- Studies on dementia as a homogenous group, where Lewy body cannot be disaggregated in the findings.

Type of data:

- Opinion-based, or editorial publications.
- Abstracts, review articles, grey literature.

Search strategy

To ensure the maximum number of eligible primary sources were identified Whittemore and Knafl's (2005) integrative review strategies were supported by the Palliative cAre Literature rEview iTeraTive mEthod (PALETTE) framework (Zwakman et al., 2018), and ‘pearl growing’ technique (Schlosser et al., 2006). PALETTE supports searching for studies which are more qualitative in nature, with poorly defined concepts which require preliminary exploration. In addition PALETTE strategies were applied to assist in identification and validation of keywords, index terms, and key authors in the field by examining key articles in the field which are referred to as ‘golden bullets’ (Zwakman et al., 2018). For this search systematic reviews within the field of Lewy body dementia and dementia experiences were examined (Connors et al., 2018; Górska et al., 2017; Inskip et al., 2016; Stinton et al., 2015). Search terms relating to experiences, family carers, and people living with Lewy body dementia were then developed with the assistance of a specialist librarian.

The search strategy in Medline is presented in Box 2.1 and was adapted for each subsequent database (CINAHL, PsycINFO, and AMED). Databases were searched using their specific subject headings, MeSH terms or thesaurus terms which related to Lewy body disease, and family carers, and experiences. These included English-language publications occurring between 1995 and 2020. In addition, a search of the ALOIS register was undertaken, as this provides details of dementia studies maintained by the Cochrane Dementia and Cognitive improvement group (alois.medsci.ox.ac.uk).

Box 2.2: Medline search strategy

"LEWY BODY DISEASE"/ or ((lewy OR Parkinson*) AND Dementia*).ti,ab

AND

((famil* OR informal OR spous* OR daughter OR son OR partner OR husband OR wife OR wives OR unpaid) AND (care* OR
caring)).ti,ab [DT 1995-2019] [Languages English] OR (patient* OR "service user*" OR "person* with dementia" OR "people with dementia").ti,ab

AND

(liv* ADJ3 experienc*).ti,ab OR (life* ADJ3 experienc*).ti,ab OR ("activities of daily living").ti,ab OR (view* OR perception* OR attribution* OR belief* OR meaning OR perspective* OR "quality of life" OR burden*).ti,ab

Please note that searches in CINHAL, PsycINFO, AMED and were adapted from this strategy. MeSH terms relating to diagnosis included - Lewy body disease (CINAHL, MEDLINE) Dementia Lewy bodies (PsycINFO)

For the literature search a start date of 1995 was chosen, as this coincided with the development of the first international criteria for the clinical diagnosis of dementia with Lewy bodies (with the latest version published in 2017; see McKeith et al., 2017). This resulted in a greater understanding of the Lewy body subtypes and an increase in research activity. The terms 'carers' and 'caregivers' were also referenced within UK policy and research at a similar time. For this review the terms dementia with Lewy bodies, Parkinson's disease dementia, carer, caregiver, and care partner will be used as reported by the specific studies.

Abstracts were screened by myself, and independently by a member of the patient and public involvement group who has knowledge of Lewy body dementia and experience of caring. This involvement was deemed important to gain a broader perspective and to ensure the selected criteria included areas of lived experience which might not be obvious in academic papers. Within an integrative review the author is expected to look for everything that has been published on a topic (Cronin and George, 2020). Support from the patient and public involvement group member provided a more balanced representation which, for example, resulted in the general case reports being included

(Londos, 2018; Stuart and Kenny, 2010). Covidence software was used to manage the papers effectively (Babineau, 2014). This enabled reviewers with different backgrounds and computer systems, (academic researchers and the patient and public involvement member), to access the papers from one central point. Covidence also enabled management of conflicts by a third person (supervisor) in a timely and concise manner (n=3). Finally, backward citation tracking of the selected articles was completed to ensure the search was comprehensive as possible (Zwakman et al., 2018).

Data extraction

Data were extracted using the headings: study aims; research questions; participants' characteristics; methods; date and length of fieldwork; analysis; results; and findings relevant to the review. Key areas for data extraction in relation to review questions were person with Lewy body dementia reported experiences, family experience of what it is like to care for a person with Lewy body dementia, and experiences and interactions with healthcare professionals. A review matrix was developed to provide a structured document for the quality appraisal and analysis process. ATLAS.ti 8 software was used to organise data extraction, coding, and synthesis of the data.

Quality appraisal

To ensure that the included studies were evaluated for their methodological quality and relevance to the review questions, a quality appraisal was conducted using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2019) and Gough's weight of evidence framework (Gough, 2007). Gough's framework assesses the 'coherence and integrity' of the research on its own merits, in addition to the appropriateness and the 'relevance of the evidence for answering the review questions' (Gough, 2007, p.11). These factors were then combined to give an overall 'weight of evidence' score. A copy of the weight of evidence framework can be found in Appendix 2. Two researchers assessed the quality and relevance of the studies. Any discrepancies in quality appraisal decisions were discussed (n=8) and consensus achieved. A summary of characteristics of included studies and quality appraisal information is provided in Appendix 3. All relevant published articles were retained for synthesis, regardless of methodological quality. Together, the articles offered different perspectives on personal experience and is congruent with the iterative review method of inclusivity (Appendix 4).

Data analysis and synthesis

Data analysis and synthesis involved three iterative phases: initially, papers were categorised according to their primary focus (Toronto and Remington, 2020; Whittemore and Knafl, 2005). Within the iterative review methodology this is considered an organisation of lower-order themes as a function of the findings of individual studies (Cronin and George, 2020). Next, a convergent integrated design was applied to facilitate the synthesis process and strengthen the interpretation stage. This involved converting quantitative data to qualitative (qualitising) (Noyes et al., 2019, p.9). ‘Qualitising’ was achieved by identifying words or phrases extracted from the data that described the statistics in included papers. Examples of ‘qualitising’ extracts to support themes are presented in Appendix 5 (Qualitative extracts to support themes). Finally, inductive ‘complete coding’ occurred to identify new themes relevant to the review questions (Braun & Clarke, 2013, p.206). Themes were verified collaboratively by myself and a supervisor. This process forms part of the high-order themes within iterative review methodology (Cronin and George, 2020).

2.5 Results

The search identified a total of 1,583 articles, two of which were retrieved by author searching (Whittemore and Knafl, 2005; Zwakman et al., 2018). A total of 26 articles from 20 individual studies were identified for further assessment against the quality appraisal criteria (Figure 2.1). Relevant papers were subjected to a full-text review by the author.

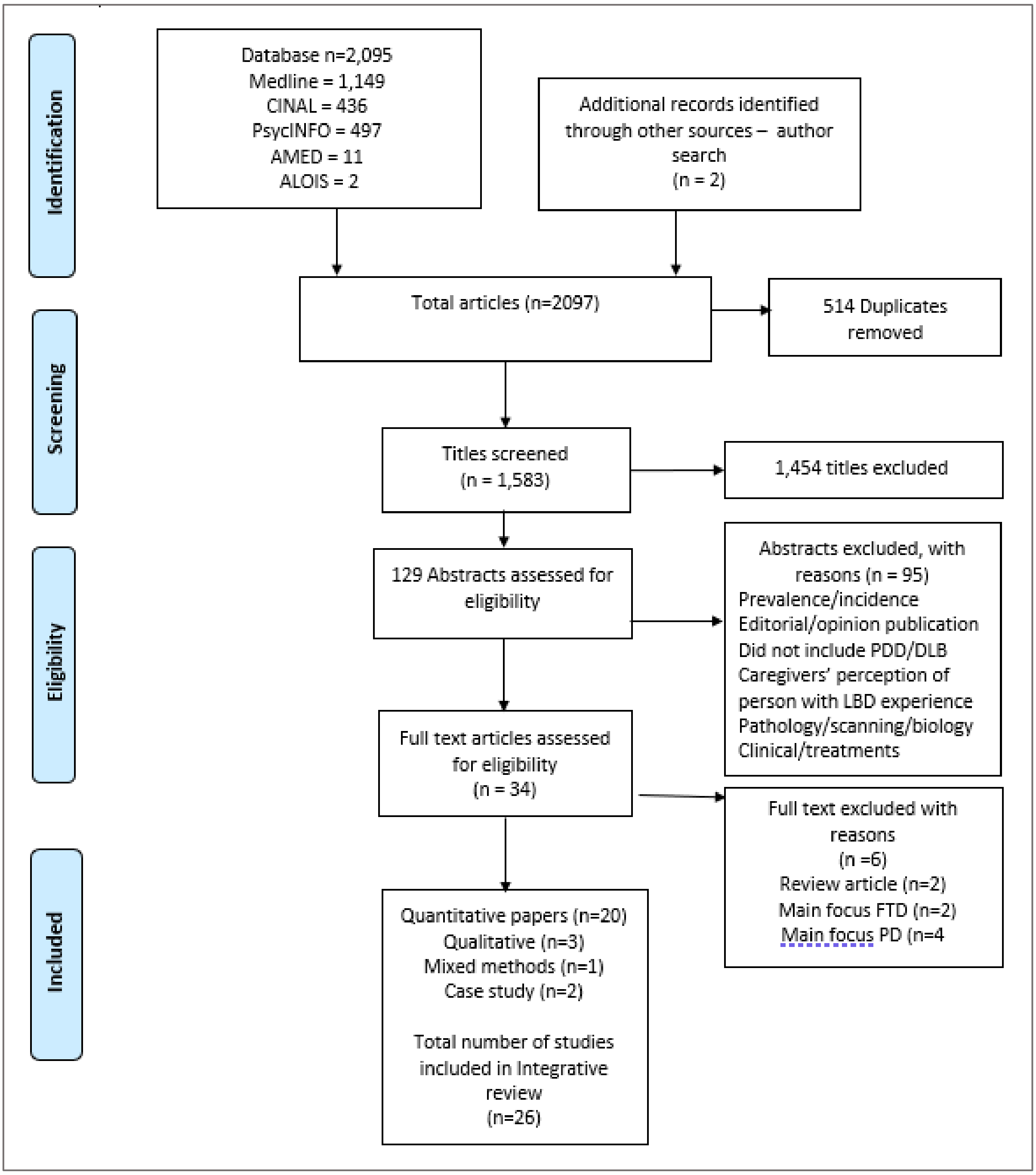


Figure 2.1: PRISMA Flow diagram of literature searches and selection, March 2020

The 26 papers originated from 20 studies which were conducted in a range of countries including: UK (n=6), USA (n=5), Sweden (n=3), Korea (n=2), Canada (n=1), Japan (n=1), New Zealand (n=1), and Norway (n=1). Among the papers a total of three were qualitative (Armstrong et al., 2019b; Larsson et al., 2019; Vatter et al., 2018b), 20 quantitative (Armstrong et al., 2019a; Boström et al., 2007; Galvin et al., 2010a, 2010b; Jones et al., 2017; Killen et al., 2016; Kurisu et al., 2016; Lee et al., 2013; Leggett et al., 2011; Leroi et al., 2012; Oh et al., 2015; Park et al., 2018; Rigby et al., 2019; Roland and Chappell, 2019; Shin et al., 2012; Svendsboe et al., 2017; Thaipisuttikul et al., 2013; Vatter et al., 2020; Vatter et al., 2018a; Wu et al., 2018), one mixed methods (McCormick et al., 2019), and two were case studies of personal experience (Londos, 2018; Stuart and Kenny, 2010). Most of the papers focused on family caregivers (n=20). The main caregiver participants were spouses/ life partners and adult daughters, who were mainly prominent in the online surveys. (Armstrong et al., 2019b; Galvin et al., 2010a; Killen et al., 2016; Leggett et al., 2011; Rigby et al., 2019). Across all studies the co-residing rates of the informal carers and the person with Lewy body dementia ranged from 57% to 100%, and most participants were female carers (62% –100%). Across all studies 3,342 carers of people with Lewy body dementia were represented. However, whilst ten studies included people with Lewy body dementia, the actual level of their contribution was limited to a small number of quantitative measurements, with only one qualitative study exploring in-depth experiences (Larsson et al., 2019).

The papers were initially sub grouped according to their predominant focus, and this forms phase one of the iterative process whereby papers were ordered and categorised (Toronto and Remington, 2020; Whittemore and Knafl, 2005). Four subgroups were identified: caregiver burden and coping; quality of life and well-being; diagnosis and clinical care; and information and support needs. These are presented in the outer circle diagrammatically in Figure 2.2.

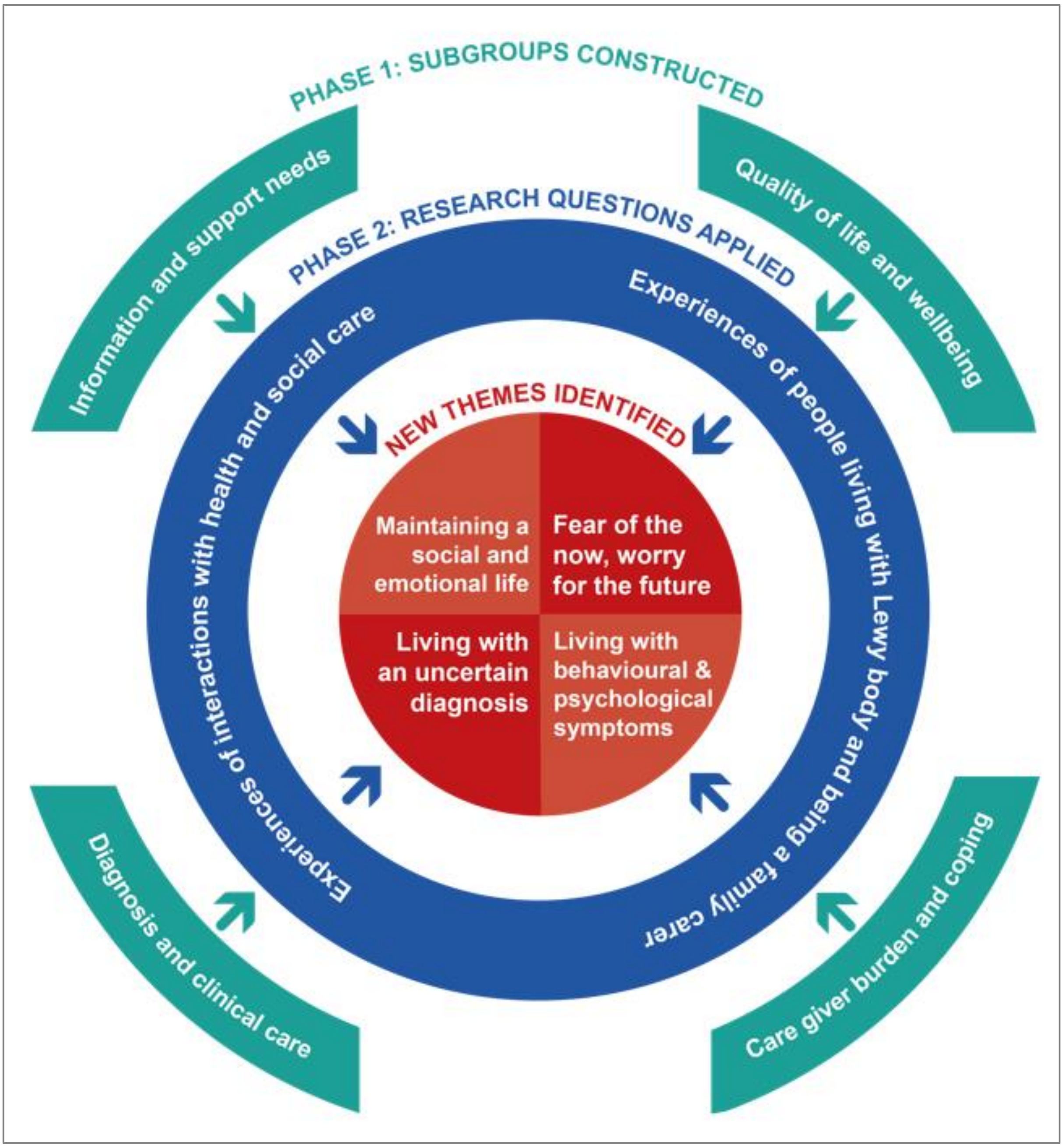


Figure 2.2: Literature review synthesis display of findings - the experiences of people living with Lewy body dementia and their family carers.

Eleven papers focused on caregiver burden and coping, and were of a cross-sectional design (Galvin et al., 2010b; Jones et al., 2017; Lee et al., 2013; Leggett et al., 2011; Leroi et al., 2012; Oh et al., 2015; Shin et al., 2012; Svendsboe et al., 2017; Thaipisuttikul et al., 2013; Vatter et al., 2020, 2018a). The Zarit Caregiver Burden Interview (Zarit et al., 1986) was frequently applied with the Neuropsychiatric Inventory

(NPI) in the included studies. These highlighted that the presence of neuropsychiatric symptoms in Lewy body dementia, such as apathy, delusions, hallucinations, agitation, anxiety, and depression, were key contributors to caregiver burden and stress (Lee et al., 2013; Oh et al., 2015; Shin et al., 2012; Thaipisuttikul et al., 2013). Neuropsychiatric symptoms together with reduced activities of daily living (ADLs) added to constraints in social life and feelings of isolation for the carers (Galvin et al., 2010a; Leggett et al., 2011; Svendsboe et al., 2017). Uncertainty and fear for the future added to the perception of burden, as did a reduction in resilience, relationship satisfaction, and quality of life (Galvin et al., 2010a; Vatter et al., 2020). Frequency of neuropsychiatric symptoms were also influential in adult child caregivers experiences, resulting in higher levels of burden and decreased quality of life compared to spouses (Rigby et al., 2019).

In the next subgroup quality of life experiences were measured using the EQ-5D, which is a self-assessed health related, quality of life questionnaire. The Quality of Life-Alzheimer's Disease (Boström et al., 2007; Rigby et al., 2019), and QOL Questionnaire for Dementia in relation to depression and burden were also applied (Park et al., 2018; Roland and Chappell, 2019). Quality of life and well-being were generally considered poorer for those with Lewy body dementia compared to other conditions such as Alzheimer's disease (Boström et al., 2007; Kurisu et al., 2016; Park et al., 2018; Roland and Chappell, 2019; Wu et al., 2018). Studies within the diagnosis and clinical care, and information and support needs subgroups were predominantly represented by online surveys (Armstrong et al., 2019a; Galvin et al., 2010b; Killen et al., 2016), qualitative studies (Armstrong et al., 2019b; Larsson et al., 2019), and case studies (Londos, 2018; Stuart and Kenny, 2010). Within the final subgroups only one intervention paper was identified. This mixed methods feasibility study found that cognitive stimulation therapy was well tolerated for people with Lewy body dementia and their care partners. However, recruitment was initially lower than expected reportedly due to apathy, care partner burden, worsening dementia, and other health issues (McCormick et al., 2019).

By applying the iterative review methodology, the process of 'qualitising' and synthesising the studies ensured that patterns were distilled from different paradigms and were abstracted into themes (Cronin and George, 2020). The process of inductive 'complete coding' was applied to identify the new themes (Braun & Clarke, 2013, p.206). Four themes were identified in this review: 1. living with an uncertain diagnosis and prognosis; 2. fear of the now, worry for the future; 3. living with behavioural and psychiatric symptoms; and 4. maintaining a social and emotional life. This is represented in Figure 2.2. The research questions applied in phase 2 (see Figure 2.2) pertain to the experiences of interactions with health and social care; and the experiences of people living with Lewy body dementia and being a family carer.

2.6 Themes

2.6.1 Theme: living with an uncertain diagnosis and prognosis

The theme 'living with an uncertain diagnosis and prognosis' was informed by quantitative and qualitative papers. It explores difficulties in gaining a diagnosis and having differing interactions with healthcare professionals, which were common experiences for people with Lewy body dementia and family carers. Typically many people with Lewy body dementia had lived with an uncertain diagnosis, sometimes for many years (Galvin et al., 2010a; Killen et al., 2016; Londos, 2018; Stuart and Kenny, 2010). Many saw multiple doctors and a large percentage of people with Lewy body dementia (78%) were diagnosed with other conditions initially, such as Alzheimer's disease, Parkinsonism, other dementias, and psychiatric diagnosis (Galvin et al., 2010a). Once diagnosed, they still encountered difficulties finding a doctor who was knowledgeable about treating Lewy body dementia and gaining support (Galvin et al., 2010a; Killen et al., 2016). Caregivers of people with Lewy body dementia were often frustrated by their experiences with physicians regarding disease course and prognosis, available community resources, referrals to appropriate services, and difficulty coordinating care across healthcare professionals (Armstrong et al., 2019a, 2019b; Galvin et al., 2010b; Stuart and Kenny, 2010). Physicians rarely discussed what to expect at the end of life. Although death was usually expected, fewer than half of caregivers felt prepared (Armstrong et al., 2019a). Follow-up interviews with 30 family caregivers found ‘not knowing what to expect’, including aspects such as symptoms, deterioration after hospitalisation and falls, and unpredictable end of life trajectory particularly challenging (Armstrong et al., 2019b).

People with Lewy body dementia and carers also report the importance of establishing a collaboration between themselves and healthcare professionals, having regular reviews, and ensuring teams worked ‘in harmony’ (Larsson et al., 2019; Londos, 2018; Stuart and Kenny, 2010). There was evidence of positive interactions when regular communication and follow-up resulted in a trusting and respectful relationship between people with Lewy body dementia and professionals (Larsson et al., 2019; Londos, 2018; McCormick et al., 2019). This was found to be important at the end of life, when families who had been involved in advance care planning discussions with professionals felt better prepared, despite the unpredictability of the condition (Armstrong et al., 2019b).

2.6.2 Theme: fear of the now, worry for the future

Fear and anxiety featured strongly in the quantitative questionnaires and narratives featuring people with Lewy body dementia and family carers (Larsson et al., 2019; Londos, 2018; Stuart and Kenny, 2010; Vatter et al., 2018a). In the web-based surveys, the most frequent burden items reported by caregivers of people with Lewy body dementia were fear or ‘concerns’ for the future for their loved ones (Galvin et al., 2010a), with feelings of fear and uncertainty frequently highlighting the ability to provide care and caregiver performance (Galvin et al., 2010b; Rigby et al., 2019). The qualitative research on spouses of people with Parkinson’s disease dementia spoke of negative feelings such as guilt, distress, and fear of the progression of the disease, in addition to worrying about the future if they were unable to provide care for their partners (Vatter et al., 2018b). The perspectives of people with Lewy body dementia, although limited in the literature, highlighted a range of emotional responses to living with Lewy body dementia: fear of hallucinations, fear of falls and frightening nightmares as a result of rapid eye movement (REM) sleep disorder (Larsson et al., 2019), and being scared of the effects of tiredness and fatigue (Londos, 2018). The symptoms of fluctuations, depression, delirium, and violence were also expressed as ‘frightening’ (Stuart and Kenny, 2010).

2.6.3 Theme: living with behavioural and psychiatric symptoms

The papers highlighted how the presence of neuropsychiatric symptoms were a major contributor for caregiver burden, distress, and reduced quality of life in caring for a person with Lewy body dementia (Galvin et al., 2010a; Jones et al., 2017; Kurisu et al., 2016; Lee et al., 2013; Leggett et al., 2011; Leroi et al., 2012; Park et al., 2018; Rigby et al., 2019; Shin et al., 2012; Svendsboe et al., 2017; Thaipisuttikul et al., 2013; Vatter et al., 2020). Caregiver burden was measured using the Zarit Caregiver Burden Interview (Zarit et al., 1986) and was frequently applied with the Neuropsychiatric Inventory (NPI) to evaluate correlation. The main symptoms affecting burden and quality of life occurred in the NPI domains of delusions and apathy, hallucinations, and psychosis (Boström et al., 2007; Lee et al., 2013; Shin et al., 2012; Svendsboe et al., 2017). People with Lewy body dementia had significantly higher apathy scores, compared to those with Alzheimer’s disease (Kurisu et al., 2016; Roland and Chappell, 2019). Apathy was portrayed as a sense of passivity, which eventually led to the withdrawal of social interactions (Larsson et al., 2019). This can affect quality of life, as well as the ability to measure those experiences (Kurisu et al., 2016). Apathy and depression made it more difficult for people to participate in therapeutic interventions or group support (McCormick et al., 2019). The presence of hallucinations were also frequently reported as particularly stressful for caregivers (Galvin et al., 2010b; Leggett et al., 2011; Londos, 2018; Park et al., 2018; Shin et al., 2012; Svendsboe et al., 2017; Thaipisuttikul et al., 2013). Hallucinations are also a prominent feature of Capgras syndrome, where people with dementia with Lewy bodies experience the delusion that someone they know well has been replaced by an identical imposter (Thaipisuttikul et al., 2013). Carers felt they needed more support and information on symptoms such as hallucinations, fluctuations, and sleep disorders, as they had a major impact on the family's ability to maintain their caring role and live well (Killen et al., 2016; Londos, 2018; Stuart and Kenny, 2010; Wu et al., 2018).

2.6.4 Theme: maintaining a social and emotional life

The need to maintain an active social life and acknowledge emotional needs was identified as being important to both people living with Lewy body dementia and their carers (Larsson et al., 2019; Londos, 2018; Park et al., 2018; Stuart & Kenny, 2010; Vatter et al., 2020; Vatter et al., 2018a; Vatter et al., 2018b). However, it was notable from the reviewed papers how little formal, paid care was being received (Galvin et al., 2010b; Vatter et al., 2018a), and the resulting difficulties in maintaining social and emotional interactions. Most people living with Lewy dementia were relying on informal support, which was often provided by adult children, other family members and friends (Galvin et al., 2010b; Vatter et al., 2018a). People with Lewy body dementia were able to offer insight into the emotional support they had from friends and family, and highlighted the immense amount of physical support that was often required in maintaining those social and supporting relationships (Larsson et al., 2019; Londos, 2018; Stuart and Kenny, 2010). They also described feeling a burden in the wider social context, and they reduced the number of social events they attended due to their increasing physical needs (Larsson et al., 2019). Frequently reported burden dimensions included social and psychological constraints, personal strain, and interference with personal life (Vatter et al., 2018a; Galvin et al., 2010b), all of which can lead to relationship dissatisfaction and resentment (Vatter et al., 2020). It was highlighted that carers were creative at building social care networks (Park et al., 2018), but as disease progresses, carers often had reduced opportunities to develop new social relationships or maintain social interactions. Fluctuating cognition, hallucinations, and the physical aspects Parkinsonism had a large impact on people's ability to maintain access to social and emotional support. This ultimately resulted in carer burden, loneliness, and isolation, as well as reduced quality of life for people living with Lewy body dementia and their caregivers (Boström et al., 2007; Galvin et al., 2010a; Larsson et al., 2019; Leggett et al., 2011; Vatter et al., 2020; Vatter et al., 2018b; Wu et al., 2018).

2.7 Findings of the integrative review and the wider literature

The literature review highlighted that difficult and delayed diagnosis meant people were not getting the timely support and treatments they needed. It was identified that 78% of people with Lewy body dementia received a different diagnosis initially, usually Alzheimer's disease (Galvin et al., 2010a), and although rates vary within the wider literature, it is considered that approximately 50% are receiving a different or delayed diagnosis (Freer, 2017). The Lewy body Composite Risk Score (Galvin, 2015) and the Lewy body dementia assessment toolkit have been developed to help earlier identification of the disease (O'Brien et al., 2021). This provides specific screening questions to assess whether a patient has any of the core features of the condition (Galvin, 2015; Thomas et al., 2017, 2018). Long delays in diagnosis can lead to people experiencing considerable challenges and struggling to find the support they need. A lack of ongoing support may add to the feelings of fear and uncertainty which featured prominently for spouses and partners in the review.

Carers found that their family member's behavioural and psychiatric symptoms, such as delusions, hallucinations, and apathy, increased their feelings of burden, and decreased their quality of life. People living with Lewy body dementia also documented feelings of anxiety, depression, and apathy, with sleep disorders and hallucinations being particularly disabling. Visual hallucinations, often featuring fully formed people, animals and objects, are common, unpleasant experiences of Lewy body dementia (Mosimann et al., 2006; O'Brien et al., 2020). Many of these symptoms are particularly difficult to treat pharmacologically (Ford and Almeida, 2020; Liu et al., 2019). Neuropsychiatric symptoms should be managed with a non-pharmacological approach when possible, yet there is limited evidence on non-pharmacological interventions for people with Lewy body dementia (Connors et al., 2018). The presence of neuropsychiatric symptoms are common reasons for hospital admissions (Spears et al., 2019), and have a negative impact on people with Lewy body dementia's ability to participate in therapeutic interventions and social activities (Larsson et al., 2019; McCormick et al., 2019; Wu et al., 2018).

Maintaining a social life and support networks is important for both people living with Lewy body dementia and the family carer. Social support is seen as an interactive process in which emotional, physical, or financial help is received from a social network, and is considered important in maintaining the caregiver role (Snyder et al., 2015). Increasing confidence and self-efficacy for carers of people with Lewy body dementia, and optimising their social support networks, are key, as self-efficacy and quality of life are considered important factors when developing carer support services (Crellin et al., 2014). For caregivers of those who were struggling with behaviour and cognitive symptoms, quality of life was seen to improve with informal and formal support (Roland and Chappell, 2019). The need for timely information and support throughout the disease trajectory for those with Lewy body dementia is consistent with the general dementia carer literature (Francis and Hanna, 2020). However, given the disabling effect of neuropsychiatric symptoms, support and information should be tailored for those with Lewy body dementia (Connors et al., 2018; Rigby et al., 2019). Greater understanding of formal services and the knowledge of the disease progression can reduce carers' feelings of frustration and isolation, and result in people feeling better prepared (Bressan et al., 2020). However, in order to address such complex physical, cognitive, and psychosocial needs those with Lewy body dementia may require life-long tailored support and services (Capouch et al., 2018).

2.8 Strengths and limitations of review

The integration of Lewy body dementia papers drawing on quantitative and qualitative results is the main strength of this review, as previous reviews of Lewy body dementia have focused on quantitative data. This enabled new insights, and therefore expanded the current evidence base, particularly around experiences.

Including a family carer from the patient and public engagement group and a second reviewer with experience in family carer research in the review process was a particular strength. This enabled direct applicability of research to people living with the condition, and aided robustness to the review process .

This integrative review had several limitations relating to methodological issues. Most of the quantitative papers in the review focused on comparing Lewy body dementia with other conditions which made it difficult to extract Lewy body-specific data. This heterogeneity of measurement tools, population groups, and the small number of papers meant it was not possible to complete a meta-analysis with the quantitative data. There is currently limited information regarding the process of 'qualitising' quantitative data, therefore findings were reliant on the conclusions of the authors and their interpretation of their data. The included papers originated from western, high-income countries, so therefore the findings provide perspective. In addition, only including papers published in English may have excluded some relevant papers. Five of papers ranked as low for quality in this review. This may result in a lack of rigour in the methodological underpinnings or quality of data included. However, all papers were retained for synthesis as they met the inclusion criteria and contributed valuable insight to lived experience.

2.9 Conclusion

The integrative literature review explored the experience of living with an uncertain disease trajectory and showed the impact this had on people's lives. Fear and worry were predominant feelings for both people with Lewy body dementia and family carers, who were also concerned about what the future might hold. The debilitating effects of living with the behavioural and psychiatric symptoms of the disease, and the importance of maintaining a social life amidst the condition-related changes were also identified as important. However, there was scarce qualitative evidence focusing on the lived experience of people with Lewy body dementia and their family carers. The dominance of cross-sectional designs to examine factors affecting aspects of caregiving and living with Lewy body dementia may affect understanding of changes over time and limit wider understanding of experiencing the course of this complex condition. Given that experiences may change and fluctuate, the literature review identified the need to incorporate a longitudinal approach in future research. This review also identified a gap in our understanding of, for both the person with Lewy body dementia and their family carer, what is like to live with Lewy body dementia as a life-limiting illness. Moreover, in the literature, there is little evidence for the application of a palliative care approach to Lewy body dementia. Within this thesis I aim to address this crucial gap with its research questions, methods, and findings.

Chapter 3: Methodology

3.1 Introduction

In this chapter I will set out the methodological approach taken, including the rationale for using narratives to explore couples' experiences of living with Lewy body dementia. I explain the study design, in particular the conceptual foundations - including its paradigmatic and theoretical perspectives - methodological processes, and methods. To address the research questions this study was conducted from an interpretivist, social constructivist stance. Conducting research within the interpretive paradigm offered insight into the experience of research participants and their subjective understanding of their social world. This involved gathering information through inductive qualitative methodologies to report stories (narrative research) and describe experience (phenomenology). Finally, I explain the procedures used to address validity and preserve quality within narrative research.

3.2 Study design

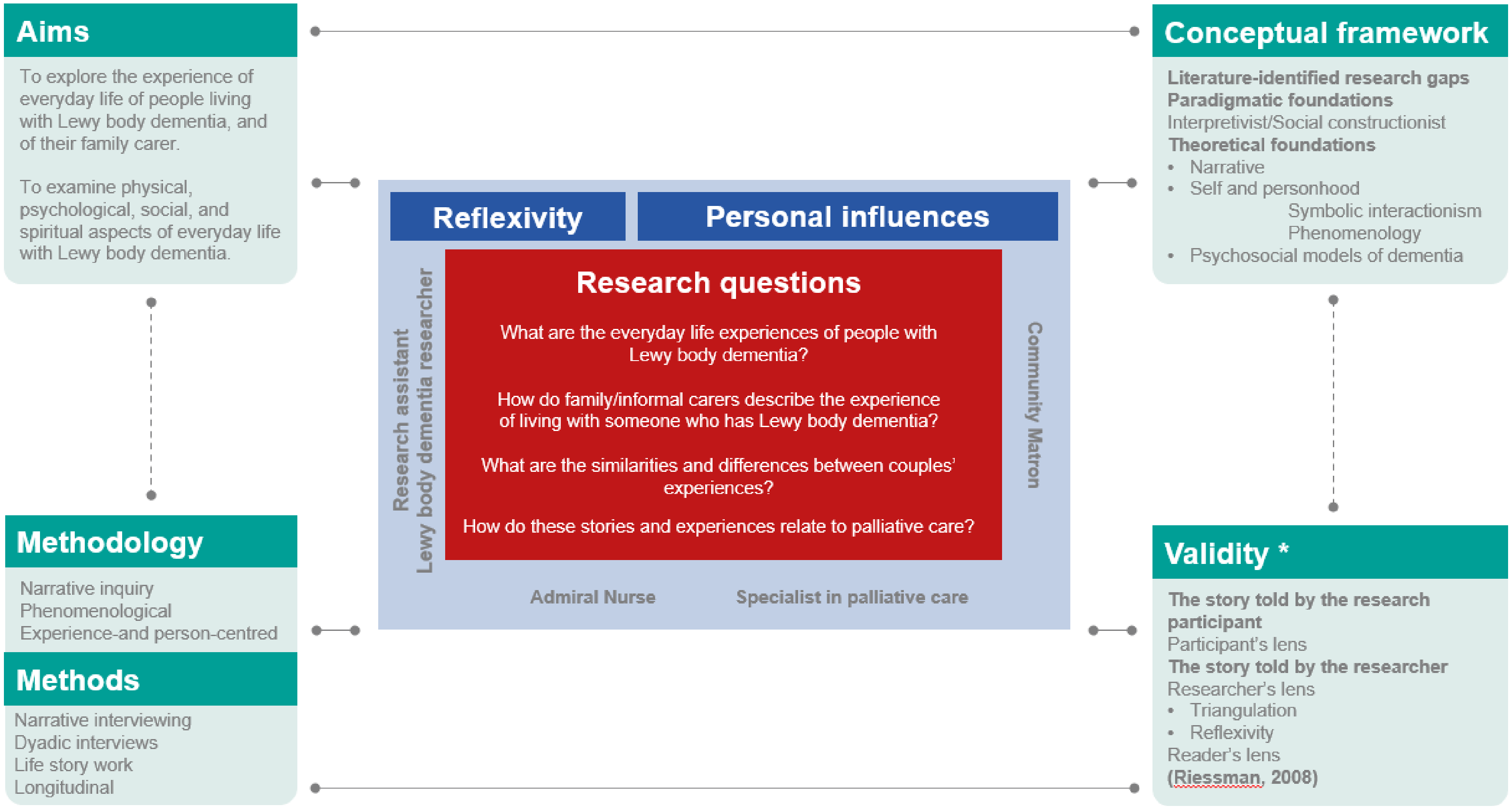
The conceptual framework is based upon the study aims and questions which are central to the design for this study. The research questions developed to address the study aims and objectives are:

- What are the everyday life experiences of people with Lewy body dementia?
- How do family/informal carers describe the experience of living with someone who has Lewy body dementia?
- What are the similarities and differences between couples' experiences?
- How do these stories and experiences relate to palliative care?

Initial patient and public involvement suggestions helped shape the research questions. The patient and public involvement group for this study reported they did not consider Lewy body dementia to be a life-limiting illness or needing palliative care

(Appendix 6: Initial patient and public involvement feedback). Palliative care was therefore not the starting point in researching people living with Lewy body dementia and that of their family carer, but a question to be applied to the findings.

Placing the research question at the centre of the design is compatible with Maxwell's (2013) interactive research design framework. This design framework, adapted to represent the methodological perspectives of this study, is represented in Figure 3.1. For Maxwell the five components of the research design (research questions, aims, conceptual framework, methodology, and validity) are connected as a whole, whilst allowing for flexibility. There should be a reflective process within qualitative research occurring throughout the project and this is represented by the blue outer box in Figure 3.1. My own initial observations, experiences, and reflections are described in Chapter 1 (section 1.4). The top squares (conceptual framework, aims, and research questions) are a closely integrated unit, as the research questions have a clear relationship to the aims, theories, and what is already known about the phenomenon. The bottom left square similarly relates, as the methods chosen must enable the research questions to be answered. Additional connections are represented by a dotted line, for example showing that the study's conceptual framework supports, and sometimes challenges, aspects of validity deemed important to the study (Maxwell, 2013).



Aims

To explore the experience of everyday life of people living with Lewy body dementia, and of their family carer.

To examine physical, psychological, social, and spiritual aspects of everyday life with Lewy body dementia.

Conceptual framework

Literature-identified research gaps
Paradigmatic foundations
Interpretivist/Social constructionist
Theoretical foundations
- Narrative
- Self and personhood
  Symbolic interactionism
  Phenomenology
- Psychosocial models of dementia

Reflexivity

Personal influences

Research questions

What are the everyday life experiences of people with Lewy body dementia?

How do family/informal carers describe the experience of living with someone who has Lewy body dementia?

What are the similarities and differences between couples' experiences?

How do these stories and experiences relate to palliative care?

Research assistant
Lewy body dementia researcher
Community Matron
Admiral Nurse
Specialist in palliative care

Methodology

Narrative inquiry
Phenomenological
Experience-and person-centred

Methods

Narrative interviewing
Dyadic interviews
Life story work
Longitudinal

Validity *

The story told by the research participant
Participant's lens
The story told by the researcher
Researcher's lens
- Triangulation
- Reflexivity

Reader's lens
(Riessman, 2008)

* The term validity used in relation to Riessman (2008) is expanded in section 3.6 and 5.4

Figure 3.1: Study framework, adapted from Maxwell's interactive model of research design (Maxwell, 2013).

3.3 Conceptual framework

The conceptual framework of a study is derived from three interrelated areas: empirical findings from the literature, the paradigmatic stance, and theory. The framework demonstrates the orientation of the study, explains its contribution to the body of knowledge, and how philosophical assumptions and the influence of theory align with the methodology (Creswell and Poth, 2018). The conceptual framework also provides the foundation and focus for the study's data analysis (Woolf and Silver, 2017).

Within Chapter 2 I highlighted the predominance of quantitative, cross-sectional studies examining patients and carers needs, met and unmet, in the current Lewy body literature (see Bentley et al., 2021a). For patients their experiences within research studies have mainly been in the form of interventions, surveys, and case studies. Object assessment (for example medical diagnosis) and objective intervention (medical treatment or palliation) provide just one important aspect of knowing in the clinical world (Hurwitz et al., 2004). Within healthcare there is a need to reconcile the tension between the subjectivity and uniqueness of the human experience with the positivist medical paradigm (Hurwitz et al., 2004). The traditional biomedical approach to dementia assumes a straightforward relationship between the type and extent of cerebral damage and signs and symptoms of the condition. Set within a mental illness framework the biomedical model of dementia is a pathological organic condition that progresses through stages, each with a set of behaviours or 'symptoms' and resulting cognitive deficits (DeTure and Dickson, 2019). The positivist stance is influenced by early philosophical arguments which suggest that being human necessitates having the qualities of agency, identity, cognition, consciousness, reasoning, and the ability to be reflective (Higgs and Gilleard, 2016).

Lewy body dementia is a complex condition and there are multiple theories that shape dementia discourse. Dementia is considered to sit at the interplay of neurodegenerative impairment, health, individual psychology, and the environment (Fazio et al., 2018).To address these challenges there is a need to consider a middle way that explores the interaction of 'objective' events and their 'subjective' interpretation (Ezzy, 1998). This study's conceptual framework seeks to add to the current literature by filling the gap in knowledge about the lived experience of people with Lewy body dementia and family carers.

3.3.1 Paradigmatic foundations

To address the gap of the lived experience I applied an interpretivist, social constructivism paradigm, applying philosophical theories of narrative, self, and personhood in relation to dementia and memory. Interpretivism grew out of the rejection of the positivist belief that all reality can be objectively measured and understood. The social constructivist position, in contrast to many biomedical approaches, takes the view that reality is shaped by beliefs, perceptions, and external influences (Creswell and Poth, 2018). For interpretivists emphasis is placed on understanding individuals, and their interpretation of their world around them. The key understanding of the interpretivist paradigm is that reality is socially constructed; the focus of research should be on how humans make meaning of their world. The ontological approach to this study is that human understanding and interpretations of their world occurs through stories, and stories are encouraged and shaped by the social context. Narratives represent a social reality influenced through language, beliefs, cultural influences, and history (Bennett et al., 2020). Multiple realities are constructed through our lived experiences and interactions with others. Therefore, epistemologically the use of the interpretivist/social constructionist approach translates, in practice, to a focus on personal knowledge and subjectivity.

3.3.2 Theoretical foundations

The theoretical foundation forms the philosophical stance which offers a pattern of beliefs and understandings from which the methodology and methods of the research project operate (Creswell and Poth, 2018). From the narrative perspective the individual self is constantly changing, adapting to new experiences that are assimilated into a person’s life story, and gives rise to how one gives meaning to one’s life. Literature on narrative identity suggests we construct and deconstruct our sense of self to provide meaning through the relationships and stories we tell ourselves. A sense of self is often viewed as an essentially human characteristic which is sometimes used synonymously with ‘personhood’. The social constructionist perspective of selfhood in people with dementia is commonly associated with the work of psychologists Steve Sabat and Rom Harré (Sabat and Harré, 1992). Here the sense of self is conceptualised as the process that provides people with the sense of coherence and individuality that define one as a unique and particular human being (Harré, 1998). At times of medical diagnosis, such as a diagnosis of dementia, the sense of self and identity can be challenged, as people face many changes to their physical, social, and psychological being (Sabat, 2001). Sabat highlights that multiple views of selfhood within dementia can lead to a deeper understanding of retained social and cognitive abilities and focusing only on the condition effectively removes the person from their social milieu and the real world (Sabat, 2021). Dementia, therefore, cannot be understood solely with reference to the neurodegenerative impacts of the condition, as human life is based on the interdependencies and interconnections of relationships. There is a need to consider the wider context, including how sociocultural factors frame these relationships and maintain interdependencies (Higgs and Gilleard, 2016). This is because the self is a social construction that takes shape through interaction (O’Brien, 2017). Self-knowledge comes through our understanding of our relation to the world, and of life with and among others, in the world (Ricœur and McLaughlin, 2009).

3.3.2.1 Philosophical theories of narrative

An early reference on the narrative form of human thinking is said to be by William James (1890), the founder of the philosophical school of pragmatism. He considered all human thinking to consist of reasoning on one hand, and narrative, descriptive, contemplative thought on the other. Within philosophy these two kinds of human thinking are presented as opposing camps in the debate on narratives. One camp subscribes to the idea that narrative is woven into the fabric of everyday experiences forming a whole pattern, and this is intrinsic to human life (Freeman, 2021). Alternatively, a positivist stance views narrative as extrinsic, where life doesn't have narrative built into it, but may be imposed. I draw from the former – that narrative is woven into the fabric of everyday experiences – and therefore epistemologically align with the social constructionist arguments in 'which language, signs, cultural codes and the positioning of the tellers and audiences are viewed as in interplay' (Squire et al., 2014). From this stance narratives represent a social reality influenced through language, beliefs, cultural influences, and history.

The ontological approach to this study is that human understanding and interpretations of the world occurs through stories, and stories are encouraged and shaped by social context. Therefore, the subjective dimension and its narrative expression is viewed as a co-constructing experience. The precise meaning of co-construction varies between approaches and traditions. For this study I consider co-construction as a social performance space, shaped by wider society (Szulc and King, 2022). People with Lewy body dementia may experience difficulties with communication due to brain and physical changes associated with Parkinsonism. This is important to acknowledge within the study design, as psychosocial interactions may change when a person has advancing dementia. In this instance there is conceivably potential for a power imbalance, which requires a re-think in how we maintain more equal connections.

One way to address potential researcher/participant inequality is to explore Buber's (1970) philosophy. According to Buber et al., 1996 there are two basic modes of encountering the world, both human and non-human. One is the *'I-it'* mode which is the objective stance to the reality before us. This refers to an 'information getting objectivity, an instrumentality, and an engagement without commitment' (Small et al., 2007 p. 115). The *I-Thou* mode*,* sometimes framed as *I-You,* mode is based fundamentally on making contact with the pure being of another. The deep, primal connections in human relatedness come from the notion of the 'between'. The 'between' is described as 'a primal category of human reality' localising the relationship between human beings (Buber and Eisenstadt, 1992). It is the *I-You* relationship that needs to be considered within social science data collecting and analysis. It is considered that researchers enter with a particular agenda – to learn about a phenomenon by engaging with certain person or groups. However empathetic or rationally minded a researcher may be there is a need to gain something from the research participants (Freeman, 2021). Buber suggests a requirement to 'let go', a concept that Reissman acknowledges may take time over the course of multiple interviews to achieve, in order to build rapport and relinquish control (Riessman, 2008). Therefore, this study's analysis process paid attention to how participants and researcher constructed, influenced, and developed the stories.

One of the strengths of philosophical narrative theory is that it provides a framework to address many of the epistemological and ontological issues raised by psychosocial and cultural studies within health and illness (Ezzy, 1998). Narrative inquiry builds on the strengths of qualitative research by exploring construction of meaning and symbolic systems within a temporal framework, thus forming a link between the humanities and social science research (Ezzy, 1998). Narrative theory has many philosophical origins, the three main approaches are said to be within symbolic interactionism, phenomenology, and cognitive psychology (Wertz, 2011).

3.3.2.2 Theories of self and personhood

The early work by James (1890) was further developed by the pragmatist thought of George Herbert Mead (1924). His work is a sociological theory, set within symbolic interactionism, that developed ideas on how individuals interact with one another to create symbolic worlds, and in turn how these worlds shape individual behaviours. From a symbolic interactionist perspective one can hold a variety of narrative identities and ways of presenting oneself, each of which is connected to different social relationships (Ezzy, 1998). Symbolic interactionism, as a theoretical perspective, deals directly with issues such as communication, language, interrelationships, and community (Crotty, 1998). It is an area focusing on social actions and interrelation of personal values and mind within social structures and cultures (Jackson, 2010; Kim, 2016). Mead (1924) highlighted three key interconnecting theories that were particularly valuable in studies of illness. These are the theories of meaning and action, development of self, and temporality (Belgrave and Charmaz, 2015). Mead built on James' (1890) discussion on the nature of thinking with the psychological distinction between the subject of knowing and experiencing (the I-self) and the object of this awareness (the me-self) (Prebble et al., 2013). Mead distinguishes between the self and the body and used the term 'I' and 'me' to distinguish between the actions and behaviours of the person, the symbolic 'I', and the internal awareness, guidance, and evaluation of this behaviour 'me'. This internal dialogue, he suggests, is guided by learned behaviour from significant others. Therefore, aspects of self involve an internal conversation with the generalised other, and externally with people or groups that are important to us. This attention to significant others and external influences I consider an important aspect in dementia care and research.

Another important theoretical perspective within dementia and self, is that of identity and memory. Ricoeur's phenomenological perspective assumes that individuals form an identity by integrating life experiences into an internalised, evolving story of the self that provides purpose and sense of unity (Ricoeur,1992). Central to Ricoeur's (1992) philosophy is the suggestion that identity has two aspects of self: selfhood (memete) and sameness (ipseite). Selfhood reflects the way an individual defines themselves as separate from others, and this may change according to our social circumstances. Sameness refers to the fact that aspects of individuality are maintained through time as our core self. Memory is considered an important aspect of identity. It is 'through the narrative function that memory is incorporated into formation of identity' (Ricœur et al., 2010 p.84).

Narrative identity theories have traditionally assumed that having a memory is key to the idea of selfhood and identity, namely, having a knowledge of the past to reflect on. The long-standing theoretical assumptions suggested that both 'self and memory are unity constructs, with the self as a central operating mechanism, and memory as the brain's storehouse' (Prebble et al., 2013 p.815). This line of reasoning has in the past led to the common misconception that a loss of memory in dementia therefore leads to a diminished sense of self (Strikwerda-Brown et al., 2019). However, it is suggested that people with dementia retain the ability to experience themselves as 'I'. Kitwood (1997) acknowledges the importance of others to ensure people feel listened to, recognised, and accepted within their self-definition – a process Buber's philosophy refers to as 'confirmation' (Strikwerda-Brown et al., 2019). This acknowledges that ontological or spiritual identity continues to exist even after autobiographical memory has been left behind (Hydén, 2011).

In addition to Ricoeur's philosophy I draw from theoretical aspects of hermeneutic phenomenology by Van Manen (1997), as I consider it applicable to areas where human relations predominate. Van Manen's phenomenology considers the notion of the lived body (corporeality) and lived human relations (relationality) are important aspects of lived experience (Van Manen, 1997). Together with lived space (spatiality) and lived time (temporality) they are said to form the fundamental structure of the lifeworld and therefore are essential for understanding people's subjective experience. From a phenomenological perspective these four 'existentials' pervade the lifeworlds of all human beings regardless of their historical, cultural, or social situatedness. They can be differentiated but not separated, forming a 'whole' referred to as the lifeworld. Drawing on elements of the work from Van Manen and Ricouer can provide a more holistic approach to underpin the physical, visuospatial, emotional, and memory changes common in Lewy body dementia. The consideration is, like everyone, people with Lewy body dementia live within a social and cultural world, and that only those who experience this are capable of communicating their lifeworlds (Van Manen, 1997). A phenomenological perspective, although less common within narrative inquiry, can explore the lived world as experienced by everyday situations and multiple and differing relations.

3.3.2.3 Psychosocial models of dementia

Narrative psychology is said to be closely related to the notion of self and personhood, identity, and meaning making (Murray, 2015). The modern study of selfhood and personhood and dementia can be traced to Sabat (US) and Kitwood (UK) who during the late 1980s and early 1990s were considering alternative understandings to the 'decline, decay, and deficiency' models of dementia they saw (Sabat and Harré, 1992). Kitwood's (1997) work on person-centred care is widely acknowledged as a major influence within the field of dementia. By conceptualising well-being in relational terms, Kitwood brought in the language of personhood – defined as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood, 1997 p.8). Therefore, he argued, maintaining 'self' is inhibited or facilitated by the behaviour and practices of others. Consequently, other people are required to support people with dementia to maintain identity through their interactions and communications (Kitwood, 1997).

Sabat and Harré (1992) viewed the self as three distinct aspects of personhood. Firstly, self-1, is seen as personal identity, the embodied experience of being continuously located in a single point over time. This is the continuous experience of events that form the narratives of our lives. It is often expressed in the pronouns ‘I’ and ‘me’, and research has shown that the self-1 is relatively preserved for those with advanced dementia (Norberg et al., 2017), Self-2 relates to physical and mental attributes such as height, weight, eye colour, and sense of humour, which can be both positive and negative (Sabat and Harré, 1992). Kitwood (1992) refers to this as the ‘experiential self’ - the feeling, knowing self, the self which is the source of a person’s well-being and relatedness. Sabet considers Self-3 consists of a multiplicity of social identities that we construct in cooperation of others – self as partner, worker, patient. This ‘self’ can become vulnerable when a person is living with dementia if it is believed these roles are no longer fulfilled. The person may be regarded as socially devalued.

Feeling devalued and subsequent altered sense of self has its roots in the social world, not in neuropathology (Sabat, 2006). Such ‘malignant positioning’ occurs as loss of self, due to the perspectives of others (Sabat and Harré, 1992). In relational terms ‘malignant positioning’ is most often expressed within the work around personhood. Personhood is a multi-layered concept which can be viewed theologically, ethically, legally, and from social and psychological perspectives. These are considered to have overlapping theories and principles within palliative care (Davies, 2020). Over the years various person-centred theories have developed as an alternative to the biomedical model, with the concept of ‘person-centredness’ embedded in many international and UK healthcare legislative policy frameworks (Department of Health, 2009).

3.4 Methodology

This study's research aims, and questions focus on human experiences of thinking and interpreting meaning, and therefore relies on qualitative research methodologies to answer the research questions. There is increasing interest as to how qualitative narrative research can provide greater psychosocial understanding of people's experiences of health and illness (Murray and Sools, 2014). The process of narrative construction has made use of narratives for understanding the constant change and disruption to everyday lives, such as personal, family, financial, and health problems, with narrative the primary means of restoring order (Sarbin, 1986).

For Sociologist Michael Bury (1982) the term 'biographical disruption' describes the way life changing illness can threaten personal identity. For Bury chronic illness was conceptualised as a particular type of disruptive event, which he categorised into stages. As time goes on this adjustment becomes more difficult and individuals strategically withdraw from social interactions under the impact of symptoms – a behaviour also noted by Strauss (1975). As the illness progresses further the 'disruption' to daily life forces a person to rethink their self, relationships, and behaviour (Bury, 1982). As a result personal stories are considered to have therapeutic functions, providing shape and order to people's experiences and the making sense of the chaos caused by the disruption of illness (Bury, 1982).

The sociologist Arthur Frank (2013) identifies the 'chaos' within narrative. This he defines as 'the anti-narrative of time without sequence, telling without mediation and speaking about oneself without being fully able to reflect on oneself' (Frank, 2013 p.98). Frank argues that the chaos narrative remains the most frequently unheard story because when individuals are overwhelmed by the intensity of their illness, to speak coherently becomes impossible. These narratives, particularly within the context of dementia, are left untold because the chaos story is most often witnessed by friends and family, who may find listening painful, difficult, and frustrating. In addition a chaos narrative reflects ongoing challenges continually lived in the present (Donnelly, 2021). The chaos narrative may also be hidden or erased due to the Western focus on stoicism, and the desire for illness narratives to inspire others. I considered the importance of how best to represent the potential ‘chaos’ narrative and acknowledged Frank’s concern with identifying the extent to which stories were an opportunity for self-care through expression, and how power imbalance can occur within illness stories. He viewed illness as an interactive experience, wherein how friends and family react to the illness affects the story, and the reconstruction of identity. It is therefore important to consider the personal dementia stories within the context of the researcher’s position, the influence of others, and wider society.

Similar to published literature, the patient and public involvement work for this study highlighted how some people with dementia may not see their condition as an ‘illness’ or life-limiting (Fox et al., 2017; Richfield et al., 2013). Therefore their story may not necessarily be framed as an ‘illness’ narrative (Bingley et al., 2008; Page and Keady, 2010). For this reason, and to gain a richer, broader understanding of experience, my theoretical perspectives are drawn from philosophies of narrative, symbolic interactionism, and phenomenology. This wide-ranging approach was considered for two main reasons: first, to address the challenge of how to reconcile the prevailing realist ontology (which assumes that the narrative reflects the world), with the meaning making, and the interactive context, of the discursive approach; second, to answer a key question raised by Mishler (1986) – how to account theoretically, methodologically, and analytically for the relationship between the events of lived experience, and the expression of these events into a narrative. Therefore, narrative inquiry, without its methodological set rules and orthodoxy enabled creativity and space to capture the lived experience of people with Lewy body dementia and their carers.

3.5 Narrative interviewing

Narrative inquiry is the process of listening, honouring, constructing, and reconstructing stories about human experience (Clandinin and Connelly, 2000). Conducting a true narrative research interview requires the researcher to give up control and to shift to a more collaborative, power-sharing relationship (Riessman, 2008). This was made possible by considering Patton’s informal conversation interview model, which aims for the interview to occur in a natural conversational manner (Patton, 2015). Mishler (1986) suggests that informal, unstructured interviews are more likely to produce stories as they allow more freedom for responding. However, conducting a narrative interview with people living with dementia has its own set of challenges, as being entirely non-directive would not necessarily create the desired ‘space’ or control for the participants.

A narrative interview places the participants at the centre of the research study by using open-ended questions to encourage storytelling. It is important to consider how people with dementia may best be supported to communicate their stories. Communication is important as a means of expressing emotions, relationships, and social interactions, and is considered an important aspect of ‘embodiment’ and self. Research has demonstrated that communication through embodiment is a valuable creative medium in preserving a sense of self (Newen, 2018). Embodiment regards self as a situated human being, engaged in a world in a bodily way through stories, desires, choices, drives, emotions, needs and attachments (Newen, 2018). Embodiment provides the underlying framework that supports the notion that self-hood and identity can endure, despite a diagnosis of dementia. Much of the work in this field has been developed by Pia Kontos (2004), who describes embodied selfhood as referring to the ‘complex interrelationship between primordial and social characteristics of the body’ (Kontos, 2004 p 837). Hydén (2013) argues for a change of focus from textual aspects of narrative to a focus on performance aspects of the embodied aspects of storytelling.

Hyden views embodiment as an interactive, collaborative resource for storytelling, rather than an individualistic expression. The work of Kontos (2004) and Hyden (2013) place emphasis on maintaining biographical continuity in dementia. By considering embodiment as a resource people with dementia can communicate without necessarily relying on verbal exchanges, as a way of enabling shared connections.

To further enhance communication, stories were viewed as both ‘big’ and ‘small’. It is suggested that a small story approach can assist people who may not have the reflective capacity to tell big stories (Sools and Schuhmann, 2014). Small stories are expressions and events contained within the narrative interview which direct attention to the other ‘big’ stories that may be hidden (Sools, 2013). Small stories talk of the ‘I’ narrative and may highlight tension between the ‘I’ narrative and the wider one of family and community expectations (Riessman, 2008). To aid identification of bigger stories, small stories are observed for continuations of plotlines, or connections, built up over the course of several interviews. Plotlines are considered the ‘dominant thread running through a number of narratives’ (Bruce et al., 2016 p.3), and can aid identification of the ’big’ stories. In turn, big stories can help identify, from a phenomenological perspective, commonalities across participants’ stories, thus contributing to the development of an overarching theory or ‘grand narrative’.

3.6 Validity in narrative research

Within qualitative social science research it is generally considered inappropriate to assess validity through quantitative measures such as reliability and statistical generalisability (Creswell and Poth, 2018). Thus, this project uses the term validity in the qualitative sense of being trustworthy, useful, and transferable (Polit and Beck, 2021). Riessman (2008) considers coherence, credibility, and transparency important to evaluating trustworthiness in narrative research. To enhance validity and preserve quality it was important to select procedures that reflect the study’s methodological approaches. Riessman (2008) suggests two aspects of validity are important within narrative research: ‘the story told by the research participant’ and ‘the story told by the researcher’ (Riessman, 2008 p.184). To demonstrate narrative validity, I add a third aspect – the ‘reader’s lens’ as described within Creswell and Poth’s (2018) validity framework. They suggest researchers apply a variety of ‘validation strategies’ to document the accuracy of the study. These strategies are organised into three groups: participant’s lens, researcher’s lens, and reader’s lens (Creswell and Poth, 2018 p.259).

3.6.1 Researcher’s lens

Researchers’ validation strategies can include corroborating evidence through triangulation, and engaging in reflexivity. Triangulation within qualitative research can be regarded as a method of enriching understanding of a phenomenon by viewing it from different perspectives (Vogl et al., 2019). This differs from a quantitative approach aimed at the convergence on a single account of the phenomenon. This approach to triangulation addresses Riessman’s validity of ‘the story told by the research participant’ (Riessman, 2008 p.184). Enriching validity through trangulation can be achieved by gathering data from different groups of people, dyadic interviewing, or by gathering data at different times from the same person.

Reflexivity is also considered an important strategy for validity (Riessman, 2008). Reflexivity can be described as having a greater social awareness around the subject of the research and the social spaces within which the research knowledge is produced (Holloway and Freshwater, 2007a). They suggest a need to create a greater sense of the personal, cultural, academic, intellectual, and historical influences of the researcher in building the research knowledge (Holloway and Freshwater, 2007b). Positional reflexivity refers to critical self apprasial regarding biases, values, and preferences about the phenomenon under investigation (Creswell and Poth, 2018). These include a researcher’s background, discipline, and privileges. Being a nurse has some advantages when interviewing people with Lewy body dementia, as the condition can fluctuate not just day by day, but minute by minute. People may suddenly fall asleep, wake up in a dream state, and sometimes hallucinate people or animals. It is therefore important that the interviewer knows how to respond in these situations. The context and relevance from my perspective as a researcher has been described in Chapter 1 (section 1.4). As the narrative interview is considered a more interactive, relational process it is also important for the researcher to pay close attention to interpersonal reflexivity. Recognised methods to enhance reflective work such as completion of field observations, engagement in the field, and using a reflective journal were included in this project (Creswell and Poth, 2018).

The second part of reflexivity included making the researcher ‘visible’ throughout the research process. This visibility occurred from the decision made in choosing the research topic, questions and design, to the selection of participants, and the interpretation of data (Bryman, 2021). Reflexivity of decisions and procedures can provide evidence of a verifiable audit trail and aid transparancy, particularly around the analysis process. The conceptual perspectives and traditions also formed the framework for the analysis process and provided the foundation to assess the validity of narrative research (Riessman, 2008). There is an increasing body of literature debating the variety of analytical approaches for analysing narrative data, however, narrative research is an emerging and evolving field with no single, clearly defined approach to data analysis (Meraz et al., 2019). The approach taken is said to depend on researcher perspective, other literature in the field, and the underlying theory used to guide the choice of research topic and questions (Woolf and Silver, 2017). Therefore, the foundation for the analysis process for this study was based on the social constructionist perspective. This acknowledges that whilst self and it’s expression can be changed by dementia ‘much of this change is attributed to how we interact with the person at interpersonal, societal and political levels' (Small et al., 2007 p.115). The analytical framework will be disccused in more detail in Chapter 4, with Chapter 5 providing a more detailed explanation of the analytical and interprative processes by drawing data from one couple as an exemplar.

3.6.2 Participant's lens

Participants can play an important role in a variety of validity strategies. Creswell (2018) suggests building rapport with participants and gatekeepers to learn their background culture and context. I had time in the field working on a variety of projects focused on people with Lewy body dementia prior to beginning data collection for this study. This included collaborating with patients, participants, and family carers within the context of patient and public involvement. Patient and public involvement is considered important for ethical, political, and methodological reasons, as well as contributing toward validity (Hoddinott et al., 2018). Active patient and public involvement ensures meaningful co-production of the research project (Burton et al., 2019). At the outset the group felt that experiences would vary and change due to numerous factors and a more longitudinal approach would likely give a range of experiences for individuals. It is recognised that the stories derived from memories, expectations, or projections are not 'set' but embedded in a dynamic, shifting, and fluid narrative (Elliot, 2005). They therefore felt it was important to offer personal choice and flexibility within the interviews. Membership included four family carers and one person living with Lewy body dementia. They participated in the design of the project, the information sheets, interview schedule, and recruitment strategies. One family member in the group contributed to the selection of abstracts for the literature review process as described in Chapter 2. Towards the end of the study, the group provided constructive feedback on the findings and assisted in writing plain English summaries for dissemination. Sharing the findings with the public and patient group also allowed for wider understanding of the persuasiveness and dependability of the ‘story told by the researcher’ (Riessman, 2008 p.184). Consultation with the group is summarised in Appendix 17.

3.6.3 Reader’s lens

Creswell and Poth (2018) suggest strategies for validating from the reader’s perspective, including generating rich, thick description with relevant excerpts and quotes, enabling external audits, and having a peer review or debriefing of the data and research process. Clandinin (2016) and Riessman (2008) consider coherence an important aspect of quality in narrative studies. Coherence of a study can be related to the extent to which it makes sense as a consistent whole. This relates to clarity of fit between the theory, research questions, methods, and interpretation. This provides evidence that the findings reflect the perspectives and traditions that frame the project, considered to be situated truths (Riessman, 2008). In addition, within narrative research demonstrating a logical sequence of the analytical process is important to guide the reader along to uncover the trail of evidence.

Consensual validation seeks the opinions of competent others, to ensure agreement of the descriptive, interpretive, and evaluative processes (Aspers and Corte, 2019). Peer validation in the form of academic feedback was sought for this project. It was provided by a professional with experience of psychology, academic study, and patient and public engagement. They also facilitated public user feedback on the findings from a different geographical area. Their comments on this can be found in Appendix 19.

3.7 Conclusion

In this chapter I discussed the interpretivist and social constructionist epistemological positions, and the situation of narrative and storytelling to address the research questions. The ontological understanding was that multiple realities are co-constructed through storying the lived experience and interactions with others. Theoretical perspectives were drawn from symbolic interactionism, narrative theory, and phenomenology. These perspectives were considered as interrelated to the methodological approach of living with Lewy body dementia from an experience-centred, narrative-based inquiry. Finally, I considered the importance of examining narrative validity from the researcher, participant, and reader’s lens.

Chapter 4: Research methods

4.1 Introduction

Within this chapter I discuss further the methods selected to answer the research questions in exploring the experiences of living with Lewy body dementia. The study aimed to explore the experience of people living with Lewy body dementia and a family carer via qualitative narrative interviews. I explain the rationale for a dyadic, longitudinal approach to narrative interviewing in allowing for a deeper understanding of changes in experiences over time. I describe the processes used for sample selection, ethical considerations, and methods used to generate and analyse narrative data. This discussion will take into consideration influences from my theoretical and professional underpinnings and the role of the patient and public involvement group.

4.2 Population: inclusion and exclusion criteria

Inclusion and exclusion criteria is dependent on the research aims, questions, and methods (Creswell and Poth, 2018). For this study inclusion and exclusion criteria were applied as per Box 4.1.

Box 4.1: Inclusion and exclusion criteria

Inclusion criteria

Person with Lewy body dementia:

- Diagnosis of either dementia with Lewy bodies (Fourth Consensus report of the DLB Consortium; McKeith et al., 2017) or Parkinson's disease dementia (Aarsland et al., 2003) as determined by clinician or participants.
- Capacity to give informed consent within the context of an interview.
- Verbal skills sufficient to engage in an interview in English, or able to take part in an assisted interview using storyboarding techniques.
- Close family member/informal carer willing to be involved.
- Living in the community (home or care home).
- Aged 18 years or over.

Family member/informal carer:

- Living with, or close involvement with, family/friend with Lewy body dementia.
- Aged 18 years or over.
- Have the capacity to consent on their own behalf.

- English language skills sufficient to engage in an interview (or able to be involved in an assisted interview using storyboarding techniques).

Exclusion criteria

Person with Lewy body dementia:
- Diagnosis not confirmed, as assessed by clinician, researcher, or participant.
- Lack capacity to consent to participate in the research, as assessed by clinician or researcher.

Family member/informal carer:
- Unable to participate in a qualitative interview using English, as assessed by clinician or researcher.
- Unable to give informed consent within the context of the research, as assessed by researcher.

The setting for the research was eastern England in the United Kingdom and involved people living in the community (own homes or care homes). The advantage of meeting in a place that is familiar to a person who has memory problems is that this may reduce anxiety, and questions can be individualised and restructured to elicit more concrete thoughts, whilst maintaining the integrity of the research (Samsi and Manthorpe, 2020). The geographical location was chosen as a convenience method to balance the challenges of achieving recruitment within a relatively small target group when resources for travelling were limited.

4.3 The sample

People with a diagnosis of Lewy body dementia and a close family member were recruited to the study using a convenience sampling strategy. The sample size of people with Lewy body dementia (n= 5–10) and their family carer (n= 5–10) was chosen to address the aims of the study, sample specificity, and analysis strategy, and allow for attrition rates. This size was deemed sufficient in part because the numbers of participants required can be considered smaller in narrative inquiry (Patton, 2015). Narrative research may be a single person or a small number of participants, and does not aim for ‘saturation’, as required for other qualitative research designs. (Bradbury-

Jones et al., 2017). Malterud et al., (2016) explains sample size in all qualitative studies should be guided by 'information power' in that the more information the sample holds relevant for the study, the lower the participants needed. The information power for this narrative research is based on the need to identify interesting stories to answer the research questions. It is further strengthened by dyadic, longitudinal data methods, and the layered analytical process. This involved collecting longitudinal data whilst keeping the stories intact.

4.4 Recruitment

Participants were identified, approached, and recruited via a two-pronged approach. They were identified via voluntary and statutory service sectors, as Lewy body dementia is a relatively rare diagnosis, and many patients are not followed up routinely in clinical services. A flowchart for identification and recruitment is provided in Appendix 7. In the voluntary sector, relevant charities (Parkinson's UK, Lewy Body Society, Alzheimer's Society, and local hospices), were approached to place a poster on their websites, and display at local support groups. The 'Join Dementia Research' database agreed to add the study to their portfolio (Appendix 8: Research poster). Potential interested participants were able to contact the researcher by phone or email to request more information. They were then posted or emailed the participant information sheet (Appendix 9: Participant Information Sheet) and 'opt in' slip (Appendix 10: Letter and 'opt in' slip). Statutory health and social care services included memory clinics, community teams (combined mental health & primary care multidisciplinary teams), and the psychiatry liaison service within the local NHS trust. Within the NHS trusts staff, initial contact was via the team managers to request clinical staff assistance in providing an introductory letter and participant information sheet to eligible participants. This included an 'opt in' reply form with stamped, addressed envelope, and the option to telephone or email.

Potential participants who responded positively to a recruitment letter were contacted to answer their questions and to set up a meeting in a place of their choosing, be it home, clinic, nursing home or a neutral place. Because they were offered a choice, participants may have felt more relaxed in a familiar setting for the interview. At that meeting the patient and family member were able to ask any further questions. Following reading the information and agreeing to participate, potential participants were asked to sign a consent form.

4.5 Consent and capacity

Dementia is characterised by a progressive diminishment of memory, reasoning and language that can have an impact on decision-making capacity (Thorogood et al., 2018). Decision-making capacity can be affected because weighing up options can be challenging and communication can be difficult (Samsi and Manthorpe, 2020). The Mental Capacity Act (2005) states that adults have the right to make their own decisions unless proved otherwise incapable , and this includes taking part in research. Specific training in assessing capacity and receiving informed consent from people with dementia was undertaken. To support the decision-making process the project was explained verbally, and information was made available in written form. Written information in plain English was suggested by the patient and public advice group. People with Lewy body dementia experience fluctuations in cognition, so the best time of day and place to make contact was taken into consideration. Capacity was assessed by the participant’s ability to indicate that they understand the research project and could retain, weigh up, and feedback this information. If the person with dementia and carer are willing, arrangements were made to visit them at home to seek consent. It was hoped that being in the home environment (or other place of their choice) would help people feel more relaxed and in control of the situation. People with Lewy body dementia often have more subtle and individual language problems, so it was important to speak in a quiet environment, use clear simple phrases, and give time for responses.

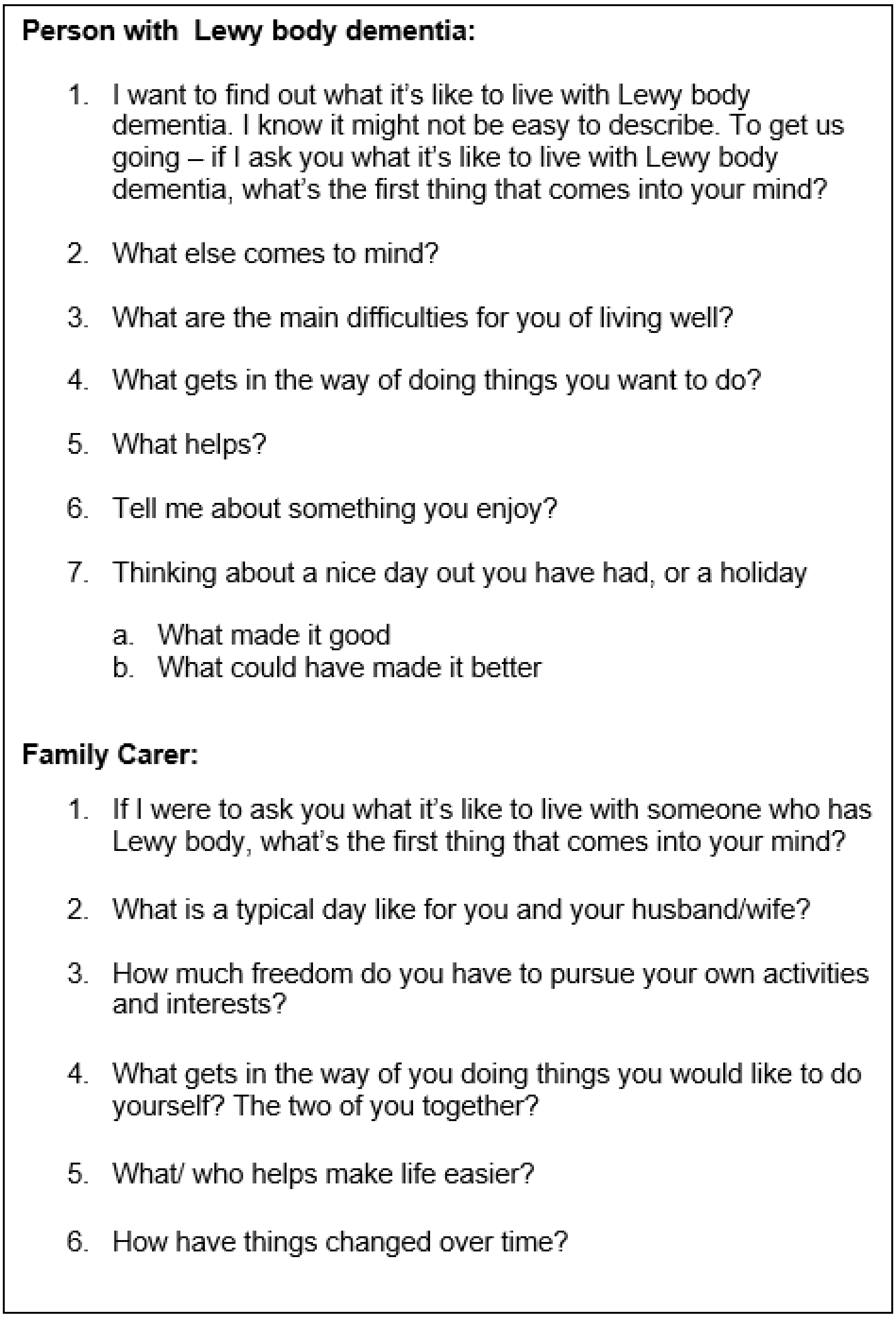
Written consent was obtained prior to the commencement of the study. The written consent form covered the different aspects of consent (Appendix 11: Consent form) and gave guidance to the purpose and nature of the study and the person's right to decline participation. It is acknowledged that due to Parkinsonian symptoms, some participants may have difficulty initialling in small boxes. The ethics committee advised it was acceptable for participants to place a tick or initials in the boxes or have support from a relative who can sign in the ‘witness’ section. Consent was gained for the interviews to be audio-recorded to ensure accuracy in transcribing the interview and allow the language of interactions to be explored (Riessman, 2008). Process-ongoing consent was in place, including checking at the start of each interview if the participants were able and willing to continue (McKeown et al 2010). If it was identified that the potential participant was unable to give informed consent the person would not be eligible for an interview. It was explained that participants could withdraw from the study at any time, without giving a reason.

4.6 Data collection of narrative interviews

For narrative research, data collection involves gathering information through interviews, direct observation, and the analysis of recorded speech or documents (Pope and Mays, 2020). Whilst narrative research privileges stories as meaning making devices, a phenomenological perspective can accommodate a wider range of data collection methods into the analysis. Observations, field notes, artwork, life story work, and photo-storying are increasingly used as ways of engaging people with dementia (Bruce et al., 2016).

From my clinical experience I was aware of the potential difficulty for people with Lewy body dementia to express themselves due to brain changes. Amongst researchers it is acknowledged that structured or direct questioning can potentially lead to anxiety and confusion for people with dementia (Samsi and Manthorpe, 2020). I therefore concur with McKeown (2017) that time and encouragement to draw out perspectives may be better represented through narratives over time (McKeown, 2017). Therefore, a longitudinal narrative approach was deemed the most appropriate method for the study, with an open-ended form of narrative interviewing to help support people with memory problems tell their stories. An interview guide was developed with the user group with five to seven broad, open questions as suggested by Reissman (2008). The questions are presented in Box 4.2, overleaf. They provided guidance, so as not to overwhelm participants, and to allow experiences to be explored within the context of the topic.

Box 4.2: Interview topic guide



Person with Lewy body dementia:

1. I want to find out what it's like to live with Lewy body dementia. I know it might not be easy to describe. To get us going – if I ask you what it's like to live with Lewy body dementia, what's the first thing that comes into your mind?
2. What else comes to mind?
3. What are the main difficulties for you of living well?
4. What gets in the way of doing things you want to do?
5. What helps?
6. Tell me about something you enjoy?
7. Thinking about a nice day out you have had, or a holiday
   a. What made it good
   b. What could have made it better

Family Carer:

1. If I were to ask you what it's like to live with someone who has Lewy body, what's the first thing that comes into your mind?
2. What is a typical day like for you and your husband/wife?
3. How much freedom do you have to pursue your own activities and interests?
4. What gets in the way of you doing things you would like to do yourself? The two of you together?
5. What/ who helps make life easier?
6. How have things changed over time?

4.6.1 Dyadic data collection

To allow for additional support for people with Lewy body dementia, and widening perspectives, this study gave the option of interviewing with a family member present. Dyadic interviews commonly involve two participants that share a pre-existing relationship, and multiple authors have discussed the potential advantages of dyadic interviews (Szulc and King, 2022). These include allowing participants to stimulate ideas in each other that might not have been recognised or remembered to provide rich data, including observations (Bjørnholt and Farstad, 2014; Orsulic-Jeras et al., 2020). An advantage is couples may probe each other in the context of their narratives and introduce new topics for discussion (Morgan, 2016). Dyadic interviews can elicit a rich understanding of experience in context and illuminate the co-construction of meaning for those with dementia (Molyneaux et al., 2012). This approach offers an interactive way of exploring the similarities and differences of experiences between people living with Lewy body dementia and family carers. It allowed more opportunity for the participants to influence the topic and data and to provide detailed narrative interactions. In collecting data for this study a dyadic approach to interviewing enabled exploration of interrelationships and nuances of experience to better understand individual situations between teller and listener, and broader societal and cultural contexts (Squire et al., 2014). This approach is useful when a phenomenon of interest has been poorly defined or conceptualised, such as palliative care in Lewy body dementia.

Five couple interviews were conducted with people living with Lewy body dementia and their family carer. With each couple three interviews were offered flexibly over a six-month period. The interviews were offered to take place together (as dyads) or separately. If the person with Lewy body dementia deteriorated it was acknowledged that interviews may be with a family carer only. This flexibility was built into the research protocol and ethics application to allow for the fluctuations and unpredictability of the condition and allow for one interview to be conducted separately for the person with Lewy body dementia where possible. This was to mitigate the disadvantages of dyadic interviewing, such as the effect of one participant silencing another (Polak and Green, 2016). For the person with Lewy body dementia this included life story work. The use of life story work in dementia care is widely acknowledged to support person-centred care (Cooney and O'Shea, 2019). For the purposes of research interviewing, it can assist as a communication method for participants with dementia to express themselves (Samsi and Manthorpe, 2020). It can also reveal a richer understanding of context as the pattern and structure of stories are shaped by conscious and unconscious social and psychological forces (Murray, 2015). A dyadic approach with one separate interview provided a rich, more in-depth understanding, and raising the profile of voices that have often been neglected within health and research structures (Sools, 2013).

All five couples were interviewed together initially at the first interview. Although for **Kath** and Ken, the initial interview then separated as he went to the kitchen to start cooking and **Kath** naturally flowed into showing me photographs of a recent holiday and what that meant to her. For **Patrick** and **Jack,** the second interview started separately with life story work, and then their spouses were interviewed separately in another room. Peter and Gayle were present during **Joan** and **Doug's** life story work as they required more assistance with verbal cues and for me as the interviewer to hear the responses (the family members were more in tune with the quiet, slow voices of their partners). **Kath** and Ken were interviewed separately for the second interview. The final interviews were a mixture as spouses moved in and out of the room whilst also carrying out their day to day lives. The decision as to how to proceed for the interviews was based on giving participants the options and listening and observing for non-verbal ques relating to tiredness, fatigue, and anxiety.

4.6.2 Longitudinal data collection

The research design also involved interviewing people with Lewy body dementia and their family member, at different time periods. The flexibility was recommended by the patient and public group and ethics committee, as it allows for potential changes in cognition, periods of illness, and better participation for busy families. In addition, stories of experiences may change and fluctuate. The stories may have differing, multifaceted layers due to cognition, dreams, hallucinations, and the use of metaphors. Mishler (1996) suggests longer narratives that are built up over the course of several interviews may provide the ability 'to transverse temporal and geographical space' (Mishler, 1986). In addition, it is highlighted that 'working ethnographically with participants in their setting over time' offers the best conditions for storytelling (Riessman, 2008 p 26). I therefore concur with McKeown (2017) that time and encouragement to draw out perspectives may be better represented through narrative form (McKeown, 2017). People do not necessarily narrate long histories in one interview but can focus on particular issues (Murray and Sools, 2015). It is said that these issues or experiences can develop, change, or fade over time (Sheilds et al., 2015).

For each participant, three interviews were conducted flexibly over a six-month period, with the second interview offering the person with dementia an option of using photographs or objects to story their experiences. This approach also allowed the participants and researcher to co-construct powerful insights. This created possibilities that could address not only their health concerns but offered new perspectives on the influences of physical, psychological, social, and spiritual constructs. Conducting three interviews with the same participants over time also allowed for building depth to stories and personal interpretation (Caldwell, 2014). The aim was to seek maximum opportunity to engage actively with the participants over time, both in dyadic interviews and in life story work.

All participants were interviewed in their own home. A risk assessment was undertaken whilst working alone, and the Lancaster University and local NHS trust lone working policies were adhered to. Narrative interviews lasting between 20 to 105 minutes duration were conducted. Interviews were transcribed verbatim by a professional transcriber following signing of a confidentiality agreement. The interviews were then checked against the audio, anonymised, and uploaded to ATLAS software for data analysis.

4.7 Data Analysis

The memory changes associated with dementia and theoretical underpinnings steers the analysis towards an experienced-centred form of analysis. Other forms of narrative analysis often focus on the recounting of past events, which entails matching a verbal sequence of clauses to the sequence of events (Labov, 1972). Riessman (2008) also considers the storyteller as connecting events into a sequence that may have consequences for action, (Riessman, 2008). However, as Ricoeur emphasised - the capacity to ‘emplot’ is not always easy (Ricœur and McLaughlin, 2009). This is particularly true of people living with dementia. Fluctuation is a key feature of Lewy body dementia, where visual hallucinations, dreams and altered perceptions merge with the past, present, and future. This highlights a tension where the central concern of narrative theory is time and identity formation, as defined by a socially dynamic process (Murray, 2002). As a consequence of the brain changes associated with Lewy body dementia storytelling that focus on structural and sequential features would seem to exclude people living with dementia (Milnes, 2006). I consider, as Sarbin points out, that ‘we do much more than catalogue a series of events. Rather we render the events into a story’ (Sarbin, 1986 p.23). For this reason, I draw from experience-centred narratives to be inclusive of a wider range of stories of personal experience, by involving the past, present, future, or imaginary experiences (Ricoeur, 1992).

Murray's (2000) levels of narrative analysis was applied to the narrative data I collected. This was chosen as it provides a multi- dimensional approach to health and illness narratives whilst acknowledging that individual experience is centralised within the interconnected social and cultural context (Murray, 2002, 2000). It takes into consideration the social constructionist perspective which acknowledges the importance of how we interact with a person diagnosed with dementia at interpersonal, societal and political levels (Small et al., 2007). It also provided a structure to encapsulate 'dialogic performance analysis' which 'requires more close reading of context, including influence of investigator, setting and social circumstances on the production and interpretation of narrative' (Riessman, 2008 p.105). The application of Murray's (2000) levels of narrarive analysis is provided in more detail in Chapter 5, by drawing data from one couple as an exemplar.

4.8 Ethical considerations

Ethical approval was obtained from an NHS Research Ethics Committee (REC reference 18/IEC08/0035; Appendix 12). The process of gaining Research Ethics Committee approval enabled academic approval from Lancaster University (FHMREC). This process is considered essential to address research governance standards to ensure the dignity, rights, safety, and well-being of actual or potential research participants (NHS 2017), particularly for groups seen as vulnerable. Plummer (2001) suggests that the key ethical issues to consider within narrative research are the issues of ownership, confidentiality, honesty (deception, exploitation), informed consent, benefit versus harm, and the importance of reflexivity.

4.8.1 Risk, benefit, and harm

It was recognised that participants might find that recalling and talking about their life story evokes difficult memories, or that thinking about the future is upsetting. The interview topic guide (Appendix 13), and supporting information, and guidance was developed with the patient and public engagement group to ensure appropriate language was used. It was important to ensure support was available following the interviews, particularly if there was a change of circumstance (e.g., if participant moved to a care home or recently died). Approaches were made sensitively to assess the situation and ask the participants if they wish to continue with the study. If they wished to continue, details of local support organisations were made available to the participants.

The study was designed to minimise the burden on participants in terms of time, but nevertheless they may feel repeated interviews onerous. To reduce this possibility the aim was for participants to be able to tell their stories in a way that left them feeling listened to and satisfied rather than instruments of research. This was addressed through an open-ended approach to interviewing, the option of using photographs, and a flexible approach to timing. The participant information sheet explained that study participants would not gain any direct benefits from taking part, but it was hoped they may find some therapeutic benefit in being able to take part in the interview and contribute to Lewy body dementia research.

4.8.2 Confidentiality and anonymity

The handling of sensitive material with confidentiality is particularly important given that people with memory problems may divulge sensitive or inappropriate personal details to researchers. The only occasions in which confidentiality should be broken is if the researcher has a serious concern about participant safety. Thus, the consent form included a section to cover the divulging of information which may present a risk to themselves or others, and that this would be discussed with a relevant healthcare professional. All data was held confidentially within the university system and was seen only by the researcher and supervisors.

As the study involves gathering and storing qualitative interview data, participants were allocated a study identity number and pseudonym, which was used in all documentation by the researcher. Participants were not identified in any reports beyond their pseudonym and role. This includes interviews and papers presented to the patient and public involvement advisory group for discussion. The study was conducted within one geographical area (Eastern England), and the pool of potential participants and carers was small, so it was necessary to omit some details to protect the identity of the participants, whilst being mindful to keep the stories intact where possible.

All participant information and data were stored as per the requirements of the General Data Protection Regulation (GDPR), May 2018. An encrypted device was used to record interviews, and the recordings were uploaded to the Lancaster University BOX system with password protected files. Once interviews were transcribed and cross-checked with the audio recording, they were then deleted from the Dictaphone. Microsoft Teams software was used to share anonymised transcripts with supervisors. The data will be kept for ten years before it is destroyed. Personal data used to identify and contact potential participants were stored securely at Lancaster University; password protected on an excel spreadsheet. At the end of the study participants were asked if they would like to be kept informed of the progress and results of the study and how they would like to be contacted. One couple requested a copy of the transcript, and one family carer asked to be kept informed of study findings via email. This information was only accessible by the researcher and supervisors. Paper data will be stored in a secure archive facility at Lancaster University following study completion. Electronic data was archived in Lancaster using the data archive PURE for ten years.

4.8.3 Reflexivity

Narrative research requires a high level of reflexivity, particularly within the process of interviewing, analysis, interpretation, and subsequent reporting (Elliott, 2005). Challenges to the integrity of the research can be addressed by considering how my own perspective – and background in community nursing, palliative care and dementia research – might influence the data, and how the subsequent interpretation was influenced by personal, historical and cultural experiences (Creswell and Creswell, 2018). These clinical roles can affect the way questions are asked and interpreted (Hunt et al., 2011), and may affect participants' responses. Conducting a clinical interview is very different from a research interview, requiring a mental shift from being someone whose expertise is being sought to someone who is an inquirer seeking out the expert experiences of others (Durkin et al., 2020; Hunt et al., 2011). I piloted and practised the questions with one of the patient and public group members to help maintain a balance of listening, space and observing the emotional experience being narrated.

During the interviews I remained conscious to maintain my research identity rather than as a nurse. This may have impacted on the earlier interviews as my previous clinical and research knowledge may have resulted in assumptions being made, where more probing may have elicited deeper understanding. However, my role and approach changed as I became more aware of the challenges in moving from clinical to research interviewing and dual roles as clinician and researcher. The transition from initial clinical style of thinking and collecting information toward qualitative research interviewing occurred over time and with practice. Whilst acknowledging that my experiences were intricately bound in the way I conduct myself and the interviews. The final interviews were more relaxed as my behaviours and mannerisms changed over the course of the interviews. They become less tense, less hypervigilant about communication styles with the participants. Interview flowed more naturally as time went on creating an atmosphere where participants seemed to feel more at ease and so talk more freely. Once the initial interviews were collected it became less about collecting data and more about being and listening. This links with Mishler's (1986) and Riessman's (2008) explanation as 'letting go', which I felt allowed for a different level of engagement. This allowed a form of listening to people's lives and recording their experiences using all the senses.

From my reflective diary I reflected that participant's also changed over time. I noted that by the third interview there was more evidence of family day to day living, such as may be noted in ethnography. One couple had their daughter and granddaughter visiting and they were cooking and popping in and out of the front room, and two of the carers were dealing with daily chores. The final interview for **Kath** was more poignant. She was always well dressed in make up and ready to receive me as a visitor. She usually maintained a positive, outward appearance, but by the final interview she had been in hospital again and was no longer dressed up as she admitted being 'tired' now.

4.9 Conclusion

In this chapter I outlined the methods used to ensure a balanced sample, recruit participants, and collect data from them. I described how ethical aspects were addressed, highlighting some of the challenges from a researcher perspective, such as conducting narrative interviews following years of experience using a more clinical style of questioning. The importance of reflexivity and transparency was considered, particularly within the analytical process. Within the next chapter I develop in more detail the data analytical framework, by drawing data from one couple as an exemplar.

Chapter 5: Demonstrating narrative analysis

5.1 Introduction

The aim of this chapter is to provide a more detailed explanation of the analytical process which led to the findings for the empirical research. Using examples from one couple I will describe the application of Murray's (2000) four levels of narrative analysis. A published version (Bentley et al., 2021b) is included in Appendix 14. The focus is to provide transparency of interpretation and demonstrate a logical sequence of the analytical process, to guide the reader along to uncover the trail of evidence (Riessman, 2008). Finally, I explore how this application relates to validity in the context of the story told by the participants and researcher.

5.2 Developing an overarching descriptive analysis

Murray's (2000) four levels of narrative analysis seeks to illuminate the complexity of health and illness narratives. This is by exploring the personal, interpersonal, positional, and societal levels at work in stories (Murray, 2000). The final stage involves identifying narrative threads and connecting the levels. To demonstrate this multi-layered approach to analysis one couple's excerpts were chosen for this chapter. This was to enable a clearer, more detailed view of the text from different perspectives, and the processes involved in connecting the levels. For the purposes of this research study, during speech quotes the pseudonyms of people with Lewy body dementia will be highlighted in **bold** to help differentiate between them and family carers. Where couples are mentioned together the person living with the diagnosis will be identified first.

Initial listening and reading of transcripts resulted in the study data being organised into an overarching narrative in the form of a short descriptive profile for each couple. This aids in the identification of the small and big stories, and enables familiarity with the key characters, features, and content of the longitudinal interviews (Murray and Sools, 2015). A single coherent narrative also helps 'to preserve the flow of the story as a whole' (Bazeley 2013, p.115). This is considered important when the raw data may be disjointed as it helps to get a sense of the whole before going into more detail on the main chapters and stories. This chapter provides excerpts from **Joan** and Peter, a retired professional couple in their early seventies who have been married for over forty years. **Joan** had first noticed changes to her mobility about five years previously and was given a diagnosis of Parkinson's which she found *'depressing'*. A few years later **Joan** had some problems with her memory, and *'started to see children and other people in the garden',* which she found *'unsettling'.* She was eventually diagnosed with Lewy body dementia. Overarching descriptive narratives for each couple are included in Appendix 15.

5.3 Analytical questioning of the data

Once the overarching narrative had been identified, repeated listening to the audio recordings and re-reading of transcripts allowed for familiarisation of both structure and content of the narrative accounts (Davidsen, 2013). Simultanously, the data was analysed in line with Murray's (2000) four levels of narrative analysis, examples of which are presented in Table 5.1.

Table 5.1: Murray's four levels and related analytical questions (adapted from Murray, 2000; Murray and Sools, 2015)

Level	Health & illness narratives	Narratives portrayed as:	Analytical considerations/questions
1	Personal	Expressions of the lived experience of the narrator.	What stories are being told? Which events are noted? Who are the main characters and sub-characters in the story? Where/what is the setting (physical or psychosocial) for the story?

			Are there divergent perspectives in dyads' experience of same story? Which stories reoccur and change over time? What is the under-lying narrative thread of the stories?
2	Interpersonal	A dialogue which is 'co-created' and structured between participants and interviewer.	In what context does the interview take place? How do couples' interactions/relationships influence the storytelling? How is it determined which stories fade, and which dominate and get told? Is there an indication that the stories are told with an intention to be read or heard? How do the participants articulate which are important stories? Are there messages to be conveyed?
3	Positional	The differences in social position between the narrators and researcher/listener.	Within the interview interaction what roles and social characteristics are known or emerge? How may the characteristics (gender, age, health status, background, role, etc) of the researcher affect the storyline? How do the interviewers' questions, responses, and behaviour influence the story?
4	Societal/ideological level	Shared stories that are shaped by the social context and ideological assumptions within which we live.	How does the social, cultural, and historical context influence the stories? What broader societal (or community-based) assumptions (thoughts, practices, language) are evident?
	Connecting the levels	An integration of the 4 different levels of narrative analysis	What is the narrative thread evident at each level?

			Is there a connecting, underlying narrative woven through each level? What new evidence does it offer?

5.3.1 Level 1: personal stories

Murray’s (2000) analysis, performed at the personal level, focuses on stories which are considered to have therapeutic functions, providing shape and order to people’s experiences (Davidsen, 2013). Most commonly this occurs in the reassessment of identity (Frank, 2013), and the making sense of the chaos caused by the disruption of illness (Bury, 1982). Initial analysis at the personal level identified the setting, plot, characters, and main event of each storyline. A title was then applied to capture the focus of the ‘small’ stories at the personal level (Murray and Sools, 2015). Within each story the narrative thread was then identified as a means of viewing underlying experiences (Puplampu et al., 2020). To observe if experiences changed over the three interviews, a time-ordered sequential matrix was developed (Table 5.2: Example personal stories: longitudinal analysis matrix. Grossoehme and Lipstein, 2016).

Table 5.2: Example personal stories (Peter and Joan): longitudinal analysis matrix; Grossoehme and Lipstein, 2016).

Story title	Interview 1	Interview 2	Interview 3
	Narrative thread	Narrative thread	Narrative thread
Healthcare interactions	Advocacy	Frustration	Restrictive, rigid system
Relationship changes	Marital disconnection	Loneliness	Adjusting to being apart
Becoming a carer	Learning through experience	Guilt	Adapting & accepting

Interviewing couples together also added another dimension to the analytical process. Dyadic interviews at the personal level allowed for a deeper understanding of divergent and convergent views on a shared experience (Polak and Green, 2016). However, it is important to observe whose story gets told, and this became apparent when analysing at Murray's (2000) interpersonal level.

5.3.2 Level 2: co-created stories

The interpersonal level of analysis is one that is 'co-created in dialogue' and as such is the result of a joint enterprise (Murray, 2000). This level is important in understanding the context, structure, and participant roles in shaping the character of the narrative account (Mishler, 1986). The couples were predominantly interviewed together; therefore, the stories are portrayed as shared expressions of their lived experience, to acknowledge the 'interdependent relationship between individuals…as a source of information rather than attempting to control for it' (Caldwell, 2014 p.488). Co-created stories can provide a common reflective space that produces rich data, both in terms of expanding and corroborating a story, and by highlighting differences and disagreements (Bjørnholt and Farstad, 2014). When analysing which stories fade or dominate it was found that spousal caregivers often influenced the direction of the stories:

> Peter*: Tell [researchers name], you had a visit from an occupational therapist, can you tell her about that? That was last Wednesday wasn't it. What did she come for, do you remember what she came for?* (Story – Healthcare interactions: Interview 3).

The question *'do you remember'?* occurs in everyday conversations but was particularly noted within the stories and became poignant for carers. It often became apparent to them during the conversational interviews that the person with Lewy body dementia did not remember or understand what is being said. This had the dual effect of making a carer aware that their partner may be 'worse' than they initially thought – a sense of realisation over time – and that many of their 'shared stories' that defined them as a couple were receding.

Due to the conversational nature of the interchanges, there were frequent interjections:

> Interviewer: *Can you tell me a bit….*
>
> Peter: *Sorry, no I was going to say, once the diagnosis had come through, that gave you some access then to a Parkinson's nurse didn't it.*
>
> **Joan**: *That's right.* (Story – Healthcare interactions: Interview 1)

Peter says he '*find[s] it quite difficult to hear* ***Joan*** *at times,'* and **Joan** did have difficulty in getting her voice heard in the interview setting. By the final interview she did make the point that '*the idea is to have a two way conversation*' when talking to Peter about her respite carer:

> Interviewer: *Do you find those visits [from the respite carer] helpful?*
>
> **Joan***: Yes, except Katie is so good at talking.Try to get a word in sometimes.*
>
> Peter: *I can imagine [laughter].*
>
> **Joan**: *But the idea is to have….[a] two-way conversation.*

The challenge to *'get a word in sometimes'* may be due to the physical and cognitive changes associated with Lewy body dementia, differing personalities, or **Joan** being viewed in the role of 'patient' or 'cared for' person. It highlights the disadvantages of joint interviewing, when the interaction may have the effect of silencing an individual's account (Polak and Green, 2016). An attempt to counterbalance this was including life story work in the study design, ideally at the second interview. However, the couple's intimate knowledge of each other may serve as an advantage in expanding conversations. Peter instigated the conversation around **Joan**’s loss of not being able to play with the grandchildren and sadness of being seen as ‘*nanna in the bed’.*

> Peter: *Not so easy for you though with youngsters is it.*
>
> *Interviewer: I was going to say how is that when [the grandchildren] come?*
>
> **Joan:** *Well I enjoy having them but find I can’t, play with them so much because I can’t get down and get up, I need some help.*
>
> Peter*: Do you find you miss that?*
>
> **Joan***: Yes.*

Analysing Murray’s interpersonal level within the context of dyadic interviews enabled greater understanding of how couple interactions and relationships influence the storytelling and whose story gets told. This can show differing perspectives of the same experiences adding to the quality, depth, and richness of the data.

5.3.3 Level 3: positional influences

Social characteristics and roles are relevant at the positional level of analysis; in particular the role of the researcher, where the issue of power relations is of principal concern in narrative enquiry (Clandinin and Connelly, 2000). Challenges to the integrity of the research can be addressed by considering how the researcher’s perspectives might be influenced by personal, historical, cultural, and academic experiences (Creswell and Creswell, 2018). Professional socialisation is considered unavoidable (Salisu et al., 2019). Within this analysis I aimed to remain ‘visible’ by retaining the interviewer dialogue within the stories. It was therefore important when analysing the stories to examine my natural orientation toward the clinical interview and ‘probing’ questions. For example, when **Joan** and Peter talked about the speech and language therapist visit:

> Peter: [S]*he was first brought in to look and see whether* ***Joan*** *was having swallowing difficulties.*

> Interviewer: *I was going to say do you find that's a bit of a problem, swallowing?*
> Peter: *Not too bad is it…*

Analysing the positional level at different time points can highlight how the roles for researcher and participants may change and evolve as they become more acquainted. For some the interview provided a therapeutic avenue to open communication between the couple. '*It's been nice today, you've talked a lot about how you feel...we've really never talked about really have we* **Joan** *your condition as such...'* By the final interview Peter says *'I've been impressed,* ***Joan's*** *talked more this morning than I've heard you in ages…. So can you come again every day [laughter].'* When considering the balance of power it is important for the researcher to ensure people feel positive about the research interaction.

5.3.4 Level 4: Societal and cultural influences

The societal level of analysis is concerned with the socially shared stories that are characteristic of certain communities or societies (Murray, 2000). Community-based assumptions were considered within cultural, social, and linguistic dimensions as this allows for broader understanding of the narrative (Andrews et al., 2013). Words such as 'medicines' and 'brain' are frequently drawn on to frame and discuss dementia in the media, and can influence shared beliefs and influences surrounding health and illness (Bailey et al., 2019). Peter had been '*looking things up*' and was particularly concerned about the effects and interactions of the medications **Joan** is on – *'my biggest worry is the interaction of medication which all seem to pinpoint the same part of the synaptic join if you like'.* Exploring societal and cultural perspectives and can illuminate tensions between self, disability, and communities (Riessman, 2008). The medicalisation of palliative care, and the western policy of framing service delivery around the ‘carer’ and ‘cared for’ was also noticed at this level. Peter had registered as a carer to access support and courses and had taken on the monitoring of **Joan’s** condition. In one interview he noted ‘*I’ve got monitors and things, I can check her oxygen saturation, I can check blood pressure’.* He had antibiotics and can decide to give them to **Joan** if she becomes unwell.

5.3.5 Connecting the levels

The final stage of analysis involved connecting and articulating the couple’s stories across the four levels (Murray, 2000). Evaluating how these levels work together can allow for a deeper understanding of human experience and enhance ‘coherence’ of the data (Riessman, 2008). Identifying connections can lead to a greater depth of analysis and contribute to the wider social narrative (Wong and Breheny, 2018). Finding the connections between these different levels is complex; however by doing so it becomes possible to challenge the dominant narrative and ‘develop a new story that enhances alternative knowledge’ (Murray, 2000 p.344). It is at this stage the data is analysed though a researcher’s lens with the purpose of gaining a deeper understanding of the participants’ experiences, aided by the theoretical underpinnings of the study (Creswell and Poth, 2018).

Joan and Peter storied many aspects of living with Lewy body dementia. Drawing these small stories together across levels and over time identified the main connecting narrative (or ‘big’ story) as ‘communication’ for this couple. Stories at the personal level highlighted the relationship between communication style, competence, and message strategies. An example of this was provided when Peter was communicating with the therapy team – *‘they started treating me like an infant’.* At the interpersonal level communication gaps were also observed within the couple’s relationship, as Peter expresses that ‘*the other frustrations are um there’s nothing from **Joan**’.* Yet **Joan**

articulated that '*the idea is to have...[a] two-way conversation'.* Analysis at the positional level reveals how the research interview acts as an avenue to open up communication between the couple: '*it's been nice today, you've talked a lot about how you feel…'.* Exploring societal and cultural perspectives identified how communication between Peter and the community health and social care teams improved as they work together to care for **Joan** at home.

5.4 Validity of the findings

Applying Murray's four levels of analysis enabled a transparent analysis process to reflect the multitude of influences which in turn can strengthen the validity of findings. From a narrative perspective this included the story told by the research participant, the story told by the researcher, and ultimately the reader's perspective (Creswell and Poth, 2018). To enhance coherence of the stories told by the research participant the stories were kept intact rather than breaking into themes. The longitudinal nature of the couple interviews provided rich data, by illuminating different experiences of the same event, for example. How people relate their experiences to others is complex, and this approach attempted to integrate the content, structure, and composition of dyadic narrative interviews in a flexible way.

From the researcher perspective the interviewer remained visible within the text which enables transparency of the analysis process to clarify and confirm the story told by the researcher (Riessman, 2008). Reflexivity is key within the analytical process. From a nursing perspective it is important to recognise that when you develop a research topic your many aspects of involvement, knowledge, and assumptions about the subject may lead to non-intentional biases. It is acknowledged that clinical roles – such as my background in community nursing, palliative care, and dementia research – can affect the way a researcher asks questions and how the answers are interpreted (Hunt et al., 2011). To address these issues two supervisors checked the initial interviews to observe for overly clinical or leading questions. They had oversight of the data analysis process as a means of corroboration, and of establishing trustworthiness of the interpretation process (Loh, 2015). Reflexivity of decisions and procedures can provide evidence of a verifiable audit trail and aide transparency, particularly around the analysis process. A research diary was used to make notes as soon as possible following the interviews and a reflective journal maintained in ATLAS.ti ‘memo’ for eighteen months during the analytical process.

5.5 Conclusion

In this chapter I provided a structured, transparent example of how data collected for this research study was able to connect and integrate Murray’s levels of analysis. It explored one couple’s stories at the personal, interpersonal, positional, and societal and cultural levels. The final stage involved connecting the levels to provide more in-depth and broader understanding of the experience of living with Lewy body dementia. Applying Murray’s four-level approach enabled a transparent analysis process to reflect the multitude of influences which in turn can strengthen the validity of findings. The interpretation of the stories, together with application of the research questions, provides the findings which will be presented in the next chapter.

Chapter 6: Findings

6.1 Introduction

Within this chapter I explore how the findings of my research, including how I identified certain experiences and their impact for couples living with Lewy body dementia over time. The profiles of the participants are initially presented. I then examine how the 'big' stories discussed in the previous chapter, *being social, self-reliance, looking for answers, communication,* and *conflict,* resulted in the identification of the overarching narrative of *social connectedness*. The narrative of social connectedness was strongly represented across stories, between couples, and over time. Seven steps of social connectedness were identified. Finally, I explore how the narrative of loss affected the ability to remain socially connected. This is presented as the shared experiences of physical, psychosocial, and social loss, with a focus on loss of voice, energy and motivation, and continence.

6.2 Participants

Five couples were interviewed between July 2019 and February 2020. The interview times ranged between 20 and 102 minutes. The mean time for an interview was 61 minutes. Table 6.1 contains brief demographic information, with the pseudonyms used to protect anonymity, and names in **bold** representing the person living with Lewy body dementia. For reporting the findings, the term *'spousal caregiver'* will be used when discussing the spouse who does not have Lewy body dementia. All participants were of white British ethnicity.

Table 6.1: Participant demographics

Participants	**Patrick**	**Kath**	**Joan**	**Jack**	**Doug**
Gender	M	F	F	M	M
Age range	70-75	70-75	70-75	65-69	70-75
Diagnosis	DLB	DLB	PDD/DLB	DLB	DLB
Years diagnosed	2 years	8 years	2 years	3 years	6 years

Caregiver	Sue - Wife	Ken - Husband	Peter- Husband	Linda - Wife	Gayle – Wife
Age range	70-75	76-80	65-69	65-69	70-75
Married – years	35+	35+	45+	35+	45+
Adult children	3	2	2	3	3

Dementia with Lewy bodies (DLB), Parkinson's disease dementia (PDD)

Participants consisted of people with Lewy body dementia (n= 3 males, 2 females) with an average age for people with Lewy body dementia 72.2 years, and family carer 70.4 years. The couples had been married for an average of 42.3 years. **Jack** and **Patrick** had been recently diagnosed with Lewy body dementia, **Kath** had been living with the condition for several years, and **Doug** and **Joan** were in the advanced stages of Lewy body dementia. They both subsequently died a few months after the interviews.

The five couples told a variety of stories which included their experiences of diagnosis, positive and negative interactions with health professionals, activities they could no longer do, and adjustments made to address the challenges they face in daily living. The 'big' stories were identified for each couple using the same analysis process which identified **Joan** and Peter's story of communication in Chapter 5. The 'big' stories were *being social, self-reliance, looking for answers, conflict,* and *communication*. For **Kath** and Ken *conflict* was evident conversationally as she made frequent references to 'fighting' the condition. It was apparent that as her physical changes threated her self-perception this resulted in adopting coping mechanisms such as fighting strategies, for example not speaking to her daughter when she purchased a wheeled walker. At the interpersonal level her exchanges with Ken were sometimes fractous. **Kath** explains she goes out into the garden when things get tense. For **Jack** and Linda the importance of *self-reliance* and being independent dominated their story. From being part of a 'self-sufficiency' smallholding group to moving house so they would be closer to services, they speak of the importance of relying on each other. Difficulty finding out about disease specific information and around accessing healthcare services was particularly challenging for Sue and she spent time *'looking for answers',* where she could. This included joining dementia groups, looking things up, revisiting the GP, and asking the researcher for advice and tips. Although some stories were unique to each couple, the final phase of the analysis examined the commonalities of their lived experience. The importance of 'social connectedness' was a shared experience that dominated for all couples across time.

6.3 Social connectedness

Through exploration of the shared stories between and across couples it was identified that all participants found it more difficult to maintain social connectedness with each other, and the wider world, over time. The term 'social connectedness' is widely used, however, here, within the study findings, applies 'when a person is actively involved with another person, object, group, or environment, and that involvement promotes a sense of comfort and well-being' (Hagerty et al., 1993 p.293). Conversely, 'social disconnectedness' can result in isolation, loneliness, loss of self-esteem, and symptoms of depression and anxiety (Santini et al., 2020). For the participants this resulted in multiple stories of losses, many of which occurred early in the disease progression for the person with Lewy body dementia.

The analysed stories highlighted sudden changes or a 'shifting' as the couples lost some connections and made efforts to develop others. These shifts occurred when people were less able to remain self-reliant, and there was an increased need for information and support, particularly around requiring answers about how to manage the condition. These shifts, or changes, are depicted as a stepwise representation in Figure 6.1. The use of a stepwise approach is partly a reflection on how the participants remembered and constructed their stories around health and illness. These were often around sudden events such as not being able to drive, or a fall resulting in prolonged hospital admissions. Although the couples made some new connections, the overall trend was a deterioration in ability to remain socially active.

Within Figure 6.1 the ‘big’ stories of *self-reliance, looking for answers,* and *conflict* are represented as phases the couples experienced. Although some stories were more dominant for each couple, they all shared similarities around trying to gain knowledge of the condition, struggling to maintain independent lives, difficulty communicating with each other and health professionals and giving up parts of their lives whilst trying to make new connections. These phases often overlap, resulting in internal and external conflict, with problems *communicating* and difficulty maintaining *social connectedness* occurring over time. The couples are placed on the diagram in the area most representative of their situation, based on the longitudinal findings. The colour blue represents where self-reliance most actively occurs, red where most conflict was experienced, with green representing times of information searching.

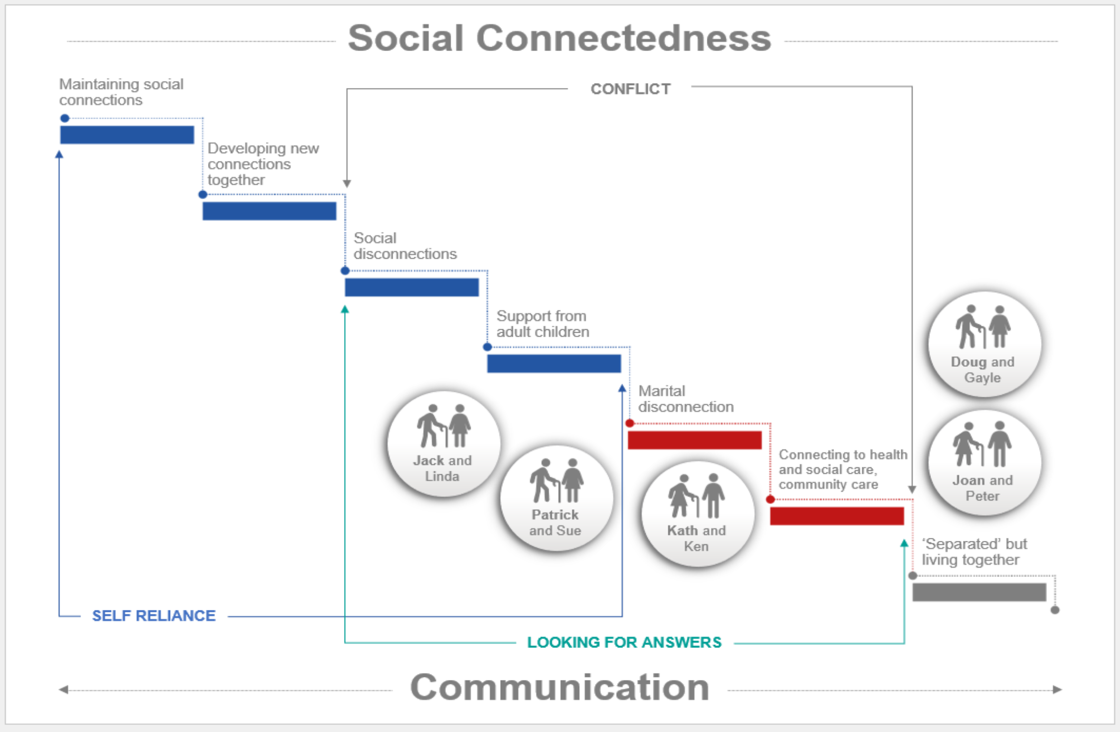


Figure 6.1: Stepwise representation of social connectedness

6.3.1 Maintaining social connections

The findings highlight the importance of maintaining social connections with people such as friends and family and groups. Couples mentioned connections with pets, objects, hobbies, music, the environment, and being involved with the wider community. The importance of socialising, being active, and the need for fun and companionship were frequently storied. **Jack** still likes to walk with long term friends. As Linda mentions *'he's got three friends and they go and walk once a month quite long walks, 'cos you've always done that haven't you'?* For **Doug** and Gayle walking the dogs was a big part of engaging with friends and keeping in contact with the wider community.

> Gayle: *You see a lot of people in the afternoon walking dogs, it's quite social…*
> **Doug**: *you also got a chance to [meet people] the dogs were a necessity. Somebody to come and chat to… .*

Linda talked of the need to get out and 'do things' and keep busy, but **Jack** acknowledged it's getting more difficult to do things together:

> Linda: *I think doing things is good, to get out and do things... .*
> **Jack***: And we do get out and do a lot of things. But it's incredibly difficult to come up with what you do and what do I do.*

The importance of retaining a sense of purposeful activity was particularly strong for **Kath**, Gayle, Linda, Sue, and Peter. For Gayle and Linda this related to a sense of personal value and contribution, as Gayle described herself as 'community spirited', and Linda and Sue were also involved with volunteer work. The importance of being self-sufficient and self-reliant featured in many of the stories. Kath described a past holiday and the joy of discovering some independence:

> **Kath**: *[W]ell I never go out on my own, that's the first time I've ventured out on but um I wanted to look round… .Oh I tell you what I thoroughly enjoyed myself, in and out the different shops, I thoroughly enjoyed it,…that was an experiment for me… . I thought I can do what I want to do, and um, it was [a] confined environment, do you know what I mean? …I'd got my stick but there was also things for me to hold onto, [with] the rails.*

References to self-sufficiency highlighted the importance of being able to draw on each other and their marital resources built up over many years. As the Lewy body dementia progressed there was a need to balance maintaining independence with acceptance for support, which gave rise to tension and conflict between the couples.

6.3.2 Developing new connections together

Although some friendships became strengthened around this time, others 'disappeared', resulting in the need to re-evaluate and adjust. The findings highlight the need to adjust to seek out new connections and friendships with people in a similar situation via local memory groups, or where they felt comfortable with their diagnosis. For example, **Jack** and Linda enjoy going to a self-sufficiency group:

> Linda: [*W]e meet in people's houses once a month don't we and talk about various things. We get on really well with people there.*
>
> **Jack:** *Yeah and I mean that's great fun 'cos we sort of have um a meeting and the women will make something to eat, you know and ….. [it's the] companionship, that sounds a bit weak…. sounds more about like wearing slippers a bit but er well it's important to me. I mean I think we, Linda more than me, are pretty good at socialising, considering that I haven't got a car, I can't drive.*

Ken says they have developed new friendships through the Alzheimer's Society:

> Ken: *Once a month we go out for lunch with a group that used to be Alzheimer's and when Alzheimer's packed up doing lunches we decided that we would still go for the lunch after the meeting and then they packed all the meetings up in favour of dementia cafes,….unfortunately er one of the chap's wives died, um so we're down to four of us now.*

6.3.3 Social disconnection

For the person with Lewy body dementia social disconnection became evident early on in their condition due to psychological and physical changes. Stopping driving, early continence issues, mobility problems, and falls were common stories. **Kath** and **Joan** found it difficult to reconcile their loss of independence throughout the course of the interviews. **Kath** said she will 'fight' the changes: *'I do fight it, very much so, 'cos I won't let it get hold of me'.* This resulted in tensions and conflict between couples – particularly around the use of assistance and mobility equipment. Peter wanted to use the electric armchair and stair lift for safety reasons, but **Joan** was still trying to remain active:

> Peter: [W]*e've got this armchair...it's not* ***Joan****'s favourite chair it's funny, all the various things that we've looked to buy that might make the house a bit more comfortable you're not that keen on are you [laughter]. You don't really feel you need it really do you, which is good, it's there...*
>
> **Joan:** *I'm sat in here all the time, I want to be exercising.*
>
> Peter: *Good point…we [also] bought a chair for the stairs, but I don't think you [are keen to use it]. Which is good you're determined to go up and down stairs but of course the worry is having a slip on the stairs would be awful.*
>
> **Joan:** *I've got a railing haven't I?*

By the final interview **Joan** was unable to get out of bed at all and expressed this situation with the use of metaphors, in particular being a prisoner, of being kept captive in her hospital bed:

> **Joan**: *I was capable of being able to walk, whereas now I'm mostly being prisoner here.*
>
> *Interviewer: Prisoner here, you mean in bed?*
>
> ***Joan**: Mmm. I have all my um meals… It's frustrating…Unfortunately she [the occupational therapist] concluded that I wasn't ready to be released.*

Kath's falls and subsequent hospital admissions led to a step down in her mental and physical function. When her mobility became notably worse, she became frustrated, and her daughter purchased her a walking aid:

> **Kath:** *Um mobility at the moment is quite frustrating for me now. I do have a walker, and [my carer] said I think it's getting time near the time when you need to get it out and start to use it, 'cos it's put away. My daughter got it for me and I was a bit upset, you know, and I wouldn't even think about it. But now I know myself mobility is getting worse, so you know…I cried… .And I just I couldn't talk to her until the next day.*

Kath differed for the other participants with Lewy body dementia in that it was she who pushed to do more, whilst Ken tried to advise her to pace.

> Ken: *Kathleen is quite determined that it won't have too much of an effect on her and that is her biggest problem is that she just won't give in to anything… . And then next day you know she's tired and wants to spend the day in bed so she's her own worst enemy in that respect but she won't try and pace herself.*

For the other participants tension occurred as the spousal caregiver tried to maintain activities as a couple and keep busy, whilst the person with Lewy body struggled with tiredness, fatigue, and eventually a lack of motivation. Linda storied the importance of maintaining an active lifestyle and keeping busy. However, **Jack** admits he's *'not always motivated'* and has to pace himself.

Jack: *I do feel that….it's good for me to take things you know not too enthusiastically.*
Linda: *But we do things, it's better if you're doing you know.*

Jack has started to accept that he can't do as much saying *'there are limits and I think I've accepted that';* but Linda has struggled to adapt. Gayle has started to accept her circumstances, expressing at times that 'I just *can't do all the things I like to do'* and **'***I've always been quite a public spirited [person] and like being involved in the village….I like to contribute [but] I can't you know as much… so I don't get the social contact that I used to'.*

Psychological and physical changes such as tiredness, hallucinations, delusions, loss of memory, word finding difficulty, and incontinence resulted in the person living with Lewy body dementia reducing their social activities and interactions. As a result, the spousal caregiver started to have to go out alone. As the social, physical, and emotional disconnections progress a further stepwise deterioration occurred. The couples sought support from outside, in the first instance from friends and family.

6.3.4 Support from adult children

Data highlighted the importance of adult children in providing opportunities for respite, supporting the person with Lewy body dementia to maintain hobbies and provide a family 'plan'. They provided practical resolutions for equipment and gave emotional support. They maintained the ethos of *'self-reliance'* within the family to provide care:

> **Jack:** *Well we've had to rely on each other to a considerable extent.*
>
> Linda: *Well I think it is just it's yourselves isn't it and it's having [the] children, they're straight in there. They sorted out this weekend themselves, and just announced it, 'Mum and Dad I'm here this weekend.' Fran does the second weekend, **Jack's** sister does the third, Colin does the fourth… .*
>
> **Jack:** *It's part of the treatment of me, family have very kindly set it all up so that I can stay at home and do as much as possible, and it's a considerable sacrifice looking after someone else, so we're impressed by that.*

Patrick and Sue's adult children also have a rota to help share the driving. **Patrick** says he has *'organised a few drivers. My wife I call "driver one."* His brother comes once a week so Sue can go out. **Patrick** enjoys his company as *'he's got a different line of talk'.* Together with a *'bank of friends in the village'* **Doug** and Gayle's adult children provide support, 'back-up cover', and advice. As Gayle explains, '*Heather comes and sits, keeps **Doug** company while I go to choir which is very generous of her, and she's still taking **Doug** to his music therapy project'.* The adult children also provided financial support for equipment and adaptations. Kath explains she needs a shower fitted, as she cannot get in the bath. **Kath** said *'it's been on the cards for a long time but it came to a head yesterday talking to my daughter'.* Adult children in this study assisted the person with Lewy body dementia to maintain their hobbies and interests to sustain a positive personal identity and support independence.

6.3.5 Marital disconnection

As the condition progressed the spouses spent more time supporting their partners in managing activities of daily living, until the partners with Lewy body dementia required full time care when they could no longer be left alone. This resulted in a gradual social, physical, and psychological disconnection within the couple relationship. Dominant stories for Peter involve his changing relationship from husband to carer. Peter talked a lot about the loss of his relationship, eventually saying '*I suppose the other things I miss most is just the companionship really'.* He feels it *'gets harder when you know friends who are off here, there, and everywhere'* and realises they won't be able to go out as a couple again.

> Peter: *[T]he thing I miss most is it's difficult to do things together as we would have done before, to get out would be lovely, I mean I can but obviously* ***Joan*** *can't but um I think that's what we miss most isn't it, just to go places and do things together?*

Peter talks about his relationship in terms of being 'divorced' and missing their shared interactions:

> Peter: *[I]t's again adjusting to our relationship because I said to some people when they'd asked me, it feels like we've in a way been divorced, but not, but still living together, because it's a different feeling between us isn't it, which is not your fault at all… . I miss what we had, a lot [laughter]. I don't think it necessarily has quite the same impact in* ***Joan****.*

Peter started to build his new life post 'divorce'. It is possible **Joan** senses that breaking of their connection. This also coincides with **Joan** being suspicious of Peter having affairs – '*she was implying I'd had affairs. I haven't but for some reason she thinks I have. It might be all the ladies that are coming and going'.* For the couples the delusions, hallucinations, and personality changes were particularly difficult for the couple's relationship. This may have been due to the resulting loss of a shared sense of reality. As Peter explains:

> Peter: *Probably sadly the most I ever talk to* ***Joan*** *about are some of those things which aren't real anyway, you know the discussions we have are about this boy*

> *called Johnny, who we don't know, but in* ***Joan****'s mind Johnny comes up every now and again.*

Sue also found the loss of shared reality dificult for their relationship. She found it particularly distressing when Patrick mistakes her identity:

> Sue: *[Sometimes] I'm a Cook. I was the gardener yesterday.… At the beginning it was really quite distressing, um but er you know I will sit and he'll suddenly say where's the nice lady that made the tea [laughter].*
>
> **Patrick:** *I can't explain that.*

Sue talked of the loss of the person she knew. As she expained; '***Patrick's*** *personality is there but it um you know it's I want to say it's changed'.* Around this time conflict occurred for the couples as they adjusted to the series of psychosocial and physical losses. Memory issues also caused some tension between the couples:

> Ken: *She didn't even remember the wedding anniversary this year.*
>
> **Kath:** *No I didn't. and he didn't remember my birthday.*
>
> Ken: *I looked after you all year, you don't need to have anything special on your birthday.*

Kath said when things get tense she takes herself to the garden: '*I find that when things get difficult between Ken and me...I go out into the garden and that has become my retreat if you like going out there'.*

In addition to continuing their everyday tasks the spousal carer also had to take on additional roles that their partner traditionally completed, such as cooking, driving, finances, and maintenance. As the condition advanced it became more difficult to reconcile the shared identity of the couple relationship and the spousal caregiver started to go out alone. This came at a time when they were increasingly reliant on support from community health and social care services.

6.3.6 Connecting to health and social community care

The couples were in contact with a wide range of community services including occupational therapy, physiotherapy, speech and language therapy, continence services, Parkinson's services, community mental health, general practitioners (GPs), social care, day care, crossroads care, hospice services, and NHS funded continuing health care. They talked about their experiences both positive and negative. However, findings highlighted how balancing medication and management of incontinence were particularly challenging for all couples. These significantly affected their quality of life, and their ability to remain socially connected.

For **Joan**, **Patrick,** and **Jack** the lack of connection to a specialist who understood the condition and complex medication regimes was particularly challenging. Peter said he has been '*looking things up' and* is particularly concerned about the effects and interactions of the medications**.** Sue explained **Patrick** *'had an awful psychotic attack'* when his Madopar medication was stopped around the time of his diagnosis. The episode resulted in **Patrick** being '*very wary'* around medications and realising the need to *'balance'* carefully. By the second interview the couple had requested a referral to a neurologist, which **Patrick** considered to be a bit of a fight:

> Sue: *[T]he idea is that we actually get somebody who will look at Patrick from both aspects of the condition because I think his medication needs tweaking, er from the Parkinson's point of view and possibly the um Lewy Body —*
>
> **Patrick:** *I won't be fighting with swords but er we need to consult with um the consultant.*

Patrick says the services ***'**are under pressure*', but by the final interview five months later they are still waiting for a referral. Sue's frustrations trying to find medication advice had left her angry:

> Sue:*They give out these quite heavy doses of medication and nobody monitors it, and I cannot get my head around it. Now do I go to the GP? This is what I don't know, do I go and hassle the GP, or do we wait for a consultant? And er I think I'm going to —*
>
> **Patrick:** *Do as your told.*
>
> Sue: *Well it's not do as you're told... . It's like banging your head against a brick wall. But you're very calm. [looking at Patrick] He deals with the anger don't you. I don't get angry very often, only when I'm very tired… .*

Jack and Linda were reliant on the local mental health services for symptom and medication advice and felt '*the big thing is about the medication really':*

> Linda: *[Jack's] also struggled 'cos they've changed his medication, he's on medication for depression, anxiety, which gave him diarrhoea, he couldn't go out anywhere...one nurse talked about something alongside the rivastigmine but that doesn't seem to be going to happen, but **Jack's** got a consultant which we saw named on this paperwork and I said well he's never met **Jack**, so I was insistent that he would meet this consultant 'cos I thought that's not ok… .He's never put eyes on you know.*

The team eventually increased the medication to help with hallucinations but had to decrease again as '*the higher dose or rivastigmine made **Jack** violently sick on a regular basis, and you know he couldn't go on being like that'.* In addition to balancing symptom management, and side effects of medications, remembering how to take the tablets was also a problem. **Jack** reported **'***I got it wrong the amount so I'm in trouble for over dosing'.* **Patrick** was trying to use a diary to remember his medication, but the past and present merged when he became stressed during the interviews. His language and analogies mixed his current medication schedule with his past work as a chemist:

> **Patrick:** *I just tick that so I woke up in the morning and I had to add some chemicals together, at er nominally eight in the morning. I put a tick in the box to say I've done this reaction…I I actually in fact found this difficult to start with, but anyway we've come to a sort of working reaction now, as people tell me I was missing some of these [tablets] out.*

Sue had recently started to connect to the continence services and Gayle reflected on the difficulty acessing contience support over the years until she eventually realised access was via their GP. When participants were able to connect to the right services at the right time participants were able to continue their social activities independently for longer. **Kath** reported having good support from health and social care. Her support worker provided by social services enabled her to maintain her interests.

> **Kath:** *I go out with Jane my carer, yesterday was a good day, we went down to the river and we had two hours, so we sat out and we had coffee… once a month I go to the bank... Um and we might go to Sainsbury's or the supermarkets to see what's going on there, or we go out to the garden centre.*

Gayle said she '*was very impressed and remain impressed with the lateral thinking*' of the occupational therapist who came up with creative solutions to enable **Doug** to continue to dog walk. They went to dog training classes and and set up a GPS system:

> Gayle: *[H]e did have a pendant alarm with GPS on it which was good…., it gave him a bit of independence…. it worked and it did save him a couple of times. One time he had fallen over and he wasn't where he said he was going to take the*

> *dogs. He was somewhere else entirely but it came up on the tracker and I couldn't get across the fields to help him but friends did and you know it worked.*

Peter had managed to gain access to a variety of services, but as Doug's condition progressed Gayle was having difficulty trying to work out how to connect to services that could support herself as a carer.

6.3.7 Emotionally separated but living together

Doug and Joan's deterioration resulted in loneliness and emotional disconnection for Peter and Gayle. Eventually **Doug** and **Joan** were confined to the house, resulting in a further stepwise deterioration for the couples. For Gayle, **Doug's** incontinence had a significant affect on her ability to find sitters and go out. Gayle noted, '*it's more a limitation for me about arranging cover…. I've got friends in the village who very kindly offer to help, but because of the loo business, not everybody you can ask to do that'.* As **Joan** becomes confined to bed, this becomes part of the couple's physical, as well as emotional 'divorce'. This period was also the start of a physical separation, as both partners were sleeping downstairs.

Peter and Gayle both faced uncertainty around prognosis. Gayle: *'I don't know where we're at in the progression of the Lewy body, you know it fluctuates but you're going down this - I think they say graph - but it's only going down one direction'.* Peter said he *'didn't anticipate the deterioration'* but, in contrast to **Doug,** Peter's spouse **Joan** has carers provided by NHS Continuing Healthcare four times a day. Initially Peter *'felt quite redundant'* from his caring role when the NHS care team came. He found *'not really doing anything with any particular purpose…except to keep the day going'* very difficult, but *'I know I've got to look after medication'* and *'learn the best way to help **Joan** eat'.* Eventually he started to take up his previous hobbies and Peter said the carers had become *'more friends than carers now'.* They are expecting a review at anytime because *'we're not paying for that care at all you know'.* Peter feels they are both well supported from the hospice. **Joan** used to attend day therapy when she was able, and Peter accessed some counselling sessions – *'they've supported me as well'.*

Peter felt the discussions around resuscitation both at the hospital and with their GP 'surprisingly frank' but feels ultimately the decision was his alone:

> Peter: *Quite surprisingly frank sort of discussion, [in the hospital] I was taken aside about 'would you like your wife to be resuscitated or not'? And it was basically advised that it would leave her in a terrible state, both in pain and quality of life wouldn't be there at all so I sort of made that decision…it had to be declared for being at home as well, so if any paramedic came in and found her in that state, they wouldn't do it, so we got over that and I'm still hopeful that that won't be the case.*

Peter says they have *'had one or two scares about er pneumonia coming back'* but he monitors **Joan's** condition – '*I've got monitors and things, I can check her oxygen saturation, I can check blood pressure'.* He has an arrangement with the surgery whereby they've given him antibiotics to give if **Joan** becomes unwell. The paramedics and GP try to keep **Joan** out of hospital: *'I think all in all they would like* ***Joan*** *to stay here, and I would like* ***Joan*** *to stay here'.* Gayle felt *'there's not the services there, that's what I find so hard',* and is '*getting more and more exasperated, feeling towards the end of my tether'.* She has managed to find a local home help for three days a week, *'largely funded by the attendance allowance, she helps [****Doug****] with his shower on the day she comes in',* but Gayle was finding it difficult to cope. At the end of the final interview, whilst **Doug** slept Gayle says *'we're beginning to look at care homes'.* They have identified two potential care homes.

> Gayle: *'[T]he other thing that's nice to see is in both [care homes] there's a lot of integration with the local community… they go across to the school's art class sometimes and the children come into the home, you know they go to Church, the men go for a pie and a pint in the [pub]'.*

The family felt it was important that the decision to move to a care home was made '*while **Doug's** able, to get around and look at places, so we feel he's had a say in it'*. They emphasised the importance of the home being integrated and linked to the local community.

6.4 Narrative of loss

The personal stories highlighted that for the person with Lewy body dementia losses started early around the time of diagnosis, with symptoms often occurring whilst still working. The bounded nature of dementia for the couples highlighted that some losses were shared by the partner without the diagnosis, but these occurred at different times for the participants in this study. The associated losses for the person with Lewy body dementia and the spouse are depicted in Figure 6.2. Stories highlighted strong feelings were associated with the losses. The participants living with Lewy body dementia commonly experienced feelings of confusion, worry, anxiety, and sadness. Spousal caregivers experienced additional feelings of fear, frustration, guilt, anger, and difficulty coming to terms with their changing role of becoming an advocate and carer. The strongest feelings were stories involving losses associated with communication, roles, being a couple, independence, continence, and energy. Appendix 16 provides relevant quotes representative of the language of loss.

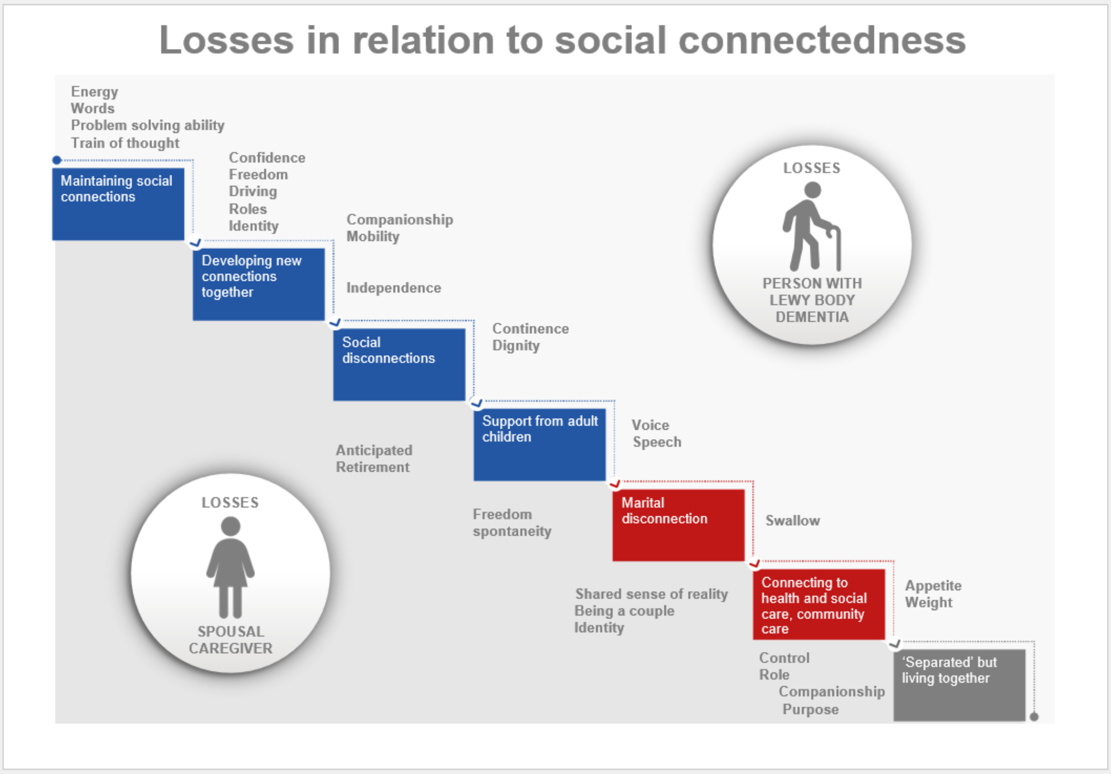


Figure 6.2 Social connectedness and associated losses – person with Lewy body dementia (represented in upper-right section) and spouce (lower-left section)

6.4.1 Losses associated with communication

Loss of voice, and communication issues, played a significant part in participants' difficulties in maintaining social connections. Cognitive and language changes started early in the disease process for the person with Lewy body dementia, resulting in communication difficulties that were evident throughout the interviews. This started with a slowness in retrieving words, loss of words, word linking, and poor memory. **Jack** described his experience of retrieval difficulties:

> **Jack:** T*here was one other thing I was going to say to you, which I can't remember, I really do suffer from a lousy memory… . I'm sure that if I could just*

> *bridge my mind it would come up with all interesting things. But I can't bridge my mind I'm afraid.*

Kath often hesitated, for instancing saying, **'***I've lost my train of thought now'*, with word finding difficulties evident during her interviews. **Patrick** was very aware of his communication difficulties and when more relaxed during life story work he said *'I'm getting nice little phrases in now'.* He described his experience of voice changes:

> **Patrick:** *I mean my vocabulary is mixed; it's gone from being quite high level to um mumble. I lost my voice early on, then it came back. I mean thinking about it, it is down, definitely up and down.*

Parkinson's-associated voice changes were particularly evident for **Doug** and **Joan**, whereby the voice becomes quieter and trails away. Peter said he found *'it quite difficult to hear **Joan** at times, you've got quieter and quieter haven't you'?* To which **Joan** responds quietly '*Yes'.* Despite their communication difficulties all participants were able to express their experiences of living with Lewy body dementia, even for **Joan** and **Doug** who were at the advanced stage of Lewy body dementia.

6.4.2 Loss of roles, adjusting to new roles

Findings highlighted that cognitive and linguistic losses, fear of performance, and physical body changes for people with Lewy body dementia gives rise to difficulty in carrying out roles and hobbies. Many of these roles had previously given the person with Lewy body dementia a sense of self-worth and social standing. Looking back even before diagnosis the person with Lewy body dementia described how they struggled completing everyday problem solving tasks. This resulted in experiences of feeling unsettling, depressed and at times frightened. The difficulties started whilst three of the participants were still working. **Jack** and Linda talked about **Jack's** successful career and how, before his diagnosis, neither understood why he was struggling at work. As a result he decided to retire early:

> Linda: *I think he was struggling with that because he changed his role, normally it wouldn't bother him but he just struggled and I thought this is really funny, you know he can't get a grip on this new [role] but he really seemed to be struggling and I thought why don't you retire…. I couldn't understand it you know what I mean.*

Doug was also working when Gayle noticed early changes:

> Gayle: *He set up on his own doing contracting work, but he had one particular person he did a lot of sub-contracting for who dropped him one summer season without any explanation, and um that hurt a lot, I think he'd got some depression.*

The spousal caregivers found adjusting to their caring role difficult, particularly around advocating, and communicating with healthcare professionals. Peter describes his experience of **Joan**'s hospital admission which is essentially the start of his caring role:

> Peter*: [S]o many different people turning up, different doctors, you couldn't tell necessarily who would be the best person to talk with. And er I think it's always difficult if you start to challenge the service [but] I felt it was important to alert them to what* ***Joan****'s needs were. I don't think I made myself very popular but er...If you don't shout, no one listens.*

For Peter interactions with health and social care professionals initially left him feeling frustrated, sometimes leading to anger and guilt:

> Peter: *Anyway I got angry, then they started treating me like an infant, why do all these people speak so loudly, this is my question, I didn’t say that to them, and then they speak to you as if ‘are you alright, do you need to sit down… .*

Sue also became angry when trying to find support for medication: ‘*He deals with the anger don’t you. I don’t get angry very often, only when I’m very tired’.* Sue felt it was partly her fault when communication between them wasn’t going well. Sue: **‘***I suppose it is down to me, I was cross and I was frustrated and of course I suppose that reflects [on me]’.* A feeling similarly expressed by Peter, when he reflects *‘it might be my fault I don’t know, but there’s not much conversation going on at all, it’s me that ends up doing the talking’.* Peter says he has been ‘*looking things up’* and *‘I'm learning as I go’* to educate himself about the disease and learn new skills to manage symptoms. Searching out information is particularly important to Peter, Sue, and Gayle. Gayle has been reading ‘*something on the Lewy body website about um dementia and delirium, and how they are related’.* Sue says that with the *‘continence ladies coming, I’ve got to learn to do all sorts of things’.*

Spousal caregiver experienced having to be an advocate, navigating services, and also learning the language of medicine and the skills of nursing. These experiences were reflected in the ‘big’ story of *looking for answers* where *conflict* and frustration often emerged as described previously and depicted in Figure 6.1 page 79*.* Through reading, looking things up, learning through experience – even taking part in research – spousal caregivers searched for a greater understanding of Lewy body dementia and how they could help their partners.

6.4.3 Loss of being a couple

The couples, who were used to talking and making shared decisions, didn't want to dwell on the diagnosis of Lewy body dementia. For **Jack** and Linda it was because they didn't want to be reminded:

> Linda: *We don't talk about it.*
>
> **Jack:** *We don't talk.*
>
> Linda: *I mean it's good that people are talking about dementia and it's good that it's in the papers and on the TV, 'cos people are more aware of it...it's good but not when you're in the middle of it.*
>
> **Jack:** *Talking about it is the worst thing going.*

Jack preferred not to think or talk about Lewy body dementia as part of his identity, saying, **'***You don't want to define yourself by your ailments do you'.* **Kath** and Ken similarly didn't tend to talk about the condition itself. Ken: *'It's part of everyday life now isn't it so um we tend to just get on with our lives and I mean* ***Kath****leen is quite um, quite determined that it won't have too much of an effect on her… .'* Peter felt it was unkind to talk to his wife, Joan, about her diagnosis. He felt the difficulty in communicating was to do with the physical changes of the brain:

> Peter: *The way our minds work and when they go wrong you can't talk like that and we've really never talked about really have we* ***Joan*** *your condition as such, it's very difficult to say if I start trying to explain what I think is happening, that's not really very kind and um… .*

Communication changes were particularly frustrating for Gayle. As Gayle says *'I can't understand what* ***Doug's*** *saying at all and it gets frustrating for both of us. And sometimes he's quite clear'.* By the final interview **Doug** is almost aphasic and Gayle says it is ‘*lonely*’. Loss of companionship also came about when cognitive changes occurred for the person with Lewy body dementia, and the resulting loss of a shared sense of reality. For Sue ‘*at the beginning it was really quite distressing’,* when **Patrick** mistook her identity, and she reflected on the loss of person:

> Sue:*… I don’t know what’s happening from one day to the next, I mean it’s the most horrendous um I was going to say medical condition. My mother had cancer, Patrick’s mum had dementia and we both decided that having cancer was better than having dementia. Although my mother knew she was very ill, she knew what was happening, whereas sometimes he doesn’t*.

Ken talked about when **Kath** experienced disturbing hallucinations which resulted in her being admitted to hospital, where she was diagnosed with Lewy body dementia:

> Ken: *[S]he kept shouting out I was trying to murder her and what not and there was people in the house who would walk from one room to another.*
> **Kath:** *I’ve got no recollection honestly of any of it.*

Loss of companionship occurred when spousal caregivers felt physically closer but emotionally further away from their partner with Lewy body dementia. All participants expressed feeling emotional pain, for instance helplessness, sorrow, grief, and distress.

6.4.4 Loss of independence

People living with Lewy body dementia in this study expressed their experiences most strongly around loss of freedom and independence, and the need to be self-sufficient where possible. The findings from the current study suggest living in rural communities created an immediate physical distancing from social relationships or usual hobbies when participants were no longer able to drive. Male participants acknowledged that driving was an integral part of themselves, which resulted in a reduced sense of agency and feeling of being *'constricted'* as described by **Patrick.** '*I'm not locked up but there is a certain constrictment, getting around'.* Giving up driving was a particularly difficult decision for **Patrick** as he had owned a classic car for many years. He described why he had decided to give up driving:

> **Patrick:** *The bottom line about that is that er it's not necessarily your vision being changed, the thing that's more dangerous is you might have a black out. You can't predict it. So that's what stops you [from driving], and I really couldn't go out and kill a few people. But it's the vision you know, it's a serious thing.*

Doug also expressed sadness when talking about giving up driving. '*Sadly I can't do it anymore'.* For **Jack** the loss of home, job, hobbies, and driving came in quick succession with his diagnosis. He describes living with Lewy body dementia as *'very off putting, it's worrying and you wish it would go away but it ain't going to. So you know, I'm distressed today'.*

Kath had a socially funded carer which enabled her to maintain some independence from Ken, be socially active, and retain her interests. The couple's shared loss of independence, freedom, and spontaneity was particularly difficult and they talked about the sadness of their situation:

> Peter*: [W]e used to enjoy [going to galleries] didn't we* ***Joan****? ...but we're not going to be able to do that anymore sadly...I think the things I miss most with* ***Joan*** *apart from being able to go to other places with her [is] having a change of view.*

Findings from the study suggest loss of independence and personal freedom caused sadness, frustration, and distress for couples living with Lewy body dementia.

6.4.5 Loss of continence

Distress came also as a direct result of internal bodily changes, made worse by lack of access to health and social care, equipment, support, and information. Stories around bowel and bladder problems highlighted the impact this had on their physical and psychological aspects of daily living, social activities, and quality of life. **Patrick** had urinary and faecal incontience and Sue described how the loss of continence was affecting **Patrick's** quality of life.

> Sue: *I find it frustrating, I just said to him I want his quality of life what's best for him, I don't mind clearing up, I really don't mind, but it doesn't make him happy and very comfortable. This morning the same thing, do you want to come shopping, 'cos we usually go together, and it's to do with if he makes a mess and I don't want that to happen do you know what I mean? I want him to be able to go out and he has incontinence pads which he wears at night but he doesn't like wearing them during the day, which is understandable. So it's not been one of the better weeks because I was cross and I was frustrated… .*

Participants expressed how loss of continence seriously affected their ability to remain socially connected. **Patrick, Jack,** and **Kath** wanted to retain a degree of independence and privacy with their continence issues, but difficulties with accessing professional advice, equipment, and accessible toilet facilities resulted limited their trips outside the home. Sue, Gayle, and Linda described how both bladder and bowel issues affected their ability to go out together with their husbands. As Gayle recalled *'I might sound cowardly but I'm frightened, I'd be worried that we'd have an incident like we had on the motorway last Summer'.* She finds dealing with incontinence difficult, at one point saying *'it's not very nice'.* Gayle had been pursuing help advice from continence services for few years:

> Gayle: *We had the continence advisor came out about a year ago with a range of techniques and gadgets but none of them suited... [even the] pads that you stick on the pants you've got to be able to manage getting them off and putting new ones on if you're going to have any independence and self-respect, so [the best thing] is pull-up pants.*

By our final interview Gayle said she was severely restricted by **Doug's** continence issues, as very few sitters would be able to cope if she went out. Gayle said she would be *'lost without your washing machine, floor mop, and the tumble dryer. Yes we get through a lot of washing'.*

For **Jack** and Linda, it was medication changes that caused restrictions. Linda said Jack *'struggled 'cos they've changed his medication, he's on medication for depression, anxiety, which gave him diarrhoea, he couldn't go out anywhere'.* Three of the carers were getting up frequently during the night, changing wet beds, and struggling to find the correct equipment and support, giving rise to feelings of tiredness, loneliness, and isolation.

6.4.6 Loss of energy

People with Lewy body dementia in this study also attributed their reduced social interaction to excessive tiredness and mental slowing down:

> **Patrick**: *Tired. I was tired this morning and I'm definitely tired now, but I've felt tired for —*

> Sue: *We have actually just been down to see a friend of Patrick's… we haven't said this, but I realised you were, you know he was tired. Both sort of physically and mentally so um we came we came back.*
>
> **Patrick:** *It does take energy out of me, but I think I, I could do two hard days.*

They acknowledged the need to pace, and even for **Kath** who was determined to *'fight'* her condition, eventually tiredness and fatigue become a major difficulty. Ken: *'**Kath** just won't give in to anything, and then next day you know she's tired and and wants to spend the day in bed so she's her own worst enemy in that respect',* Kath later on in the interview admits *'I am tired. That's how I feel, um at the moment'.* Gayle reports **Doug** is sleeping more and more and due to night-time behaviours and *'can sleep on a military lined alley'* during the day. Recently he had slept *'a huge amount but then we had been out quite late the evening before so he was really tired, but there's no real pattern to it, he just nods off'.*

Analysis of the interviews suggests that the process of social disconnection became evident early on in their condition due to tiredness, fatigue, and lack of motivation. Tiredness was also common for the spouses and contributed to the overall loss of companionship and having the energy to do things together.

6.5 Methodological reflections on the findings

The narrative approach of this study enabled the participants to tell stories which were important to them. The challenge of narrative interviewing is finding a balance between letting participants tell their stories and ultimately addressing the study aims and research questions (Squire et al., 2014). The 'small' and 'big' approach to capturing stories ensured participant's voices and stories were kept in their entirety during analysis.

Couples were given the opportunity to be interviewed together or separately, and life story work was conducted on the second visit with the person with Lewy body dementia. Life story work was chosen as a method to allow space for communication, to draw deeper into experiences from, and beyond, autobiographical, and episodic memory. Autobiographical memory is a complex mental system that allows people to recollect information, events, and experiences from the past. The same autobiographical event has the ability to be recalled as either a conceptualised or perceptual episodic memory (Sheldon et al., 2019).

Longitudinal narrative interviewing may have enabled the components of self which ‘relate’ to autobiographical memory to be revealed and explored in more depth. Prebble et al (2013) sense of self framework identifies four components of self which ‘relate’ to autobiographical memory. Firstly, Prebble distinguished between the conscious, phenomenological experience of selfhood (subjective sense of I-self), the area where self-awareness occurs. Secondly, they consider the mental representation of self, compromising all the things that we perceive and know about ourselves (content of Me-self) where reflective thought exists. This distinction is important in research examining memory ‘as there may be cases when the capacity for self-reflection dissociates from the content of these reflections’ (Prebble et al., 2013 p 817). Narrative research with life story work may provide opportunity to re-associate content and reflections for people with advancing Lewy body dementia. Thirdly, the framework distinguishes between aspects of self that relate to the present (present self), and those over time (temporally extended self). This often occurs in discussions relating to autobiographical memory, which is inherently related to the past. Prebble et al (2013) suggest that these four processes act together to create a ‘unity’ that becomes the experience of ‘sense of self’.

Freeman (2021) postulates that identity persists in near absence of an autobiographical self, due to the collective, supra personal dimension whereby ‘narrative unconscious remains operative’ (Freeman, 2021 p.89). This aspect of identity is more culturally rooted and fashioned, and often goes unrecognised as we become naturalised. Conversations with **Joan** and **Doug** towards the end of life revealed their personal qualities, the individuality that is maintained through time particularly around independence and having fun. This preservation can be seen as linking to the self-2 person (Sabat and Harré, 1992) and what Freeman refers to as the ‘felt core self’. This mode of memory surfaces most in context of exchanges with intimate people and highlights the importance of the relational dimension of memory and identity. The couple’s intimate knowledge of each other provided a common reflective space that produced rich data, both in terms of expanding and corroborating a story:

> *Peter: Not so easy for you though with youngsters is it?*
>
> ***Joan:*** *Well I enjoy having them but find I can’t, play with them so much because I can’t get down and get up, I need some help.*
>
> *Peter: Do you find you miss that?*

Stories at the interpersonal level highlighted differences and disagreements such as when **Jack** was talking about his hallucinations:

> **Jack:** *[The hallucinations] were so realistic… I assumed it was real. But Linda said no they’re not, who has the right of it, I don’t know.*
>
> Linda: *Me [Laughter].*
>
> **Jack:** *Well that’s inevitable, I’ve lost already…. Yeah I mean you know you could get two very different answers depending in whether it’s me or Linda that’s being interviewed.*

Findings also highlighted those spousal caregivers took on a variety of roles within the research interview. These included research participant, questioner, and advocate for the person with Lewy body dementia. The couples discussed how they found it difficult talking about their situation or the condition. Peter admits that he *‘sometimes takes over, and that isn’t sort of right’.* Due to **Joan’s** and **Doug’s** advanced stages Gayle and Peter were the key narrators and influenced the direction of their stories as a couple:

> *Peter: Tell [the researcher], you had a visit from an occupational therapist, can you tell her about that? That was last Wednesday wasn’t it. Do you remember what she came for?*
>
> ***Joan****: Oh she came to see if whether I could sit in a chair, and do various other ——*
>
> *Peter: What conclusion did she come to?*
>
> ***Joan****: Unfortunately she concluded that I wasn’t ready to be released.*

Due to the physical and cognitive changes associated with Lewy body dementia, or differing personalities the challenge to *‘get a word in sometimes’* was evident within the joint interviews. There were examples when the interaction had the effect of silencing an individual’s account such as when one partner finished the other’s sentences. For example when Patrick says *‘so I, I was helping with the with the quiz game and there were,* Sue: *Can I interject? Just Patrick…, you were tolling up the scores weren’t you’.* **Joan** did have difficulty in getting her voice heard but by the final interview she found her voice and made the point that ‘*the idea is to have a two way conversation*’ when talking to Peter about her respite carer.

6.6 Conclusion

The findings in this chapter presented deeper insights into the experiences of living and dying with Lewy body dementia and demonstrate that although communication could be problematic, for some people with Lewy body dementia emotions and losses were expressed up until the end-of-life stage. The narrative approach built on the five ‘big’ stories identified for each couple; social connections, communication, conflict, looking for answers, and self-sufficiency. Similarities across the ‘big’ stories identifed the overarching narrative of *social connectedness.* The longitudinal narrative data highlights that connectedness can be viewed as a stepwise decline, with associated losses. Participant stories show that whilst new connections could be made, there was an overwhelming sense of individual, and shared loss. The implications of these findings will be discussed in Chapter 7 withn the context of the existing literature, loss, and palliative care.

Chapter 7: Discussion

7.1 Introduction

In this chapter I discuss how a longitudinal narrative approach exploring the everyday experiences of people living with Lewy body dementia, and their spousal caregiver, offers rare insights into the experiences from the perspective of the person living with Lewy body dementia over time. In the first part of the chapter, I review how the findings on social connectedness presented in the previous chapter relate to wider literature. I then discuss the findings from the perspective of persons with Lewy body dementia. When the experiences of people with Lewy body dementia are viewed through the lens of loss, grief and liminality, the value of palliative care approaches is highlighted.

7.2 Social connectedness and the wider literature

Participants within this study described the impact Lewy body dementia had on their personal ability to remain socially connected to friends and family, with each other as a couple, and their interactions within wider society. The need to maintain an active social life and acknowledgement of emotional needs for people living with Lewy body dementia and their carers was one of the themes identified within the study literature review (Bentley et al., 2021a). The theme ‘maintaining a social and emotional life’ is represented at the centre of figure 7.2, with the big stories forming the next circle and feeding into the overarching narrative of social connectedness. This links to Figure 6.1 and the stepwise representation of social connectedness.

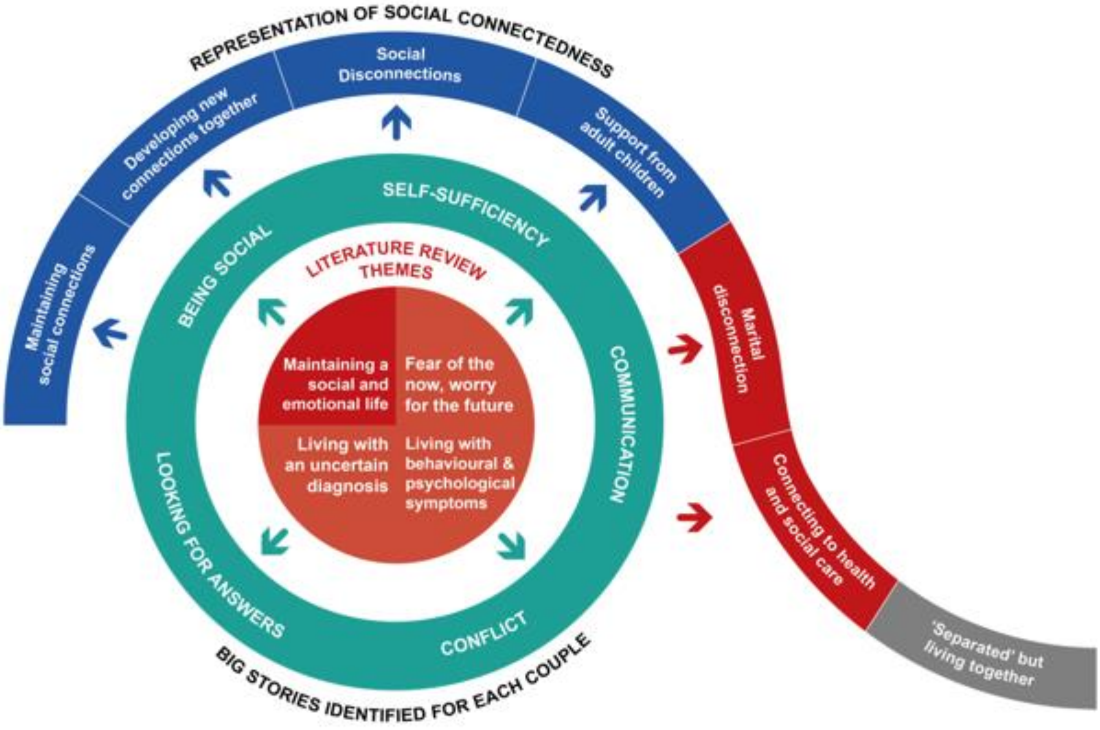


Figure 7.1 Literature review theme linking to empirical findings.

Within the literature review it was highlighted that most people living with Lewy dementia were relying on informal support, which was often provided by adult children, other family members and friends to maintain social and supporting relationships (Larsson et al., 2019; Londos, 2018; Stuart and Kenny, 2010). The literature review also described how people with Lewy body dementia felt a burden in the wider social context, and they reduced the number of social events they attended due to their increasing physical needs (Larsson et al., 2019). This was also highlighted within the empirical data, where spousal caregivers were creative at building social care networks but as disease progresses, they often had reduced opportunities to develop new social relationships or maintain social interactions.

Social connectedness is said to occur ‘when a person is actively involved with another person, object, group, or environment, and that involvement promotes a sense of comfort and well-being’ (Hagerty et al., 1993 p.293). When people with Lewy body dementia were able to socially interact, they talked of the importance of companionship, family, and having fun. These findings are consistent with the wider literature wherein retaining positive, caring, and respectful social connections with family, friends and the wider community has been identified as a key factor to living well and sustaining quality of life for people with dementia (Birt et al., 2020; Górska et al., 2017). Conversely as Santini et al (2020) reports – a decline in social relationships can result in loneliness and loss of self-esteem and give rise to symptoms of depression and anxiety. This can result in increased isolation (Sun et al., 2021). For people with Lewy body dementia early decrease in social interactions occurred due to both physical, and psychosocial influences.

From a theoretical perspective the effects of these physical and psychosocial influences can be seen to relate to Sabat and Harré's (1992) models of self, as discussed in Chapter 4. Factors such as societal expectations, lack of health and social care resources, and relational difficulties further contributed to their social disconnectedness. These findings highlighted the external factors where the self-3 can become vulnerable. Difficulty carrying out roles that had previously given a sense of self-worth and social standing, and the actions of others, unintentionally resulted in ‘a stifling of agency’ for the person with dementia (Birt et al., 2020 p.36). As found in this study, evidence indicates that people’s ability to have a sense of agency may be constrained by both the neuropathology, symptoms of dementia and by the external actions of others (Birt et al., 2017). Findings from the present study raised the possibility that people with Lewy body dementia may become socially disconnected earlier than people with Parkinson’s disease, and other forms of dementia. The combination of physical and psychosocial changes were commonly expressed experiences amongst the participants.

7.2.1 Physical influences on social connectedness

Physical, disease-related changes resulted in the person living with Lewy body dementia reducing interactions with others. These changes also impacted on the spousal caregiver. As their partners required increasing support and eventually constant monitoring, they too had to reduce their social activities. Communication changes, tiredness, incontinence, and reduced mobility due to falls were key influences in reducing social interactions.

7.2.1.1 Communication

Changes in communication and ability to interact played a significant part in the loss of connections for people with Lewy body dementia in this study. Larsson et al (2019) noted loss of identity, skills, traits, and physical and communication difficulties all were associated with a decreased desire to be active outside the home. Findings from this study and Larsson et al (2019) supports the findings from a meta-synthesis of experiences of living with all types of dementia, where people frequently reported ‘difficulty engaging and sustaining meaningful, coherent conversations with others’, which resulted in a gradual withdrawal of social interactions (Górska et al., 2017 p.189). However, the findings from this study highlighted that given the right environment (time, space, and familiarity), verbal and expressive communication, as well as insight, may be well preserved in some people with advancing stages of Lewy body dementia. For two participants, the ability to verbally interact, and to express insight and emotions was evident up until the end-of-life stage.

Recently it has been considered that people with Lewy body dementia had limited capacity for self-reporting and insight into their condition and day to day experiences when completing quantitative questionnaires (Killen et al., 2021; Mueller et al., 2017). Zweig and Galvin (2014) acknowledged people with Lewy body dementia retain insight into their condition for longer than people with Alzheimer's dementia and Larsson et al (2019) found that despite altered verbal fluency, people with dementia with Lewy bodies demonstrated insight into the complexities of their own cognition, emotions and symptoms (Larsson et al., 2019). The ability for emotional expression was also reported in the psychosocial intervention to support people with dementia with Lewy bodies and family care partners (Killen et al., 2021). However, there is limited research specifically on communication with Lewy body dementia as a sub-form of dementia, and there is mixed reporting around insight.

7.2.1.2 Tiredness

Tiredness and lack of motivation was highlighted as an issue within the current study, and people with Lewy body dementia gave a good account of understanding the need to pace. The longitudinal findings of this study raised highlighted insights into how the tiredness and lack of motivation were experienced by participants, and how this can lead to feelings of frustration and potential conflict within couples. Findings around tiredness are consistent with that of Londos, (2018 p.16) – whereby the most disturbing symptom was 'the immense tiredness'. For some excessive tiredness was considered 'profound' and 'debilitating' (Larsson et al., 2019 p.4). Tiredness and fatigue may also be attributed to changes in the autonomic (involuntary) nervous system, which can be particularly impaired in Lewy body dementia. This is due to the presence of alpha-synuclein within the peripheral autonomic nervous system, which is associated with a chronic, progressive generalised form of autonomic failure (Benarroch, 2014). This slows down involuntary functions resulting in symptoms such as orthostatic hypotension, syncope, fatigue, gastrointestinal changes, urinary, and bowel problems (Taylor et al., 2020). People with Lewy dementia in this study experienced excessive tiredness and mental slowing down which they acknowledged reduced their social activities.

Wider dementia literature also highlights the exhausting nature of the work required in maintaining roles, social relationships, and managing an impression the person with dementia wanted to present (Birt et al., 2020). Tiredness may precede a feeling of lack of motivation and apathy (Breitve et al., 2018; Drijgers et al., 2010; Eglit et al., 2021; Liu et al., 2019). Apathy is a commonly reported neuropsychiatric symptom of Lewy body dementia. It can result in of loss of motivation, reduced social interests, emotional blunting, and decline in self-starting behaviour (Robert et al., 2009). It is said to be associated with low mood and depression, faster cognitive decline, and early nursing home admission (Breitve et al., 2018). The effects of tiredness and lack of motivation were experienced by both the person with Lewy body dementia and their spousal caregiver.

Data from systematic reviews and individual studies demonstrated that managing behavioural and psychological symptoms, particularly apathy is burdensome and stressful for Lewy body dementia caregivers. The presence of apathy adds to caregiver burden, as it leads to a decrease in engaging in social activities (Zweig and Galvin, 2014). This can lead to a reduction in quality of life (Terum et al., 2019; van de Beek et al., 2019). The spousal caregivers expressed extreme tiredness due to their additional caring roles, lack of sleep, and respite care. Similar experiences were also reported by other family caregivers of people with Lewy body dementia. It was found dealing with mood swings, sleep issues and apathy concerning, and gave rise to disturbed sleep for the caregivers (Stacy et al., 2021). Tension occurred when the spousal caregiver saw the need to keep the family member with Lewy body dementia busy with social interactions, therapies, and other activities. However, tiredness, the need to pace, and difficulties with communication and motivation often prevented this.

7.2.1.3 Continence and falls

The findings demonstrated that people with Lewy body dementia suffered with debilitating constipation, faecal and urinary incontinence. This occurred early in the condition whilst still trying to maintain independence and was a dominant concern over time for all couples. Continence issues exacerbated feelings of tiredness, loneliness, and isolation for the couples. Both general dementia literature and Lewy body dementia studies highlight continence issues for the person with dementia had profound effects on quality of life, with the main challenges being the availability of support, financial cost, as well as social, relational and emotional issues (Allan et al., 2006; Gove et al., 2017b; Lee et al., 2018). This can also result in Lewy body dementia caregivers ‘feeling isolated because of incontinence’ (Stacy et al., 2021 p.8).

Incontinence is also associated with increased risk of falling in both the general and older populations (Moon et al., 2021). For **Kath** and **Joan**, the loss of independence and reduced ability for social participation was further exacerbated by hospital admissions due to falls. Falls are common in patients with Lewy body dementia, and form part of dementia with Lewy body diagnostic criteria (McKeith et al., 2017). A retrospective study of causes and outcomes of hospitalisations in Lewy body dementia found 24% of admission reason was as a result of falls (Spears et al., 2019). A recent qualitative study found fear of falling and being injured also resulted in increased isolation and reduced quality of life (Larsson et al., 2019).

These physical experiences highlighted some of the influencing factors contributing to the person with Lewy body dementia’s changes of the self, and in particular Sabat and Harré's (1992) three constructs of self. Incontinence negatively affected participants physical sense of self- 2, their self-1 personal roles and identity, and the influences of others on the self-3. Loss of self-3 was influenced by a lack of information about treatments and products, and access to specialist advice. Findings also highlighted that fear of falling was also a concern of the spousal caregivers and healthcare professionals, ultimately requiring a careful balance between risk of harm, independence, and dependence. This exacerbated the problem of maintaining connections and independence for both person with dementia and spousal caregivers.

7.2.2 Psychosocial influences on social connectedness

Findings from the empirical study suggested that people with Lewy body dementia were still active and wanted to retain their independence and dignity. When participants were agentic in making and managing their social connections, they were more able to maintain their ‘experiential self’ which is the self which closely affects the feelings of wellbeing and relatedness. Distancing from social relations and known activities can be understood as either wanting to disconnect from others, or others disconnecting from them (Eriksen et al., 2016). However, factors such as difficulty remaining independent, changes in relationships and lack of health and social care information and resources contributed to social disconnectedness.

7.2.2.1 Remaining independent

People living with Lewy body dementia in this study experienced loss of independence whilst at the same time struggling to remain self-sufficient. Freeman (2021) speaks of the strong cultural narrative of ‘the vital, self-sufficient individual who vigorously resists the feelings of fragility, vulnerability and dependency’ (Freeman, 2021 p.48). Self-sufficiency, he suggests is a deeply rooted cultural narrative embedded within identity, which is highly resistant to modification. It is said people with Lewy body dementia may lose independence earlier than other forms of dementia (Galvin et al., 2010a), and that giving up driving and reduced mobility in particular diminished independence and self-sufficiency (Larsson et al., 2019). Similar to current findings, independence, importance of socialisation, and quality of life was found to be a high priority in a recent published research priority exercise for people living with Lewy body dementia (Armstrong et al., 2020).

Findings identified spouses were unsure as to when to promote independence and self-management and when to assist with or take over certain tasks. This is an experience also highlighted by other carers of people with Lewy body dementia (Stacy et al., 2021). Freeman (2021) suggests the dilemma is one of how to support the narrative of self-sufficiency and maintaining independence, whilst recognising that this support, this affirmation of autonomy may, unintentionally add to frustration and anger. For the participants these feelings of frustration and anger often occurred due to tensions between dependence and independence, inactivity, and activity. The need for independence, autonomy, and a sense of agency for people living with Lewy body dementia was sometimes at odds with the spousal caregiver, as their roles and relationships changed.

7.2.2.2 Changing relationships

All participants in this study referred to the importance of family and friends relationships in maintaining socially connected and acknowledged how their changing relationships affected this. People are situated within their relationships and their social, cultural, and physical world, which in turn informs part of the relational character of personhood (Hydén et al., 2014). Findings in the current study suggested there is a reduction and range of social connections a person can maintain or develop, whilst managing societal and family expectations of remaining ‘busy’. Western culture places a high value on the productive autonomous self, and on being busy (Gilmour and Brannelly, 2010), paradoxically devaluing adaptation and compromise. Socially legitimated, full personhood is ‘earned by achieving and maintaining social roles and ideals’ (Luborsky, 1994 p.240). A recent multi perspective view of personhood in dementia found some of the core elements of personhood to include family, place, and social interaction (Hennelly and O’Shea, 2021). A tension existed between the core elements of personhood which at times caused dilemmas and conflict for family relationships in this study.

Spousal caregivers and adult children in the current study played a crucial part in supporting important social connections for persons with Lewy body dementia. Also highlighted was the significant influence adult children played in helping both parents to ‘maintain a social and emotional life’, a main theme identified in the literature review (Bentley et al., 2021a). Whilst Stacy et al (2021) found 40% of carers expressed they did not want to burden their adult children, couples in the current study acknowledged the important role their adult children played but were aware of the financial, emotional, and time related impact. For this reason, relationships with others such as family, friends and healthcare personnel become increasingly important in the lives of couples living with Lewy body dementia.

Spousal caregivers in this current study expressed at times their frustration about managing symptoms, anger about accessing services, and feelings of guilt, helplessness, and isolation around life changes. Studies have reported the negative impact on caring for someone with Lewy body dementia and the effects on long term relationships. Relationship satisfaction decreased because of progression in their partners condition. This was closely linked with partners reduced ability to communicate and the transition to caring role for the life partners. Alongside reduced relationship satisfaction, emotional, social, recreational, intellectual, and physical closeness had altered (Armstrong et al., 2019b; Stacy et al., 2021; Vatter et al., 2020, 2018b). This resulted in them feeling emotionally distanced from their partner despite spending more time together, a factor also identified in this study.

The notion of being physically closer but feeling emotionally further away from their partner was articulated most by Gayle and Peter in the current study. This ‘emotional disconnection’ has been described in the field of dementia (Evans and Lee, 2014), and likewise the term ‘married widowhood’ (Pozzebon et al., 2016). Peter described a feeling of being ‘*divorced but living together.’* This detachment can result in pre-loss, pre-death grief, commonly reported in the general dementia literature (Blandin and Pepin, 2017; Lindauer and Harvath, 2014; Singer et al., 2021). Within the Lewy body dementia literature, a large cross-sectional online survey with caregivers found social support may protect against the effects of caregiver grief (Park and Galvin, 2021). This highlights the importance of identifying the important aspects and timings of social support for people living with Lewy body dementia and their families.

7.2.2.3 Support and knowledge

Participants in this study were looking for answers about medication and how to manage symptoms such as hallucinations, Capgras (mistaken identity), diarrhoea, constipation, and incontinence. Similar to findings in the general dementia literature, they also sought advice on how to promote independence, and access services. A recent meta-analysis identified a range of support needs. These were around education of symptom management, problem solving approaches to deal with challenges, knowledge of services and technology to help allow for increased self-awareness, and coping mechanisms (Curnow et al., 2021). To date literature for Lewy body dementia support and information has mainly focused on needs regarding diagnosis (Killen et al., 2016) and end-of-life care (Armstrong et al., 2019b, 2019a). These studies mainly used an online survey format, and by requiring retrospective information from family caregivers. However, they provide consistent information on the support needs of carers around managing behavioural and psychological symptoms, particularly around hallucinations (Killen et al., 2016). In addition, living with behavioural and psychiatric symptoms was also identified as a key theme in the literature reviewed for Chapter 2 (Bentley et al., 2021a). This highlights that the information and support needs for people with Lewy body dementia may be more specific, in terms of symptoms and timings, than other forms of dementia.

Deeper insight was gained from the participants around the complexities of managing medications, specifically from the perspective of people living with Lewy body dementia, as well as caregivers. **Patrick** and **Jack** were aware they had missed medication, became anxious and described the struggle with the side effects such as constipation and diarrhoea. This resulted in them unable, or reluctant to leave the home. Medications had to be taken frequently, often multiple times during the day, and usually at or before mealtimes. This resulted in lengthy and tiring morning routines. The unmet need around medication knowledge and support is frequently reported by Lewy body dementia caregivers (Armstrong et al., 2019b; Killen et al., 2016; Stacy et al., 2021). For many caregivers 'Knowledge is power' (Stacy et al., 2021 p.8), and can increase a sense of agency and reduce psychological strain and potential burden (Galvin et al., 2010a; Leggett et al., 2011; Zweig and Galvin, 2014). Having awareness and a level of knowledge about the condition is also considered an important contributing factor in reducing social isolation (Sun et al., 2021). Having differing support and information needs for the participants, and the spousal caregivers is important to recognise, as this was an addition cause of stress between couples.

7.2.2.4 Connecting to services – end of life care

This study captured the 'in the time' experiences of the last year of life for people with Lewy body dementia. **Joan** died at home nine months following our final interview, and **Doug** died in a nursing home facility eight months following his. For both the time between diagnosis of Lewy body dementia and death was around six years. The findings of this study highlighted differing pathways for end-of-life care. **Joan** had hospital admissions for falls and pneumonia, both common causes of hospital admissions and mortality for people with Lewy body dementia (Armstrong et al., 2019a). Her admissions enabled access to NHS continuing care funding and a variety of additional services, in addition to the sitting service her spouse Peter had already set up through carer support. Peter had advanced care and admission avoidance plans in place and had discussed do not resuscitate orders. He had some understanding of disease trajectory, hospice involvement, and psychological support. In contrast Gayle and **Doug**, although they experienced almost similar complex and full-time care needs, were struggling to find services and support. By the time the final interview took place Gayle admitted to not coping, and they were looking at self-funding a care home placement for **Doug**. It is reported that caregiver stress and burden is considered to be a contributing factor to care home admission (Mueller et al., 2017). In addition pre-loss, or anticipatory grief can result in increased burden, anxiety and depression amongst Lewy body dementia care givers (Park and Galvin, 2021; Rigby et al., 2019). This is exacerbated due to the often protracted and unpredictable end stages of the disease, and poor understanding of the natural history of the condition (Mueller et al., 2017).

7.3 Loss and grief

Multiple losses, with physical and psychosocial contributors were identified in the findings. Loss of companionship, personal freedom, and control found in the current study are consistent with the literature on pre loss grief for carers (Chan et al., 2013). In addition, the presence of neuropsychiatric symptoms, a lack of services, or quality care, can result in increased carer anxiety, burden, and stress. This is thought to exacerbate pre-loss grief (Park et al., 2021; Bartlett et al., 2017). For spousal caregivers in this study compounded serial losses built in number and magnitude as their partner's condition progressed. Due to the severity of neuropsychiatric symptoms, early compromised functional abilities, and shorter duration of disease suggests there is less time for carers to adjust compared to other forms of dementia, such as Alzheimer's (Rigby et al., 2021). Family members of people with dementia are said to experience greater pre loss grief than those with cancer (Singer et al., 2021). However, for those in this study, apart from Peter, there was little access for individual support or opportunity to acknowledge their own grieving process.

In addition to spousal caregivers experiences of loss and grief, the findings offer deeper insight into the losses identified from the perspective of the person with Lewy body dementia. People with dementia in this study talked of many physical and psychological losses including social roles, mobility, memory, independence and living arrangements. Loss of roles and hobbies occurred in part due to cognitive and linguistic losses, fear of performance, and physical body changes for people with Lewy body dementia. Many of which may have previously given the person with Lewy body dementia a sense of self-worth and social standing. Chapter 6, figure 6.2 highlighted the differences in losses and timings between the person with Lewy body dementia and their family carer. Like people with young onset dementia, people with Lewy body dementia suffered from loss of self-identity, income, and socialisation associated with leaving employment early, and the psychological burden of an unexpected diagnosis and role changes associated with becoming a dependent family member (Thorsen et al., 2020). For the person with Lewy body dementia these compounded serial losses clustering early in their disease process, may be considered 'traumatic' and 'ambiguous' (Boss, 2010). In the context of loss experienced by dementia carers, ambiguous loss can be described as when a person is physically present, but psychologically absent (Boss, 2010). Ambiguous loss is considered to be 'a unique kind of loss that complicates grief, confuses relationships, and prevents closure' (Boss, 2010 p.137). As a result, the ability to cope and adapt may be blocked.

Blandin and Pepin's (2017) theory of dementia grief describes characteristics of grief within the context of compounded loss, ambiguous loss, and receding of the self. The grief model suggests grief cycles occurs in three states for dementia caregivers: separation, liminality, and re-emergence. A person is considered to be in a state of separation when they suffer significant loss. Although this model is based around dementia caregivers, findings identified from this study suggested that for the person with dementia this state of separation can be particularly difficult as they face significant losses over a short period of time. Blandin and Pepin's (2017) theory also considers the changes to sense of self, with complex loss and fluctuating uncertainty further contributing to the feeling of ambiguous loss. This gives rise to difficulty adjusting or accepting those losses many of which are irresolvable, and often leads to an overwhelming sense of anxiety. For the person with Lewy body dementia each loss was experienced as a separation from the known ‘self’ and separation from others, contributing to social disconnection.

7.4 Liminality

Unacknowledged loss and grief can result in a form of liminality which can result in existential threat (Blandin and Pepin, 2017). For people with dementia and caregivers there are no social processes in dealing with such losses so people may be ‘suspended’ in a liminal state with none of the usual support for grieving (Blandin and Pepin, 2017). Liminality is a ‘state of transition, of being in-between a previous situation and an emerging situation’, which can result in experiences of uncertainty and ambiguity (Blandin and Pepin, 2017 p.73). Freeman (2021) refers to this liminal mode of existence as ‘dislocation’ in which people with dementia experience a profound sense of ‘being exiled from the world’ of being caught in the middle of broken narratives (Freeman, 2021 p.74).

It has been suggested that a physical, social and emotional liminal state may begin with ambiguity around diagnosis (Birt et al., 2017). Diagnosis is often a protracted and difficult process for people with Lewy body dementia (Surendranathan et al., 2020). People present with a wide range of complaints leading to different initial diagnosis such as Alzheimer's, vascular dementia, depression, delusional disorders and Parkinson's disease (Moylett et al., 2019; Surendranathan et al., 2020). **Joan** and **Patrick** both initially received a diagnosis of Parkinson's disease for which they were *'relieved'* as they felt it was *'treatable,'* but this soon followed with a Lewy body dementia diagnosis. Lewy body dementia is also a condition characterised by fluctuating cognition, with notable 'good and bad days' which can result in confusion and ambiguity (Chin et al., 2019). It is said that when losses are complicated by ambiguity the person may become immobilised and isolated (Boss, 2010). There has been a societal and political shift to move beyond loss in dementia, to a focus on abilities and agency (Hydén et al., 2014). However, to move beyond loss requires a cultural self-consciousness – an awareness that cultural narratives have become constitutive of identity (Freeman, 2021). The challenge is how to live with the irresolvable issue of ambiguous loss, with its lack of resolution (Boss, 2010). Findings suggest that traumatic and complicated loss for the person with Lewy body dementia was often not acknowledged or discussed. This may result, physically and psychosocially, in an extended liminal state (Birt et al.,2017).

Descriptions of liminality within health literature and with dementia carers often focus on transitions and temporary experiences that people work to move beyond and resolve. Freeman describes how his mother with Alzheimer's lived through four phases: protest, presence, dislocation, and release (Freeman, 2021 p.5). In the protest phase her liminal state occurred because of the 'clinging' to her autobiographical self. He explains there exists a need to move beyond the autobiographical narrative, a need to 'let go,' and 'be let go' which can be a distressing time for both the person with dementia and their family. Freeman (2021) notes that relief from the protest phase can occur intermittently, within a ‘presence’ phase. Here it is possible to move beyond ‘narrative self’ to experience the ‘core self,’ to reveal what remains amidst devastation and loss. The dislocation phase he reports was when his mother was at her most existentially distressed, where she had no sense of who she was, or of her own life story, and did not recognise her relatives. He highlights that life without narrative is chaos, caused because of a lack of anchorage, or some sense of ‘locatedness’. For him this is confirmation that narrative is part of the fabric of life because it was when that fabric started to unravel that his mother was at her most existentially dislocated (Freeman, 2021 p.67). Participants’ stories also highlighted elements of dislocation and narrative chaos. These were situated within feelings of fear, and lack of control, and were particularly difficult experiences for the couples. Just as with ambiguous loss, it is important to acknowledge the chaos narrative, as ‘chaos is never transcended but must be accepted’ (Frank, 2013 p.110).

Within the study personal identity was particularly affected by dislocation within the narrative thought-line, where ‘experience of one’s continuity in time, relies on preservation of the past’ (Freeman, 2021 p.71). For Kitwood (1992) and Sabat and Harré, (1992) maintaining this connection to the past requires a supportive environment, or person to provide that anchorage or link. Within the social environment actions of others can result in reduced agency for person with dementia (Birt et al., 2020). It is said that when we are denied the opportunity to express our agency, we experience suffering (Ricoeur, 1992). This could give rise to a liminal state for the participants in which external factors can decrease a sense of agency for people with Lewy body dementia. This may lead to a physical, social, psychological, or spiritual form of suffering. Accounts of suffering reveal ‘restraint on our free agency’ (Murray, 2015 p.88). This was most notable for **Joan**, who came home from hospital to die, but then stabilised. In this liminal state between life and death, her physical restrictions from being in bed resulted in a state of physical and social stasis. There followed a narrative of deficit and loss, a sense of living with a condition which she had very little control over. As **Jack** says, *'you want to be able to control it, but you can't.'* There was a general sense of life being 'out of control' and 'restricted' by others. 'Liminality' as a state or process to be moved through may not be possible for some people with Lewy body dementia. They may not enter the final, calmer 'release' phase that Freeman (2021) describes. Similar to the experiences of people living with AIDS dementia, there needs to be a 'social and emotional space in which people live not with loss, but '*in'* loss,' (Kelly, 2008 p.335).

Understanding how to support the complexities and paradoxical nature of living with Lewy body dementia is therefore complex. Medical and social discourses around dementia have more recently focused on early diagnosis, with a shift in the UK policy to the living well agenda (Birt et al., 2017, DoH 2009, WHO 2012). While this has been an important shift for people living with dementia, this may have resulted in a polarised stance between stigma and negativity on the one side (Low and Purwaningrum, 2020), and the positivity and 'living well' agenda on the other (McParland et al., 2017). This then reduces the possibilities for learning to live with liminality or move beyond it. At its worst it may result in people living within a state of 'liminal suffering'.

7.5 Palliative care

One way to redress the dichotomy of this polarisation is to re-examine the application of a palliative and person-centred approach in dementia. When considered in relation to studies of the self, person-centredness can be seen as an 'ethical stance which gives prominence to both suffering and capability of the individual as a person' (Öhlén et al., 2017 p.1). Palliative care is an approach aimed at the 'prevention and relief of suffering' (WHO 2010). For Freeman (2021) the essence of understanding suffering and noticing capability rests in accepting the person in their 'otherness', that they have a different perception of the world. It is therefore important to incorporate cultural and societal perspectives within holistic person-centred palliative care. This in turn may lead to improved quality of life for those living in extended liminality, and the possibility to live as an active citizen with agentic interdependence (Birt et al., 2017 p.27). To 'live with loss' or 'move beyond loss' requires an acceptance of liminality. This would address the overly individualistic perspective on capabilities and help address the suffering and 'uncertainty' that living and dying with Lewy body dementia brings.

Findings highlighted how there is a need for regular assessment and follow up with a multidisciplinary team knowledgeable about this complex condition. Managing physical autonomic and motor symptoms, counselling around neuropsychiatric behaviours, and addressing social disconnectedness are all important in supporting well-being and alleviating potential distress. Given the short survival time, accelerated decline and complex symptoms associated with dementia with Lewy bodies (Price et al., 2017) a palliative care approach would seem appropriate. Applying a palliative and supportive care approach may ultimately open space to optimising opportunities for improving and preserving physical, psychological, and social well-being. Managing physical autonomic and motor symptoms, counselling around neuropsychiatric behaviours, and addressing social disconnectedness are all important in supporting well-being and alleviating potential distress.

7.6 Conclusion

There is a need to consider ways of conceptualising experiences of loss and disconnection, to support people with Lewy body dementia to live in a balanced liminal state. It is important to acknowledge that internalising losses, and external influences may contribute to a form of liminal distress and suffering. Both the biomedical discourse of loss of function, decline and death, or the living well narratives can give rise to a feeling of social isolation and potential liminal suffering. There is a need to understand how to support people with Lewy body dementia to live in a balanced liminal state. It is therefore important from a sociological, clinical and research perspective to acknowledge that the ‘in-between’ liminal space where most people may live.

Chapter 8: Conclusion and recommendations

8.1 Introduction

The aim of this thesis was to explore the experiences of people living with Lewy body dementia and their family caregivers, and the relevance of these experiences to palliative care. In this chapter I consider the main points from this thesis and draw overall conclusions, clarifying the potential contribution of this research to the understanding and care of persons with Lewy body dementia. I reflect on how my experiences as researcher, and the involvement of the patient and public engagement group, contributed to the value of this research. Strengths and limitations of the research are discussed, and I conclude with recommendations for clinical practice and future research.

8.2 Contributions of the thesis

On completing this thesis, I argue that the social connectedness experienced over time by people with Lewy body and dementia, and their spousal caregivers would be better addressed by a clinical approach that is holistic and palliative. This is to address the overriding experiences of loss, grief and stress identified in the empirical research and the literature review. The literature review demonstrated that carer experiences of stress, burden, and grief have widely been explored from a cross-sectional quantitative perspective. It highlighted that qualitative research focusing on couples living with Lewy body dementia is limited.

Within the empirical research I applied an analytical process using Murray's (2000) interpretive framework to demonstrate how a narrative-based methodology can discover the shared and differing experiences of people living with the condition, and their spousal caregiver, and thus challenge the current assumptions such as the 'living well with dementia' agenda. Specifically, the findings from this longitudinal study enabled a deeper understanding of how people tried to maintain positive social connections. Within social connectedness, the ‘big’ stories of *being social, self-reliance, looking for answers, communication* and *conflict* highlighted potential phases the couples experienced. Although represented diagrammatically as a stepwise deterioration, these experiences often overlapped, resulting in internal and external conflict, with problems *communicating* and difficulty *being social* occurring throughout. The stories also highlights where connections most frequently break down, such as when people with Lewy body dementia find communication difficult. This often coincides with multiple losses and a lack of voice, both physically and metaphorically.

Living with multiples losses can result in feelings of extended liminality, raising questions of how palliative care might be used to support people with Lewy body dementia and their families. The narratives tell of levels of distress and suffering at times, which further adds to a physical, social, psychological, or spiritual disconnection. A refocus on a holistic, palliative care approach could redress the balance between acknowledging grief and suffering and living well with a life-limiting condition.

This thesis, therefore, contributes to our understanding of what it is like to live with Lewy body dementia by bringing to the fore the voices of people living with the condition, infrequently heard within academic literature. This is important, as it is only through carrying out research with people experiencing the condition that their experiences be fully understood, allowing improvements in care. In addition, having support from people living with Lewy body dementia beyond the role of ‘participant’ enabled a more flexible, responsive, and adaptive approach to study design. This had the advantage of producing deeper, wider insights. One example is that of participants who articulated insight into their situation, which was preserved until last year of life. This is uncommon in other forms of dementia such as Alzheimer’s.

This thesis also contributes to methodological knowledge by exemplifying a strategy to connect the personal, interpersonal, positional, and societal levels of analysis. This approach integrates the content, structure, and composition of dyadic narrative interviews in a flexible way and thus contributes to the growing body of analytic methods for interpreting stories. The dyadic longitudinal narrative approach can provide a richer understanding of lived experience, allowing for deeper social, clinical, and academic insight. This study highlighted the many facets of social connectedness for people with Lewy body dementia and their spousal caregiver, which was presented diagrammatically as a stepwise process. Previous studies reported on only one side of a social connection, such as the person with dementia, or family caregivers. However, the co-construction method of this study has offered a more nuanced understanding by exploring the impressions and actions of individuals and couples, as well as the external influences on various social interactions, including healthcare. This advances our understanding as to how healthcare professionals, family, and researchers may influence, and support, people with Lewy body dementia's self-expression and independence. This study's findings raise questions about how we ensure people with people remain connected to their social world rather than having their opportunities for social connections inappropriately narrowed.

8.3 Strengths of the study

A strength of the longitudinal, dyadic approach was that it elicited narratives which made differing and convergent aspects of social connectedness more visible. The specific approach of collecting narrative, longitudinal data for this study made it possible to capture the intensity of feelings of loss, grief, and liminality in a way that other studies may have not. By adopting a narrative methodology that engages with elements of talk through small stories and life story work this study has been able to engage with the perspectives of people considered to have significant cognitive impairment, some of whom had been described by others as ‘confused’ or unable to ‘get anything back’. The narrative longitudinal approach has established that even when experiencing a level of communication changes that affects the convention of ‘social accepted’ conversation, people with Lewy body dementia engaged in rich meaning-making. They communicated important messages about how they wish to continue to live and die with a life-limiting illness, the importance of agency, and the support required to maintain some control and independence over their own lives. Taking a dyadic narrative approach also enabled an appreciation of different and similar perspectives on the same experiences, such as adapting to changes in quality of life and having to balance risks.

Longitudinal data from the cohort of people with Lewy body dementia and their caregivers has previously been limited, with interview-based studies often involving cross-sectional designs or focused on specific pre and post intervention evaluations. By utilising a longitudinal approach in the current project, it was possible to demonstrate the evolution of a narrative across successive interviews and between participants. This revealed how various core and noteworthy features of the condition escalate and gain new meaning over time. Although the six months’ timeframe used in this research is a relatively short period in terms of the general dementia disease trajectory, recent analysis of a Lewy body dementia dataset found clinically significant rates of change in the main clinical features could be detected and quantified over a similar six-month period (Matar et al., 2021). The narratives within this study reflected participants physical and psychosocial changes occurring over a six-month period, whilst also capturing what remains consistent.

The integration of patient and carer involvement throughout the research process can be considered a strength of the project. In recent decades psychosocial research has made progress in developing our understanding of how people living with dementia, carers, and the public can guide research projects (Gove et al., 2018). For this thesis people living with Lewy body dementia and carers were approached through the local NHS trust service user and involvement group. This ensured that I as a researcher, and the patients and carers, were trained and supported by an experienced manager in this field. In line with recommendations, patient and public involvement was planned, incorporated into the study protocol, budgeted, and monitored, with regular communication and feedback processes in place (Gove et al., 2018). The groups' unique and valuable experiential knowledge of living with Lewy body dementia, in addition to their work and life experience, contributed and shaped the direction, approach, and outputs for this project. Their advice such as repeat interviews, life story work, and photography was incorporated in the study design to ensure that all voices participants and carers were heard and acknowledged.

The patient and public involvement group work further contributed to the transparency, validity, and legitimacy of the research project by providing different views and perspectives on the topic and methods. Two of the original group members were involved throughout the five years of this project. This enabled us to build trust and openness and provided a platform for me to challenge my own biases. The local group gave feedback on the findings (Appendix 17) and assisted with plain English summaries (Appendix 18). The summary was then circulated to an independent patient and public involvement group from a different geographical location, in a process that was facilitated by a colleague to reduce the potential for bias. The group consisted of three former spouse carers, one current spouse carer and one daughter. Anonymised summaries of the discussions held by this group can be found at Appendix 19. A further strength may be considered by the use of external feedback from a fellow academic researcher which provided additional information about this study's potential strengths and limitations, and this can be found at Appendix 20.

8.4 Limitations of the study

The study was limited by the geographical area in which participants could be recruited from, which was predominantly rural. This effectively excluded potential participants from more urban areas where experiences of maintaining social connections may have differed. The transferability of findings is affected by the relatively narrow demographic of participants. Only the perspectives of white British people and couples were included in this study, therefore there is no representation of people living alone, or from ethnically diverse backgrounds. A greater representation of participants with dementia who live alone or from a wider diverse cultural background may lead to a presentation of different experiences. However, the anonymised findings were shared with family caregivers from a different, urban geographical location, who found similar experiences (Appendix 20).

It is important to acknowledge that this study represents my personal interpretation of the participants' stories, and that the stories themselves are co-constructed. Therefore, the findings may differ if approached by researchers from other backgrounds and specialities. In addition, only two sides of social connectedness: the person with Lewy body dementia, and their spousal caregiver, were considered. However, in co-constructing experiences a more nuanced understanding may be gained by interviewing other key people involved in the participants' stories. These might include health professionals or adult children as they featured in many of the social interactions described in this study. This might give further insight into how other people or institutions support, or hinder, the ability of people with Lewy body dementia to maintain positive social interactions.

8.5 Recommendations for clinical practice

The importance of social connectedness is highlighted and the study identifies where people with Lewy body dementia may require more focused intervention from health and social care professionals. Increasingly evidence points to social health factors playing a role in maintaining brain structure and cognitive reserve, and social interactions and improved communication are associated with better functioning of activity of daily living (Budgett et al., 2019). Some of the common reasons for people with Lewy body dementia to reduce their social connections are potentially modifiable. Opportunities for improved care include regular assessment from a team knowledgeable about the condition, with support from interdisciplinary teams. The couples were in contact with a wide range of community services; however, these referrals were inconsistent, and limited by service availability.

The first recommendation for clinical practice is the need for tailored communication skills training for health and social care professionals, and support for the person with Lewy body dementia and family members in adapting to changes in communication. As this study shows, noting how the changes in language and memory experienced by those with Lewy body dementia may differ from that of other dementia diagnosis may improve the quality of the interaction with healthcare professionals. Where connections between healthcare professionals were positive people felt supported and less worried. When communication broke down this resulted in frustration and conflict, and less effective interactions. For families, having more knowledge around communication may help to reduce the feelings of confusion, anger, and guilt couples experienced when communication between them wasn’t going well.

The second recommendation is to ensure countrywide access for family support. This could be via the Admiral nurse model (Brown et al., 2022), or by extending programmes that are currently in the research phase which provide strategies adapted specifically for families affected by Lewy body dementia (Foley et al., 2020; Killen et al., 2021). This is because offering tailored psychosocial and education interventions is key to providing better support for people. Consideration should also be given to the relational aspects of living with Lewy body dementia, maintaining quality of life, and improving psychological well-being. It is important to support couples and family relationships, taking into consideration that spouses and adult children may be the predominant caregivers.

The third recommendation identifies the need to consider developing and ensuring a consistent, interdisciplinary care pathway for people with Lewy body dementia. The rationale for this is that a lack of a clear pathway can make it particularly difficult to instigate timely support, management, and care for people with Lewy body dementia and family carers. The result is that people are rarely prepared with the necessary information and resources to live well, which can increase stress and frustration, as identified in the findings relating to 'looking for answers'. This is particularly relevant for those with a dementia with Lewy body dementia diagnosis because current practice varies across the UK, even where specialist research clinics exist. Depending on local service configuration and available resources, an interdisciplinary approach to the review and management of symptoms experienced by people with Lewy body dementia should be considered. Such an approach might make use of a joint clinic with psychiatric services, due to high incidence of neuropsychiatric symptoms (Bentley et al., 2021a), as well as Parkinson's input due to the impact of motor and non-motor symptoms on quality of life. Targeted psychosocial interventions and referral for psychological support should be embedded in the care pathway, together with specialist neurological pharmacist or pharmacy technician input. This study highlighted the complexity of managing complex medication regimes. The spousal caregivers were particularly concerned about the effects and interactions of the medications, as well as how and when their partners should take tablets. In addition, it is important for clinical practice to ensure that early on in disease trajectory patients access therapy advice regarding exercise, pacing, and rest, and that this input is embed into the care pathway.

The fourth recommendation is to consider expanding the use of existing management guidelines, such as the Lewy body dementia assessment and management toolkit (O'Brien et al., 2021; Thomas et al., 2018). These guidelines are designed to provide clinical staff in secondary care with a concise aid for diagnosing and managing the condition. Specifically, the toolkit offers treatment and medication options for core features and symptoms of the condition. This study highlighted the complexity of managing symptoms such as memory loss, falls, bowel and bladder issues, and neuropsychiatric symptoms, many of which negatively influenced participants' daily living, social activities, and quality of life.

8.6 Future research

This empirical research highlights the need to further examine whether people with Lewy body dementia lose abilities sooner than people with other forms of dementia. It is important to consider if they experience the losses at similar or different times, if indeed these are the same losses, and if people with Lewy body dementia these losses with greater awareness and therefore more intense feelings of grief and loss.

There is also a need to consider research which can bridge 'the divide between biomedical and psychosocial' within dementia research (Vernooij-Dassen et al., 2021 p.206). Lewy body dementia, as with all types of dementia, is recognised as a multifactorial condition which requires understanding from different research paradigms and approaches. The continuation of neurobiological research is necessary; however, this research is disconnected from the lived experience of people with Lewy body dementia. Unfortunately, within dementia research there has been a lack of investment on the role of social factors important in maintaining social health (Vernooij-

Dassen et al., 2021). Therefore, future research should consider, from interdisciplinary perspectives and with a focus on concepts of social health, how people, their social networks, and wider society interact with the condition.

A multidisciplinary approach to future research could help inform societal and clinical direction on supporting capabilities for people with Lewy body dementia and offer deeper insight than the current needs-based model of deficits. People with Lewy body dementia depend on others for practical and emotional support, and for help in finding the balance between limitations and capabilities, dependency, and independence. Given reduced quality of life and poor prognosis, future research should focus on the whole disease spectrum from diagnosis to palliative care, and how memory, physical health, pain, and co-morbidities affect quality of life and well-being. In addition, findings from this research highlight a need to further examine the notion of ‘living well’; how this is enacted within our western societal structures influences the individual and family with dementia.

The inclusion of public and patient engagement in dementia studies is still in its infancy compared to other research disciplines. This thesis explored novel ways to engage people with Lewy body dementia, however its main engagement was with family caregivers, with only one person with the condition forming part of the group for this project. There is a need to evaluate current practices and benefits of meaningful engagement. Future research should explore and expand the notion of true co-production. The patient and public engagement model employed in this study used focus groups, sharing reading materials via email; as well as technology such as Covidence to select articles for literature review. To truly explore the co-production of meaning in the lived experiences of people with Lewy body dementia, new models and approaches may be needed that includes greater input from people living with the condition.

8.7 Reflections as a clinical academic researcher

Conducting narrative research draws to the fore the continuous need to reflect, debate, and reconsider. This process of reflection takes on a higher significance as I the researcher, too, was a participant in the research process, co-constructing the narratives with the couples and, in turn, interpreting meanings within their stories. Listening to stories as a researcher, and not the person's clinician, highlighted my own lack of power and agency. I could listen and record with the hope of sharing the stories with a wider audience but could only direct them to other avenues for clinical support. To see and hear stories where people could benefit from improved medical, nursing, and social input was at times frustrating. Then the pandemic arrived and the final interview for this project occurred in the days leading up to a full closing of the dementia projects my colleagues and I had been working on. As a clinical academic the drive and reason behind embarking on a PhD was the need to articulate new evidence and put findings into practice, to ensure dissemination, and lead clinical change. For me these changing perspectives and priorities occurring during the process have meant a return to clinical practice. The drive is to try to implement locally a pathway for people with Lewy body dementia and join a national drive to improve knowledge amongst allied healthcare professionals.

8.8 Concluding remarks

Maintaining a social life and support network was important for both people living with Lewy body dementia and the family carer. Social support was seen as an interactive process in which social, emotional, physical, or financial help was received from a social network. Maintaining a social network was considered important in maintaining the spousal caregiver role. However, physical changes, communication challenges, and personality and behavioural difficulties undermined the established social connections for the couples. Therefore, an advantage of identifying the 'big' stories of *being social*, *self-reliance, looking for answers, communication,* and *conflict* is the potential to identify modifiable factors, to support and maintain social connections for longer.

The participants were constantly seeking answers to the problems raised by day to day living with Lewy body dementia. Access to information, and to health and social care professionals who understand this complex condition, was difficult for all couples. As highlighted by this thesis the specific needs of people with Lewy body dementia may differ from those of people with other forms of dementia, and indeed from the needs of their carers, therefore support and information should be more tailored and responsive. Greater understanding of formal services and knowledge of the disease progression can reduce carers' feelings of frustration and isolation, and result in people feeling better prepared (Bressan et al., 2020). However, to address the complex physical, cognitive, and psychological needs of people with Lewy body dementia, this support may be required lifelong.

Help from adult children and friends, and a supportive environment, enabled social connections to continue and new ones to be established. This support contributed to the couple's ability to remain self-sufficient. For carers of people with Lewy body dementia, increasing their confidence and self-efficacy, and optimising their social support networks, is key in reducing loneliness, anxiety, and depression. *Being social*, *self-reliance, looking for answers, communication,* and *conflict* were identified as underpinning the overall narrative of social connectedness. These findings can provide guidance for more targeted healthcare interventions and support for the management of Lewy body dementia, and guide future research priorities for people living with Lewy body dementia and their family caregivers.

9: References

Aarsland, D., Zaccai, J., Brayne, C., 2005. A systematic review of prevalence studies of dementia in Parkinson's disease. Mov. Disord. 20, 1255–1263. https://doi.org/10.1002/mds.20527

Allan, L., McKeith, I., Ballard, C., Kenny, R.A., 2006. The prevalence of autonomic symptoms in dementia and their association with physical activity, activities of daily living and quality of life. Dement. Geriatr. Cogn. Disord. 22, 230–237. https://doi.org/10.1159/000094971

American Psychiatric Association., 2013. Neurocognitive disorders. In *Diagnostic and statistical manual of mental disorders DSM-5-TR* (5th ed)

Andrews, M., Squire, C., Tamboukou, M. (Eds.), 2013. Doing narrative research, Second edition. ed. SAGE, Los Angeles, California.

Armstrong, M.J., Alliance, S., Corsentino, P., DeKosky, S.T., Taylor, A., 2019a. Cause of Death and End-of-Life Experiences in Individuals with Dementia with Lewy Bodies. J. Am. Geriatr. Soc. 67, 67–73.

Armstrong, M.J., Alliance, S., Taylor, A., Corsentino, P., Galvin, J.E., 2019b. End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former caregivers. PLOS ONE 14, e0217039. https://doi.org/10.1371/journal.pone.0217039

Armstrong, M.J., Gamez, N., Alliance, S., Majid, T., Taylor, A., Kurasz, A.M., Patel, B., Smith, G., 2020. Research priorities of caregivers and individuals with dementia with Lewy bodies: An interview study. PLOS ONE 15, e0239279. https://doi.org/10.1371/journal.pone.0239279

Aspers, P., Corte, U., 2019. What is Qualitative in Qualitative Research. Qual. Sociol. 42, 139–160. https://doi.org/10.1007/s11133-019-9413-7

Alzheimer's Australia., 2012 *Lewy body disease: Information for care facilities.* Factsheet. https://www.alzheimerswa.org.au/wp content/uploads/2017/06/Helpsheet-LewyBodyDisease10-InformationForCareFacilities_english.pdf accessed Sept 2017

Aveyard, H., Payne, S., Preston, N., 2021. A post-graduate's guide to doing a literature review in health and social care, Second edition. ed. Open University Press, London.

Babineau, J., 2014. Product Review: Covidence (Systematic Review Software). J. Can. Health Libr. Assoc. J. Assoc. Bibl. Santé Can. 35, 68–71. https://doi.org/10.5596/c14-016

Bailey, A., Dening, T., Harvey, K., 2019. Battles and breakthroughs: representations of dementia in the British press. Ageing Soc. 1–15. https://doi.org/10.1017/S0144686X19001120

Barker, W.W., Luis, C.A., Kashuba, A., Luis, M., Harwood, D.G., Loewenstein, D., Waters, C., Jimison, P., Shepherd, E., Sevush, S., Graff-Radford, N., Newland, D., Todd, M., Miller, B., Gold, M., Heilman, K., Doty, L., Goodman, I., Robinson, B., Pearl, G., Dickson, D., Duara, R., 2002. Relative frequencies of Alzheimer disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank. Alzheimer Dis. Assoc. Disord. 16, 203–212.

Bartlett, R., Windemuth-Wolfson, L., Oliver, K., Dening, T., 2017. Suffering with dementia: the other side of “living well’’. Int. Psychogeriatr. 29, 177–179. https://doi.org/10.1017/S104161021600199X

Bazeley, P., 2013. Qualitative data analysis: practical strategies. SAGE, London.

Belgrave, L.L., Charmaz, K., 2015. George Herbert Mead: Meanings and Selves in Illness, in: Collyer, F. (Ed.), The Palgrave Handbook of Social Theory in Health, Illness and Medicine. Palgrave Macmillan UK, London, pp. 107–123. https://doi.org/10.1057/9781137355621_7

Benarroch, E.E., 2014. The clinical approach to autonomic failure in neurological disorders. Nat. Rev. Neurol. 10, 396–407. https://doi.org/10.1038/nrneurol.2014.88

Bennett, C.R., Shive, N., Coats, H., 2020. What Mattered Then, Now, and Always: Illness Narratives From Persons of Color. J. Hosp. Palliat. Nurs. 22, 392–400. https://doi.org/10.1097/NJH.0000000000000682

Bentley, A., Morgan, T., Salifu, Y., Walshe, C., 2021a. Exploring the experiences of living with Lewy body dementia: An integrative review. J. Adv. Nurs. jan.14932. https://doi.org/10.1111/jan.14932

Bentley, A., Salifu, Y., Walshe, C., 2021b. Applying an Analytical Process to Longitudinal Narrative Interviews With Couples Living and Dying With Lewy Body Dementia. Int. J. Qual. Methods 20, 160940692110606. https://doi.org/10.1177/16094069211060653

Berman, R., Davies, A., Cooksley, T., Gralla, R., Carter, L., Darlington, E., Scotté, F., Higham, C., 2020. Supportive Care: An Indispensable Component of Modern Oncology. Clin. Oncol. 32, 781–788. https://doi.org/10.1016/j.clon.2020.07.020

Bingley, A., Thomas, C., Brown, J., Reeve, J., Payne, S., 2008. Developing narrative research in supportive and palliative care: the focus on illness narratives. Palliat. Med. 22, 653–658. https://doi.org/10.1177/0269216308089842

Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P., Poland, F., 2020. Maintaining Social Connections in Dementia: A Qualitative Synthesis. Qual. Health Res. 30, 23–42. https://doi.org/10.1177/1049732319874782

Birt, L., Poland, F., Csipke, E., Charlesworth, G., 2017. Shifting dementia discourses from deficit to active citizenship. Sociol. Health Illn. 39, 199–211. https://doi.org/10.1111/1467-9566.12530

Bjørnholt, M., Farstad, G.R., 2014. ‘Am I rambling?’ on the advantages of interviewing couples together. Qual. Res. 14, 3–19. https://doi.org/10.1177/1468794112459671

Blandin, K., Pepin, R., 2017. Dementia grief: A theoretical model of a unique grief experience. Dementia 16, 67–78. https://doi.org/10.1177/1471301215581081

Boss, P., 2010. The Trauma and Complicated Grief of Ambiguous Loss. Pastor. Psychol. 59, 137–145. https://doi.org/10.1007/s11089-009-0264-0

Boström, F., Jönsson, L., Minthon, L., Londos, E., 2007. Patients with Dementia with Lewy Bodies have more impaired quality of life than patients with Alzheimer disease. Alzheimer Dis. Assoc. Disord. 21, 150–154.

Bradbury-Jones, C., Breckenridge, J., Clark, M.T., Herber, O.R., Wagstaff, C., Taylor, J., 2017. The state of qualitative research in health and social science literature: a focused mapping review and synthesis. Int. J. Soc. Res. Methodol. 20, 627–645. https://doi.org/10.1080/13645579.2016.1270583

Braun, V., Clarke, V., 2013. Successful qualitative research: a practical guide for beginners, First published. ed. SAGE, Los Angeles London New Delhi.

Breitve, M.H., Brønnick, K., Chwiszczuk, L.J., Hynninen, M.J., Aarsland, D., Rongve, A., 2018. Apathy is associated with faster global cognitive decline and early nursing home admission in dementia with Lewy bodies. Alzheimers Res. Ther. 10, 83. https://doi.org/10.1186/s13195-018-0416-5

Bressan, V., Visintini, C., Palese, A., 2020. What do family caregivers of people with dementia need? A mixed-method systematic review. Health Soc. Care Community 28, 1942–1960. https://doi.org/10.1111/hsc.13048

Brown, L.J.E., Aldridge, Z., Pepper, A., Leroi, I., Dening, K.H., 2022. 'It's just incredible the difference it has made': family carers' experiences of a specialist Lewy body dementia Admiral Nurse service. Age Ageing 51, afac207. https://doi.org/10.1093/ageing/afac207

Bruce, A., Beuthin, R., Sheilds, L., Molzahn, A., Schick-Makaroff, K., 2016. Narrative Research Evolving: Evolving Through Narrative Research. Int. J. Qual. Methods 15, 160940691665929. https://doi.org/10.1177/1609406916659292

Bryman, A., 2021. Social research methods, 6th. ed. Oxford University Press, Oxford ; New York.

Buber, M., Eisenstadt, S.N., 1992. On intersubjectivity and cultural creativity, The Heritage of sociology. University of Chicago Press, Chicago.

Buber, M., Kaufmann, W., Buber, M., 1996. I and thou, 46. print., 1. Touchstone ed. ed, A Touchstone book. Simon & Schuster, New York.

Budgett, J., Brown, A., Daley, S., Page, T.E., Banerjee, S., Livingston, G., Sommerlad, A., 2019. The social functioning in dementia scale (SF-DEM): Exploratory factor analysis and psychometric properties in mild, moderate, and severe dementia. Alzheimers Dement. Diagn. Assess. Dis. Monit. 11, 45–52. https://doi.org/10.1016/j.dadm.2018.11.001

Burton, A., Ogden, M., Cooper, C., 2019. Planning and enabling meaningful patient and public involvement in dementia research. Curr. Opin. Psychiatry 32, 557–562. https://doi.org/10.1097/YCO.0000000000000548

Bury, M., 1982. Chronic illness as biographical disruption. Sociol. Health Illn. 4, 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Caldwell, K., 2014. Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. Qual. Res. 14, 488–507. https://doi.org/10.1177/1468794113490718

Capouch, S.D., Farlow, M.R., Brosch, J.R., 2018. A Review of Dementia with Lewy Bodies' Impact, Diagnostic Criteria and Treatment. Neurol. Ther. 7, 249–263. https://doi.org/10.1007/s40120-018-0104-1

Chan, D., Livingston, G., Jones, L., Sampson, E.L., 2013. Grief reactions in dementia carers: a systematic review: Systematic review of grief reactions in carers of people with dementia. Int. J. Geriatr. Psychiatry 28, 1–17. https://doi.org/10.1002/gps.3795

Chin, K.S., Teodorczuk, A., Watson, R., 2019. Dementia with Lewy bodies: Challenges in the diagnosis and management. Aust. N. Z. J. Psychiatry 53, 291–303.

Clandinin, D.J., 2016. Engaging in Narrative Inquiry, 0 ed. Routledge. https://doi.org/10.4324/9781315429618

Clandinin, D.J., Connelly, F.M., 2000. Narrative inquiry: experience and story in qualitative research. Jossey-Bass, San Francisco, Calif.

Connors, M.H., Quinto, L., McKeith, I., Brodaty, H., Allan, L., Bamford, C., Thomas, A., Taylor, J.-P., O'Brien, J.T., 2018. Non-pharmacological interventions for Lewy body dementia: a systematic review. Psychol. Med. 48, 1749–1758. https://doi.org/10.1017/S0033291717003257

Cooney, A., O'Shea, E., 2019. The impact of life story work on person-centred care for people with dementia living in long-stay care settings in Ireland. Dementia 18, 2731–2746. https://doi.org/10.1177/1471301218756123

Crellin, N.E., Orrell, M., McDermott, O., Charlesworth, G., 2014. Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. Aging Ment. Health 18, 954–969. https://doi.org/10.1080/13607863.2014.915921

Creswell, J.W., Creswell, J.D., 2018. Research design: qualitative, quantitative, and mixed methods approaches, Fifth edition. ed. SAGE, Los Angeles.

Creswell, J.W., Poth, C.N., 2018. Qualitative inquiry & research design: choosing among five approaches, Fourth edition, international student edition. ed. SAGE, Los Angeles London New Dehli Singapore Washington DC Melbourne.

Cronin, M.A., George, E., 2020. The Why and How of the Integrative Review. Organ. Res. Methods 109442812093550. https://doi.org/10.1177/1094428120935507

Crotty, M., 1998. The foundations of social research: meaning and perspective in the research process. Sage Publications, London ; Thousand Oaks, Calif.

Curnow, E., Rush, R., Maciver, D., Górska, S., Forsyth, K., 2021. Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis. Aging Ment. Health 25, 397–407. https://doi.org/10.1080/13607863.2019.1695741

Davidsen, A.S., 2013. Phenomenological Approaches in Psychology and Health Sciences. Qual. Res. Psychol. 10, 318–339. https://doi.org/10.1080/14780887.2011.608466

Davies, D.J., 2020. Dividual identity in grief theories, palliative and bereavement care. Palliat. Care Soc. Pract. 14, 263235242092186. https://doi.org/10.1177/2632352420921867

Dementia UK., 2018. What is an admiral nurse https://www.dementiauk.org/get-support/what-is-an-admiral-nurse/ accessed 24 Sept 2019

Department of Health., 2008. End of life Care Strategy: London, DH https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

Department of Health., 2009. *Living well with Dementia*: a national dementia strategy. https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy accessed Apr 2018

DeTure, M.A., Dickson, D.W., 2019. The neuropathological diagnosis of Alzheimer's disease. Mol. Neurodegener. 14, 32. https://doi.org/10.1186/s13024-019-0333-5

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., Sutton, A.J., 2006. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC Med. Res. Methodol. 6, 35. https://doi.org/10.1186/1471-2288-6-35

Donnelly, C., 2021. Claiming chaos narrative, emerging from silence. Disabil. Soc. 1–15. https://doi.org/10.1080/09687599.2021.1983420

Drijgers, R.L., Dujardin, K., Reijnders, J.S.A.M., Defebvre, L., Leentjens, A.F.G., 2010. Validation of diagnostic criteria for apathy in Parkinson's disease. Parkinsonism Relat. Disord. 16, 656–660. https://doi.org/10.1016/j.parkreldis.2010.08.015

Dubois, B., Burn, D., Goetz, C., Aarsland, D., Brown, R.G., Broe, G.A., Dickson, D., Duyckaerts, C., Cummings, J., Gauthier, S., Korczyn, A., Lees, A., Levy, R., Litvan, I., Mizuno, Y., McKeith, I.G., Olanow, C.W., Poewe, W., Sampaio, C., Tolosa, E., Emre, M., 2007. Diagnostic procedures for Parkinson's disease dementia: recommendations from the movement disorder society task force. Mov. Disord. Off. J. Mov. Disord. Soc. 22, 2314–2324. https://doi.org/10.1002/mds.21844

Durkin, J., Jackson, D., Usher, K., 2020. Qualitative research interviewing: reflections on power, silence and assumptions. Nurse Res. 28, 31–35. https://doi.org/10.7748/nr.2020.e1725

Eglit, G.M.L., Lopez, F., Schiehser, D.M., Pirogovsky-Turk, E., Litvan, I., Lessig, S., Filoteo, J.V., 2021. Delineation of Apathy Subgroups in Parkinson's Disease: Differences in Clinical Presentation, Functional Ability, Health-related Quality of Life, and Caregiver Burden. Mov. Disord. Clin. Pract. 8, 92–99. https://doi.org/10.1002/mdc3.13127

Elliott, J., 2005. Using narrative in social research: qualitative and quantitative approaches. SAGE, London ; Thousand Oaks.

Enguidanos, S., Lomeli, S., Kogan, A.C., Rahman, A., Lewis, N., 2022. Home-Based Palliative Care Team Perspectives on Challenges in Patient Referral and Enrollment. J. Pain Symptom Manage. S088539242200032X. https://doi.org/10.1016/j.jpainsymman.2022.01.011

Eriksen, S., Helvik, A.-S., Juvet, L.K., Skovdahl, K., Førsund, L.H., Grov, E.K., 2016. The Experience of Relations in Persons with Dementia: A Systematic Meta-Synthesis. Dement. Geriatr. Cogn. Disord. 42, 342–368. https://doi.org/10.1159/000452404

Evans, D., Lee, E., 2014. Impact of dementia on marriage: A qualitative systematic review. Dementia 13, 330–349. https://doi.org/10.1177/1471301212473882

Ezzy, D., 1998. Theorizing Narrative Identity: Symbolic Interactionism and Hermeneutics. Sociol. Q. 39, 239–252. https://doi.org/10.1111/j.1533-8525.1998.tb00502.x

Fazio, S., Pace, D., Flinner, J., Kallmyer, B., 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia. The Gerontologist 58, S10–S19. https://doi.org/10.1093/geront/gnx122

Foley, J.A., Dore, C., Zarkali, A., Livingston, G., Cipolotti, L., Mummery, C.J., Weil, R.S., 2020. Evaluation of START (STrAtegies for RelaTives) adapted for carers of people with Lewy body dementia. Future Healthc. J. 7, e27–e29. https://doi.org/10.7861/fhj.2020-0003

Ford, A., Almeida, O.P., 2020. Effect of biological treatments on psychotic symptoms in lewy body disease: A systematic review and META-ANALYSIS of randomized controlled trials. Int. J. Geriatr. Psychiatry 35, 1083–1096. https://doi.org/10.1002/gps.5376

Fox, S., Cashell, A., Kernohan, W.G., Lynch, M., McGlade, C., O'Brien, T., O'Sullivan, S.S., Foley, M.J., Timmons, S., 2017. Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview. Palliat. Med. 31, 634–641. https://doi.org/10.1177/0269216316669922

Fox, S., FitzGerald, C., Harrison Dening, K., Irving, K., Kernohan, W.G., Treloar, A., Oliver, D., Guerin, S., Timmons, S., 2018. Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. BMC Palliat. Care 17. https://doi.org/10.1186/s12904-017-0221-0

Francis, N., Hanna, P., 2020. Informal carer experiences of UK dementia services—A systematic review. J. Psychiatr. Ment. Health Nurs. jpm.12698. https://doi.org/10.1111/jpm.12698

Frank, A.W., 2013. The wounded storyteller: body, illness, and ethics, Second edition. ed. The University of Chicago Press, Chicago.

Freeman, M., 2021. Do I look at you with love? reimagining the story of dementia, Personal/public scholarship. Brill Sense, Leiden ; Boston.

Freer, J., 2017. UK lags far behind Europe on diagnosis of dementia with Lewy bodies. BMJ j3319. https://doi.org/10.1136/bmj.j3319

Galvin, J.E., 2015. IMPROVING THE CLINICAL DETECTION OF LEWY BODY DEMENTIA WITH THE LEWY BODY COMPOSITE RISK SCORE. Alzheimers Dement. Amst. Neth. 1, 316–324.

Galvin, J.E., Duda, J.E., Kaufer, D.I., Lippa, C.F., Taylor, A., Zarit, S.H., 2010a. Lewy body dementia: The caregiver experience of clinical care. Parkinsonism Relat. Disord. 16, 388–392.

Galvin, J.E., Duda, J.E., Kaufer, D.I., Lippa, C.F., Taylor, A., Zarit, S.H., 2010b. Lewy body dementia: caregiver burden and unmet needs. Alzheimer Dis. Assoc. Disord. 24, 177–181. https://doi.org/10.1097/WAD.0b013e3181c72b5d

GBD 2019 Collaborators, Nichols, E., Abd-Allah, F., Abdoli, A., Abosetugn, A.E., Vos, T., 2021. Global mortality from dementia: Application of a new method and results from the Global Burden of Disease Study 2019. Alzheimers Dement. Transl. Res. Clin. Interv. 7. https://doi.org/10.1002/trc2.12200

Gilmour, J.A., Brannelly, T., 2010. Representations of people with dementia - subaltern, person, citizen: Representations of people with dementia. Nurs. Inq. 17, 240–247. https://doi.org/10.1111/j.1440-1800.2009.00475.x

Goetz, C.G., Emre, M., Dubois, B., 2009. Parkinson's disease dementia: Definitions, guidelines, and research perspectives in diagnosis. Ann. Neurol. 64, S81–S92. https://doi.org/10.1002/ana.21455

Górska, S., Forsyth, K., Maciver, D., 2017. Living With Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience. The Gerontologist gnw195. https://doi.org/10.1093/geront/gnw195

Gough, D., 2007. Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. Res. Pap. Educ. 22, 213–228. https://doi.org/10.1080/02671520701296189

Gove, D., Diaz-Ponce, A., Georges, J., 2017a. Palliative care covers more than end-of-life issues: why is this not common practice in dementia care and what are the implications? Ann. Palliat. Med. 6, 390–392. https://doi.org/10.21037/apm.2017.06.25

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., Øksnebjerg, L., The European Working Group of People with Dementia, 2018. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging Ment. Health 22, 723–729. https://doi.org/10.1080/13607863.2017.1317334

Gove, D., Scerri, A., Georges, J., van Houten, P., Huige, N., Hayder-Beichel, D., Leichsenring, K., Morris, V.C., 2017b. Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges. J. Clin. Nurs. 26, 356–365. https://doi.org/10.1111/jocn.13582

Grossoehme, D., Lipstein, E., 2016. Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. BMC Res. Notes 9, 136. https://doi.org/10.1186/s13104-016-1954-1

Hagerty, B.M.K., Lynch-Sauer, J., Patusky, K.L., Bouwsema, M., 1993. An Emerging Theory of Human Relatedness. Image J. Nurs. Sch. 25, 291–296. https://doi.org/10.1111/j.1547-5069.1993.tb00262.x

Harré, R., 1998. The singular self: an introduction to the psychology of personhood. Sage Publications, London ; Thousand Oaks, Calif.

Harrison Dening, K., Crowther, J., Tolman, S., 2017. Admiral Nursing: combining specialist dementia and hospice care. Nurs. Palliat. Care 2. https://doi.org/10.15761/NPC.1000151

Harrison Dening, K., Sampson, E.L., De Vries, K., 2019. Advance care planning in dementia: recommendations for healthcare professionals. Palliat. Care Res. Treat. 12, 117822421982657. https://doi.org/10.1177/1178224219826579

Hennelly, N., O'Shea, E., 2021. A multiple perspective view of personhood in dementia. Ageing Soc. 1–19. https://doi.org/10.1017/S0144686X20002007

Higgs, P., Gilleard, C., 2016. Interrogating personhood and dementia. Aging Ment. Health 20, 773–780. https://doi.org/10.1080/13607863.2015.1118012

Birt, L., Poland, F., Csipke, E., Charlesworth, G. 2017 'Shifting dementia discourses from deficit to active citizenship' In: Higgs, P., Gilleard, C.J., 2017. Ageing, dementia and the social mind, Sociology of health and illness monographs. Wiley-Blackwell, Hoboken. 24-36

Hoddinott P, Pollock A, O'Cathain A, Boyer I, Taylor J, MacDonald C, Oliver S, Donovan JL. How to incorporate patient and public perspectives into the design and conduct of research. F1000Res. 2018 Jun 18;7:752. doi: 10.12688/f1000research.15162.1. PMID: 30364075; PMCID: PMC6192439.

Holloway, I., Freshwater, D., 2007a. Narrative research in nursing. Blackwell Pub, Oxford, UK ; Malden, MA.

Holloway, I., Freshwater, D., 2007b. Vulnerable story telling: narrative research in nursing. J. Res. Nurs. 12, 703–711. https://doi.org/10.1177/1744987107084669

Hong, Q.N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O’Cathain, A., Rousseau, M.-C., Vedel, I., 2019. Improving the content validity of the mixed methods appraisal tool: a modified e-Delphi study. J. Clin. Epidemiol. 111, 49-59.e1. https://doi.org/10.1016/j.jclinepi.2019.03.008

Hospice UK., 2015. *Hospice enabled dementia care. The first steps*. Mar 2015. Accessed 24 Sept 2019 https://professionals.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/dementia-network/hospice-enabled-dementia-care---the-first-steps.pdf?sfvrsn=0

Huang, W.-C., Chang, M.-C., Wang, W.-F., Jhang, K.-M., 2022. A Comparison of Caregiver Burden for Different Types of Dementia: An 18-Month Retrospective Cohort Study. Front. Psychol. 12, 798315. https://doi.org/10.3389/fpsyg.2021.798315

Hunt, M.R., Chan, L.S., Mehta, A., 2011. Transitioning from Clinical to Qualitative Research Interviewing. Int. J. Qual. Methods 10, 191–201. https://doi.org/10.1177/160940691101000301

Hurwitz, B., Greenhalgh, T., Skultans, V. (Eds.), 2004. Narrative research in health and illness. BMJ Books, Malden, Mass.

Hydén, L.-C., 2013. Storytelling in dementia: Embodiment as a resource. Dementia 12, 359–367. https://doi.org/10.1177/1471301213476290

Hydén, L.-C. (Ed.), 2011. Health, illness and culture: broken narratives, 1. issued in pbk. ed, Routledge studies in health and social welfare. Routledge, London.

Hydén, L.C., Lindemann, H., Brockmeier, J. (Eds.), 2014. Beyond Loss: Dementia, Identity, Personhood. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199969265.001.0001

Inskip, M., Mavros, Y., Sachdev, P.S., Fiatarone Singh, M.A., 2016. Exercise for Individuals with Lewy Body Dementia: A Systematic Review. PLOS ONE 11, e0156520. https://doi.org/10.1371/journal.pone.0156520

Jackson, S., 2010. Self, Time and Narrative: Re-thinking the Contribution of G. H. Mead. Life Writ. 7, 123–136. https://doi.org/10.1080/14484520903445255

Jellinger, K.A., Korczyn, A.D., 2018. Are dementia with Lewy bodies and Parkinson's disease dementia the same disease? BMC Med. 16, 34. https://doi.org/10.1186/s12916-018-1016-8

Jerant AF, Azari RS, Nesbitt TS, Meyers FJ. The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. Ann Fam Med. 2004 Jan-Feb;2(1):54-60. doi: 10.1370/afm.29. PMID: 15053284; PMCID: PMC1466621.

Jones, A.J., Kuijer, R.G., Livingston, L., Myall, D., Horne, K., MacAskill, M., Pitcher, T., Barrett, P.T., Anderson, T.J., Dalrymple-Alford, J.C., 2017. Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI). Transl. Neurodegener. 6, 17

Kane, J.P.M., Surendranathan, A., Bentley, A., Barker, S.A.H., Taylor, J.-P., Thomas, A.J., Allan, L.M., McNally, R.J., James, P.W., McKeith, I.G., Burn, D.J., O'Brien, J.T., 2018. Clinical prevalence of Lewy body dementia. Alzheimers Res. Ther. 10, 19. https://doi.org/10.1186/s13195-018-0350-6

Kelly, A., 2008. Living loss: an exploration of the internal space of liminality. Mortality 13, 335–350. https://doi.org/10.1080/13576270802383915

Killen, A., Flynn, D., O'Brien, N., O'Brien, J., Thomas, A.J., McKeith, I., Taylor, J.-P., 2016. Support and information needs following a diagnosis of dementia with Lewy bodies. Int. Psychogeriatr. 28, 495–501. https://doi.org/10.1017/S1041610215001362

Killen, A., Flynn, D., O'Brien, N., Taylor, J.-P., 2021. The feasibility and acceptability of a psychosocial intervention to support people with dementia with Lewy bodies and family care partners. Dementia 147130122110285. https://doi.org/10.1177/14713012211028501

Kim, J.-H., 2016. Understanding narrative inquiry: the crafting and analysis of stories as research. SAGE, Los Angeles.

Kitwood, T.M., 1997. Dementia reconsidered: the person comes first, Rethinking ageing series. Open University Press, Buckingham [England] ; Philadelphia.

Kitwood, T.M., & Bredin K. (1992) Towards a theory of dementia care: personhood and well being. Aging and Society 12, 269–287.

Kluger, B.M., Fox, S., Timmons, S., Katz, M., Galifianakis, N.B., Subramanian, I., Carter, J.H., Johnson, M.J., Richfield, E.W., Bekelman, D., Kutner, J.S., Miyasaki, J., 2017. Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research. Parkinsonism Relat. Disord. 37, 19–26. https://doi.org/10.1016/j.parkreldis.2017.01.008

Kontos, P.C., 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. Ageing Soc. 24, 829–849. https://doi.org/10.1017/S0144686X04002375

Kurisu, K., Terada, S., Oshima, E., Horiuchi, M., Imai, N., Yabe, M., Yokota, O., Ishihara, T., Yamada, N., 2016. Comparison of QOL between patients with different degenerative dementias, focusing especially on positive and negative affect. Int. Psychogeriatr. 28, 1355–1361.

Labov, William (1972) *Socioloinguistic Patterns.* Philadelphia: University of Pennsylvania Press.

Lane, C.E., Conroy, M.L., 2022. Pharmacological Management of Lewy Body Dementia: A Systematic Review and Meta-analysis, in: Tampi, R.R., Tampi, D.J., Young, J.J., Balasubramaniam, M., Joshi, P. (Eds.), Essential Reviews in Geriatric Psychiatry. Springer International Publishing, Cham, pp. 343–347. https://doi.org/10.1007/978-3-030-94960-0_60

Larsson, V., Holmbom-Larsen, A., Torisson, G., Strandberg, E.L., Londos, E., 2019. Living with dementia with Lewy bodies: an interpretative phenomenological analysis. BMJ Open 9, e024983.

Lee, C.-Y., Cheng, S.-J., Lin, H.-C., Liao, Y.-L., Chen, P.-H., 2018. Quality of life in patients with dementia with Lewy bodies. Behav. Neurol. 2018.

Lee DR, McKeith I, Mosimann U, Ghosh-Nodyal A, Thomas AJ, Lee, D.R., McKeith, I., Mosimann, U., Ghosh-Nodyal, A., Thomas, A.J., 2013. Examining carer stress in dementia: the role of subtype diagnosis and neuropsychiatric symptoms. Int. J. Geriatr. Psychiatry 28, 135–141.

Leggett, A. N., Zarit, S., Taylor, A., Galvin, J.E., 2011. Stress and Burden Among Caregivers of Patients with Lewy Body Dementia. The Gerontologist 51, 76–85. https://doi.org/10.1093/geront/gnq055

Leroi, I., McDonald, K., Pantula, H., Harbishettar, V., 2012. Cognitive Impairment in Parkinson Disease: Impact on Quality of Life, Disability, and Caregiver Burden. J. Geriatr. Psychiatry Neurol. 25, 208–214. https://doi.org/10.1177/0891988712464823

Liang, C.-S., Li, D.-J., Yang, F.-C., Tseng, P.-T., Carvalho, A.F., Stubbs, B., Thompson, T., Mueller, C., Shin, J.I., Radua, J., Stewart, R., Rajji, T.K., Tu, Y.-K., Chen, T.-Y., Yeh, T.-C., Tsai, C.-K., Yu, C.-L., Pan, C.-C., Chu, C.-S., 2021. Mortality rates in Alzheimer’s disease and non-Alzheimer’s dementias: a systematic review and meta-analysis. Lancet Healthy Longev. 2, e479–e488. https://doi.org/10.1016/S2666-7568(21)00140-9

Lindauer, A., Harvath, T.A., 2014. Pre-death grief in the context of dementia caregiving: a concept analysis. J. Adv. Nurs. 70, 2196–2207. https://doi.org/10.1111/jan.12411

Liu, J., Cooper, C.A., Weintraub, D., Dahodwala, N., 2019. Pharmacological treatment of apathy in Lewy body disorders: A systematic review. Parkinsonism Relat. Disord. 60, 14–24. https://doi.org/10.1016/j.parkreldis.2018.11.002

Loh, J., 2015. Inquiry into Issues of Trustworthiness and Quality in Narrative Studies: A Perspective. Qual. Rep. https://doi.org/10.46743/2160-3715/2013.1477

Londos, E., 2018a. Practical Treatment of Lewy Body Disease in the Clinic: Patient and Physician Perspectives. Neurol. Ther. 7, 13–22.

Low, L.-F., Purwaningrum, F., 2020. Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma. BMC Geriatr. 20, 477. https://doi.org/10.1186/s12877-020-01754-x

Luborsky, M.R., 1994. The cultural adversity of physical disability: Erosion of full adult personhood. J. Aging Stud. 8, 239–253. https://doi.org/10.1016/0890-4065(94)90002-7

Lunney, J.R., 2003. Patterns of Functional Decline at the End of Life. JAMA 289, 2387. https://doi.org/10.1001/jama.289.18.2387

MacMahon, D.G., Thomas, S. and Campbell, S., 1999. Validation of pathways paradigm for the management of PD, *Parkinsonism & Related Disorders*, 5:S53.

Malterud, K., Siersma, V.D., Guassora, A.D., 2016. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qual. Health Res. 26, 1753–1760. https://doi.org/10.1177/1049732315617444

Mataqi, M., Aslanpour, Z., 2020. Factors influencing palliative care in advanced dementia: a systematic review. BMJ Support. Palliat. Care 10, 145–156. https://doi.org/10.1136/bmjspcare-2018-001692

Matar, E., White, S.R., Taylor, J.-P., Thomas, A., McKeith, I.G., Kane, J.P.M., Surendranathan, A., Halliday, G.M., Lewis, S.J.G., O'Brien, J.T., 2021. Progression of Clinical Features in Lewy Body Dementia Can Be Detected Over 6 Months. Neurology 97, e1031–e1040. https://doi.org/10.1212/WNL.0000000000012450

Maxwell, J.A., 2013. Qualitative research design: an interactive approach, 3rd ed. ed, Applied social research methods. SAGE Publications, Thousand Oaks, Calif.

McCormick, S.A., Vatter, S., Carter, L.-A., Smith, S.J., Orgeta, V., Poliakoff, E., Silverdale, M.A., Raw, J., Ahearn, D.J., Taylor, C., Rodda, J., Abdel-Ghany, T., Kwapong, B., Leroi, I., 2019. Parkinson's-adapted cognitive stimulation therapy: feasibility and acceptability in Lewy body spectrum disorders. J. Neurol. 266, 1756–1770. https://doi.org/10.1007/s00415-019-09329-6

McIlfatrick, S., Noble, H., McCorry, N.K., Roulston, A., Hasson, F., McLaughlin, D., Johnston, G., Rutherford, L., Payne, C., Kernohan, G., Kelly, S., Craig, A., 2014. Exploring public awareness and perceptions of palliative care: A qualitative study. Palliat. Med. 28, 273–280. https://doi.org/10.1177/0269216313502372

McKeith, I.G., Boeve, B.F., Dickson, D.W., Halliday, G., Taylor, J.-P., Weintraub, D., Aarsland, D., Galvin, J., Attems, J., Ballard, C.G., Bayston, A., Beach, T.G., Blanc, F., Bohnen, N., Bonanni, L., Bras, J., Brundin, P., Burn, D., Chen-Plotkin, A., Duda, J.E., El-Agnaf, O., Feldman, H., Ferman, T.J., ffytche, D., Fujishiro, H., Galasko, D., Goldman, J.G., Gomperts, S.N., Graff-Radford, N.R., Honig, L.S., Iranzo, A., Kantarci, K., Kaufer, D., Kukull, W., Lee, V.M.Y., Leverenz, J.B., Lewis, S., Lippa, C., Lunde, A., Masellis, M., Masliah, E., McLean, P., Mollenhauer, B., Montine, T.J., Moreno, E., Mori, E., Murray, M., O'Brien, J.T., Orimo, S., Postuma, R.B., Ramaswamy, S., Ross, O.A., Salmon, D.P., Singleton, A., Taylor, A., Thomas, A., Tiraboschi, P., Toledo, J.B., Trojanowski, J.Q., Tsuang, D., Walker, Z., Yamada, M., Kosaka, K., 2017. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. Neurology 10.1212/WNL.0000000000004058. https://doi.org/10.1212/WNL.0000000000004058

McKeith, I.G., Galasko, D., Kosaka, K., Perry, E.K., Dickson, D.W., Hansen, L.A., Salmon, D.P., Lowe, J., Mirra, S.S., Byrne, E.J., Lennox, G., Quinn, N.P., Edwardson, J.A., Ince, P.G., Bergeron, C., Burns, A., Miller, B.L., Lovestone, S., Collerton, D., Jansen, E.N.H., Ballard, C., de Vos, R.A.I., Wilcock, G.K., Jellinger, K.A., Perry, R.H., 1996. Consensus guidelines for the clinical and pathologic diagnosis of dementia with Lewy bodies (DLB): Report of the consortium on DLB international workshop. Neurology 47, 1113–1124. https://doi.org/10.1212/WNL.47.5.1113

McKeown, J., 2017. Researching with People with Dementia, in: Liamputtong, P. (Ed.), Handbook of Research Methods in Health Social Sciences. Springer Singapore, Singapore, pp. 1–15. https://doi.org/10.1007/978-981-10-2779-6_128-1

McParland, P., Kelly, F., Innes, A., 2017. Dichotomising dementia: is there another way? Sociol. Health Illn. 39, 258–269. https://doi.org/10.1111/1467-9566.12438

Mental Capacity Act., 2005. [online] Available at:< http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf > [Accessed 16 Feb 2018].

Meraz, R.L., Osteen, K., McGee, J., 2019. Applying Multiple Methods of Systematic Evaluation in Narrative Analysis for Greater Validity and Deeper Meaning. Int. J. Qual. Methods 18, 160940691989247. https://doi.org/10.1177/1609406919892472

Middleton-Green, L., Chatterjee, J., Downs, M., 2017. End of life care for people with dementia: a person-centred approach. Jessica Kingsley Publishers, London ; Philadelphia.

Milnes, K., University of Huddersfield, 2006. Narrative, memory, and knowledge: representations, aesthetics, and contexts. University of Huddersfield, Huddersfield.

Mishler, E.G., 1986. Research interviewing: context and narrative. Harvard University, Press, Cambridge, Mass London.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., for the PRISMA Group, 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ 339, b2535–b2535. https://doi.org/10.1136/bmj.b2535

Molyneaux, V.J., Butchard, S., Simpson, J., Murray, C., 2012. The co-construction of couplehood in dementia. Dementia 11, 483–502. https://doi.org/10.1177/1471301211421070

Moon, S., Chung, H.S., Kim, Y.J., Kim, S.J., Kwon, O., Lee, Y.G., Yu, J.M., Cho, S.T., 2021. The impact of urinary incontinence on falls: A systematic review and meta-analysis. PLOS ONE 16, e0251711. https://doi.org/10.1371/journal.pone.0251711

Morgan, D.L., 2016. Essentials of Dyadic Interviewing, 0 ed. Routledge. https://doi.org/10.4324/9781315429373

Mosimann, U.P., Rowan, E.N., Partington, C.E., Collerton, D., Littlewood, E., O'Brien, J.T., Burn, D.J., McKeith, I.G., 2006. Characteristics of Visual Hallucinations in Parkinson Disease Dementia and Dementia With Lewy Bodies. Am. J. Geriatr. Psychiatry 14, 153–160. https://doi.org/10.1097/01.JGP.0000192480.89813.80

Moylett, S., Price, A., Cardinal, R.N., Aarsland, D., Mueller, C., Stewart, R., O'Brien, J.T., 2019. Clinical Presentation, Diagnostic Features, and Mortality in Dementia with Lewy Bodies. J. Alzheimers Dis. 67, 995–1005. https://doi.org/10.3233/JAD-180877

Mueller, C., Ballard, C., Corbett, A., Aarsland, D., 2017. The prognosis of dementia with Lewy bodies. Lancet Neurol. 16, 390–398. https://doi.org/10.1016/S1474-4422(17)30074-1

Mueller, C., Perera, G., Rajkumar, A.P., Bhattarai, M., Price, A., O'Brien, J.T., Ballard, C., Stewart, R., Aarsland, D., 2018. Hospitalization in people with dementia with Lewy bodies:

Frequency, duration, and cost implications. Alzheimers Dement. Diagn. Assess. Dis. Monit. 10, 143–152. https://doi.org/10.1016/j.dadm.2017.12.001

Mueller, C., Soysal, P., Rongve, A., Isik, A.T., Thompson, T., Maggi, S., Smith, L., Basso, C., Stewart, R., Ballard, C., O'Brien, J.T., Aarsland, D., Stubbs, B., Veronese, N., 2019. Survival time and differences between dementia with Lewy bodies and Alzheimer's disease following diagnosis: A meta-analysis of longitudinal studies. Ageing Res. Rev. 50, 72–80. https://doi.org/10.1016/j.arr.2019.01.005

Murray, M., 2002. Connecting Narrative and Social Representation Theory in Health Research. Soc. Sci. Inf. 41, 653–673. https://doi.org/10.1177/0539018402041004008

Murray, M., 2000. Levels of Narrative Analysis in Health Psychology. J. Health Psychol. 5, 337–347. https://doi.org/10.1177/135910530000500305

Murray, M., 2015 'Narrative Psychology' in Smith, J.A., *Qualitiative Psychology.* SAGE publications Ltd. pp 85-108

Murray, M., Sools, A., 2015 'Narrative research' in: Rohleder, P., Lyons, A.C. (Eds.). Qualitative research in clinical and health psychology. Palgrave Macmillan, Houndmills, Basingstoke, Hampshire ; New York, NY. 113-155

Murray, S.A., Kendall, M., Boyd, K., Sheikh, A., 2005. Illness trajectories and palliative care. BMJ 330, 1007–1011. https://doi.org/10.1136/bmj.330.7498.1007

Newen, A., 2018. The Embodied Self, the Pattern Theory of Self, and the Predictive Mind. Front. Psychol. 9, 2270. https://doi.org/10.3389/fpsyg.2018.02270

National Institute for Health and Care Excellence NICE., 2018. *Dementia: assessment, management and support for people living with dementia and their carers.* NG97 https://www.nice.org.uk/guidance/ng97

Nichols, E., Steinmetz, J.D., Vollset, S.E., Fukutaki, K., Chalek, J., Abd-Allah, F., Vos, T., 2022. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. Lancet Public Health 7, e105–e125. https://doi.org/10.1016/S2468-2667(21)00249-8

Norberg, A., Ternestedt, B.-M., Lundman, B., 2017. Moments of homecoming among people with advanced dementia disease in a residential care facility. Dementia 16, 629–641. https://doi.org/10.1177/1471301215613699

Noyes, J., Booth, A., Moore, G., Flemming, K., Tunçalp, Ö., Shakibazadeh, E., 2019. Synthesising quantitative and qualitative evidence to inform guidelines on complex interventions: clarifying the purposes, designs and outlining some methods. BMJ Glob. Health 4, e000893. https://doi.org/10.1136/bmjgh-2018-000893

O'Brien, J. (Ed.), 2017. The production of reality: essays and readings on social interaction, Sixth edition. ed. SAGE, Los Angeles.

O'Brien, J., Taylor, J.P., Ballard, C., Barker, R.A., Bradley, C., Burns, A., Collerton, D., Dave, S., Dudley, R., Francis, P., Gibbons, A., Harris, K., Lawrence, V., Leroi, I., McKeith, I., Michaelides, M., Naik, C., O'Callaghan, C., Olsen, K., Onofrj, M., Pinto, R., Russell, G., Swann, P., Thomas, A., Urwyler, P., Weil, R.S., ffytche, D., 2020. Visual hallucinations in neurological and ophthalmological disease: pathophysiology and management. J. Neurol. Neurosurg. Psychiatry 91, 512–519. https://doi.org/10.1136/jnnp-2019-322702

O'Brien, J.T., McKeith, I.G., Thomas, A.J., Bamford, C., Vale, L., Hill, S., Allan, L., Finch, T., McNally, R., Hayes, L., Surendranathan, A., Kane, J.P.M., Dunn, S., Bentley, A., Barker, S., Mason, J., Burn, D., Taylor, J., 2021. Introduction of a Management Toolkit for Lewy Body Dementia: A Pilot Cluster-Randomized Trial. Mov. Disord. 36, 143–151. https://doi.org/10.1002/mds.28282

Oesterhus, R., Soennesyn, H., Rongve, A., Ballard, C., Aarsland, D., Vossius, C., 2014. Long-term mortality in a cohort of home-dwelling elderly with mild Alzheimer's disease and Lewy body dementia. Dement. Geriatr. Cogn. Disord. 38, 161–169. https://doi.org/10.1159/000358051

Oh, Y.-S., Lee, J.E., Lee, P.H., Kim, J.-S., 2015. Neuropsychiatric symptoms in Parkinson's disease dementia are associated with increased caregiver burden. J. Mov. Disord. 8, 26–32.

Öhlén, J., Reimer-Kirkham, S., Astle, B., Håkanson, C., Lee, J., Eriksson, M., Sawatzky, R., 2017. Person-centred care dialectics-Inquired in the context of palliative care. Nurs. Philos. 18, e12177. https://doi.org/10.1111/nup.12177

Olfati, N., Shoeibi, A., Litvan, I., 2019. Progress in the treatment of Parkinson-Plus syndromes. Parkinsonism Relat. Disord. 59, 101–110. https://doi.org/10.1016/j.parkreldis.2018.10.006

Orsulic-Jeras, S., Whitlatch, C.J., Powers, S.M., Johnson, J., 2020. A dyadic perspective on assessment in Alzheimer's dementia: Supporting both care partners across the disease continuum. Alzheimers Dement. Transl. Res. Clin. Interv. 6. https://doi.org/10.1002/trc2.12037

Outeiro, T.F., Koss, D.J., Erskine, D., Walker, L., Kurzawa-Akanbi, M., Burn, D., Donaghy, P., Morris, C., Taylor, J.-P., Thomas, A., Attems, J., McKeith, I., 2019. Dementia with Lewy bodies: an update and outlook. Mol. Neurodegener. 14, 5. https://doi.org/10.1186/s13024-019-0306-8

Page, S., Keady, J., 2010. Sharing stories: a meta-ethnographic analysis of 12 autobiographies written by people with dementia between 1989 and 2007. Ageing Soc. 30, 511–526. https://doi.org/10.1017/S0144686X09990365

Park, J., Galvin, J.E., 2021. Pre-Loss Grief in Caregivers of Older Adults with Dementia with Lewy Bodies. J. Alzheimers Dis. 82, 1847–1859. https://doi.org/10.3233/JAD-210616

Park, J., Tolea, M.I., Arcay, V., Lopes, Y., Galvin, J.E., 2019. Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with Lewy bodies, Parkinson's disease dementia, or Alzheimer's disease. Soc. Work Ment. Health 17, 253–278.

Park, J., Tolea, M.I., Arcay, V., Lopes, Y., Galvin, J.E., 2018. Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with lewy bodies, parkinson's disease dementia, or alzheimer's disease. Soc. Work Ment. Health.

Parkinson J., *An Essay on the Shaking Palsy 1817.* Oxford, UK: Wiley-Blackwell 2010

Patton, M.Q., 2015. Qualitative research & evaluation methods: integrating theory and practice, Fourth edition. ed. SAGE Publications, Inc, Thousand Oaks, California.

Plummer, K., 2001. Documents of life 2: an invitation to a critical humanism. Sage Publications, London ; Thousand Oaks, Calif.

Polak, L., Green, J., 2016. Using Joint Interviews to Add Analytic Value. Qual. Health Res. 26, 1638–1648. https://doi.org/10.1177/1049732315580103

Polit, D.F., Beck, C.T., 2021. Nursing research: generating and assessing evidence for nursing practice, Eleventh edition. ed. Wolters Kluwer, Philadelphia.

Pope, C., Mays, N. (Eds.), 2020. Qualitative research in health care, 4th ed. ed. Blackwell Pub./BMJ Books, Malden, Mass.

Pozzebon, M., Douglas, J., Ames, D., 2016. Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. Int. Psychogeriatr. 28, 537–556. https://doi.org/10.1017/S1041610215002239

Prebble, S.C., Addis, D.R., Tippett, L.J., 2013. Autobiographical memory and sense of self. Psychol. Bull. 139, 815–840. https://doi.org/10.1037/a0030146

Price, A., Farooq, R., Yuan, J.-M., Menon, V.B., Cardinal, R.N., O'Brien, J.T., 2017. Mortality in dementia with Lewy bodies compared with Alzheimer's dementia: a retrospective naturalistic cohort study. BMJ Open 7, e017504. https://doi.org/10.1136/bmjopen-2017-017504

Puplampu, G.L., Caine, V., Clandinin, J.D., 2020. Sustaining hope: A narrative inquiry into the experiences of hope for nurses who work alongside people living with HIV in Ghana. Nurs. Open 7, 879–886. https://doi.org/10.1002/nop2.465

Reilly, J., Rodriguez, A.D., Lamy, M., Neils-Strunjas, J., 2010. Cognition, language, and clinical pathological features of non-Alzheimer's dementias: An overview. J. Commun. Disord. 43, 438–452. https://doi.org/10.1016/j.jcomdis.2010.04.011

Revolta, C., Orrell, M., Spector, A., 2016. The biopsychosocial (BPS) model of dementia as a tool for clinical practice. A pilot study. Int. Psychogeriatr. 28, 1079–1089. https://doi.org/10.1017/S1041610215002379

Richfield, E.W., Jones, E.J., Alty, J.E., 2013. Palliative care for Parkinson's disease: A summary of the evidence and future directions. Palliat. Med. 27, 805–810. https://doi.org/10.1177/0269216313495287

Ricoeur, P., 1992. *Oneself as another.* University of Chicago Press.

Ricœur, P., Blamey, K., Pellauer, D., Ricœur, P., 2010. Memory, history, forgetting, Paperback ed., [Nachdr.]. ed. Univ. of Chicago Press, Chicago, Ill.

Ricœur, P., McLaughlin, K., 2009. Time and narrative. Vol. 1: ..., Repr. ed. Univ. of Chicago Press, Chicago, Ill.

Riessman, C.K., 2008. Narrative methods for the human sciences. Sage Publications, Los Angeles.

Rigby, T., Ashwill, R.T., Johnson, D.K., Galvin, J.E., 2019. Differences in the Experience of Caregiving Between Spouse and Adult Child Caregivers in Dementia With Lewy Bodies. Innov. Aging 3, igz027.

Robert, P., Onyike, C.U., Leentjens, A.F.G., Dujardin, K., Aalten, P., Starkstein, S., Verhey, F.R.J., Yessavage, J., Clement, J.P., Drapier, D., Bayle, F., Benoit, M., Boyer, P., Lorca, P.M., Thibaut, F., Gauthier, S., Grossberg, G., Vellas, B., Byrne, J., 2009. Proposed diagnostic criteria for apathy in Alzheimer's disease and other neuropsychiatric disorders. Eur. Psychiatry 24, 98–104. https://doi.org/10.1016/j.eurpsy.2008.09.001

Rodrigues e Silva, A.M., Geldsetzer, F., Holdorff, B., Kielhorn, F.W., Balzer-Geldsetzer, M., Oertel, W.H., Hurtig, H., Dodel, R., 2010. Who was the man who discovered the "Lewy bodies"?: The Life of F.H. Lewy. Mov. Disord. 25, 1765–1773. https://doi.org/10.1002/mds.22956

Roland, K.P., Chappell, N.L., 2019. Caregiver Experiences Across Three Neurodegenerative Diseases: Alzheimer's, Parkinson's, and Parkinson's With Dementia. J. Aging Health 31, 256–279.

Ryan, S., Wong, J., Chow, R., Zimmermann, C., 2020. Evolving Definitions of Palliative Care: Upstream Migration or Confusion? Curr. Treat. Options Oncol. 21, 20. https://doi.org/10.1007/s11864-020-0716-4

Sabat, S.R., 2021. Cognitive and social strengths of people living with dementia: Discoveries through Harré's method. *Journal for the Theory of Social Behaviour* 51(2) 232-248 10.1111/jtsb.12287

Sabat, S.R., 2006. Mind, meaning and personhood in dementia: The effects of positioning. In: Hughes JC, Louw S, Sabat SR, editors. Dementia: Mind, meaning and the person. Oxford: Oxford University Press; pp. 287–302.

Sabat, S.R., 2001. The experience of Alzheimer's disease: life through a tangled veil. Blackwell Publishers, Oxford, UK ; Malden, Mass., USA.

Sabat, S.R., Harré, R., 1992. The Construction and Deconstruction of Self in Alzheimer's Disease. Ageing Soc. 12, 443–461. https://doi.org/10.1017/S0144686X00005262

Salisu, W.J., Dehghan Nayeri, N., Yakubu, I., Ebrahimpour, F., 2019. Challenges and facilitators of professional socialization: A systematic review. Nurs. Open 6, 1289–1298. https://doi.org/10.1002/nop2.341

Samsi, K and Manthorpe, J., 2020. Interviewing people living with dementia in social care. Methods review. NIHR School for Social Care Research. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR022.pdf accessed April 2021

Santini, Z.I., Jose, P.E., York Cornwell, E., Koyanagi, A., Nielsen, L., Hinrichsen, C., Meilstrup, C., Madsen, K.R., Koushede, V., 2020. Social disconnectedness, perceived isolation, and symptoms of depression and anxiety among older Americans (NSHAP): a longitudinal mediation analysis. Lancet Public Health 5, e62–e70. https://doi.org/10.1016/S2468-2667(19)30230-0

Sarbin, T.(Ed.), 1986 *Narrative Psychology: The Storied Nature of Human Conduct.* Newy York: Praeger

Schlosser, R.W., Wendt, O., Bhavnani, S., Nail-Chiwetalu, B., 2006. Use of information-seeking strategies for developing systematic reviews and engaging in evidence-based practice: the application of traditional and comprehensive Pearl Growing. A review. Int. J. Lang. Commun. Disord. 41, 567–582. https://doi.org/10.1080/13682820600742190

Sclan, S.G., Reisberg, B., 1992. Functional Assessment Staging (FAST) in Alzheimer’s Disease: Reliability, Validity, and Ordinality. Int. Psychogeriatr. 4, 55–69. https://doi.org/10.1017/S1041610292001157

Senderovich, H., Jimenez Lopez, B., 2021. Integration of palliative care in Parkinson’s disease management. Curr. Med. Res. Opin. 37, 1745–1759. https://doi.org/10.1080/03007995.2021.1954895

Sheilds, L., Molzahn, A., Bruce, A., Schick Makaroff, K., Stajduhar, K., Beuthin, R., Shermak, S., 2015. Contrasting stories of life-threatening illness: A narrative inquiry. Int. J. Nurs. Stud. 52, 207–215. https://doi.org/10.1016/j.ijnurstu.2014.10.008

Sheldon, S., Fenerci, C., Gurguryan, L., 2019. A Neurocognitive Perspective on the Forms and Functions of Autobiographical Memory Retrieval. Front. Syst. Neurosci. 13, 4. https://doi.org/10.3389/fnsys.2019.00004

Shin, H., Youn, J., Kim, J.S., Lee, J.-Y., Cho, J.W., 2012. Caregiver burden in parkinson disease with dementia compared to alzheimer disease in korea. J. Geriatr. Psychiatry Neurol. 25, 222–226.

Singer, J., Shrout, M.R., Papa, A., 2021. Rates and prospective psychosocial correlates of pre-loss grief in cancer and dementia family members. J. Health Psychol. 135910532199594. https://doi.org/10.1177/1359105321995945

Small, N., Froggatt, K., Downs, M., 2007. Living and dying with dementia: dialogues about palliative care. Oxford University Press, Oxford ; New York.

Snyder, C.M., Fauth, E., Wanzek, J., Piercy, K.W., Norton, M.C., Corcoran, C., Rabins, P.V., Lyketsos, C.G., Tschanz, J.T., 2015. Dementia caregivers’ coping strategies and their relationship to health and well-being: the Cache County Study. Aging Ment. Health 19, 390–399. https://doi.org/10.1080/13607863.2014.939610

Snyder, H., 2019. Literature review as a research methodology: An overview and guidelines. J. Bus. Res. 104, 333–339. https://doi.org/10.1016/j.jbusres.2019.07.039

Sools, A., 2013. Narrative health research: Exploring big and small stories as analytical tools. Health Interdiscip. J. Soc. Study Health Illn. Med. 17, 93–110. https://doi.org/10.1177/1363459312447259

Sools, A., Schuhmann, C., 2014. Theorizing the Narrative Dimension of Psychotherapy and Counseling: A Big and Small Story Approach. J. Contemp. Psychother. 44, 191–200. https://doi.org/10.1007/s10879-014-9260-5

Spears, C.C., Besharat, A., Monari, E.H., Martinez-Ramirez, D., Almeida, L., Armstrong, M.J., 2019. Causes and outcomes of hospitalization in Lewy body dementia: A retrospective cohort study. Parkinsonism Relat. Disord. 64, 106–111. https://doi.org/10.1016/j.parkreldis.2019.03.014

Squire, C., Andrews, M., Davis, M., Esin, C. (Eds.), 2014. What is narrative research? Bloomsbury, London.

Stacy, K.E., Perazzo, J., Shatz, R., Bakas, T., 2021. Needs and Concerns of Lewy Body Disease Family Caregivers: A Qualitative Study. West. J. Nurs. Res. 019394592110509. https://doi.org/10.1177/01939459211050957

Stinton, C., McKeith, I., Taylor, J.-P., Lafortune, L., Mioshi, E., Mak, E., Cambridge, V., Mason, J., Thomas, A., O'Brien, J.T., 2015. Pharmacological Management of Lewy Body Dementia: A Systematic Review and Meta-Analysis. Am. J. Psychiatry 172, 731–742. https://doi.org/10.1176/appi.ajp.2015.14121582

Strikwerda-Brown, C., Grilli, M.D., Andrews-Hanna, J., Irish, M., 2019. "All is not lost"—Rethinking the nature of memory and the self in dementia. Ageing Res. Rev. 54, 100932. https://doi.org/10.1016/j.arr.2019.100932

Strauss, A. L. (1975), Chronic Illness and the Quality of Life, Mosby, St Louis.

Stuart J, Kenny S, 2010. Parkinson's/Lewy body dementia: a carer's perspective. J. Dement. Care 18, 18–19.

Stubendorff, K., Aarsland, D., Minthon, L., Londos, E., 2012. The impact of autonomic dysfunction on survival in patients with dementia with Lewy bodies and Parkinson's disease with dementia. PloS One 7, e45451. https://doi.org/10.1371/journal.pone.0045451

Sun, W., Bartfay, E., Smye, V., Biswas, S., Newton, D., Pepin, M., Ashtarieh, B., 2021. Living well with dementia: The role volunteer-based social recreational programs in promoting social connectedness of people with dementia and their caregivers. Aging Ment. Health 1–14. https://doi.org/10.1080/13607863.2021.1950614

Surendranathan, A., Kane, J.P.M., Bentley, A., Barker, S.A.H., Taylor, J.-P., Thomas, A.J., Allan, L.M., McNally, R.J., James, P.W., McKeith, I.G., Burn, D.J., O'Brien, J.T., 2020. Clinical diagnosis of Lewy body dementia. BJPsych Open 6, e61. https://doi.org/10.1192/bjo.2020.44

Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A., Rongve, A., 2017. "Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease": Corrigendum. Int. J. Geriatr. Psychiatry 32, 470.

Szulc, J., King, N., 2022. The Practice of Dyadic Interviewing: Strengths, Limitations and Key Decisions. Forum Qual. Sozialforschung Forum Qual. Soc. Res. Vol. 22 No. 2 (2022). https://doi.org/10.17169/FQS-22.2.3776

Taylor, J.-P., McKeith, I.G., Burn, D.J., Boeve, B.F., Weintraub, D., Bamford, C., Allan, L.M., Thomas, A.J., O'Brien, J.T., 2020a. New evidence on the management of Lewy body dementia. Lancet Neurol. 19, 157–169. https://doi.org/10.1016/S1474-4422(19)30153-X

Terum, T.M., Testad, I., Rongve, A., Aarsland, D., Svendsboe, E., Andersen, J.R., 2019. The association between specific neuropsychiatric disturbances in people with Alzheimer's disease and dementia with Lewy bodies and carer distress. Int. J. Geriatr. Psychiatry 34, 1421–1428. https://doi.org/10.1002/gps.5134

Thaipisuttikul, P., Lobach, I., Zweig, Y., Gurnani, A., Galvin, J.E., 2013. Capgras syndrome in Dementia with Lewy Bodies. Int. Psychogeriatr. 25, 843–849.

Thomas, A.J., Taylor, J.P., McKeith, I., Bamford, C., Burn, D., Allan, L., O'Brien, J., 2018. Revision of assessment toolkits for improving the diagnosis of Lewy body dementia: The DIAMOND Lewy study. Int. J. Geriatr. Psychiatry 33, 1293–1304. https://doi.org/10.1002/gps.4948

Thomas, A.J., Taylor, J.P., McKeith, I., Bamford, C., Burn, D., Allan, L., O'Brien, J., 2017. Development of assessment toolkits for improving the diagnosis of the Lewy body dementias: feasibility study within the DIAMOND Lewy study: Assessment toolkits for Lewy body dementias. Int. J. Geriatr. Psychiatry. https://doi.org/10.1002/gps.4609

Thorogood, A., Mäki-Petäjä-Leinonen, A., Brodaty, H., Dalpé, G., Gastmans, C., Gauthier, S., Gove, D., Harding, R., Knoppers, B.M., Rossor, M., Bobrow, M., Global Alliance for Genomics and Health, Ageing and Dementia Task Team, 2018. Consent recommendations for research and international data sharing involving persons with dementia. Alzheimers Dement. 14, 1334–1343. https://doi.org/10.1016/j.jalz.2018.05.011

Thorsen, K., Dourado, M.C.N., Johannessen, A., 2020. Developing dementia: The existential experience of the quality of life with young-onset dementia – A longitudinal case study. Dementia 19, 878–893. https://doi.org/10.1177/1471301218789990

Tong, A., Flemming, K., McInnes, E., Oliver, S., Craig, J., 2012. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med. Res. Methodol. 12, 181. https://doi.org/10.1186/1471-2288-12-181

Toronto, C.E., Remington, R., 2020. A Step-by-Step Guide to Conducting an Integrative Review. https//doi.org/10.1007/978-3-030-37504-1

van de Beek, M., van Steenoven, I., Ramakers, I.H.G.B., Aalten, P., Koek, H.L., Olde Rikkert, M.G.M., Manniën, J., Papma, J.M., de Jong, F.J., Lemstra, A.W., van der Flier, W.M., 2019. Trajectories and Determinants of Quality of Life in Dementia with Lewy Bodies and Alzheimer's Disease. J. Alzheimers Dis. 70, 387–395.

van der Steen, J.T., Lemos Dekker, N., Gijsberts, M.-J.H.E., Vermeulen, L.H., Mahler, M.M., The, B.A.-M., 2017. Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. BMC Palliat. Care 16. https://doi.org/10.1186/s12904-017-0201-4

van der Steen, J.T., Lennaerts, H., Hommel, D., Augustijn, B., Groot, M., Hasselaar, J., Bloem, B.R., Koopmans, R.T.C.M., 2019. Dementia and Parkinson's Disease: Similar and Divergent Challenges in Providing Palliative Care. Front. Neurol. 10, 54. https://doi.org/10.3389/fneur.2019.00054

Van Manen, M (1997) *Researching Lived Experience. Human Science for an Action Sensitive Pedagogy.* The Althouse Press: Canada

Vann Jones, S.A., O'Brien, J.T., 2014. The prevalence and incidence of dementia with Lewy bodies: a systematic review of population and clinical studies. Psychol. Med. 44, 673–683. https://doi.org/10.1017/S0033291713000494

Vatter, S., McDonald, K.R., Stanmore, E., Clare, L., Leroi, I., 2018a. Multidimensional care burden in Parkinson-related dementia. J. Geriatr. Psychiatry Neurol. 31, 319–328.

Vatter, S., McDonald, K.R., Stanmore, E., Clare, L., McCormick, S.A., Leroi, I., 2018b. A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. Age Ageing 47, 604–610. https://doi.org/10.1093/ageing/afy049

Vatter, S., Stanmore, E., Clare, L., McDonald, K.R., McCormick, S.A., Leroi, I., 2020. Care Burden and Mental Ill Health in Spouses of People With Parkinson Disease Dementia and Lewy Body Dementia. J. Geriatr. Psychiatry Neurol. 33, 3–14. https://doi.org/10.1177/0891988719853043

Vernooij-Dassen, M., Moniz-Cook, E., Verhey, F., Chattat, R., Woods, B., Meiland, F., Franco, M., Holmerova, I., Orrell, M., de Vugt, M., 2021. Bridging the divide between biomedical and psychosocial approaches in dementia research: the 2019 INTERDEM manifesto. Aging Ment. Health 25, 206–212. https://doi.org/10.1080/13607863.2019.1693968

Vogl, S., Schmidt, E.-M., Zartler, U., 2019. Triangulating perspectives: ontology and epistemology in the analysis of qualitative multiple perspective interviews. Int. J. Soc. Res. Methodol. 22, 611–624. https://doi.org/10.1080/13645579.2019.1630901

Watts, K.E., Storr, N.J., Barr, P.G., Rajkumar, A.P., 2022. Systematic review of pharmacological interventions for people with Lewy body dementia. Aging Ment. Health 1–14. https://doi.org/10.1080/13607863.2022.2032601

Wertz, F.J. (Ed.), 2011. Five ways of doing qualitative analysis: phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry. Guilford Press, New York.

Whittemore, R., Knafl, K., 2005. The integrative review: updated methodology. J. Adv. Nurs. 52, 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C., Kingston, A., 2019. The costs of dementia in England. Int. J. Geriatr. Psychiatry 34, 1095–1103. https://doi.org/10.1002/gps.5113

Wong, G., Breheny, M., 2018. Narrative analysis in health psychology: a guide for analysis. Health Psychol. Behav. Med. 6, 245–261. https://doi.org/10.1080/21642850.2018.1515017

Woolf, N.H., Silver, C., 2017. Qualitative Analysis Using ATLAS.ti: The Five-Level QDA® Method, 1st ed. Routledge, Abingdon, Oxon ; New York, NY : Routledge, 2017. https://doi.org/10.4324/9781315181684

World Health Organisation., 2012. *DEMENTIA:* A public health priority. https://www.who.int/mental_healt h/publications/dementia_report_2012/en/

World Health Organisation., 2015. *Supporting informal caregivers of people living with Dementia*. https://www.who.int/mental_health/neuro logy/dementia/dementia_thematic brief_informal_care.pdf accessed Jan 2021

World Health Organisation., 2020. *Palliative care*: Factsheet https://www.who.int/news-room/fact-sheets/detail/palliative-care accessed Sept 2020

World Health Organisation., 2021. *Dementia*: Factsheet https://www.who.int/news-room/fact-sheets/detail/dementia accessed Oct 2021 https://www.who.int/news-room/fact-sheets/detail/dementia

Wu, Y.-T., Clare, L., Hindle, J.V., Nelis, S.M., Martyr, A., Matthews, F.E., 2018. Dementia subtype and living well: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. BMC Med. 16.

Zarit, S.H., Todd, P.A., Zarit, J.M., 1986. Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study. The Gerontologist 26, 260–266. https://doi.org/10.1093/geront/26.3.260

Zwakman, M., Verberne, L.M., Kars, M.C., Hooft, L., van Delden, J.J.M., Spijker, R., 2018. Introducing PALETTE: an iterative method for conducting a literature search for a review in palliative care. BMC Palliat. Care 17, 82. https://doi.org/10.1186/s12904-018-0335-z

Zweig, Y.R., Galvin, J.E., 2014. Lewy body dementia: the impact on patients and caregivers. Alzheimers Res. Ther. 6, 21. https://doi.org/10.1186/alzrt251

10: Appendices

Appendix 1: Exploring the experiences of Living with Lewy body dementia: An integrative review

Received: 9 December 2020 | Revised: 12 May 2021 | Accepted: 24 May 2021
DOI: 10.1111/jan.14932

JAN Leading Global Nursing Research WILEY

REVIEW

Exploring the experiences of living with Lewy body dementia: An integrative review

Allison Bentley[1,2] | Tessa Morgan[3] | Yakubu Salifu[2] | Catherine Walshe[2]

[1]Cambridgeshire and Peterborough NHS Foundation Trust, Windsor Research Unit, Fulbourn Hospital, Cambridge, UK
[2]International Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, Health Innovation One, Lancaster University, Lancaster, UK
[3]Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK

Correspondence
Allison Bentley, Cambridgeshire and Peterborough NHS Foundation Trust, Windsor Research Unit, Fulbourn Hospital, Fulbourn, Cambridge CB21 5EF & International Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, Health Innovation One, Lancaster University, Lancaster, LA1 4AT, UK.
Email: allison.bentley@cpft.nhs.uk

Funding information
The first author conducted this integrative literature review as a chapter for a PhD at Lancaster University which was part funded by a Florence Nightingale Research Scholarship 2017-2018.

Abstract

Aim: Lewy body dementia is a common neurodegenerative dementia with unique challenges in managing day-to-day life. A more in-depth multifaceted picture of the Lewy body dementia lived experience will enable identification of best practice and future research direction. The review aim was to explore experiences of people living with Lewy body dementia and their family carers.

Design: Integrative review method informed by Whittemore and Knafl, supported by the information retrieval framework PALETTE. A convergent integrated approach enabled synthesis of key findings and theme identification.

Data sources: Medline, CINAHL, PsycINFO, AMED, and ALOIS databases were systematically searched to find studies published between 1995 and 2020.

Review Methods: Twenty-six articles from twenty studies were synthesized (from 1583 retrieved). Quality and relevance were appraised using the Mixed-Methods Appraisal Tool and Gough's 'Weight of Evidence' framework. Data management was supported by ATLAS.ti 8 and COVIDENCE software.

Results: Four themes were identified: living with an uncertain diagnosis and prognosis; fear of the now – worry for the future; living with behavioural and psychiatric symptoms; and maintaining a social and emotional life. People reported difficulty finding information and support around diagnosis, disease progression and managing complex symptoms. The result is increased caregiver burden, grief and stress and reduced quality of life.

Conclusion: Delayed diagnosis and complex symptom burden means people are not getting the timely support and information they need to live and die well. Current evidence is largely quantitative, with a focus on family caregiver burden and unmet need. The challenge remains in how to capture a more holistic picture of the lived experience for people living with Lewy body dementia and those who care for them.

Impact: This review highlighted current knowledge and identified gaps in exploring the lived experience for people with Lewy body dementia and their families.

KEYWORDS
caregivers, carer, dementia with Lewy bodies, experience, family, informal care, integrative review, Lewy body dementia, nursing, Parkinson's disease dementia

1 | INTRODUCTION

Lewy body dementia is an umbrella term that includes both Parkinson's disease dementia and dementia with Lewy bodies. Pathology studies report it to be the second most common cause of neurodegenerative dementia after Alzheimer's disease (Barker et al., 2002). Epidemiological and neuropathological studies estimate dementia with Lewy bodies to account for 7.5% of all dementia cases (Vann Jones & O'Brien, 2014), with the prevalence of Parkinson's disease dementia in those with Parkinson's disease said to be between 24% and 31% (Aarsland et al., 2005). Clinical numbers are often reported to be lower than pathological studies (Surendranathan et al., 2020) as people with Lewy body dementia are often underdiagnosed or misdiagnosed (Chin et al., 2019). This is likely to have a negative effect on their experiences of healthcare, and limit their support options (Kane et al., 2018). It is said that people with Lewy body dementia have poorer survival time compared with Alzheimer's dementia (Mueller et al., 2017; Price et al., 2017), accelerated cognitive decline, more comorbid conditions and have complex symptoms leading to poorer quality of life (Allan et al., 2006; Tahami Monfared et al., 2019). As healthcare costs continue to rise and availability of community services decrease, families are often called on to manage and coordinate many aspects of dementia care including physical, social and medical needs (World Health Organisation, 2012).

1.1 | Background

People with Lewy body dementia often live with an array of symptoms such as cognitive fluctuations, visual hallucinations, falls and motor features of Parkinsonism. Other prominent features include disability, recurrent behavioural and emotional problems, rapid eye movement (REM) sleep behaviour disorder and autonomic dysfunction (Dubois et al., 2007; McKeith et al., 2017). This poses many challenges for people with Lewy body dementia and family members providing for their care. It is unclear how this is affecting people their day-to-day lives and how professionals can best support them. Systematic reviews to date have largely focused on pharmacology and non-pharmacological interventions for those with Lewy body dementia (Connors et al., 2018; Inskip et al., 2016; Morrin et al., 2018; Stinton et al., 2015). There is increasing literature on the lived experience of family carers of those with dementia, but most studies do not distinguish between the various types of dementia (Górska et al., 2017). This review is important to gain a more in-depth multifaceted picture of Lewy body dementia to inform the best approaches to care and support.

2 | THE REVIEW

2.1 | Aims

The aim of this integrative review was to synthesize published research to explore the experiences of people living with Lewy body dementia and family carers. The specific focus was experiences of day-to-day living and interactions with healthcare professionals. Studies had to include data that addressed at least one of the following questions:

1. What are the day-to-day experiences for people living with Lewy body dementia (dementia with Lewy bodies & Parkinson's disease dementia)?
2. What is it like to be a family carer of someone living with Lewy body dementia?
3. How does the person with Lewy body dementia describe experiences around their health and social care?
4. How do families describe and experience the interactions with healthcare professionals?

3 | METHODS

3.1 | Design

An integrative literature review based on Whittemore and Knafl's (2005) method was chosen, as it allows for the synthesis of heterogeneous evidence (Knafl & Whittemore, 2017). The process follows several stages: problem identification; literature search; data evaluation; data analysis and synthesis; and presentation stage (Whittemore & Knafl, 2005). A convergent integrated design was applied to facilitate synthesis process (Noyes et al., 2019). The Enhancing Transparency in Reporting the Synthesis of Quality Research guidelines (ENTREQ; Tong et al., 2012); and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher et al., 2009) guidelines are reported, as currently there is no specific reporting guidance for integrative reviews (Toronto & Remington, 2020).

3.2 | Search method

To ensure that a maximum number of eligible primary sources were identified, Whittemore and Knafl's, (2005) strategies were supported by the Palliative cAre Literature rEview iTeraTive mEthod (PALETTE) framework (Zwakman et al., 2018). Using a 'pearl growing' technique, search terms relating to experiences, family carers and people living with Lewy body dementia were developed with the assistance of a specialist librarian. Systematic reviews in the field of Lewy body dementia and dementia experiences were examined (Connors et al., 2018; Górska et al., 2017; Inskip et al., 2016; Stinton et al., 2015). These strategies assisted in identification of keywords, index terms and key authors in the field (Zwakman et al., 2018), and informed the inclusion and exclusion criteria (Box 1).

Medline, CINAHL, PsycINFO, and AMED databases were searched for English language publications occurring between 1995 and 2020. The ALOIS register was also checked, as this is a register of dementia studies maintained by the Cochrane Dementia and Cognitive improvement group (alois.medsci.ox.ac.uk). The Medline search strategy is presented in Box 2 and was subsequently adapted for CINAHL, PsycINFO, and AMED.

BOX 1 Inclusion and exclusion criteria

Inclusion criteria

- Published papers on the experiences of living with Lewy body dementia.
- People with a diagnosis of Lewy body dementia (dementia with Lewy bodies, Parkinson's disease dementia) and family carers (aged 18 years and over).
- "*Family caregivers can be defined by the relationship (spouse, adult children, daughters and sons-in-law, friends, neighbours), living arrangements (co-resident with the care recipient or living separately), and care input (regular, occasional or routine).*" (World Health Organisation, 2015, p 1).
- Studies of those with all sub-types of dementia, where the perspectives of those with Lewy body or their family carers can be disaggregated.
- Published, peer-reviewed quantitative and qualitative studies and case studies.
- Key areas for data extraction:
- Person with Lewy body dementia reported experiences;
- Family experience of what it is like to care for a person with Lewy body dementia;
- Experiences and interactions with healthcare professionals.
- Studies published between 1995 and 2020.
- English language full text.

Exclusion criteria

- NO diagnosis of Lewy body dementia (dementia with Lewy bodies, Parkinson's disease dementia).
- Formal and paid carers who are not defined as 'family carers'.
- Professional (Doctors, nurses, allied health professionals, social workers) views and experiences.
- Prevalence/incidence, genetics, pathology, scanning, treatments and/or symptom measurement only studies.
- Carer's perception of what it is like for the person with Lewy body dementia.
- Studies on dementia as a homogenous group, where Lewy body cannot be disaggregated in the findings.
- Opinion-based, abstracts and editorial publications.
- Review articles.
- Grey literature.

BOX 2 Medline search strategy

"LEWY BODY DISEASE"/ or ((lewy OR Parkinson*) AND Dementia*).ti,ab.
AND
((famil* OR informal OR spous* OR daughter OR son OR partner OR husband OR wife OR wives OR unpaid) AND (care* OR caring)).ti,ab [DT 1995–2019] [Languages English] OR (patient* OR "service user*" OR "person* with dementia" OR "people with dementia").ti,ab.
AND
(liv* ADJ3 experienc*).ti,ab OR (life* ADJ3 experienc*).ti,ab OR ("activities of daily living").ti,ab OR (view* OR perception* OR attribution* OR belief* OR meaning OR perspective* OR "quality of life" OR burden*).ti,ab.
Searches in CINHAL, PsycINFO, AMED and were adapted from this strategy. MeSH terms relating to diagnosis included - Lewy body disease (CINAHL, MEDLINE) Dementia Lewy bodies (PsycINFO).

For the literature search, a start date of 1995 was chosen, as this coincided with the development of the first International criteria for the clinical diagnosis of dementia with Lewy bodies, with the latest version published in 2017 (McKeith et al., 2017). This resulted in a greater understanding of the Lewy body sub-types and an increase in research activity. Policy and terminology acknowledging 'carers' and 'caregivers' were also identified at a similar time. For this review, the terms dementia with Lewy bodies, Parkinson's disease dementia, carer, caregiver and care partner will be used as reported by the specific studies.

3.3 | Search outcome

The search identified a total of 1,583 articles, two of which were retrieved by author searching (Whittemore & Knafl, 2005; Zwakman et al., 2018). Following exclusion of duplicates, title screening and eligibility checks were completed by three of the authors. Abstracts were screened by the main author and independently by a member of the patient and public involvement (PPI) group, with knowledge of Lewy body dementia, and experience of caring. This involvement was deemed important to gain a broader perspective and to ensure that the selected criteria applied the lived experience to the academic papers. Covidence software was used to manage the papers effectively (Babineau, 2014). This enabled reviewers with different experiences to access the papers, ensure independent screening of abstracts and manage conflicts by a third author ($n = 3$). A total of 26 articles from 20 unique studies were identified for further assessment against the quality appraisal criteria. (Figure 1).

Relevant papers were subjected to a full-text review by the author. Finally, backward citation tracking of the selected articles was completed to ensure that the search was as comprehensive as possible (Zwakman et al., 2018).

3.4 | Quality appraisal

The included studies were evaluated for their methodological quality, and overall relevance to the review questions by applying the

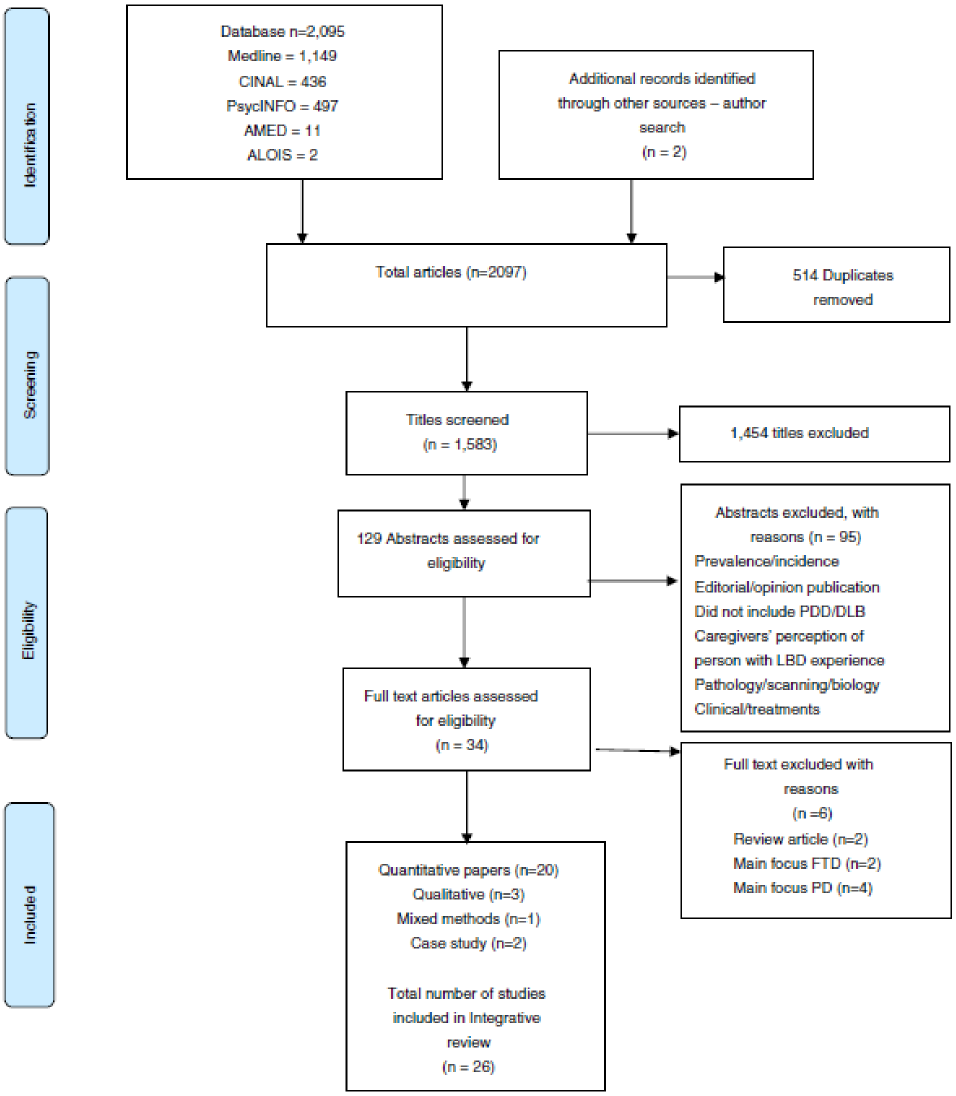


FIGURE 1 PRISMA Flow diagram of literature searches and selection, March 2020

Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2019), and Gough's weight of evidence framework (Gough, 2007). This framework assesses the 'coherence and integrity' of the research on its own merits, in addition to the appropriateness and the 'relevance of the evidence for answering the review questions'. These factors were then combined to give an overall 'weight of evidence' score. (Gough, 2007, p.11; Box S3). Of the four authors, two assessed the quality and relevance of the studies and discrepancies in quality appraisal decisions were discussed ($n = 8$) and consensus was achieved. A summary of characteristics of included studies and quality appraisal information is provided in Table S1. It was decided to retain all articles for synthesis, regardless of methodological quality, as they offered different perspectives on personal experience (Table 1).

3.5 | Data extraction

Data were extracted using the headings: study aims; research questions; participant characteristics; methods; date and length of fieldwork; analysis; results; and findings relevant to the review. A review matrix was developed to provide a structured document for the quality appraisal and analysis process (Quality appraisal of selected articles: Table S1). ATLAS.ti 8 software was used for organization of data extraction, coding and synthesis of the data.

3.6 | Data analysis and synthesis

Data analysis and synthesis involved three iterative phases: (a) papers were ordered and categorized according to their primary focus (Toronto & Remington, 2020; Whittemore & Knafl, 2005); (b) a convergent integrated design was applied to convert quantitative data to qualitative (qualitizing) (Noyes et al., 2019, p.9). 'Qualitizing' was achieved by identifying words or phrases related to frequent and recurring descriptive statistics in the results sections. Examples of 'qualitizing' extracts to support themes are presented in Supplementary Table S2; (c) inductive 'complete coding' occurred to identify new themes relevant to the review questions (Braun & Clarke, 2013, p.206). Themes were verified collaboratively by two of the authors and the process is presented diagrammatically (Figure 2).

TABLE 1 Summary of included articles

Author, Date, Country, Title	Study design, aim, sample
Vatter et al. (2020), UK Care burden and mental health in spouses of people with PDD and LBD.	Quantitative descriptive; To explore and compare levels of mental health, care burden, and relationship satisfaction; $N = 136$ Lewy body dementia caregiving spouses PD-MCI ($n = 37$) PDD ($n = 50$) DLB ($n = 49$)
Armstrong, Alliance, Corsentino, et al. (2019), USA Cause of death and end-of-life experiences in individuals with DLB.	Quantitative descriptive survey; To investigate cause of death and DLB carer experiences at end of life; $N = 658$ Caregivers DLB (death occurred in previous 5 years)
Armstrong, Alliance, Taylor, et al. (2019), USA End-of-life experiences in DLB: Qualitative interviews with former caregivers.	Qualitative: semi structured interviews; To investigate caregiver-reported EOL experiences of individuals with DLB and their families; $N = 30$ Caregivers DLB (death occurred in previous 5 years)
Rigby et al. (2019), USA Differences in the experiences of caregiving between spouse and adult child caregivers in DLB.	Quantitative descriptive survey; To examine differences in DLB caregiving experience between spouse and adult children. $N = 415$ Spouse ($n = 255$) child ($n = 160$)
McCormick et al. (2019), UK Parkinson's-adapted cognitive stimulation therapy: feasibility and acceptability in Lewy body spectrum disorders.	RCT mixed methods; To evaluate the feasibility, acceptability and tolerability of Cognitive Stimulation Therapy; $N = 76$ dyads (quantitative) 11 dyads (qualitative): PD MCI ($n = 6$), PDD ($n = 4$),DLB ($n = 1$).
Larsson et al. (2019), Sweden Living with dementia with Lewy bodies: an interpretative phenomenological analysis.	Qualitative research & Interpretive phenomenological approach; To explore the subjective experience, and factors influencing well-being whilst living with DLB; $N = 5$ DLB
Roland et al. (2019), Canada Caregiver Experiences Across Three Neurodegenerative Diseases: AD, PD, and PDD.	Quantitative descriptive survey; To compare QoL experiences of AD, PD, and PDD spouse caregivers; $N = 105$ caregivers AD ($n = 41$), PD ($n = 43$), and PDD ($n = 21$).
Londos E. (2018), Sweden Practical treatment of Lewy body disease in the clinic: Patient and Physician perspectives.	Descriptive case report; To describe the clinical medical treatment and experience of DLB patient. $N = 2$ DLB & Carer
Park et al. (2018), USA Self-efficacy and social support for psychological well-being of family caregivers of care recipients with DLB, PDD, or AD.	Quantitative descriptive survey; To examine the relationships between depressive symptoms, social support, and psychological wellbeing in caregivers of persons with DLB, AD, and PDD. $N = 604$ family members DLB ($n = 453$) AD ($n = 78$) PDD ($n = 75$).

(Continues)

TABLE 1 (Continued)

Author, Date, Country, Title	Study design, aim, sample
Vatter, McDonald, Stanmore, Clare, and Leroi (2018),UK Multidimensional care burden in Parkinson-Related Dementia.	Quantitative descriptive; To explore the factor structure of the Zarit Burden Interview in life partners of people with PDD, and examine relationships among the emerging factors and the demographic and clinical features; *N* = 136 life partners PD-MCI (*n* = 37) PDD (*n* = 50) DLB (*n* = 49).
Vatter, McDonald, Stanmore, Clare, McCormick, et al. (2018),UK A qualitative study of female caregiving spouses' experiences of intimate Relationships as cognition declines in Parkinson's disease.	Qualitative research: semi-structured interviews; To explore the changes in long-term intimate relationships in PDD, as perceived by spouses; *N* = 12 cohabiting partners. PD-MCI (*n* = 4) PDD (*n* = 5) DLB (*n* = 3).
Wu et al. (2018), UK Dementia sub-types and living well: results from IDEAL Study.	Quantitative descriptive; To investigate the potential impact of dementia subtypes on the capability to live well for both people with dementia and their carers; *N* = 1283 dyads. PDD (*n* = 43) LBD (*n* = 43) AD (*n* = 715) Others (*n* = 482)
Jones et al. (2017), New Zealand Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI).	Quantitative descriptive; To examine whether coping strategies can explain variables in caregiver outcomes; *N* = 96 caregivers PDD (*n* = 15) PD-MCI (*n* = 30) PD (*n* = 51)
Killen et al. (2016), UK Support and information needs following diagnosis of dementia with Lewy bodies.	Quantitative descriptive survey; To explore the information and support needs of people with DLB & Caregiver around diagnosis; *N* = 125 carers (*n* = 122) people with DLB (*n* = 3)
Kurisu et al. (2016), Japan Comparison of QoL between patients with different degenerative dementias, focusing especially on positive and negative affect.	Quantitative descriptive; To explore the difference in quality of life between dementia sub-groups *N* = 279 AD (*n* = 231) DLB (*n* = 28) FTD (*n* = 20)
Svendsboe et al. (2016), Norway Caregiver burden in family carers of people with DLB and AD	Quantitative descriptive; To characterise the differences in caregiver distress between DLB with AD carers; *N* = 186 caregivers DLB (*n* = 86) AD (*n* = 100)
Oh et al. (2015), Korea Neuropsychiatric symptoms in PDD are associated with increase caregiver burden.	Quantitative descriptive; To investigate which neuropsychiatric symptoms contribute to increased PDD caregiver burden; *N* = 48 caregivers
Thaipisuttikul et al. (2013), USA Capgras syndrome in dementia with Lewy bodies.	Quantitative descriptive; To compare DLB patients with and without Capgras syndrome and assess the potential impact on DLB caregivers. *N* = 55 DLB with Capgras (*n* = 11), 44 without (*n* = 44).
Shin et al. (2012), Korea Caregiver burden in PDD compared to AD in Korea.	Quantitative descriptive; To compare caregiver burden in PDD and AD and examine the predicting factors contributing to carer burden; *N* = 151 Caregivers & people with PDD (*n* = 42) AD (*n* = 109)
Lee et al. (2013), UK Examining carer stress in dementia: the role of subtype diagnosis and neuropsychiatric symptoms.	Quantitative descriptive; To investigate impact of neuropsychiatric symptoms on carer stress between dementia sub-types. *N* = 121 Caregivers PDD (*n* = 32) DLB (*n* = 29) AD (*n* = 30) VaD (*n* = 30)
Leroi et al. (2012), UK Cognitive impairment in PD: Impact on QoL, disability and caregiver burden.	Quantitative descriptive; To compare QoL, Disability and caregiver burden in people with PD, PD-MCI, PDD. *N* = 96 caregivers PDD (*n* = 25) PD-MCI (*n* = 43) PD (*n* = 34)
Stuart and Kenny (2010), UK Parkinson's/Lewy body dementia: a carer's perspective.	Descriptive case report; To highlight the difficulties of diagnosing LBD and discuss examples of good practice; *N* = 1 PDD carer
Galvin et al. (2010a), USA Lewy body dementia: Caregiver burden and unmet need.	Quantitative descriptive survey; To ascertain the unmet needs of LBD caregivers to inform educational and caregiver support; *N* = 962 Caregivers

(Continues)

TABLE 1 (Continued)

Author, Date, Country, Title	Study design, aim, sample
Galvin et al. (2010b), USA Lewy body dementia: The caregivers experience of clinical care.	Quantitative descriptive survey; The aim of the survey was to ascertain the experiences of LBD caregivers and collect data to improve diagnosis and management of LBD; *N* = 962 Caregivers
Leggett et al. (2011), USA Stress and burden among caregivers of patients with Lewy body dementia.	Quantitative descriptive survey; To examine dimensions of subjective burden of caregivers of patients with LBD; *N* = 611 Caregivers LBD
Bostrom et al. (2007), Sweden Patients with dementia with Lewy bodies have more impaired quality of life than patients with AD.	Quantitative cross-sectional study; To compare and investigate determinants of quality of life in patients with DLB and AD. *N* = 68 DLB *n* = 34 matched to AD (*n* = 34) on Gender, Age and MMSE.

Abbreviations: AD, Alzheimer's dementia; DLB, dementia with Lewy bodies; FTD, fronto-temporal dementia; LBD, Lewy body dementia; MMSE, mini mental state examination; PDD, Parkinson's disease dementia; PD-MCI, Parkinson's disease-mild cognitive impairment; QoL, quality of life.

4 | RESULTS

In all, 26 papers originated from 20 studies which were conducted in a range of countries including: UK (*n* = 6), USA (*n* = 5), Sweden (*n* = 3), Korea (*n* = 2), Canada (*n* = 1), Japan (*n* = 1), New Zealand (*n* = 1) and Norway (*n* = 1). Among the papers, a total of three were qualitative (Armstrong, Alliance, Taylor, et al., 2019; Larsson et al., 2019; Vatter, McDonald, Stanmore, Clare, McCormick, et al., 2018), 20 quantitative (Armstrong, Alliance, Corsentino, et al., 2019; Boström et al., 2007; Galvin et al., 2010a, 2010b; Jones et al., 2017; Killen et al., 2016; Kurisu et al., 2016; Lee et al., 2013; Leggett et al., 2011; Leroi et al., 2012; Oh et al., 2015; Park et al., 2018; Rigby et al., 2019; Roland & Chappell, 2019; Shin et al., 2012; Svendsboe et al., 2016; Thaipisuttikul et al., 2013; Vatter et al., 2018, 2020; Wu et al., 2018), one mixed-method (McCormick et al., 2019) and two were case studies of personal experience (Londos, 2018; Stuart & Kenny, 2010).

Most of the papers focused on family caregivers (*n* = 20). The main caregiver participants were spouses/ life partners and adult daughters, who were mainly prominent in the online surveys. (Armstrong, Alliance, Taylor, et al., 2019; Galvin et al., 2010a; Killen et al., 2016; Leggett et al., 2011; Rigby et al., 2019). Across all studies, the co-residing rates of the informal carers and the person with Lewy body dementia ranged from 57% to 100%, and most participants were female carers (62%–100%). Totally 3342 carers of people with Lewy body dementia were represented across all studies. However, whilst ten studies included people with Lewy body dementia, the actual level of their contribution was limited, with only one qualitative study exploring in-depth experiences (Larsson et al., 2019).

The papers were initially sub-grouped according to their predominant focus of caregiver burden and coping, quality of life and well-being, diagnosis and clinical care, and information and support needs (Figure 2). Eleven papers focused on caregiver burden and were of a cross-sectional design (Galvin et al., 2010a; Jones et al., 2017; Leggett et al., 2011; Leroi et al., 2012; Oh et al., 2015; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018; Vatter et al., 2020). The Zarit Caregiver Burden Interview (Zarit et al., 1986) was frequently applied with the Neuropsychiatric Inventory (NPI) which showed that the presence of neuropsychiatric symptoms in Lewy body dementia, such as apathy, delusions, hallucinations, agitation, anxiety and depression, were key contributors to caregiver burden and stress (Lee et al., 2013; Oh et al., 2015; Shin et al., 2012; Thaipisuttikul et al., 2013). Neuropsychiatric symptoms together with reduced activities of daily living (ADLs) added to constraints in social life and feelings of isolation for the carers (Galvin et al., 2010a; Leggett et al., 2011; Svendsboe et al., 2016). Uncertainty and fear for the future further adding to the perception of burden, as did reduced resilience, relationship satisfaction and quality of life (Galvin et al., 2010a; Vatter et al., 2020). Frequency of neuropsychiatric symptoms was also influential in adult child caregivers experiences, resulting in higher levels of burden and decreased quality of life compared with spouses (Rigby et al., 2019). Quality-of-life experiences were measured using the EQ-5D (Boström et al., 2007; Shin et al., 2012; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018; Vatter et al., 2020), the Quality of Life-Alzheimer's Disease (Boström et al., 2007; Rigby et al., 2019), QOL Questionnaire for Dementia in relation to depression and burden, (Park et al., 2018; Roland & Chappell, 2019). Quality of life and well-being were generally considered poorer for those with Lewy body dementia compared with other conditions such as Alzheimer's disease (Boström et al., 2007; Kurisu et al., 2016; Park et al., 2018; Roland & Chappell, 2019; Wu et al., 2018).

Experience of diagnosis, clinical care, support and information needs were predominantly represented by online surveys (Armstrong, Alliance, Corsentino, et al., 2019; Galvin et al., 2010b; Killen et al., 2016) qualitative (Armstrong, Alliance, Taylor, et al., 2019; Larsson et al., 2019) and non-empirical papers (Londos, 2018; Stuart & Kenny, 2010). Only one intervention paper was identified. This mixed-methods feasibility study showed that cognitive stimulation therapy was well tolerated for people with Lewy body dementia and their care partners. However, recruitment was initially lower than expected reportedly due to apathy, care partner burden, worsening dementia, and other health issues (McCormick et al., 2019).

As shown in Figure 2, four themes were identified in this review: 1. living with an uncertain diagnosis and prognosis, 2. fear of the now – worry for the future, 3. living with behavioural and psychiatric

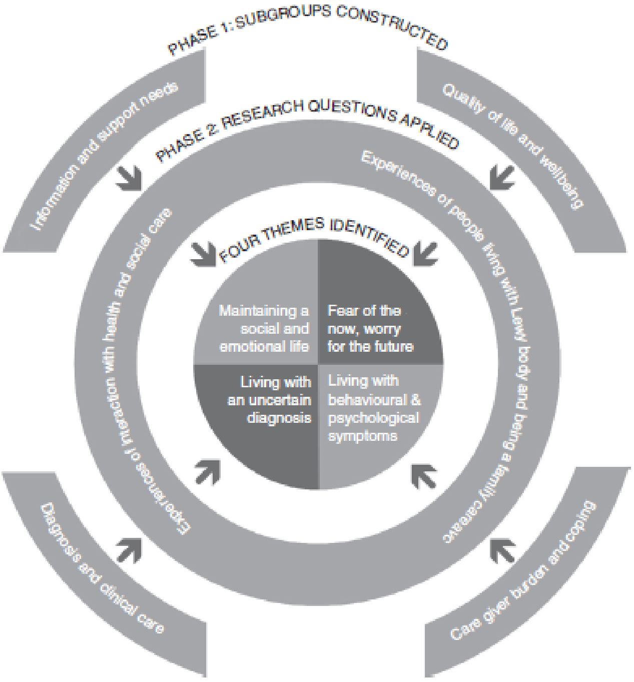


FIGURE 2 Display of findings - the experiences of people living with Lewy body dementia and their family carers

symptoms and 4. maintaining a social and emotional life. The research questions applied in phase 2 (see Figure 2) pertain to the experiences of interactions with health and social care; and the experiences of people living with Lewy body dementia and being a family carer.

4.1 | *Theme 1*: Living with an uncertain diagnosis and prognosis

Difficulty gaining a diagnosis and differing interactions with healthcare professionals were common experiences, and the theme 'living with an uncertain diagnosis and prognosis' was informed by quantitative and qualitative papers. People with Lewy body dementia and carers experienced living with an uncertain diagnosis, sometimes for many years (Galvin et al., 2010a; Killen et al., 2016; Londos, 2018; Stuart & Kenny, 2010). Many saw multiple doctors and a large percentage of people (78%) were diagnosed with other conditions initially, such as Alzheimer's disease, parkinsonism, other dementias and psychiatric diagnosis (Galvin et al., 2010b). Once diagnosed, there were still difficulties finding a doctor who was knowledgeable about treating Lewy body dementia and gaining support (Galvin et al., 2010b; Killen et al., 2016). Caregivers of people with Lewy body dementia were often frustrated by their experiences with physicians about disease course and prognosis, available community resources, referrals to appropriate services and difficulty coordinating care across healthcare professionals (Armstrong, Alliance, Corsentino, et al., 2019; Armstrong, Alliance, Taylor, et al., 2019; Galvin et al., 2010b; Stuart & Kenny, 2010). Physicians rarely discussed what to expect at the end of life. Although death was usually expected, fewer than half of caregivers felt prepared (Armstrong, Alliance, Corsentino, et al., 2019). Follow-up interviews with 30 family caregivers showed 'not knowing what to expect' including aspects such as symptoms, deterioration after hospitalization and falls and unpredictable end-of-life trajectory particularly challenging (Armstrong, Alliance, Taylor, et al., 2019).

People with Lewy body dementias and carers also report the importance of establishing a collaboration between themselves and healthcare professionals and regular reviews and the need for teams to work 'in harmony' (Larsson et al., 2019; Londos, 2018; Stuart & Kenny, 2010). There was evidence of positive interactions – when regular communication and follow-up resulted in a trusting and respectful relationship between people with Lewy body dementia and professionals (Larsson et al., 2019; Londos, 2018; McCormick et al., 2019). This was shown to be important at the end of life, where families who had been involved in advanced care planning discussions with professionals felt better prepared, despite the unpredictability of the condition (Armstrong, Alliance, Taylor, et al., 2019).

4.2 | *Theme 2*: Fear of the now – worry for the future

Fear and anxiety featured strongly in the quantitative questionnaires and people with Lewy body dementia and carer narratives (Larsson et al., 2019; Londos, 2018; Stuart & Kenny, 2010; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018). In the web-based surveys, the most frequent burden items reported by Lewy body dementia caregivers were fear or 'concerns' for the future for their loved ones (Galvin et al., 2010a), with feelings of fear and uncertainty frequently highlighted around the ability to provide care and caregiver performance (Galvin et al., 2010b; Rigby et al., 2019). The qualitative research of Parkinson's disease dementia spouses spoke of negative feelings such as guilt, distress and fear of the progression of the disease, in addition to worrying about the future if they were unable to provide care for their partners (Vatter, McDonald, Stanmore, Clare, McCormick, et al., 2018). People with Lewy body dementia perspectives, although limited, highlighted a range of emotional responses to living with Lewy body – fear of hallucinations, fear of falls and frightening nightmares as a result of REM sleep disorder (Larsson et al., 2019) and being scared of the effects of tiredness, and fatigue (Londos, 2018). The symptoms of fluctuations, depression, delirium and violence were also expressed as 'frightening' (Stuart & Kenny, 2010).

4.3 | *Theme 3*: Living with behavioural and psychiatric symptoms

The papers highlighted that the presence of neuropsychiatric symptoms was a major contributor for caregiver burden, distress and reduced quality of life in caring for a person with Lewy body dementia (Galvin et al., 2010a; Jones et al., 2017; Kurisu et al., 2016; Lee et al., 2013; Leggett et al., 2011; Leroi et al., 2012; Park et al., 2018; Rigby et al., 2019; Shin et al., 2012; Svendsboe et al., 2016; Thaipisuttikul et al., 2013; Vatter et al., 2020). Caregiver burden was measured using the Zarit Caregiver Burden Interview (Zarit et al., 1986) and frequently applied with the Neuropsychiatric Inventory (NPI) to evaluate correlation. The main symptoms affecting burden and quality of life occurred in the NPI domains of delusions and apathy, hallucinations and psychosis (Boström et al., 2007; Lee et al., 2013; Shin et al., 2012; Svendsboe et al., 2016). People with Lewy body dementia had significantly higher apathy scores, compared with those with Alzheimer's disease (Kurisu et al., 2016; Roland & Chappell, 2019). Apathy was portrayed as a sense of passivity, eventually leading to the withdrawal of social interactions (Larsson et al., 2019), affected quality of life and the ability to measure those experiences (Kurisu et al., 2016). Apathy and depression made it more difficult for people to participate in therapeutic interventions or group support (McCormick et al., 2019). The presence of hallucinations was also frequently reported as particularly stressful for caregivers (Galvin et al., 2010a; Leggett et al., 2011; Londos, 2018; Park et al., 2018; Shin et al., 2012; Svendsboe et al., 2016; Thaipisuttikul et al., 2013). They are also a prominent feature of Capgras syndrome, where people with dementia with Lewy bodies experience the delusion that someone they know well has been replaced by an identical imposter (Thaipisuttikul et al., 2013). Carers felt that they needed most support and information on symptoms such as hallucinations, fluctuations and sleep disorders, as they had a major impact on the family's ability to maintain their caring role and live well (Killen et al., 2016; Londos, 2018; Stuart & Kenny, 2010; Wu et al., 2018).

4.4 | *Theme 4*: Maintaining a social and emotional life

The need to maintain an active social life and acknowledge emotional needs was identified as being important to both people living with Lewy body dementia and their carers (Larsson et al., 2019; Londos, 2018; Park et al., 2018; Stuart & Kenny, 2010; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018; Vatter, McDonald, Stanmore, Clare, McCormick, et al., 2018; Vatter et al., 2020). However, it was notable from the reviewed papers how little formal paid care was being received (Galvin et al., 2010b; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018) and the resulting difficulties this had on maintaining social and emotional interactions. Most were relying on informal support, which was often received from adult children, other family members and friends (Galvin et al., 2010b; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018). People with Lewy body dementia were able to offer insight into the emotional support they had from friends and family, which highlighted the immense amount of physical support that was often required in maintaining those social and supporting relationships (Larsson et al., 2019; Londos, 2018; Stuart & Kenny, 2010). They also described feeling a burden in the wider social context, as they reduce attending social events due to their increasing physical needs (Larsson et al., 2019). Frequently reported burden dimensions included social and psychological constraints, personal strain and interference with personal life (Galvin et al., 2010b; Vatter, McDonald, Stanmore, Clare, & Leroi, 2018), which can lead to relationship dissatisfaction and resentment (Vatter et al., 2020). It was highlighted that carers were creative at building social care networks, (Park et al., 2018) but as disease progresses, carers often had reduced opportunities to develop new social relationships or maintain social interactions. Fluctuating cognition, hallucinations and the physical aspects parkinsonism had a large impact on people's ability to maintain access to social and emotional support. This ultimately resulted in carer burden, loneliness, isolation and reduced quality of life for people living with Lewy body dementia and their caregivers (Boström et al., 2007; Galvin et al., 2010a; Larsson et al., 2019; Leggett et al., 2011; Vatter, McDonald, Stanmore, Clare, McCormick, et al., 2018; Vatter et al., 2020; Wu et al., 2018).

5 | DISCUSSION

Four themes highlighted the experience of living with an uncertain disease trajectory and showed the impact this had on people's lives.

Fear and worry were predominant feelings for both people with Lewy body dementia and family carers, who were also concerned about what the future might hold. The debilitating effects of living with the behavioural and psychiatric symptoms and the importance of maintaining a social life amidst the condition-related changes were also identified as important.

The literature review highlighted that difficult and delayed diagnosis meant that people were not getting the timely support and treatments they needed. It was identified that 78% of people with Lewy body dementias received a different diagnosis initially, usually Alzheimer's disease (Galvin et al., 2010a) and although rates vary in the wider literature, it is considered that approximately 50% are receiving a different or delayed diagnosis (Freer, 2017). The Lewy body Composite Risk Score (Galvin, 2015) and the Lewy body dementia assessment toolkit have been developed to help earlier identification of the disease (O'Brien et al., 2021). This provides specific screening questions to assess whether a patient has any of the core features of the condition (Galvin, 2015; Thomas et al., 2017, 2018). Long delays in diagnosis can lead to people experiencing considerable challenges, struggling to find the support they need. A lack of ongoing support may add to the feelings of fear and uncertainty, which featured prominently for spouses and partners in the review.

Carers showed that their family member's behavioural and psychiatric symptoms, such as delusions, hallucinations and apathy, increased their feelings of burden and decreased their quality of life. People living with Lewy body dementia also documented feelings of anxiety, depression, and apathy, with sleep disorders and hallucinations being particularly disabling. Visual hallucinations are common, unpleasant experiences of Lewy body dementia, often featuring fully formed people, animals and objects. (Mosimann et al., 2006; O'Brien et al., 2020). Many of these symptoms are particularly difficult to treat pharmacologically (Ford & Almeida, 2020; Liu et al., 2019). Neuropsychiatric symptoms should be managed with a non-pharmacological approach when possible; yet, there is limited evidence on non-pharmacological interventions for people with Lewy body dementia (Connors et al., 2018). The presence of neuropsychiatric symptoms are common reasons for hospital admissions (Spears et al., 2019), and have a negative impact on people with Lewy body dementia's ability to participate in therapeutic interventions and social activities (Larsson et al., 2019; McCormick et al., 2019; Wu et al., 2018).

Maintaining a social life and support networks is important for both people living with Lewy body dementia and the family carer. Social support is seen as an interactive process in which emotional, physical or financial help is received from a social network, and is considered important in maintaining the caregiver role (Snyder et al., 2015). Increasing confidence and self-efficacy for carers of people with Lewy body dementia, and optimizing their social support networks are key, as self-efficacy and quality of life are considered important factors when developing carer support services (Crellin et al., 2014). Quality of life for caregivers for those who were struggling with behaviour and cognitive symptoms was seen to improve with informal and formal support (Roland & Chappell, 2019). The need for timely information and support throughout the disease trajectory for those with Lewy body dementia is consistent with the general dementia carer literature (Francis & Hanna, 2020). However, given the disabling effect of neuropsychiatric symptoms, support and information should be tailored for those with Lewy body dementia (Connors et al., 2018; Rigby et al., 2019). Greater understanding of formal services and knowledge of the disease progression can reduce carers' feeling of frustration and isolation, and result in people feeling better prepared (Bressan et al., 2020). However, to address the complex physical, cognitive and psychosocial needs, those with Lewy body dementia may require lifelong tailored support and services (Capouch et al., 2018).

5.1 | Strengths and limitations

The systematic integration of Lewy body dementia papers drawing on quantitative and qualitative results is the main strength of this review. An additional benefit was including a family carer from the PPI group and a second reviewer with experience in family carer research in the review process. This provided a balance to the main author's experiences, and reduces any potential bias. However, this integrative review had several limitations relating to methodological issues. Most of the quantitative papers in the review focused on comparing Lewy body dementia with other conditions such as Alzheimer's disease, Parkinson's and fronto-temporal dementia that made it difficult to extract Lewy body-specific data. There was limited literature on the subjective experience, with the focus of the papers being carer burden, and quality of life, often measured against cognitive and physical decline. Due to the limited number of papers and the heterogeneity of population groups, this resulted in difficulties synthesizing the quantitative data. In addition, there were a limited number of papers ranked as medium or above for quality, so all papers were retained for synthesis, even those considered low quality overall. Most studies used a cross-sectional design to examine factors affecting aspects of caregiving and living with Lewy body dementia, which may affect our understanding of changes over time.

5.2 | Implications for future research

This review highlights a need for a wider range of methodologies in understanding living with Lewy body dementia. A large proportion of the reviewed literature focused on family carer experiences, and were mainly limited to quantitative papers, with only a small number of qualitative papers. People with Lewy body dementia were under-represented in this review; therefore, future studies should consider how to best support more people with the diagnosis to take part in research. Most studies used a cross-sectional design to measure factors affecting aspects of caregiving and focused on measuring the quality of life and well-being against physical and cognition decline. However, these research approaches may limit our wider understanding of experiencing the course of this complex condition. Given that experiences may change and fluctuate, there is a need to incorporate a longitudinal approach in future research.

5.3 | Implications for practice

Increased awareness and training on diagnosis, managing symptoms and offering tailored psych-social and educational interventions may be key to offering better support for people with Lewy body dementia and their family carers. The use of guidance, such as the Lewy body assessment toolkit, provides clinical staff with a simple and quick aid for use in busy practice areas to assist in diagnosing the condition. It provides specific screening questions to assess whether people with Lewy body dementia have any of the core features of the condition (Thomas et al., 2017, 2018). Support should also be aimed at improving knowledge of treatments and therapeutic strategies to help manage the balance between cognitive, neuropsychiatric, sleep and motor symptoms (Taylor et al., 2020), and optimize treatments, including those of depression, which can occur concurrently with apathy. Targeting psychosocial interventions and referrals for psychological support for both people with Lewy body dementias and carers should be key service options for Lewy body dementia.

Consideration should be given to the relational aspects of living with Lewy body dementia. It is important to support couples and family relationships, taking into consideration that spouses and adult daughters may be the predominant caregivers. Focusing on quality of life and self-efficacy to improve psychological well-being is considered important when developing carer support services.

6 | CONCLUSION

It is understood that this is the first review to explore the evidence focusing on the lived experience of people with Lewy body dementia and their family carers, with previous reviews examining dementia experience as a homogeneous group (Górska et al., 2017). Most of the papers reviewed had a bio-psycho-social focus and were constructed around comparisons between Lewy body dementia and other diseases, such as such as Alzheimer's and Parkinson's disease without dementia, and tended to examine quantitative measures of burden, quality of life and unmet need. This study highlights the need for further high-quality qualitative research that explores the lived experience for both people with Lewy body dementia and family carers.

Clinically, the reviewed evidence highlighted the difficulty in diagnosing and managing the symptoms of Lewy body dementia, and the challenges family carers face. A lack of knowledge by clinicians about disease trajectory and prognosis can make it particularly difficult to instigate support, management and care for carers and people with Lewy body dementia. The result is that people with Lewy body dementia and their families are rarely prepared with the necessary information, support and resources to live well. It is important to consider how best to tailor support for people with Lewy body dementia and family carers, particularly around behavioural and psychiatric symptoms.

ACKNOWLEDGEMENTS

With grateful thanks to Iliana Rokkou, Manager of the Cambridgeshire and Peterborough NHS Foundation Trust Service User and Carer Research Group, and the members involved with article screening for this review.

AUTHOR CONTRIBUTIONS

AB, CW, YS,TM: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; AB, CW, YS,TM: Involved in drafting the manuscript or revising it critically for important intellectual content; AB, CW, YS,TM: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; AB, CW, YS: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

DATA AVAILABILITY STATEMENT

Author elects to not share data.

PEER REVIEW

The peer review history for this article is available at https://publons.com/publon/10.1111/jan.14932.

ORCID

Allison Bentley https://orcid.org/0000-0001-9673-580X

REFERENCES

Aarsland, D., Zaccai, J., & Brayne, C. (2005). A systematic review of prevalence studies of dementia in Parkinson's disease. *Movement Disorders*, *20*(10), 1255–1263. https://doi.org/10.1002/mds.20527

Allan, L., McKeith, I., Ballard, C., & Kenny, R. A. (2006). The prevalence of autonomic symptoms in dementia and their association with physical activity, activities of daily living and quality of life. *Dementia and Geriatric Cognitive Disorders*, *22*(3), 230–237. https://doi.org/10.1159/000094971

Armstrong, M. J., Alliance, S., Corsentino, P., DeKosky, S. T., & Taylor, A. (2019). Cause of death and end-of-life experiences in individuals with dementia with Lewy bodies. *Journal of the American Geriatrics Society*, *67*(1), 67–73. https://doi.org/10.1111/jgs.15608

Armstrong, M. J., Alliance, S., Taylor, A., Corsentino, P., & Galvin, J. E. (2019). End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former caregivers. *PLoS One*, *14*(5), e0217039. https://doi.org/10.1371/journal.pone.0217039

Babineau, J. (2014). Product review: Covidence (Systematic Review Software). *Journal of the Canadian Health Libraries Association / Journal De L'association Des Bibliothèques De La Santé Du Canada*, *35*(2), 68–71. https://doi.org/10.5596/c14-016

Barker, W. W., Luis, C. A., Kashuba, A., Luis, M., Harwood, D. G., Loewenstein, D., Waters, C., Jimison, P., Shepherd, E., Sevush, S., Graff-Radford, N., Newland, D., Todd, M., Miller, B., Gold, M., Heilman, K., Doty, L., Goodman, I., Robinson, B., … Duara, R. (2002).

Relative frequencies of Alzheimer disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank. *Alzheimer Disease and Associated Disorders*, *16*(4), 203–212. https://doi.org/10.1097/00002093-200210000-00001

Boström, F., Jönsson, L., Minthon, L., & Londos, E. (2007). Patients with dementia with Lewy bodies have more impaired quality of life than patients with Alzheimer disease. *Alzheimer Disease and Associated Disorders*, *21*(2), 150–154. https://doi.org/10.1097/WAD.0b013e318065c4a9

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners (First published)*. SAGE.

Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, *28*(6), 1942–1960. https://doi.org/10.1111/hsc.13048

Capouch, S. D., Farlow, M. R., & Brosch, J. R. (2018). A review of dementia with Lewy bodies' impact, diagnostic criteria and treatment. *Neurology and Therapy*, *7*(2), 249–263. https://doi.org/10.1007/s40120-018-0104-1

Chin, K. S., Teodorczuk, A., & Watson, R. (2019). Dementia with Lewy bodies: Challenges in the diagnosis and management. *Australian & New Zealand Journal of Psychiatry*, *53*(4), 291–303. https://doi.org/10.1177/0004867419835029

Connors, M. H., Quinto, L., McKeith, I., Brodaty, H., Allan, L., Bamford, C., Thomas, A., Taylor, J.-P., & O'Brien, J. T. (2018). Non-pharmacological interventions for Lewy body dementia: A systematic review. *Psychological Medicine*, 48(11), 1749–1758. https://doi.org/10.1017/S0033291717003257

Crellin, N. E., Orrell, M., McDermott, O., & Charlesworth, G. (2014). Self-efficacy and health-related quality of life in family carers of people with dementia: A systematic review. *Aging & Mental Health*, *18*(8), 954–969. https://doi.org/10.1080/13607863.2014.915921

Dubois, B., Burn, D., Goetz, C., Aarsland, D., Brown, R. G., Broe, G. A., Dickson, D., Duyckaerts, C., Cummings, J., Gauthier, S., Korczyn, A., Lees, A., Levy, R., Litvan, I., Mizuno, Y., McKeith, I. G., Olanow, C. W., Poewe, W., Sampaio, C., … Emre, M. (2007). Diagnostic procedures for Parkinson's disease dementia: Recommendations from the movement disorder society task force. *Movement Disorders: Official Journal of the Movement Disorder Society*, *22*(16), 2314–2324. https://doi.org/10.1002/mds.21844

Ford, A., & Almeida, O. P. (2020). Effect of biological treatments on psychotic symptoms in Lewy body disease: A systematic review and META-ANALYSIS of randomized controlled trials. *International Journal of Geriatric Psychiatry*, *35*(10), 1083–1096. https://doi.org/10.1002/gps.5376

Francis, N., & Hanna, P. (2020). Informal carer experiences of UK dementia services—A systematic review. *Journal of Psychiatric and Mental Health Nursing*, jpm.12698, https://doi.org/10.1111/jpm.12698

Freer, J. (2017). UK lags far behind Europe on diagnosis of dementia with Lewy bodies. *BMJ*, j3319, https://doi.org/10.1136/bmj.j3319

Galvin, J. E. (2015). Improving the clinical detection of Lewy body dementia with the Lewy body composite risk score. *Alzheimer's & Dementia (Amsterdam, Netherlands)*, 1(3), 316–324. https://doi.org/10.1016/j.dadm.2015.05.004

Galvin, J. E., Duda, J. E., Kaufer, D. I., Lippa, C. F., Taylor, A., & Zarit, S. H. (2010a). Lewy body dementia: Caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders*, 24(2), 177–181. https://doi.org/10.1097/WAD.0b013e3181c72b5d

Galvin, J. E., Duda, J. E., Kaufer, D. I., Lippa, C. F., Taylor, A., & Zarit, S. H. (2010b). Lewy body dementia: The caregiver experience of clinical care. *Parkinsonism & Related Disorders*, 16(6), 388–392. https://doi.org/10.1016/j.parkreldis.2010.03.007

Górska, S., Forsyth, K., & Maciver, D. (2017). Living with dementia: A meta-synthesis of qualitative research on the lived experience. *The Gerontologist*, gnw195, https://doi.org/10.1093/geront/gnw195

Gough, D. (2007). Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, 22(2), 213–228. https://doi.org/10.1080/02671520701296189

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M.-C., & Vedel, I. (2019). Improving the content validity of the mixed methods appraisal tool: A modified e-Delphi study. *Journal of Clinical Epidemiology*, *111*, 49–59.e1. https://doi.org/10.1016/j.jclinepi.2019.03.008

Inskip, M., Mavros, Y., Sachdev, P. S., & Fiatarone Singh, M. A. (2016). Exercise for individuals with Lewy body dementia: A systematic review. *PLoS One*, 11(6), e0156520. https://doi.org/10.1371/journal.pone.0156520

Jones, A. J., Kuijer, R. G., Livingston, L., Myall, D., Horne, K., MacAskill, M., Pitcher, T., Barrett, P. T., Anderson, T. J., & Dalrymple-Alford, J. C. (2017). Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI). *Translational Neurodegeneration*, 6, 17. https://doi.org/10.1186/s40035-017-0085-5

Kane, J. P. M., Surendranathan, A., Bentley, A., Barker, S. A. H., Taylor, J.-P., Thomas, A. J., Allan, L. M., McNally, R. J., James, P. W., McKeith, I. G., Burn, D. J., & O'Brien, J. T. (2018). Clinical prevalence of Lewy body dementia. *Alzheimer's Research & Therapy*, 10(1), 19. https://doi.org/10.1186/s13195-018-0350-6

Killen, A., Flynn, D., De Brún, A., O'Brien, N., O'Brien, J., Thomas, A. J., McKeith, I., & Taylor, J.-P. (2016). Support and information needs following a diagnosis of dementia with Lewy bodies. *International Psychogeriatrics*, 28(03), 495–501. https://doi.org/10.1017/S1041610215001362

Knafl, K., & Whittemore, R. (2017). Top 10 tips for undertaking synthesis research: Synthesis research. *Research in Nursing & Health*, 40(3), 189–193. https://doi.org/10.1002/nur.21790

Kurisu, K., Terada, S., Oshima, E., Horiuchi, M., Imai, N., Yabe, M., Yokota, O., Ishihara, T., & Yamada, N. (2016). Comparison of QOL between patients with different degenerative dementias, focusing especially on positive and negative affect. *International Psychogeriatrics*, 28(8), 1355–1361. https://doi.org/10.1017/S1041610216000491

Larsson, V., Holmbom-Larsen, A., Torisson, G., Strandberg, E. L., & Londos, E. (2019). Living with dementia with Lewy bodies: An interpretative phenomenological analysis. *British Medical Journal Open*, 9(1), e024983. https://doi.org/10.1136/bmjopen-2018-024983

Lee, D. R., McKeith, I., Mosimann, U., Ghosh-Nodyal, A., Thomas, A. J., Lee, D. R., McKeith, I., Mosimann, U., Ghosh-Nodyal, A., & Thomas, A. J. (2013). Examining carer stress in dementia: The role of subtype diagnosis and neuropsychiatric symptoms. *International Journal of Geriatric Psychiatry*, 28(2), 135–141. https://doi.org/10.1002/gps.3799

Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist*, *51*(1), 76–85. https://doi.org/10.1093/geront/gnq055

Leroi, I., McDonald, K., Pantula, H., & Harbishettar, V. (2012). Cognitive impairment in Parkinson disease: Impact on quality of life, disability, and caregiver burden. *Journal of Geriatric Psychiatry and Neurology*, 25(4), 208–214. https://doi.org/10.1177/0891988712464823

Liu, J., Cooper, C. A., Weintraub, D., & Dahodwala, N. (2019). Pharmacological treatment of apathy in Lewy body disorders: A systematic review. *Parkinsonism & Related Disorders*, *60*, 14–24. https://doi.org/10.1016/j.parkreldis.2018.11.002

Londos, E. (2018). Practical treatment of Lewy body disease in the clinic: Patient and physician perspectives. *Neurology and Therapy*, *7*(1), 13–22. https://doi.org/10.1007/s40120-017-0090-8

McCormick, S. A., Vatter, S., Carter, L.-A., Smith, S. J., Orgeta, V., Poliakoff, E., Silverdale, M. A., Raw, J., Ahearn, D. J., Taylor, C., Rodda, J., Abdel-Ghany, T., Kwapong, B., & Leroi, I. (2019). Parkinson's-adapted cognitive stimulation therapy: Feasibility and acceptability in Lewy body spectrum disorders. *Journal of Neurology*, *266*(7), 1756–1770. https://doi.org/10.1007/s00415-019-09329-6

McKeith, I. G., Boeve, B. F., Dickson, D. W., Halliday, G., Taylor, J.-P., Weintraub, D., Aarsland, D., Galvin, J., Attems, J., Ballard, C. G., Bayston, A., Beach, T. G., Blanc, F., Bohnen, N., Bonanni, L., Bras, J., Brundin, P., Burn, D., Chen-Plotkin, A., … Kosaka, K. (2017). Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. *Neurology*, *89*(1), 88–100. https://doi.org/10.1212/WNL.0000000000004058

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G.; for the PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *BMJ*, *339*(jul21 1), b2535. https://doi.org/10.1136/bmj.b2535

Morrin, H., Fang, T., Servant, D., Aarsland, D., & Rajkumar, A. P. (2018). Systematic review of the efficacy of non-pharmacological interventions in people with Lewy body dementia. *International Psychogeriatrics*, *30*(3), 395–407. https://doi.org/10.1017/S1041610217002010

Mosimann, U. P., Rowan, E. N., Partington, C. E., Collerton, D., Littlewood, E., O'Brien, J. T., Burn, D. J., & McKeith, I. G. (2006). Characteristics of visual hallucinations in parkinson disease dementia and dementia with Lewy bodies. *The American Journal of Geriatric Psychiatry*, *14*(2), 153–160. https://doi.org/10.1097/01.JGP.0000192480.89813.80

Mueller, C., Ballard, C., Corbett, A., & Aarsland, D. (2017). The prognosis of dementia with Lewy bodies. *The Lancet Neurology*, *16*(5), 390–398. https://doi.org/10.1016/S1474-4422(17)30074-1

Noyes, J., Booth, A., Moore, G., Flemming, K., Tunçalp, Ö., & Shakibazadeh, E. (2019). Synthesising quantitative and qualitative evidence to inform guidelines on complex interventions: Clarifying the purposes, designs and outlining some methods. *BMJ Global Health*, 4(Suppl 1), e000893. https://doi.org/10.1136/bmjgh-2018-000893

O'Brien, J. T., McKeith, I. G., Thomas, A. J., Bamford, C., Vale, L., Hill, S., Allan, L., Finch, T., McNally, R., Hayes, L., Surendranathan, A., Kane, J. P. M., Dunn, S., Bentley, A., Barker, S., Mason, J., Burn, D., & Taylor, J. (2021). Introduction of a management toolkit for Lewy body dementia: A pilot cluster-randomized trial. *Movement Disorders*, *36*(1), 143–151. https://doi.org/10.1002/mds.28282

O'Brien, J., Taylor, J. P., Ballard, C., Barker, R. A., Bradley, C., Burns, A., Collerton, D., Dave, S., Dudley, R., Francis, P., Gibbons, A., Harris, K., Lawrence, V., Leroi, I., McKeith, I., Michaelides, M., Naik, C., O'Callaghan, C., Olsen, K., … ffytche, D. (2020). Visual hallucinations in neurological and ophthalmological disease: Pathophysiology and management. *Journal of Neurology, Neurosurgery & Psychiatry*, *91*(5), 512–519. https://doi.org/10.1136/jnnp-2019-322702

Oh, Y.-S., Lee, J. E., Lee, P. H., & Kim, J.-S. (2015). Neuropsychiatric symptoms in Parkinson's disease dementia are associated with increased caregiver burden. *Journal of Movement Disorders*, *8*(1), 26–32. https://doi.org/10.14802/jmd.14019

Park, J., Tolea, M. I., Arcay, V., Lopes, Y., & Galvin, J. E. (2018). Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with Lewy bodies, parkinson's disease dementia, or alzheimer's disease. *Social Work in Mental Health*.

Price, A., Farooq, R., Yuan, J.-M., Menon, V. B., Cardinal, R. N., & O'Brien, J. T. (2017). Mortality in dementia with Lewy bodies compared with Alzheimer's dementia: A retrospective naturalistic cohort study. *British Medical Journal Open*, *7*(11), e017504. https://doi.org/10.1136/bmjopen-2017-017504

Rigby, T., Ashwill, R. T., Johnson, D. K., & Galvin, J. E. (2019). Differences in the experience of caregiving between spouse and adult child caregivers in dementia with Lewy bodies. *Innovation Aging*, *3*(3), igz027. https://doi.org/10.1093/geroni/igz027

Roland, K. P., & Chappell, N. L. (2019). Caregiver experiences across three neurodegenerative diseases: Alzheimer's, parkinson's, and parkinson's with dementia. *Journal of Aging & Health*, *31*(2), 256–279. https://doi.org/10.1177/0898264317729980

Shin, H., Youn, J., Kim, J. S., Lee, J.-Y., & Cho, J. W. (2012). Caregiver burden in parkinson disease with dementia compared to alzheimer disease in korea. *Journal of Geriatric Psychiatry and Neurology*, *25*(4), 222–226. https://doi.org/10.1177/0891988712464819

Snyder, C. M., Fauth, E., Wanzek, J., Piercy, K. W., Norton, M. C., Corcoran, C., Rabins, P. V., Lyketsos, C. G., & Tschanz, J. T. (2015). Dementia caregivers' coping strategies and their relationship to health and well-being: The cache county study. *Aging & Mental Health*, *19*(5), 390–399. https://doi.org/10.1080/13607863.2014.939610

Spears, C. C., Besharat, A., Monari, E. H., Martinez-Ramirez, D., Almeida, L., & Armstrong, M. J. (2019). Causes and outcomes of hospitalization in Lewy body dementia: A retrospective cohort study. *Parkinsonism & Related Disorders*, *64*, 106–111. https://doi.org/10.1016/j.parkreldis.2019.03.014

Stinton, C., McKeith, I., Taylor, J.-P., Lafortune, L., Mioshi, E., Mak, E., Cambridge, V., Mason, J., Thomas, A., & O'Brien, J. T. (2015). Pharmacological management of Lewy body dementia: A systematic review and meta-analysis. *The American Journal of Psychiatry*, *172*(8), 731–742. https://doi.org/10.1176/appi.ajp.2015.14121582

Stuart, J., & Kenny, S. (2010). Parkinson's/Lewy body dementia: A carer's perspective. *Journal of Dementia Care*, *18*(3), 18–19.

Surendranathan, A., Kane, J. P. M., Bentley, A., Barker, S. A. H., Taylor, J.-P., Thomas, A. J., Allan, L. M., McNally, R. J., James, P. W., McKeith, I. G., Burn, D. J., & O'Brien, J. T. (2020). Clinical diagnosis of Lewy body dementia. *Bjpsych Open*, *6*(4), e61. https://doi.org/10.1192/bjo.2020.44

Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A., & Rongve, A. (2016). Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease. *International Journal of Geriatric Psychiatry*, *31*(9), 1075–1083. https://doi.org/10.1002/gps.4433

Tahami Monfared, A. A., Meier, G., Perry, R., & Joe, D. (2019). Burden of disease and current management of dementia with Lewy bodies: A literature review. *Neurology and Therapy*, *8*(2), 289–305. https://doi.org/10.1007/s40120-019-00154-7

Taylor, J.-P., McKeith, I. G., Burn, D. J., Boeve, B. F., Weintraub, D., Bamford, C., Allan, L. M., Thomas, A. J., & O'Brien, J. T. (2020). New evidence on the management of Lewy body dementia. *The Lancet Neurology*, *19*(2), 157–169. https://doi.org/10.1016/S1474-4422(19)30153-X

Thaipisuttikul, P., Lobach, I., Zweig, Y., Gurnani, A., & Galvin, J. E. (2013). Capgras syndrome in Dementia with Lewy Bodies. *International Psychogeriatrics*, *25*(5), 843–849. https://doi.org/10.1017/S1041610212002189

Thomas, A. J., Taylor, J. P., McKeith, I., Bamford, C., Burn, D., Allan, L., & O'Brien, J. (2017). Development of assessment toolkits for improving the diagnosis of the Lewy body dementias: Feasibility study within the DIAMOND Lewy study: Assessment toolkits for Lewy body dementias. *International Journal of Geriatric Psychiatry*, https://doi.org/10.1002/gps.4609

Thomas, A. J., Taylor, J. P., McKeith, I., Bamford, C., Burn, D., Allan, L., & O'Brien, J. (2018). Revision of assessment toolkits for improving the diagnosis of Lewy body dementia: The DIAMOND Lewy study. *International Journal of Geriatric Psychiatry*, *33*(10), 1293–1304. https://doi.org/10.1002/gps.4948

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(1), 181. https://doi.org/10.1186/1471-2288-12-181

Toronto, C. E., & Remington, R. (2020). *A step-by-step guide to conducting an integrative review*. https://doi.org/10.1007/978-3-030-37504-1

Vann Jones, S. A., & O'Brien, J. T. (2014). The prevalence and incidence of dementia with Lewy bodies: A systematic review of population and clinical studies. *Psychological Medicine*, *44*(4), 673–683. https://doi.org/10.1017/S0033291713000494

Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., & Leroi, I. (2018). Multidimensional care burden in Parkinson-related dementia. *Journal of Geriatric Psychiatry and Neurology*, *31*(6), 319–328. https://doi.org/10.1177/0891988718802104

Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., McCormick, S. A., & Leroi, I. (2018). A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age and Ageing*, *47*(4), 604–610. https://doi.org/10.1093/ageing/afy049

Vatter, S., Stanmore, E., Clare, L., McDonald, K. R., McCormick, S. A., & Leroi, I. (2020). Care burden and mental Ill health in spouses of people with parkinson disease dementia and Lewy body dementia. *Journal of Geriatric Psychiatry and Neurology*, *33*(1), 3–14. https://doi.org/10.1177/0891988719853043

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

World Health Organisation (2012). DEMENTIA: A public health priority. https://www.who.int/mental_health/publications/dementia_report_2012/en/

World Health Organisation (2015). Supporting informal caregivers of people living with Dementia. https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_informal_care.pdf

Wu, Y.-T., Clare, L., Hindle, J. V., Nelis, S. M., Martyr, A., & Matthews, F. E. (2018). Dementia subtype and living well: Results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. *BMC Medicine*, *16*(1). https://doi.org/10.1186/s12916-018-1135-2

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, *26*(3), 260–266. https://doi.org/10.1093/geront/26.3.260

Zwakman, M., Verberne, L. M., Kars, M. C., Hooft, L., van Delden, J. J. M., & Spijker, R. (2018). Introducing PALETTE: An iterative method for conducting a literature search for a review in palliative care. *BMC Palliative Care*, *17*(1), 82. https://doi.org/10.1186/s12904-018-0335-z

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Bentley, A., Morgan, T., Salifu, Y., & Walshe, C. (2021). Exploring the experiences of living with Lewy body dementia: An integrative review. *Journal of Advanced Nursing*, 00, 1–14. https://doi.org/10.1111/jan.14932

Appendix 2: Gough's weight of evidence score

A framework for the appraisal of the quality and relevance of evidence.

Gough's Weight of evidence (2007)	Domains of evidence	Notes on the domains of evidence	Evidence Ratings
A framework for the appraisal of the quality and relevance of evidence **'**Weight of evidence is a useful heuristic for considering how to make separate judgements on different generic and review specific criteria' (Gough p.11)	1.Relevance of research design. 2.Study execution. 3.Relevance of the focus/context of evidence.	1. A review specific judgement about the appropriateness of that form of evidence for answering the review question. 2. Generally accepted criteria for evaluating the quality of evidence 3. A review specific judgement about the relevance of the focus of the evidence for the review question.	**Weight of evidence A:** Coherence and integrity of the evidence in its own terms **Weight of evidence B:** Relates to the appropriateness of the study design to the review question. **Weight of evidence C:** Relevance of the evidence for answering review question. **Weight of evidence D:** The above three scores are combined to give the overall 'weight of evidence' as **high/medium/low**

Appendix 3: Quality appraisal of studies with MMAT criteria and Gough's rating

Author(s) year	Category of study design	Aims	Sample size and characteristics	Key findings relevant to review PwLBD	Key findings relevant to review CARER	**Mixed Methods Appraisal Tool (MMAT) v 2018** Methodological quality criteria. Key: Y=Yes N=No Can't tell S1. Are there clear research questions? S2. Do the collected data allow to address the research questions?	**Gough's (2007) Weight of evidence - ratings** **Weight of evidence A:** Coherence and integrity of the evidence in its own terms **Weight of evidence B:** Appropriateness of the study design to the review question. **Weight of evidence C:** Relevance of the evidence for answering review question. **Weight of evidence D:** scores **high/medium/low** are combined to give the overall 'weight of evidence'
Vatter et al. (2020)	Quantitative inferential	To explore and compare levels of mental health, care burden, and relationship satisfaction	*N* =136 LBD caregiving spouses PD-MCI (*n*=37) PDD (*n*=50) DLB (*n*=49) **Same sample as Vatter 2018**	Not assessed in the study.	Spouses of people with PDD and DLB have high rates of burden, stress, relationship dissatisfaction and resentment.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:High Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

Armstrong et al. (2019a)	Quantitative descriptive Internet-based survey via the Lewy Body Dementia Association.	To investigate cause of death and experiences of individuals with DLB and their families at end of life.	*N* = 658 Caregivers DLB (death occurred within previous 5 years) 54% child respondent, 40% partner, 6% other.	Not assessed in the study.	Discussion by physicians as to what to expect at end of life limited and not always helpful. Families didn't feel prepared for what to expect. Deaths were attributed to failure to thrive (65%) pneumonia and swallowing difficulties (23%), co-existing medical conditions and falls (10%).	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A: Medium Weight of evidence B: Medium Weight of evidence C: Medium Weight of evidence D: **Medium**
Armstrong et al. (2019b)	Qualitative	To investigate caregiver-reported End of Life (EOL) experiences of individuals with DLB and their families.	*N* = 30 Caregivers DLB (death occurred within previous 5 years)	Not assessed in the study.	'not knowing what to expect' including aspects such as symptoms, deterioration after hospitalisation and falls, and unpredictable end of life trajectory particularly challenging	Is the qualitative approach appropriate to answer the research question? **Y** Are the qualitative data collection methods adequate to address the research question? **Y** Are the findings adequately derived from the data? Is the interpretation of results sufficiently substantiated by data? **Y**	Weight of evidence A: High Weight of evidence B: High Weight of evidence C:Medium Weight of evidence D: **High**

						Is there coherence between qualitative data sources, collection, analysis and interpretation? **Y**	
Rigby et al. (2019)	Quantitative inferential Internet-based survey via the Lewy Body Dementia Association.	To examine differences in the caregiving experience between spouse and adult child caregivers of DLB	*N=415* Spouse (*n*=255) 87.4% female Adult child (*n*=160) 91.1 % female	Not assessed	Adult child caregivers had more social support and reported lower QoL life than spouse caregivers of DLB. adult child caregivers' QoL was predicted by burden, and that burden was significantly predicted by the frequency of neuropsychiatric symptoms in the care recipient.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A: Medium Weight of evidence B: Medium Weight of evidence C: Medium Weight of evidence D: **Medium**
McCormick et al. (2019)	Mixed methods	To evaluate the feasibility acceptability and tolerability of Cognitive Stimulation	*N* = 76 dyads (quantitative) 11 dyads (qualitative): PD MCI (*n*=6), PDD (*n*=4),D	5 themes: Themes supporting quat findings. Interest New opportunities Mastery Lack of time		Is there an adequate rationale for using a mixed-methods design to address the research question? **Y** Are the different components of the study effectively integrated to answer the research question? **Y**	Weight of evidence A: High Weight of evidence B: Medium Weight of evidence C: Low Weight of evidence D: **Medium**

		Therapy – for PD	LB(*n*=1). MOcA median score 17.5 internvention arm. RCT mixed method - Feasibility Intervention study Semi structured interviews.	Theme refuting quant findings: Challenges in delivering CST.		Are the outputs of the integration of qualitative and quantitative components adequately interpreted? **Y** Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? **Y** Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? **Y**	
Larsson et al. (2019)	Qualitative	To explore the subjective experience of living with dementia with	**5 Males** dementia with Lewy bodies Age range 78-88	Pw DLB described the experience of symptoms. Positive and negative Interactions with	Not assessed in the study.	Is the qualitative approach appropriate to answer the research question? **Y** Are the qualitative data collection methods adequate to address the research question? **Y** Are the findings adequately derived from the data? **Y**	Weight of evidence A:High Weight of evidence B:High Weight of evidence C:Medium Weight of evidence D: **High**

		Lewy bodies. To identify factors influencing disease-experience and well-being.	MMSE 18-29 Mild to moderate.	healthcare professionals can affect self-perception and the disease experience.		Is the interpretation of results sufficiently substantiated by data? **Y** Is there coherence between qualitative data sources, collection, analysis and interpretation? **Y**	
Roland et al. (2019)	Quantitative inferential	To compare QoL experiences of AD, PD, and PDD spouse caregivers, and cluster outcomes that contribute to QoL experiences.	*N* =105 caregivers AD (*n*=41), PD (*n*=43), and PDD (*n*= 21). contacted by posters and flyers	Not assessed in the study.	PDD caregivers cared for more persons with cognitive impairment, Independent ADLs dysfunction, and behavioural problems. They faced greater stressors; were significantly more burdened and depressed, experienced decreased life satisfaction; and were in most need of assistance compared with AD and PD caregiver groups.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A: High Weight of evidence B: High Weight of evidence C: Medium Weight of evidence D: **High**

Londos. (2018)	Non empirical study	To describe the practical consideration in the clinical medical treatment of dementia with Lewy body (DLB) patients.	1 male 82-year-old with DLB, & wife. **Pw DLB & Carer** Memory clinic	Reports on a husband and wife attending regular reviews within a memory clinic. Describes the benefits of timely medication and treatment strategies on quality of Life.	Family carer described difficult experiences around diagnosis. Described how regular reviews helped managing symptom and offered support.	Non-empirical study.	Weight of evidence A:Low Weight of evidence B:Low Weight of evidence C:Medium Weight of evidence D: **Low**
Park et al. (2018)	Quantitative inferential	To examine the relationships among burnout, depressive symptoms, social support and psychological	*N* =604 family members DLB (*n*=453) AD (*n*=78) PDD (*n*=75). Wife 274 Daughter 209 Husband 84	Not assessed in the study.	Having care responsibilities for a person with memory, behavioural problems, own self-efficacy, grief, and tangible, emotional and affectionate support are most likely to affect depressive symptoms. Having self-efficacy improves	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate	Weight of evidence A:Medium Weight of evidence B: Medium Weight of evidence C: Medium Weight of evidence D: **Medium**

		well-being in caregivers of persons with DLB, AD, and PDD.	Son 18 Other relative 19 DLB & PDD Carers Internet-based survey		psychological well-being.	to answer the research question? **Y**	
Vatter et al. (2018a)	Quantitative Descriptive &Inferential	To explore the factor structure of the Zarit Burden Interview in life partners of people with Parkinson's Dementia. To examine relationships among the emerging factors	*N*=136 life partners PD-MCI (*n*=37) PDD (*n*=50) DLB (*n*=49). Zarit, QoL, NPI	Not assessed	Carers experience of burden in living with partner who has PDD. An exploratory factor analysis revealed 5 burden dimensions: Social and psychological constraints, personal strain, interference with personal life, concerns about future & Guilt.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:High Weight of evidence B:Low Weight of evidence C:Medium Weight of evidence D: **Medium**

		and the demographic and clinical features					
Vatter et al.(2018b)	Qualitative	To explore the changes in long-term intimate relationships in Parkinson's-related dementia, as perceived by spouses	*N* = 12 cohabiting female partners. PD-MCI (*n*=4) PDD (*n*=5) DLB (*n*=3). Average age = 69.3 years.	Not assessed	The three key themes identified: Altered relationship: care partner challenges: acceptance and adjustment. Satisfaction with intimate relationships decreased more at the advanced cognitive impairment stage.	Is the qualitative approach appropriate to answer the research question? Are the qualitative data collection methods adequate to address the research question? Are the findings adequately derived from the data? Is the interpretation of results sufficiently substantiated by data? Is there coherence between qualitative data sources, collection, analysis and interpretation?	Weight of evidence A:High Weight of evidence B:High Weight of evidence C:Low Weight of evidence D: **Medium**
Wu et al. (2018)	Quantitative inferential	To investigate the potential impact of dementia subtypes on the capability	*N* = 1283 dyads. PDD (*n*= 43) LBD (*n*=43) AD (*n*=715)	PDD & LBD had strongest impact on living well, compared to other sub-groups.	For carers, those caring for people with PDD and LBD reported lower scores on living well measures than carers of people with AD.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y**	Weight of evidence A:High Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

		to live well for both people with dementia and their carers.	Others (*n*=482) (Spouse/partner 1039 81% family/friend 244 19%)		After adjusting for demographic factors and comorbidity, PDD and LBD continued to have the strongest impact on both people with dementia and their carers.	Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	
Jones et al. (2017)	Quantitative inferential	To examine whether coping strategies can explain variables in caregiver outcomes	*N*= 96 caregivers PDD (*n*=15) PD-MCI (*n*=30) PD (*n*=51) Caregivers of PDD group Average age 66.87 yrs Convenience sample from existing longitud	Not assessed	The use of coping strategies (problem-focused coping, emotion-focused coping, and dysfunctional coping) increased as the patient's cognition worsened.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Low Weight of evidence C:Low Weight of evidence D: **Low**

			inal study				
Killen et al. (2016)	Quantitative descriptive	To explore the information and support needs of people with DLB & Caregiver around the time of diagnosis.	*N* = 125 carers (*n*=122) people with DLB (*n*=3) female: 89%	People with DLB and family members were inadequately supported at diagnosis.	The most highly rated area where respondents felt people should receive information and support was hallucinations (96%). Other issues which were rated highly related to fluctuations and sleep disorders which also have a major impact on carers' ability to maintain their caring role.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**
Kurisu et al. (2016)	Quantitative inferential	The study aims to explore the difference in quality of life between sub-groups AD,FTD, DLB	279 consecutive outpatients with AD (*n*= 231) DLB (*n*= 28) MMSE 20+/-4.4 FTD (*n*= 20)	DLB patients had significantly higher apathy scores. The apathy and depression of DLB patients might affect the	Not assessed	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

				lower positive affect of DLB patients compared to AD patients.		to answer the research question? **Y**	
Svendsboe et al. (2016)	Quantitative inferential	To characterise the differences in caregiver distress between carers of people diagnosed with DLB with AD	*N* = 186 caregivers DLB (*n*= 86) MMSE 23.4+/-3.2 AD (*n*=100) Part of 2 large Norwegian studies (Demvest)	Not assessed	Carers experience moderate-high burden which may translate to a higher level of mental health issues in the early stage of dementia. Neuropsychiatric symptoms and reduced ADL's are key drivers for caregiver burden in caring for a person with DLB.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Low Weight of evidence D: **Medium**
Oh et al. (2015)	Quantitative inferential	To investigate neuropsychiatric symptoms that	*N* = 48 caregivers 48 PDD (28 male,	Both male and female people with PDD show frequent	Carers experience of living with mental and behavioural problems of PDD The domains of delusion,	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? N	Weight of evidence A:Medium Weight of evidence B:Low Weight of evidence C:Low Weight of evidence D: **Low**

		may contribute to increased caregiver burden in PDD patients.	20 female) MMSE 19.8+/-4.0	neuropsychiatric symptoms of anxiety and apathy (70.8%), depression (68.7%), night-time behaviour disorder (58.3%) appetite change (47.9%).	hallucination, agitation and aggression, anxiety, irritability and lability, and aberrant motor behaviour were associated with caregiver stress. Total NPI score was significantly associated with caregiver burden.	Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	
Thaipisuttikul et al. (2013)	Quantitative inferential	To compare DLB patients with and without Capgras syndrome to assess potential impact on DLB caregivers.	*N=55* 11 DLB with Capgras, MMSE 19.7 44 without. MMSE 19.3 Informants: spouses (69%), adult children (24%),	DLB-Capgras patients experienced more visual hallucinations and self-reported anxiety, had higher NPI scores.	DLB carers of those with Capgras had higher caregiver burden than those without.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

			paid caregivers (7%). Mild-moderate Dementia (MMSE & CDR)				
Shin et al. (2012)	Quantitative inferential	To compare caregiver burden in PDD to that in AD and examine the predicting factors contributing to carer burden in PDD.	*N* = 151 Caregivers & people with PDD (*n*=42) AD (*n*=109) Age 60.0 (13.8) Gender (M/F) 16/26 Time with patient (hour/d) 15.3 (8.6)	Not assessed	PDD Carers experience of living with PDD symptoms. Caregiver burden is higher in PDD than in AD, and factors predicting burden are different in AD and PDD. In patients with PDD, the neuropsychiatric problems are the major contributor to caregiver burden.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? Y, but NPI also relevant Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Low Weight of evidence C:Low Weight of evidence D: **Low**

			Cohabitation (%) 80.9				
Lee et al. (2012)	Quantitative inferential	To investigate impact of neuropsychiatric symptoms on carer stress between dementia subtypes	*N* = 121 Caregivers & people with PDD (*n*=32) DLB (*n*=29) AD (*n*=30) VaD (*n*=30) MMSE DLB 15.8 mean, PDD 19.7 mean.	Not assessed	DLB & PDD Carers have more stress than AD and VaD. Psychosis, mood factors from NPI and cognitive fluctuations were associated with carer stress. NPI, Carer distress scale, Dementia Cognitive Fluctuations Scale (DCFS).	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? Y, but NPI also relevant Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Low Weight of evidence C:Medium Weight of evidence D: **Medium**
Leroi et al. (2012)	Quantitative inferential	To compare QoL, Disability and	*N*= 96 caregivers PDD (*n*=25)	Not assessed	The presence of dementia significantly increases caregiver burden and decreases QoL.	Is the sampling strategy relevant to address the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Low Weight of evidence C:Medium Weight of evidence D: **Medium**

		caregiver burden	PD-MCI (*n*=43) PD (*n*=34) PDD MMSE average score 19.36		Disability and dependency increased as cognitive impairment increased.	Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	
Stuart & Kenny (2010)	Non empirical study	To highlight the difficulties of diagnosing dementia with Lewy bodies and offer examples of good practice.	*N*=1 female carer (spouse) - PDD	Not assessed in the study.	Carer experiences of neuropsychiatric symptoms, getting a diagnosis, setting up care packages and the importance of having support from a coordinator of care and the need for emotional support.	Non-empirical study.	Weight of evidence A:Low Weight of evidence B:Low Weight of evidence C:Low Weight of evidence D: **Low**
Galvin et al. (2010a)	Quantitative inferential	To ascertain burden and unmet	*N* = 962 Caregivers mean	Not assessed in the study.	36% reported moderate burden and 38% reported feeling very to extremely burdened on 7 out	Is the sampling strategy relevant to address the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

		needs of LBD caregivers and collect data to inform educational programming and enhance caregiver support.	age 56 years, 88% female Spouse 40.6% Child 51.7% Former Caregiver 21% Cohabiting 46.3% The Lewy Body Dementia Association web-based survey of self-reported LBD caregivers over a 6-month period.		of 11 items measuring burden. The most frequent burden items reported by LBD caregivers were fear of the future for their loved ones (77%), stress between caring for their relative and personal responsibilities (53%), that caregiving has significantly interfered with the caregivers' social life (52%), and uncertainty about what to do (50%). Most respondents were not currently receiving paid help to assist with care.	Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	

Galvin et al. (2010b)	Quantitative inferential	The aim of the survey was to ascertain the experiences of LBD caregivers and collect data to improve diagnosis and management of LBD.	*N* = 962 Caregivers mean age 56 years, 88% female Spouse 40.6% Child 51.7% Former Caregiver 21% Cohabiting 46.3%	Not assessed	Caregivers of patients with LBD are often frustrated by their experiences with physicians regarding disease course/prognosis, available resources and referrals.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**
Leggett et al. (2010)	Quantitative inferential	To examine dimensions of subjective burden of caregivers of patients with LBD	*N=611* LBD caregivers. Internet survey Wife 35.8% Husband 6.2%, daughter,43%, Son 5.5%	Not assessed	Carers living with LBD experience significant perceptions of burden that is increased with behavioural and psychiatric symptoms, impaired activities of daily living, sense of isolation and challenges	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Can't tell**	Weight of evidence A:Medium Weight of evidence B:Medium Weight of evidence C:Medium Weight of evidence D: **Medium**

			other 9.3%		with the diagnostic experience.	Is the statistical analysis appropriate to answer the research question? **Y**	
Bostrom et al. (2007)	Quantitative inferential	To compare quality of life in patients with Dementia with Lewy Bodies and patients with Alzheimer disease. To investigate determinants of QoL in DLB.	*N* = 68 DLB *n*=34 matched to AD (*n*=34) on Gender, Age and MMSE. Primary caregiver to the DLB patients were: spouse (n=20) patient's child (n=11) sibling (n=3).	Patients with DLB had significantly lower QoL than patients with AD regardless of instrument or whether patient or caregiver reported QoL was used.	Found that caregiver-reported QoL was considerably lower than patient-reported QoL for all measurements.	Is the sampling strategy relevant to address the research question? **Y** Is the sample representative of the target population? **Y but small numbers** Are the measurements appropriate? **Y** Is the risk of nonresponse bias low? **Y** Is the statistical analysis appropriate to answer the research question? **Y**	Weight of evidence A: Medium Weight of evidence B: Medium Weight of evidence C: Medium Weight of evidence D: **Medium**

Appendix 4: Summary of included articles

Author, Date, Country, Title	Study design, aim, sample
Vatter et al. (2020), UK Care burden and mental health in spouses of people with PDD and LBD.	Quantitative descriptive. To explore and compare levels of mental health, care burden, and relationship satisfaction. *N* =136 Lewy body dementia caregiving spouses PD-MCI (*n*=37) PDD (*n*=50) DLB (*n*=49)
Armstrong et al. (2019a), USA Cause of death and end-of-life experiences in individuals with DLB.	Quantitative descriptive survey. To investigate cause of death and DLB carer experiences at end of life. *N* = 658 Caregivers DLB (death occurred within previous 5 years)
Armstrong et al. (2019b), USA End-of-life experiences in DLB: Qualitative interviews with former caregivers.	Qualitative: semi structured interviews. To investigate caregiver reported EOL experiences of individuals with DLB and their families. *N* = 30 Caregivers DLB (death occurred within previous 5 years)
Rigby et al. (2019), USA Differences in the experiences of caregiving between spouse and adult child caregivers in DLB.	Quantitative descriptive survey. To examine differences in DLB caregiving experience between spouse and adult children. *N=415* Spouse (*n*=255) child (*n*=160)
McCormick et al. (2019),UK Parkinson's-adapted cognitive stimulation therapy: feasibility and acceptability in Lewy body spectrum disorders.	RCT mixed methods. To evaluate the feasibility, acceptability, and tolerability of Cognitive Stimulation Therapy. *N* = 76 dyads (quantitative) 11 dyads (qualitative): PD MCI (*n*=6), PDD (*n*=4),DLB (*n*=1).
Larsson et al. (2019),Sweden Living with dementia with Lewy bodies: an interpretative phenomenological analysis.	Qualitative research & Interpretive phenomenological approach. To explore the subjective experience, and factors influencing well-being whilst living with DLB. *N* = 5 DLB
Roland et al. (2019), Canada Caregiver Experiences Across Three Neurodegenerative Diseases: AD, PD, and PDD.	Quantitative descriptive survey. To compare QoL experiences of AD, PD, and PDD spouse caregivers. *N* =105 caregivers AD (*n*=41), PD (*n*=43), and PDD (*n*= 21).
Londos, E. (2018),Sweden Practical treatment of Lewy body disease in the clinic: Patient and Physician perspectives.	Descriptive case report. To describe the clinical medical treatment and experience of DLB patient. *N*=2 DLB & Carer
Park et al. (2018), USA Self-efficacy and social support for psychological well-being of family caregivers of care recipients with DLB, PDD, or AD.	Quantitative descriptive survey. To examine the relationships between depressive symptoms, social support, and psychological well-being in caregivers of persons with DLB, AD, and PDD. *N* = 604 family members DLB (*n*=453) AD (*n*=78) PDD (*n*=75).

Vatter et al. (2018a),UK Multidimensional care burden in Parkinson-Related Dementia.	Quantitative descriptive. To explore the factor structure of the Zarit Burden Interview in life partners of people with PDD and examine relationships among the emerging factors and the demographic and clinical features. *N*=136 life partners PD-MCI (*n*=37) PDD (*n*=50) DLB (*n*=49).
Vatter et al. (2018b),UK A qualitative study of female caregiving spouses' experiences of intimate Relationships as cognition declines in Parkinson's disease.	Qualitative research: semi-structured interviews. To explore the changes in long-term intimate relationships in PDD, as perceived by spouses. *N* = 12 cohabiting partners. PD-MCI (*n*=4) PDD (*n*=5) DLB (*n*=3).
Wu et al. (2018), UK Dementia subtypes and living well: results from IDEAL Study.	Quantitative descriptive. To investigate the potential impact of dementia subtypes on the capability to live well for both people with dementia and their carers. *N* = 1283 dyads. PDD (*n*= 43) LBD (*n*=43) AD (*n*=715) Others (*n*=482)
Jones et al. (2017), New Zealand Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI).	Quantitative descriptive. To examine whether coping strategies can explain variables in caregiver outcomes. *N*= 96 caregivers PDD (*n*=15) PD-MCI (*n*=30) PD (*n*=51)
Killen et al. (2016), UK Support and information needs following diagnosis of dementia with Lewy bodies.	Quantitative descriptive survey. To explore the information and support needs of people with DLB & Caregiver around diagnosis. *N* = 125 carers (*n*=122) people with DLB (*n*=3)
Kurisu et al. (2016), Japan Comparison of QoL between patients with different degenerative dementias, focusing especially on positive and negative affect.	Quantitative descriptive. To explore the difference in quality of life between dementia sub-groups *N*= 279 AD (*n*= 231) DLB (*n*= 28) FTD (*n*= 20)
Svendsboe et al. (2016), Norway Caregiver burden in family carers of people with DLB and AD	Quantitative descriptive. To characterise the differences in caregiver distress between DLB with AD carers. *N* = 186 caregivers DLB (*n*= 86) AD (*n*=100)
Oh et al. (2015), Korea Neuropsychiatric symptoms in PDD are associated with increase caregiver burden.	Quantitative descriptive. To investigate which neuropsychiatric symptoms contribute to increased PDD caregiver burden. *N* = 48 caregivers
Thaipisuttikul et al. (2013), USA Capgras syndrome in dementia with Lewy bodies.	Quantitative descriptive. To compare DLB patients with and without Capgras syndrome and assess the potential impact on DLB caregivers. *N=55* DLB with Capgras (*n*=11), 44 without (*n*=44).
Shin et al. (2012), Korea	Quantitative descriptive.

Caregiver burden in PDD compared to AD in Korea.	To compare caregiver burden in PDD and AD and examine the predicting factors contributing to carer burden. *N* = 151 Caregivers & people with PDD (*n*=42) AD (*n*=109)
Lee et al. (2012), UK Examining carer stress in dementia: the role of subtype diagnosis and neuropsychiatric symptoms.	Quantitative descriptive. To investigate impact of neuropsychiatric symptoms on carer stress between dementia subtypes. *N* = 121 Caregivers PDD (*n*=32) DLB (*n*=29) AD (*n*=30) VaD (*n*=30)
Leroi et al. (2012), UK Cognitive impairment in PD: Impact on QoL, disability and caregiver burden.	Quantitative descriptive. To compare QoL, Disability and caregiver burden in people with PD, PD-MCI, PDD. *N*= 96 caregivers PDD (*n*=25) PD-MCI (*n*=43) PD (*n*=34)
Stuart & Kenny. (2010), UK Parkinson's/Lewy body dementia: a carer's perspective.	Descriptive case report. To highlight the difficulties of diagnosing LBD and discuss examples of good practice. *N* = 1 PDD carer
Galvin et al. (2010a), USA Lewy body dementia: Caregiver burden and unmet need.	Quantitative descriptive survey. To ascertain the unmet needs of LBD caregivers to inform educational and caregiver support. *N* = 962 Caregivers
Galvin et al. (2010b), USA Lewy body dementia: The caregivers experience of clinical care.	Quantitative descriptive survey. The aim of the survey was to ascertain the experiences of LBD caregivers and collect data to improve diagnosis and management of LBD. *N* = 962 Caregivers
Leggett et al. (2010), USA Stress and burden among caregivers of patients with Lewy body dementia.	Quantitative descriptive survey. To examine dimensions of subjective burden of caregivers of patients with LBD. *N* = 611 Caregivers LBD
Bostrom et al. (2007),Sweden Patients with dementia with Lewy bodies have more impaired quality of life than patients with AD.	Quantitative cross-sectional study. To compare and investigate determinants of quality of life in patients with DLB and AD. *N* = 68 DLB *n*=34 matched to AD (*n*=34) on Gender, Age and MMSE.

Appendix 5: Qualitative extracts to support themes

Theme	Paper	Quotes
Theme 1: Living with an uncertain diagnosis and prognosis	**Armstrong et al. (2019b)**	*When we first got the diagnosis of DLB*, *it was kind of like here's your diagnosis*. *And at that point*, *we were kind of on our own to figure out what that meant*. (#10, son) *Where I figured out that she was gonna die is from reading all the material I could get*. *But the doctor*, *I don't think*, *ever said she is gonna die*. *And I think that's important for this person to know*. . . *I think the doctor needs to be very specific with the caretaker*. *Now*, *the patient may not wanna hear it*. (#6, husband) *We were told*. . . *three times within the year that she was probably coming to the last few weeks of her life*. *So, we were saying*, *estimating about a month*. *And then she rallied*. (#20,daughter-in-law). *"She stopped eating and I guess over, um, a period of about six or seven days she held on. Didn't eat, didn't drink and slowly, you know, went down. And then did finally, it took a good two or three days where hospice kept saying, "It's gonna be any minute, any," you know. She held on."* (#13, daughter) And so it's, it's very difficult knowing is this the night, is this the day, and you keep asking hospice and they, they, you know, you know, there are certain signs, but no one knows. (#21, wife) Every night, I would think, "Maybe he'll die tonight". And the next night, "Maybe he'll die tonight". And then next night, maybe, so when it actually happened, you know, I didn't really know when it was gonna happen. " Participants reported distress relating to the duration and unpredictability of the dying process and lack of communication that this was to be expected.
	Armstrong et al. (2019a)	Physicians rarely discussed what to expect at the end of life (40% total, but only 22% to a helpful degree) and that the caregiver usually initiated such conversations. Death was usually expected, but fewer than half of respondents felt prepared for what to expect.
	Galvin et al. (2010b)	Caregivers of patients with LBD are often frustrated by their experiences with physicians. **Obtaining a LBD diagnosis often required multiple visits to multiple physicians,** causing

		significant delay in initiation of therapy. Over 40% of caregivers reported that it took more than 18 months to arrive at an LBD diagnosis from the time of the first visit to a physician, regardless of the initial symptom presentation.
	Killen et al. (2016),	This study highlights the lack of information and support provided to people with DLB and their caregivers around the point of diagnosis. Respondents identified the importance of tangible support and information around diagnosis, yet nearly 50% stated they were not offered this.
	Londos. (2018)	Carer: *"I was worried and made an appointment with a doctor for him. The conclusion after the consultation was that he was stressed and 'burned out.' He became worse and worse. On several occasions I had to call 911 because I suspected he suffered a stroke! On his third time at the emergency unit, we met a doctor who took the symptoms seriously and conducted an investigation. After a week at the hospital my husband was discharged with the diagnosis Dementia NOS."*
	Stuart & Kenny (2010)	Looking back on the experience. "*Early signs of disease progression were ignored ("hallucinations dismissed as side effects of the medication"). Symptoms were not picked up by any professionals he saw. Reassured by GP "He did not have Alzheimer's. Eventually "I reached an overburdened social worker on the CMHT and asked for advice"……. "eventually we were very carefully and sensitively* ***given the diagnosis …but it had taken five years".***
***Theme 2*: Fear of the now, worry for the future**	**Vatter et al.(2018b)**	By the time dementia had emerged, the role of spouses had transitioned into that of caregiver accompanied by feelings of frustration, anger, sadness, resentment, **worry for the future** as well as loss of own freedom and independence.
	Galvin et al. (2010a)	The **most frequent burden items reported by LBD caregivers were fear of the future for their loved ones** (77%), stress between caring for their relative and personal responsibilities (53%), that caregiving has significantly interfered with the caregivers' social life (52%),
	Armstrong et al. (2019b)	Fear of dying process*: When it got to that point*, ***there was underlying fear*** *that it wouldn't be it yet*, *and* ***it was a fear because she was really ready to die*** *finally*. (#2, daughter)
	Londos. (2018)	"*But we know that we have to prepare and 'pay' by resting before and after undertaking more unusual activities. When the tiredness hits him, I no longer* ***get scared.*** *I let him rest and have confidence in the experience that he will get better again, and he does".*(carer) *"I used to have a lot of unpleasant dreams, nightmares, but they have disappeared. …..most disturbing symptom for me is the immense tiredness which makes me feel as if my brain is not catching up. But compared to where I could have been—I have gotten my life back!"* (patient)
	Larsson et al. (2019)	Physical changes were highlighted, with accounts of unsteadiness, stiffness, and slowness, sometimes leading to frightening experiences. …..Frightening nightmares were also described,

		as well as difficulties in separating dreams from reality, indicative of REM sleep behaviour disorder. Participants' accounts would indicate subsequent fear of falling, which in turn led to risk behaviours… *"I noticed a difficulty in remembering names…* ***this is what I was most worried about…*** *because it wasn't… well… it was my memory… which is the part of my body that I have been working the most with".* (patient)
	Leggett et al. (2010),	Worry about performance as a carer: "we found worry about performance, a third factor not typically found in ZBI factor analyses, to be endorsed the most strongly by LBD caregivers".
	Stuart & Kenny (2010)	*"Patrick was hospitalised with another bout of urinary tract infection. He became delirious and violent"…came out of hospital with "fluctuating periods of lucidity, depression and at times incontinent. I began to employ night carers to allow myself some rest,* ***but the expense was frightening".*** *"Nights were marked by vivid and violent dreams; he would wander around and sometimes act roughly".*
Theme 3: Living with behavioural and psychiatric symptoms	**Leggett et al. (2010),**	Behaviour and emotional problems most frequently seen in LBD and distinct from other dementias, particularly until later stages of the disease (delusions, depression, sleep disturbances, irritability, and hallucinations), made a major contribution to personal strain, where general BEPs did not.
	Galvin et al. (2010a),	LBD caregivers indicated the LBD patients had high rates of cognitive and behavioral problems. LBD patients had significant difficulties with memory (96%) and judgment (91%); hallucinations (71%) and delusions (63%); depression (70%), anxiety (76%) and apathy (69%).
	Armstrong et al. (2019b)	*"I think the biggest thing was, for us was the rapid decline…… he started having these hallucinations. He was seeing people. He was seeing like, animals and like stuff, but then it started getting a lot—a bit more severe to where he was actually recognizing the people he saw—like people that he didn't really see and weren't really here, you know what I mean?"* (#19, daughter)
	Killen et al. (2016),	The most highly rated area where respondents felt people should receive information and support was hallucinations (96%).
	Lee et al. (2012),	Examining carers of the PDD and DLB (LBD) groups with the AD and VaD (other dementia) groups identified delusions and hallucinations as significantly more stressful for LBD carers than those caring for people with other dementias….. Consistent with caring for people with LBD being more stressful, it was found that psychosis and mood factors from the NPI and cognitive fluctuations were also significantly associated with carer stress total scores.

	Oh et al. (2015)	Neuropsychiatric symptoms are frequent and severe in patients with PDD and are associated with increased caregiver distress. The three most frequent neuropsychiatric symptoms were apathy (70.8%) and anxiety (70.8%), followed by depression (68.7%). More severe neuropsychiatric symptoms were significantly correlated with increased caregiver burden. The domains of delusion, hallucination, agitation and aggression, anxiety, irritability and lability, and aberrant motor behaviour were associated with caregiver stress. After controlling for age and other potential confounding variables, total NPI score was significantly associated with caregiver burden.
	Park et al. (2018)	The severity of the care recipient's behavioural and memory problems predicted the caregiver's depressive symptoms. Behavioural problems, for example, included waking the caregiver at night, engaging in behaviour that is potentially dangerous to self or others, and being verbally aggressive, all of which were associated with caregiver burden and other emotional distress and eventually associated with depressive symptoms.
	Rigby et al. (2019)	Adult child caregivers' quality of life was significantly predicted by burden, and that burden was significantly predicted by the frequency of neuropsychiatric symptoms in the care recipient.
	Roland et al. (2019)	Caregivers managing the greatest symptoms had the greatest negative experiences (burden, depression), irrespective of diagnosis. The clusters *Getting by with support (76% of PDD participants)* and *Struggling* had the greatest symptom presentation, which necessitated greater care hours. Caregivers in the *Getting by* group cared for the greatest problem behaviours and IADL disability, yet the use of formal services and expressive support likely mitigated the negative impact on QoL in this group.
	Londos. (2018)	*"I would never have been able to manage all this without my wife, who takes such good care of me. I used to have a lot of unpleasant dreams, nightmares, but they have disappeared. As have the figures I used to see during daytime. I never see them nowadays".*
	Vatter et al.(2018b)	Despite the fact that cognitive impairment and neuropsychiatric symptoms were difficult to manage, spouses did not renounce their marital vows and exhibited acceptance and resilience towards the situation they were in.
	Kurisu et al. (2016)	DLB patients had significantly higher apathy scores than those of patients with AD. The apathy and depression of DLB patients might affect the lower positive affect of DLB patients compared to AD patients.
	Boström, et al (2007)	DLB patients have significantly lower QoL than the AD patients regardless of whether patient or caregiver reported QoL was used. Apathy and delusions were the only NPI items that were individually significant determinants of QoL in DLB.

	Svendsboe et al. (2016)	Carers experience moderate-high burden which may translate to a higher level of mental health issues. Neuropsychiatric symptoms and reduced ADL’s are key drivers for caregiver burden in caring for a person with DLB.
	Thaipisuttikul et al. (2013)	The presence of Capgras significantly increased caregiver burden and led to the caregiver (typically the object of the delusion) to express more depressive symptoms. Patients reported symptoms of anxiety, which was the single best predictor of Capgras in DLB with a tenfold increased risk.
	Shin et al. (2012)	Neuropsychiatric problems of patients with PDD were the main predictors of Carer Burden. Depressed and motor symptoms are also a predictor of Caregiver burden.
Theme 4: maintaining a social and emotional life.	**Larsson et al. (2019)**	‘Excessive tiredness was profound for some, needing and sometimes debilitating to life with lack of improvement with pharmacological treatment….. For the participants of this study, the primary cognitive culprits were identified to be excessive tiredness, reduced mental speed and passivity, which was described as risk of falling asleep, not following conversations and reduced interest in the social situation. **These cognitive barriers, limiting meaningful interactions, could ultimately result in withdrawal from social settings’.** *“…then people will help me up the stairs… and then the wheelchair is up there… but* ***I want it less and less… I don’t want to go there****… I think it… it causes such hell of a sensation… people needing two living supports to get somewhere…”* (patient). *“I am… unfortunately very lonely […] yes… I had this card playing gang… but* ***I’ve let that go because I can’t hear what they say…*** *I think I told you before… so I can’t give fun replies to jokes […] it passes by… it goes so quickly so that when I have finally come up with what reply I am going to give… then they have already moved on […]* ***I don’t go there anymore […] It is sad… very sad”*** *“It is tiresome for my spouse… as we are…* ***my spouse is locked down as a result… if she need to drive… she doesn’t dare being gone for too long…”*** ‘Social and psychological isolation was expressed and viewed as negative consequences of the illness, with less friends, family or former colleagues reaching out or wanting to remain in contact……. However: Other participants would find or develop new roles. This could involve joining clubs or societies to seek out new acquaintances and resist isolation, or even partake in dementia research, anything where a meaningful role could be found’.
	Londos. (2018)	Carer: … after several months, the solution seemed to be a nursing home. *“But then we managed to get an appointment at the Memory Clinic with a doctor and a nurse. Step by step, the*

		medication was changed, and new drugs were added…. a decline does not necessarily mean a permanent deterioration, but that with rest he will return to his starting position”. Patient: *“Nowadays I can travel alone by airplane and participate in the board meetings of my company, but I have to prepare myself by sleeping almost 2 days and nights before the meeting and at lunch-time during the meeting”.… The most disturbing symptom for me is the immense tiredness which makes me feel as if my brain is not catching up. But compared to where I could have been—I have gotten my life back!’’*
	Galvin et al. (2010a)	The most frequent burden items reported by LBD caregivers were fear of the future for their loved ones (77%), stress between caring for their relative and personal responsibilities (53%), that caregiving has significantly interfered with the caregivers’ social life (52%).
	Jones et al. (2017)	Increased use of all three coping strategies was related to higher burden scores across the whole PD sample. For dysfunctional coping (disengaging from the situation or emotions) these findings are in line with other studies on dementia, and for problem focused coping these findings add to a growing literature suggesting that responding with problem-focused strategies to situations that are beyond one’s control, such as when caring for an individual with a deteriorating illness, may not be effective. For emotion-focused coping, however, these findings are not in line with studies of dementia caregivers showing that emotion focused coping (managing one’s emotional response to stress) was associated with better caregiver outcomes (lower levels of anxiety and depression).
	Park et al. (2018)	Higher levels of emotional support (e.g., someone available to understand a problem and give good advice, receiving suggestions about how to deal with a personal problem) were associated with the likelihood of depressive symptoms. In contrast, affectionate support (e.g., showing love and affection) was associated with lower levels of depressive symptoms.
	Rigby et al. (2019)	Despite social support typically providing a buffer against caregiver burden and depression, resulting in higher quality of life and a greater sense of well-being, adult child caregivers in this study perceived receiving more social support and reported a lower quality of life than spouse caregivers of DLB.
	Vatter et al. (2020)	Over 75% of respondents reported good resilience highlighting that spouses could adapt well to stressful situations and 97.1% reported feeling satisfied with their caring role. Intrapersonal aspects (i.e. own anxiety, depression, quality of life, resilience) as well as interpersonal aspects (i.e. burden, stress, strain, resentment and anger related to care provision) resulted in lower spouses’ mental health. Over half of spouses displayed resentment and low relationship satisfaction, and these were associated with higher burden. Burden (ZBI) significantly correlated

		with stress, strain depression and anxiety, mental health, quality of life, resilience, resentment, and anger.
	Roland et al. (2019),	*Getting by with support:* 76% of all PDD caregivers clustered in *Getting by*, that is, cared for problematic behaviours for the longest duration and utilized lots of formal and expressive support.
	Vatter et al.(2018a)	An exploratory factor analysis revealed 5 burden dimensions: Social and psychological constraints, personal strain, interference with personal life, concerns about future & guilt.
	Vatter et al.(2018b)	Eight spouses reported sleeping in separate bedrooms to their husband due to motor and non-motor symptoms of PD and noted that the level of physical closeness and intimacy with their partner, including hugs, holding hands, caresses, cuddles, and sex, had decreased……. Increased spousal care responsibilities resulted in partners spending more time together but feeling emotionally more distanced. The three themes identified were: altered relationships; care partner challenges; acceptance and adjustment.
	Leroi et al. (2012)	Cognitive impairment alone is not sufficient to impair quality of life, but rather that the impairment must be of sufficient magnitude to impact on the functional ability, which is the differentiating feature between the PD-MCI and the PDD.
	McCormick et al. (2019)	12 weeks of Cognitive stimulation therapy was seen to provide interest, increased motivation and a sense of achievement for people with PDD and DLB. The themes supporting the quantitative findings were: Interest/enjoyment; New opportunities; Mastery; Lack of time/availability.

Appendix 6: Initial patient and public involvement feedback

Initial Advice from established Palliative Care PPI Group on setting up my own group Sept 2017

- Ethics may have guidance how soon participants can be involved in research after bereavement. From a PPI perspective MJ says there is no right/wrong length of time – it's individual and some people really value being able to speak of their experience.
- Always acknowledge about recent loss
- 2-3 people in a group on average works best.
- Open and honest from the start – what it may involve – prompts to need more information
- Don't use the term 'ground RULES' but remind confidential.
- No question or comment silly- always valid
- Don't use term distressing – use 'up-setting' – if upsetting come to talk to us
- Handwritten envelopes more likely to get opened if sending out invitations for research. Blue and yellow best colour on leaflets
- Always offer transport costs and time if possible
- Ensure PPI have induction/ training, so they appreciate what is expected and understand difference between 'support group' and 'advisory group'
- MJ would like to be kept in touch about how we get on.

Dear Allison,

Thank you for your email.

Great to meet you and it was a pleasure to help – not sure I imparted anything you didn't already know, but maybe I helped reinforce ideas.

I feel quite guilty for forgetting the really important issue of funding. You really do need a budget to cover at least travel expenses and to think about payment for time, but also payment for training, which should include funding for attendance at relevant meetings which will serve to inform and train and allow important networking. I know many of us help anyway as we feel passionately about research but respecting a volunteer's expertise and time commitment is important – INVOLVE have guidelines, though I am sure you are aware of the organisation. They have their conference at the end of November this year. It is important that a PPI rep understands the difference between being involved in research and attending a support group. I think I did say that.

The expenses business does nurture respect and value and of course equality in the research process. I know budgets for PhDs may not be enough to cover PPI, but if well thought out and with the acceptance that research relevant to the patient is paramount, a PPI budget in grant applications should be a must. PPI involvement from the beginning, the thinking stage, would feature in grant applications anyway, so it follows that PPI should feature in the budgeting.

Probably speaking to the converted!

Every good wish in your work and I would love to be kept informed of what you do.

PPI Feedback (email) of initial ideas Palliative Care and Lewy Body Dementia 09.10.2017

Is Palliative Care something people with Lewy body and their families are aware of?

Most of my clients don't see LBD as life-limiting, so initially I can't think of any who would consider discussing palliative care.

Would it be acceptable to interview people about what their understanding is – do they access palliative care services – what are their palliative care 'needs' – if any?

If you have individuals and their families who are more enlightened before they are facing imminent end of life. They may well appreciate knowing what their options are when the time comes.

If bereaved relatives wanted to take part, what additional support may they need, and could they be interviewed at any time after they have lost a loved one?

Again, and only in my experience I believe that the most meaningful info from your point of view will be retrospectively from bereaved relative.

I was ready to talk about dads passing after 3 months but that may be too early and too raw for others. I think most people are willing to offer info if they believe it may aid the suffering and sadness of other people going through a similar thing.

In terms of support, it might be helpful to have a volunteer who has themselves been through the experience to offer empathy and support. Our experience of end of life was pretty awful in hospital.

Inhalation pneumonia is the way most of those I knew have passed away including dad. The biggest frustration for us was that it was left to us to point out dads issues at the end, such as choking on saliva, whereupon the offer of a patch to dry up his secretions was made...same with pain.. all reactive rather than proactive which left us feeling guilty and questioning if we had indeed made the right decisions.

Neither the hospital nor the nursing home was in our opinion fit for purpose in allowing dad a dignified and pain-free death. Since then, I have been on end-of-life training courses at the local Hospice. I had no idea what hospices can really offer in terms of support for the family and the individual with an end of life (18 months) prognosis. Respite, holistic therapies, peer support groups, counselling, community care as well as a well-managed death as an inpatient or at home.

I think there is a lot of misunderstanding around hospices especially that they are there for people solely with cancer.

Any other issues you think I should be focusing on?

Honesty soon after diagnosis as to LBD being life-limiting so carer and loved one can come to terms with the reality and plan for the time that remains. Enjoying that time as well as putting affairs in order - registering lasting power of attorney for health and financial matter (and understanding that the attorney is empowered to act in their loved ones best interests if get no longer have capacity, and not to be afraid to speak up if they feel the medical professionals may be missing something or are not listening to the family, making a will, getting an OT involved to make their own home as safe (wet room/ showers stool/ intro of professional care and convenient as possible to have the option of staying at home for a long as possible

An understanding of what to expect towards the end and how to access best care. (Daughter of Father who died with LBD)

PPI Feedback: Face to face meeting 06.02.2018 (11-1pm)

PhD research is looking at palliative care from the point of LBD diagnosis forwards and includes: physical, psychological, social and spiritual needs, to maximise quality of life.

Present:

Allison Bentley
Catherine (research nurse)
Sister to person with LBD
Husband of person with LBD
Wife of person with LBD
Pw LBD and wife

1) **At which stage of your research did this PPI activity take place?**

☒ Initial design ☐Advice on recruitment ☐Dissemination

☐Review of funding application ☒Data collection/interviewing

☐Review of application to ethics ☐Data analysis

2) **Was this feedback useful to you?** YES
3) **If so, how has it made a difference? What have you changed?**

Not necessary to include palliative care terminology – focus on what I'm trying to explore more. Focus on 'living well' with Dementia instead. Consider interviewing people at different time points if time available with PhD – Possibly 3 interviews. Initial, one month later and 6 months later? Consider the 'journey' more. The ideas from the group about asking open questions hugely helpful.

Discussion included:
-what makes a good quality of life?? To focus on only the last few weeks of life is not appropriate.
-power of attorney, at what stage of the disease process is it raised?
-information re practical assistance: e.g. fire detection services, Council Tax reduction
-emphasise role of hospice as revolving door (not just for end of life)
-a 'living well' focus may be more appropriate; may be more empowering, people are asked what they think. Palliative care focus is too passive.

-‘nothing about us without us’
-ask what you can’t do now, what do you miss that you can’t do?
-timing: a journey for all involved
-timeliness: getting in early, continuing engagement of patient and carer
-recognition that need to access support varies and changes due to numerous factors
-how to identify best practice and relate it to what’s already available?
-what are the gaps in need for information?

Example of questions to ask:

- **What was the first time you noticed…?**
- **What did you do?**
- **What do you miss?**
- **What might help you?**
- **Not too many questions, more listening time**

Need to find a lead in with the individual. Questions which suggest empowerment, not neediness. How to capture strengths, not always deficit model. Trying for specifics - what makes xxxx difficult, what makes that easier, what do you do to help yourself when ...

4) **Next steps**

Help preparing participant information leaflets/ consent forms if possible.
Appropriate/sensitive terminology and should I use the terms – Lewy body disease/ or dementia?

5) What will be the next stage of you project?

☐Application for funding ☐Analysis/interpretation ☒Other (please note below)

☐HRA/Ethical approval ☐Preliminary results ___________________

☐Participant recruitment ☐Publication/dissemination

6) When do you anticipate reaching the next stage?

Tuesday 6th March 2018 10.30- 12.30 to look at letter, leaflets, consent forms, poster for advertising study.

Email 13.02.2018

Resulted in considering narrative research, photography and storyboard – life story work to stimulate/aide conversation.

“Some kind of “This is me” collage activity using pictures, words? Might stimulate a dialogue. Would a dialogue and collaboration be possible in the study design? Dialogues/ conversations more than interviews. But of course, time and demands of validity etc make thus so challenging”.

PPI meeting 06.03.2018 10.30-12.30

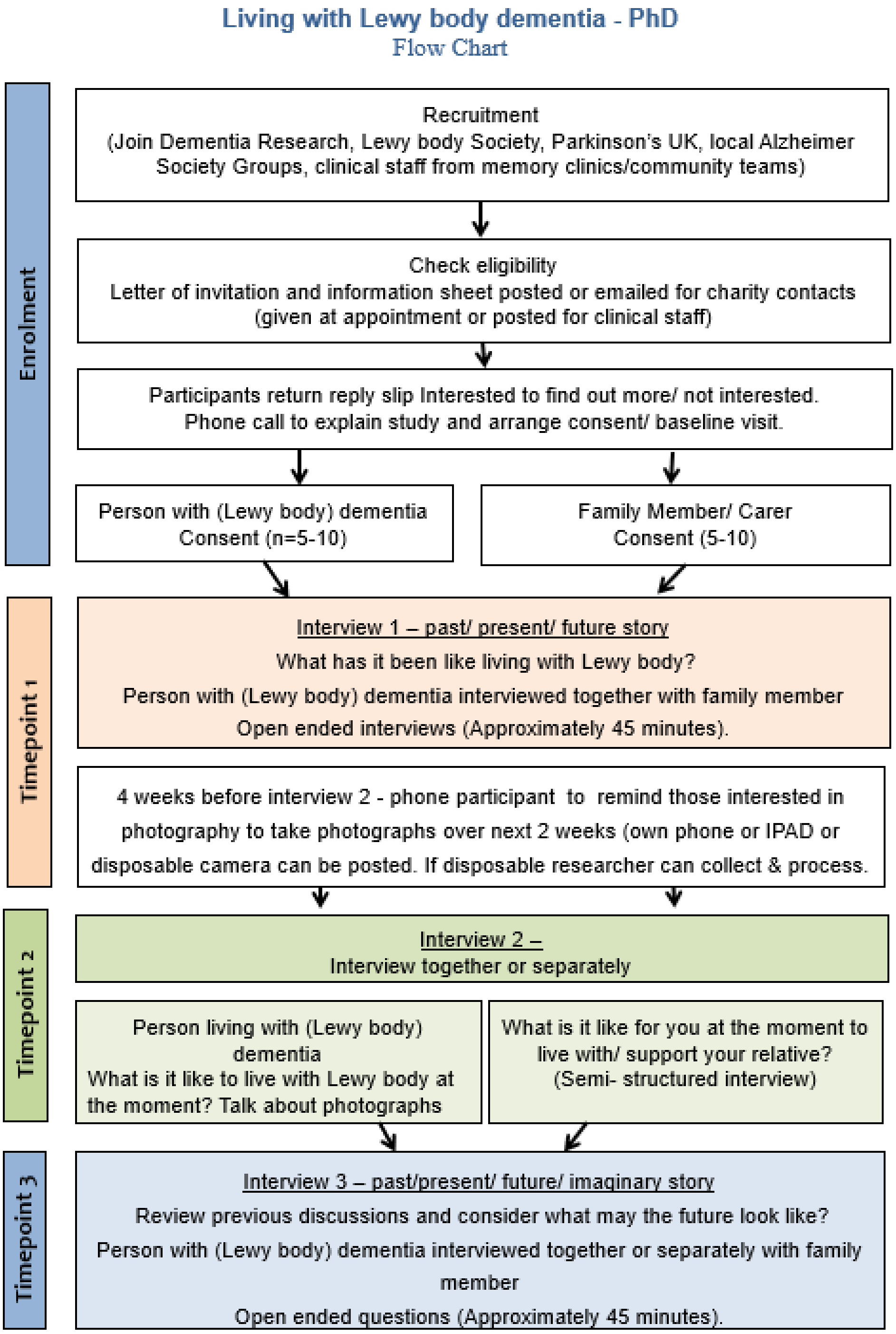
Discussion about when in the stages of LBD will I be accessing people. Straight after diagnosis too early group thought, but keen to include people with advanced dementia as important for palliative care then. Would I select a group from a large sample? According to stages, but some group explain stages not helpful, as we are all different. Difficult with current protocol and aim of research. Group keen for carers to be involved – is it possible to do observational study with more advanced stages? Different ways to engage person with advanced dementia?

1. Carer suggests a relative could sign for the person (consultee form,) as person may be able and willing to participate, but not be able to re-call, process to sign own consent form. I discussed about small boxes and trying to sign name – tiring and difficult for people with PD in hands.
2. Some of the group keen on person with taking photographs, but others less so – they feel it may be too difficult – would need clear instructions about what I would like them to take photos of. I suggested a laminated card with 3 or 4 simple instructions.
3. T not so keen on using a camera - His partner agrees it may be too difficult. However other suggest offer photography, but a range of other arts. Newspaper cuttings, journals, painting – can relate to what would suit the person more.
4. What you enjoy in everyday life, what do you struggle with? What new things are you trying? (Accepting). Can be both positive and negative.
5. Suggest if enough time and budget I could interview a third person – family member such as daughter/son friend. (But considered would that help answer the question – what is it like for them being related to someone with LBD? Or what do they think it's like for others to live with?)
6. Looked at draft 1 of leaflet and some examples. Group felt it does not need to be too simple – as LBD often have good insight and understanding – but plain terminology will be good.
7. Use the term Lewy body dementia – don't be vague about 'memory problems' group suggest as I specifically want people with Lewy body – say so.
8. Change the bullet points around and don't break down into 3 visits – simplify and use less words.
9. Be clear who this information is aimed at. The use of 'you', 'your' refers to the person with LBD, but (name removed) is at the stage where she would not be able to absorb and understand what is being said, but it is relevant to my understanding. To what extent in general do mental and physical symptoms run in parallel? (Name removed) mental capacity had declined very significantly - she is not now able to take the initiative in tackling the emerging problems.
10. As a carer I would have liked to have more of this information at an earlier stage so as to know what to expect.
11. Advice and support from various health professionals is often mentioned but given current resource constraints I'm less that optimistic about the ability to get this in a timely way. (husband and carer for person with DLB)

Email feedback regarding participant facing information APRIL 2018

"It's good to hear you are making progress with the study.
The issues that were raised during the discussions seem to have been resolved and the documents all look fine.
I hope the study goes well and do let me know if I can give any further help".

Appendix 7: Recruitment flow chart



Living with Lewy body dementia - PhD

Flow Chart

Recruitment
(Join Dementia Research, Lewy body Society, Parkinson's UK, local Alzheimer Society Groups, clinical staff from memory clinics/community teams)

Check eligibility
Letter of invitation and information sheet posted or emailed for charity contacts (given at appointment or posted for clinical staff)

Participants return reply slip Interested to find out more/ not interested.
Phone call to explain study and arrange consent/ baseline visit.

Person with (Lewy body) dementia
Consent (n=5-10)

Family Member/ Carer
Consent (5-10)

Interview 1 – past/ present/ future story

What has it been like living with Lewy body?

Person with (Lewy body) dementia interviewed together with family member

Open ended interviews (Approximately 45 minutes).

4 weeks before interview 2 - phone participant to remind those interested in photography to take photographs over next 2 weeks (own phone or IPAD or disposable camera can be posted. If disposable researcher can collect & process.

Interview 2 –
Interview together or separately

Person living with (Lewy body) dementia
What is it like to live with Lewy body at the moment? Talk about photographs

What is it like for you at the moment to live with/ support your relative?
(Semi- structured interview)

Interview 3 – past/present/ future/ imaginary story

Review previous discussions and consider what may the future look like?

Person with (Lewy body) dementia interviewed together or separately with family member

Open ended questions (Approximately 45 minutes).

Appendix 8: Research poster

Are you, or someone you care for, living with with a diagnosis of Lewy body dementia?

Would you be willing to share your views and experiences by taking part in research?

Living with Lewy body dementia: Stories of Everyday Experience is a research study aimed at finding out your experiences of day to day living with Lewy body, so it can inform future nursing practices and care.

Taking part involves three interview lasting about 45 minutes each. They can take place either in your own home, or somewhere else if you would prefer, at a time convenient to you.

The interview would explore:

- Your everyday life experiences of living with Lewy body dementia
- How Lewy body dementia affects your day to day living.
- How you and your family manage.

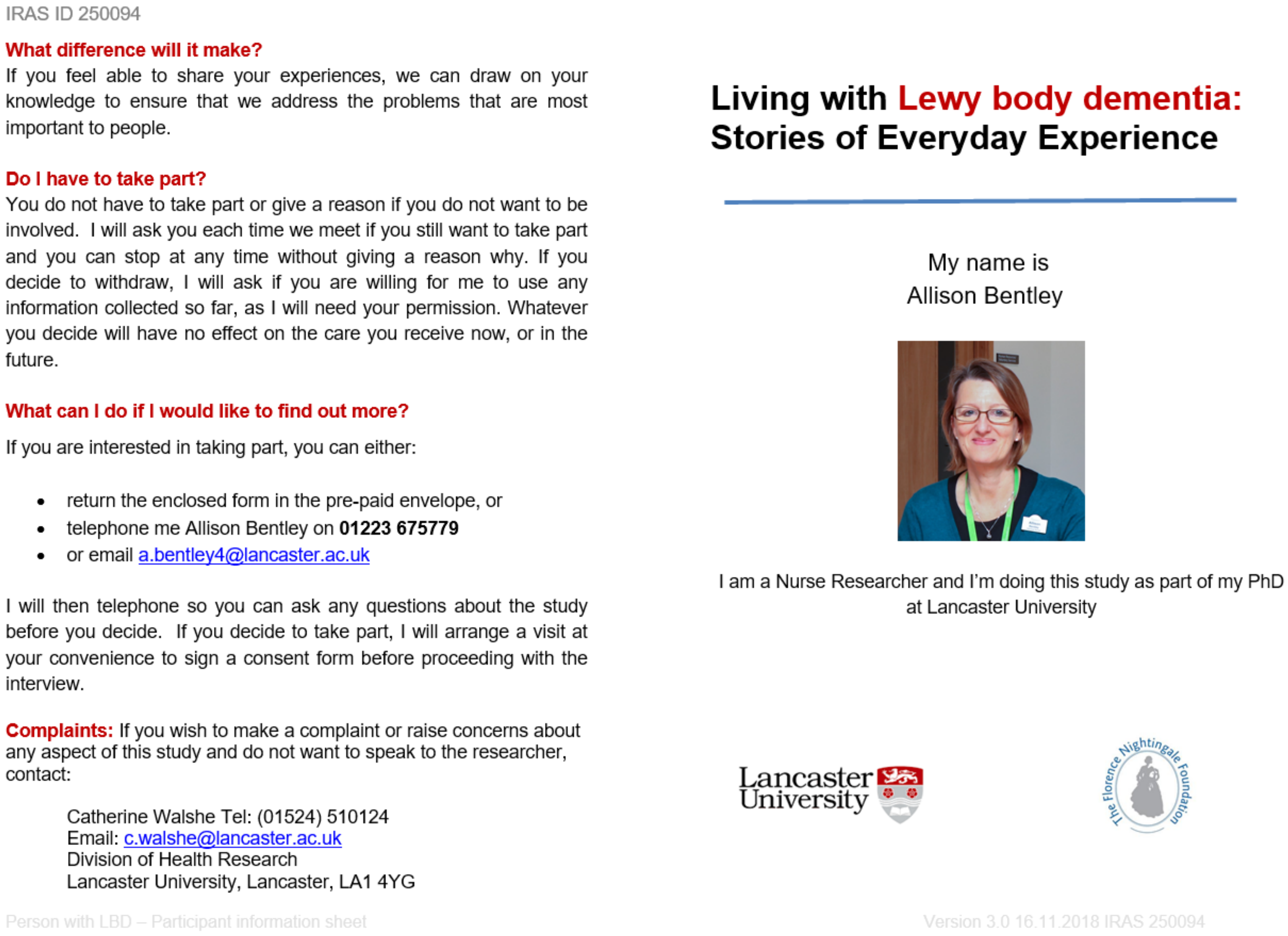
Allison - Nurse Researcher & PhD student
Department of Health Research
Lancaster University

If you would like to be involved, or would like more information call:
Allison Bentley on 01223 767037 or
email: a.bentley4@Lancaster.ac.uk

This study has been awarded funding from a Florence Nightingale Research Scholarship, and Cambridgeshire & Peterborough NHS Foundation Trust. The findings will be used to write a thesis for a PhD at Lancaster University.

VERSION 1.0
30/07/2018
IRAS 250094

Appendix 9: Participant information sheets



IRAS ID 250094

What difference will it make?

If you feel able to share your experiences, we can draw on your knowledge to ensure that we address the problems that are most important to people.

Do I have to take part?

You do not have to take part or give a reason if you do not want to be involved. I will ask you each time we meet if you still want to take part and you can stop at any time without giving a reason why. If you decide to withdraw, I will ask if you are willing for me to use any information collected so far, as I will need your permission. Whatever you decide will have no effect on the care you receive now, or in the future.

What can I do if I would like to find out more?

If you are interested in taking part, you can either:

- return the enclosed form in the pre-paid envelope, or
- telephone me Allison Bentley on **01223 675779**
- or email a.bentley4@lancaster.ac.uk

I will then telephone so you can ask any questions about the study before you decide. If you decide to take part, I will arrange a visit at your convenience to sign a consent form before proceeding with the interview.

Complaints: If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, contact:

Catherine Walshe Tel: (01524) 510124
Email: c.walshe@lancaster.ac.uk
Division of Health Research
Lancaster University, Lancaster, LA1 4YG

Person with LBD – Participant information sheet

Living with Lewy body dementia: Stories of Everyday Experience

My name is
Allison Bentley

I am a Nurse Researcher and I'm doing this study as part of my PhD at Lancaster University

Lancaster University

The Florence Nightingale Foundation

Version 3.0 16.11.2018 IRAS 250094

Why have I been given this leaflet?

You have been given this leaflet because you may have seen a professional about your memory problems and been diagnosed with Lewy body dementia or have volunteered to be considered for research projects.

What is the study about?

- Following a diagnosis of dementia people are often discharged from NHS services, with the result that little is known in detail about how they and their families are affected by their condition.
- Recent government policy and guidelines suggest health and social care professionals should adopt a 'palliative care approach' from the time of diagnosis in conditions such as Lewy body. There is currently not enough information about what this might entail.
- This study addresses these gaps. The approach is to find out about your experiences of day to day living with Lewy body and how it affects you physically, psychologically, socially and spiritually. The aim is for the results to be used to inform future nursing practices and care.

What will happen to the study results?

The findings will be used to write a thesis for a PhD in Palliative Care at Lancaster University and may be shared for publication in professional journals and carers magazines.

What does taking part involve?

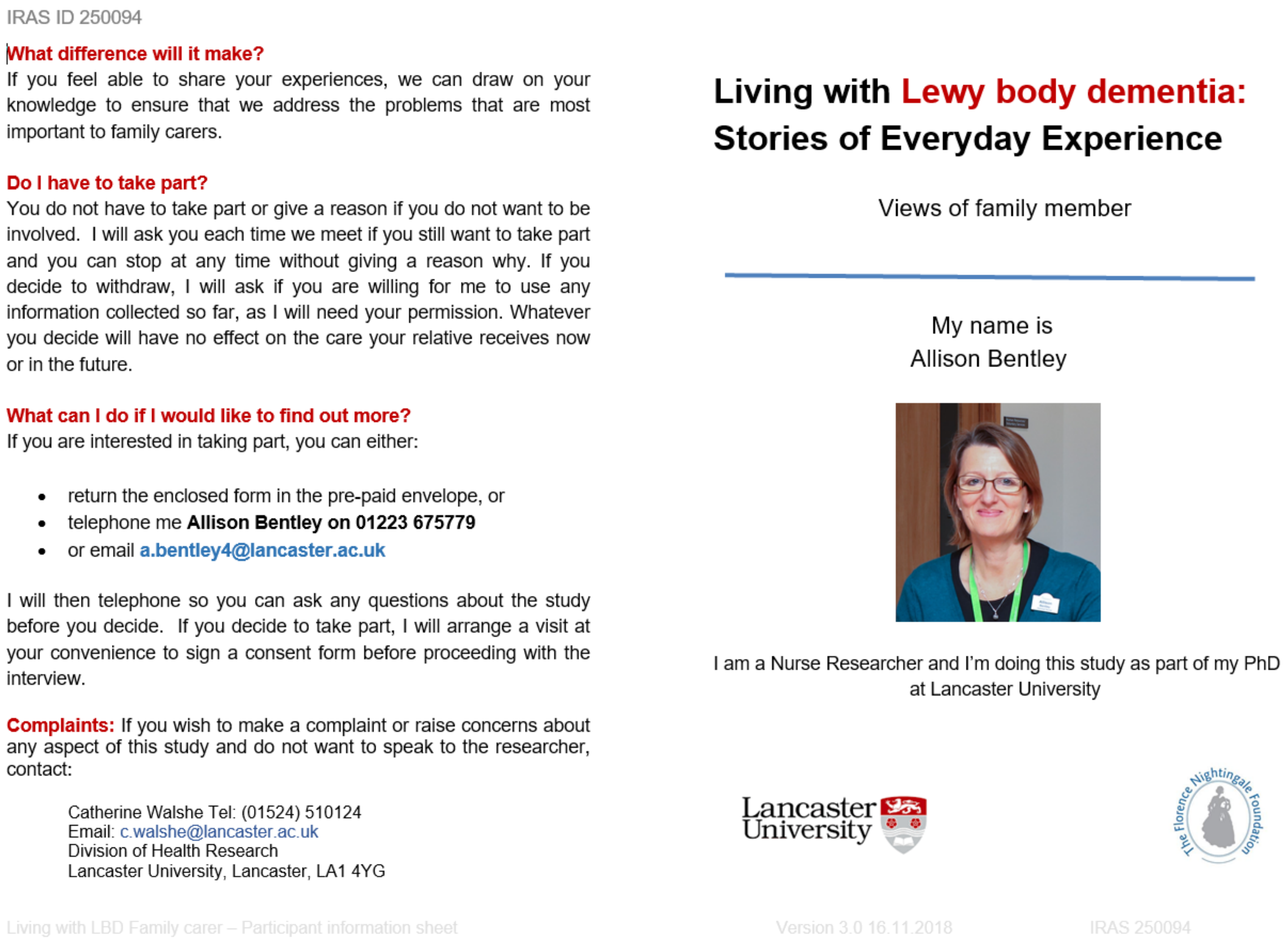
Taking part means I will come and talk to you, and with your permission, someone who knows you well - in your own home at a time convenient to you (or somewhere else if you would prefer). This will involve two to three visits, over six months, each lasting about 45 minutes. You can choose if you would like to be interviewed together with your family member, or alone. With your permission I will use a small audio machine to record the conversation. Before the second interview there will be an optional opportunity to take photographs, to help identify what's important to you. I am really interested to hear your experiences, however, if you find the interviews raise difficulties for you, we can arrange a telephone call where I can provide details of where to find additional advice and support.

Privacy

If you have been sent this leaflet by your health professional, they will keep your personal details confidential and will not pass this information to Lancaster University. They may use your name and address to contact you about the research study, and make sure that relevant information about the study is recorded in your clinical notes. If you agree to take part I will keep your name, address and telephone number until the study is completed, or for up to three years if you would like to be kept in contact about the research findings. Your personal details will be kept separate from your interviews. If your memory changes and you become too unwell to continue I, with your permission I would like to keep the interviews already collected. The study supervisors and Patient & Public Involvement group may analyse selected interviews, once they have been anonymised. Audio recordings will be sent to an external company for transcription, and paper copies will be kept securely in a locked cabinet or password protected computer for 10 years.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your study. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection There are some limits to confidentiality: if you tell me something that I feel may be a serious risk to you, or other people's safety and well-being, I would then need to share this with appropriate professionals or services.

Family member information sheet



IRAS ID 250094

What difference will it make?

If you feel able to share your experiences, we can draw on your knowledge to ensure that we address the problems that are most important to family carers.

Do I have to take part?

You do not have to take part or give a reason if you do not want to be involved. I will ask you each time we meet if you still want to take part and you can stop at any time without giving a reason why. If you decide to withdraw, I will ask if you are willing for me to use any information collected so far, as I will need your permission. Whatever you decide will have no effect on the care your relative receives now or in the future.

What can I do if I would like to find out more?

If you are interested in taking part, you can either:

- return the enclosed form in the pre-paid envelope, or
- telephone me **Allison Bentley on 01223 675779**
- or email **a.bentley4@lancaster.ac.uk**

I will then telephone so you can ask any questions about the study before you decide. If you decide to take part, I will arrange a visit at your convenience to sign a consent form before proceeding with the interview.

Complaints: If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, contact:

Catherine Walshe Tel: (01524) 510124
Email: c.walshe@lancaster.ac.uk
Division of Health Research
Lancaster University, Lancaster, LA1 4YG

Living with Lewy body dementia: Stories of Everyday Experience

Views of family member

My name is
Allison Bentley

I am a Nurse Researcher and I'm doing this study as part of my PhD at Lancaster University

Why have I been given this leaflet?

You have been sent this leaflet because your relative has a diagnosis of Lewy body dementia and may have been seen recently by a local healthcare professional. Alternatively, you or your relative may have responded to a poster on a charity website or be registered with 'Join Dementia Research.' I am interested in your views as a close family member.

What is the study about?

- Following a diagnosis of dementia people are often discharged from NHS services, with the result that little is known in detail about how they and their families are affected by their condition.
- Recent government policy and guidelines suggest health and social care professionals should adopt a 'palliative care approach' from the time of diagnosis in conditions such as Lewy body. There is currently not enough information about what this might entail.
- This study addresses these gaps. The approach is to find out about your experiences as a family member/carer of day to day living with someone who has Lewy body dementia. The aim is for the results to be used to inform future nursing practices and care.

What will happen to the study results?

The findings will be used to write a thesis for a PhD in Palliative Care at Lancaster University and may be shared for publication in professional journals and carers magazines.

What does taking part involve?

This will involve two to three visits, over six months, each lasting about 45 minutes. You can choose if you would like to be interviewed together with your family member, or alone. With your permission I will use a small audio machine to record the conversation. I am really interested to hear your experiences, however, if you find the interviews raise difficulties for you, we can arrange a telephone call where I can provide details of where to find additional advice and support. Before the second visit your relative will be offered the opportunity take photographs to help identify what's important to them, but this is optional.

Privacy

If you have been sent this leaflet by your relative's health professional, they will keep your name, and contact details confidential and will not pass this information to Lancaster University. They may use your name and address to contact you about the research study, and make sure that relevant information about the study is recorded in your clinical notes. The study supervisors and Patient & Public Involvement group may analyse selected interviews. The information will be anonymised, and they will not be able to identify you. Audio recordings will be sent to an external company for transcription, and paper copies will be kept securely in a locked cabinet or password protected computer for 10 years. If you agree to take part I will keep your name, address and telephone number until the study is completed, or for up to three years if you would like to be kept in contact about the research findings. If for some reason you are unable to continue, with your permission I would like to keep the interviews already collected but will remove your identifiable details. If you tell me something that I feel may be a serious risk to you, or other people's safety and well-being, I would then need to share this with appropriate professionals or services.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage www.lancaster.ac.uk/research/data-protection.

Appendix 10: Letter and opt in slip
Date:
Participant's Name and Address:

Dear

Living with Lewy body dementia: Stories of Everyday Experience

I am writing to invite you to help with the above research project. The aim of the study is to explore people's experiences and stories of living with Lewy body dementia. We hope that the research will inform clinical services, for example, by making sure that any physical symptoms are picked up quickly, treated, or referred in the right way. The researcher, Allison Bentley would like to meet to carry out 3 interviews with people living with Lewy body disease and a family member involved with their care. This would take place over a six month period at a time and place convenient to you both. This study has been awarded funding from a Florence Nightingale Research Scholarship, and Cambridgeshire & Peterborough NHS Foundation Trust, and will form part of a PhD thesis.

I am enclosing a leaflet with more information about the study. If you have any questions for the researcher you can contact her by telephone on 01223 767037. Alternatively you can complete and return the reply slip in the pre-paid envelope provided or email Allison at allison.bentley2@nhs.net .

I understand that you may be concerned about privacy and would like to reassure you that all information will be treated in the strictest confidence and all data will be anonymised prior to analysis. Participation in this study is completely up to you. Should you decline to take part, this will not affect any of your relative's care. Even if you do agree to take part, you can always change your mind at a later date without having to give a reason.

Thank you for taking the time to read this letter.

Yours sincerely

Allison Bentley

Living with Lewy body dementia:

Stories of Everyday Experience

Reply form

Please complete and return to let us know if you would like the researcher to contact you to discuss the study and arrange an interview.

Your name:

Patient/ Family member

Phone number:

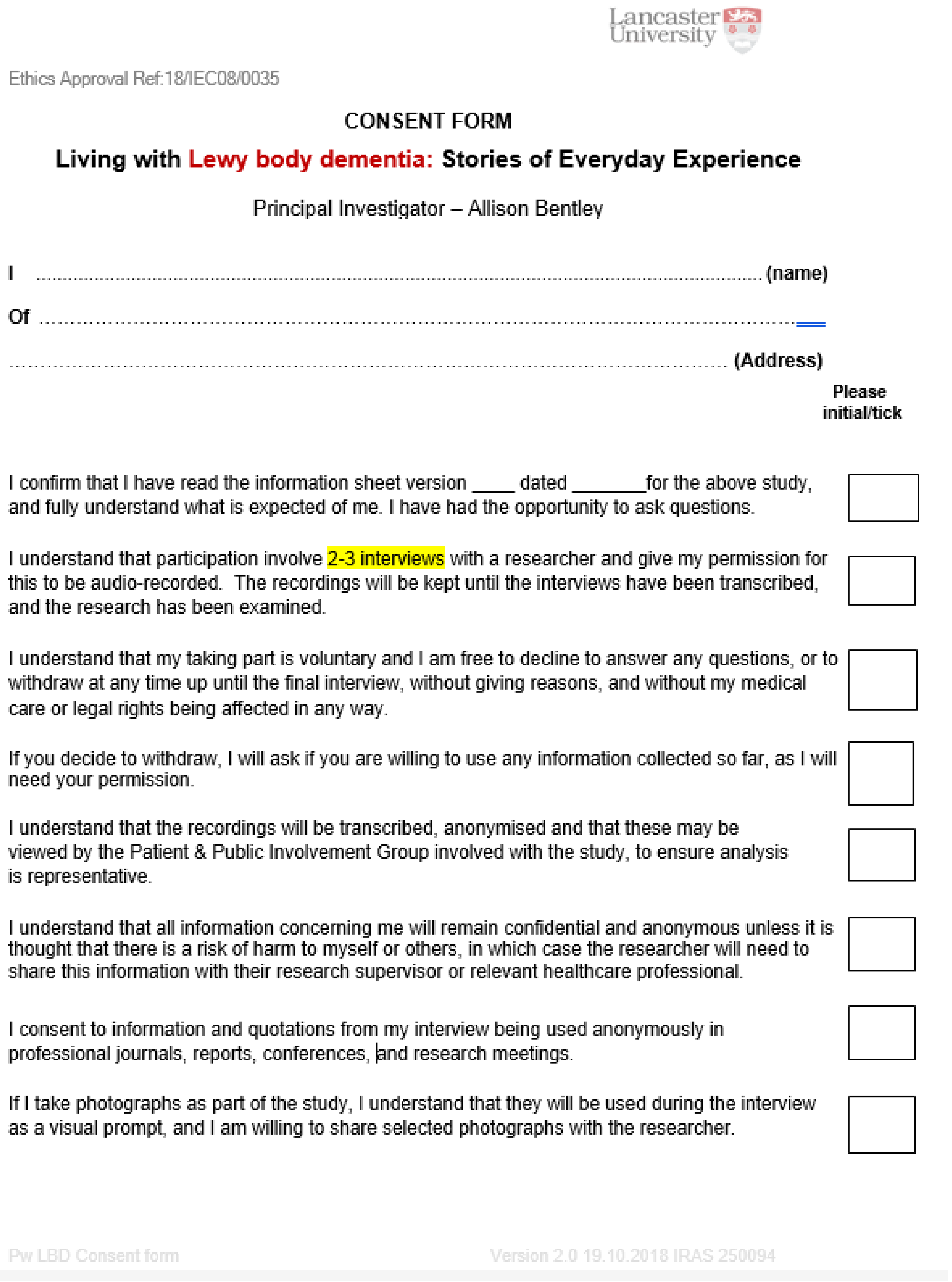
Email address

May I leave a message on your answerphone? **Yes/ No/ Not applicable**

What is the best time to contact you?

Please return in the pre-paid envelope – no stamp required

Appendix 11: Consent forms



Lancaster University

Ethics Approval Ref:18/IEC08/0035

CONSENT FORM

Living with Lewy body dementia: Stories of Everyday Experience

Principal Investigator – Allison Bentley

I .... **(name)**

Of ....

.... **(Address)**

	Please initial/tick
I confirm that I have read the information sheet version ____ dated _______for the above study, and fully understand what is expected of me. I have had the opportunity to ask questions.	☐
I understand that participation involve 2-3 interviews with a researcher and give my permission for this to be audio-recorded. The recordings will be kept until the interviews have been transcribed, and the research has been examined.	☐
I understand that my taking part is voluntary and I am free to decline to answer any questions, or to withdraw at any time up until the final interview, without giving reasons, and without my medical care or legal rights being affected in any way.	☐
If you decide to withdraw, I will ask if you are willing to use any information collected so far, as I will need your permission.	☐
I understand that the recordings will be transcribed, anonymised and that these may be viewed by the Patient & Public Involvement Group involved with the study, to ensure analysis is representative.	☐
I understand that all information concerning me will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share this information with their research supervisor or relevant healthcare professional.	☐
I consent to information and quotations from my interview being used anonymously in professional journals, reports, conferences, and research meetings.	☐
If I take photographs as part of the study, I understand that they will be used during the interview as a visual prompt, and I am willing to share selected photographs with the researcher.	☐

Pw LBD Consent form Version 2.0 19.10.2018 IRAS 250094

I understand that all information concerning me will be stored on a password-protected computer, in an anonymous form and labelled using a unique ID code. The data will not be linked to me personally and my name will be kept confidential to those directly involved in this research project. ☐

I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

I agree to take part in this study. ☐

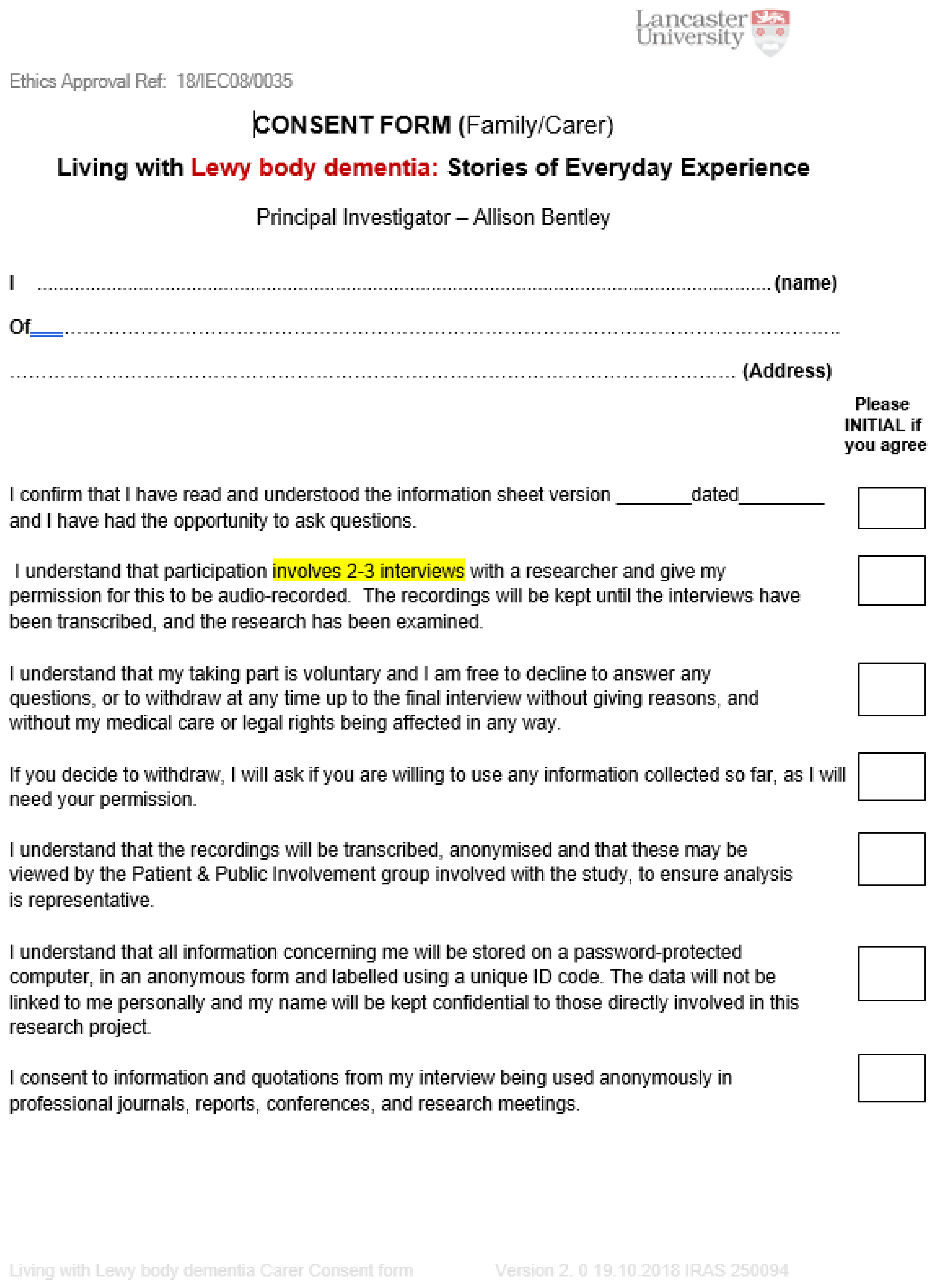
………………………………	………………………………	………………………………
Name of Participant	Signature	Date
………………………………	………………………………	………………………………
Verbal Consent YES/NO	Details of Verbal Consent	Date
………………………………	………………………………	………………………………
Name of Researcher	Signature	Date

If you have any further questions or worries please contact;

Allison Bentley on 01223 ………………………………… or by email a.bentley4@lancaster.ac.uk

PwLBD consent form Version 2.0 19.10.2018 IRAS 250094

Family member consent form



Lancaster University

Ethics Approval Ref: 18/IEC08/0035

CONSENT FORM (Family/Carer)

Living with Lewy body dementia: Stories of Everyday Experience

Principal Investigator – Allison Bentley

I .... **(name)**

Of___...

.... **(Address)**

	Please INITIAL if you agree
I confirm that I have read and understood the information sheet version ________dated_________ and I have had the opportunity to ask questions.	☐
I understand that participation involves 2-3 interviews with a researcher and give my permission for this to be audio-recorded. The recordings will be kept until the interviews have been transcribed, and the research has been examined.	☐
I understand that my taking part is voluntary and I am free to decline to answer any questions, or to withdraw at any time up to the final interview without giving reasons, and without my medical care or legal rights being affected in any way.	☐
If you decide to withdraw, I will ask if you are willing to use any information collected so far, as I will need your permission.	☐
I understand that the recordings will be transcribed, anonymised and that these may be viewed by the Patient & Public Involvement group involved with the study, to ensure analysis is representative.	☐
I understand that all information concerning me will be stored on a password-protected computer, in an anonymous form and labelled using a unique ID code. The data will not be linked to me personally and my name will be kept confidential to those directly involved in this research project.	☐
I consent to information and quotations from my interview being used anonymously in professional journals, reports, conferences, and research meetings.	☐

Living with Lewy body dementia Carer Consent form Version 2. 0 19.10.2018 IRAS 250094

I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

I understand that if I tell you anything that suggests that someone may be at risk, the researcher may be obliged to pass this information on to a relevant health care professional. ☐

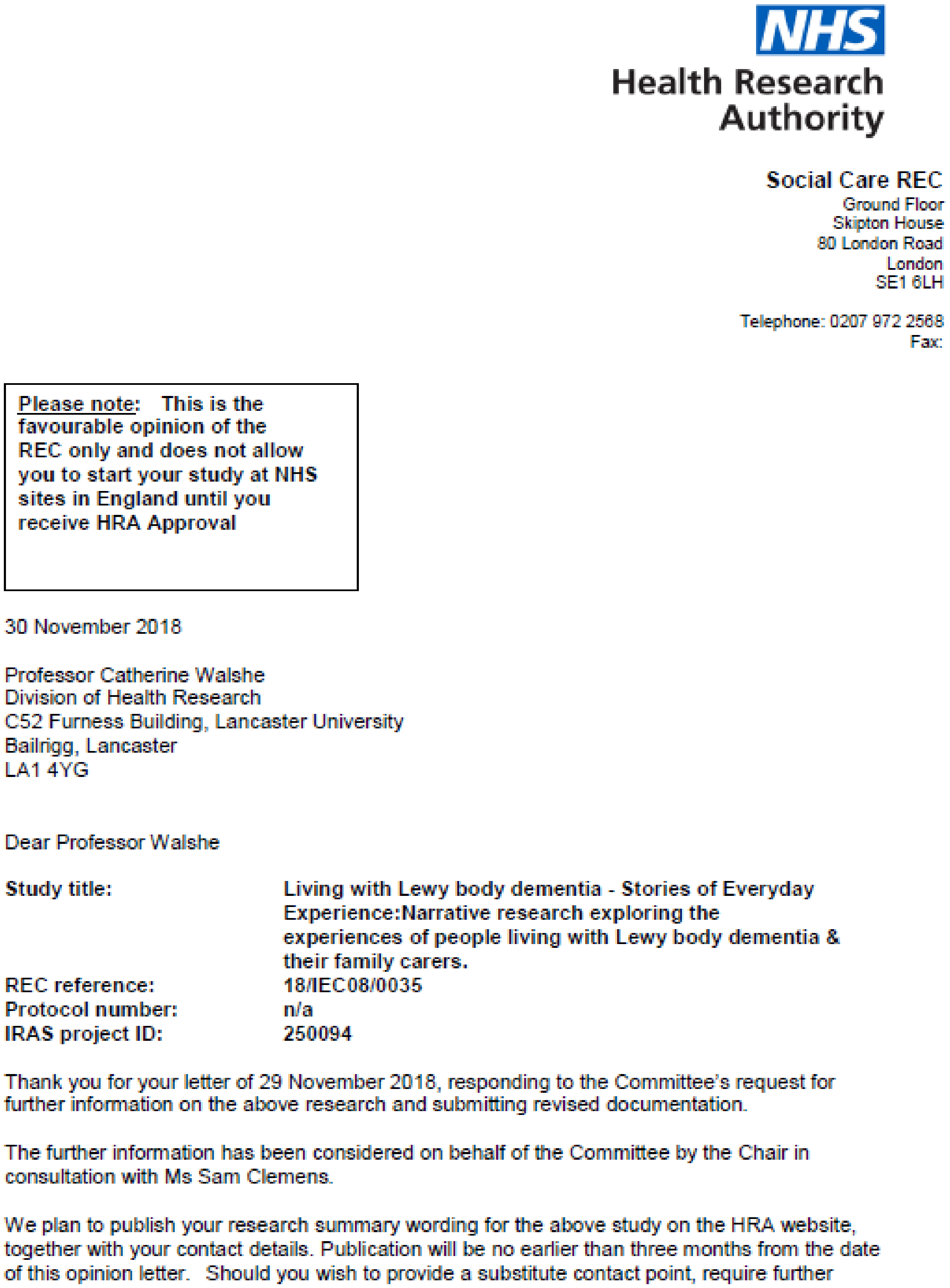
I agree to take part in this study. ☐

....	....	....
Name of Participant	Signature	Date
....	....	....
Name of Researcher	Signature	Date

<u>If you have any further questions or worries please contact;</u>

Allison Bentley on ……………………………………………or by email a.bentley4@lancaster.ac.uk

Appendix 12: Letter of ethical approval



NHS
Health Research
Authority

Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568
Fax:

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

30 November 2018

Professor Catherine Walshe
Division of Health Research
C52 Furness Building, Lancaster University
Bailrigg, Lancaster
LA1 4YG

Dear Professor Walshe

Study title:	**Living with Lewy body dementia - Stories of Everyday Experience:Narrative research exploring the experiences of people living with Lewy body dementia & their family carers.**
REC reference:	**18/IEC08/0035**
Protocol number:	**n/a**
IRAS project ID:	**250094**

Thank you for your letter of 29 November 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with Ms Sam Clemens.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Advice Only – Not Part of the Ethical Decision

It was noted by the reviewers that there were a number of typographical errors on the PISs. They would therefore like to recommend that these documents are proof-read.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Living with Lewy body research poster]	1.0	30 July 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance document]	1.0	19 July 2018
Interview schedules or topic guides for participants [Living with Lewy body - Interview questions]	1.0	20 August 2018
IRAS Application Form [IRAS_Form_20092018]		20 September 2018
Letter from sponsor [Letter from sponsor]	1.0	10 September 2018
Letters of invitation to participant [Living with Lewy body Invitation letter & reply slip]	1.0	20 August 2018
Other [PPI Study feedback]	1.0	15 April 2018
Other [Insurance documents]	1.0	19 July 2018
Other [Insurance document 2]	1.0	19 July 2018
Other [Living with Lewy body dementia - Sources of Advice & Support]	1.0	20 August 2018
Other [CV Second Superivor Katherine Froggatt]	1.0	21 September 2018
Other [Safeguarding protocol]	1.0	18 October 2018
Other [Lone working policy]	1.0	15 July 2017
Other [Response to REC]	1.0	19 November 2018
Participant consent form [PwLBD Consent]	2.0	19 October 2018
Participant consent form [Family carer consent]	2.0	19 October 2018
Participant information sheet (PIS) [Living with Lewy body PwLBD PIS]	3.0	16 November 2018
Participant information sheet (PIS) [Living with lewy body	3.0	16 November 2018

family/Carer PIS]		
Research protocol or project proposal [Living with Lewy body dementia - Stories of everyday experience Protocol]	1.0	20 August 2018
Sample diary card/patient card [Photo diary participant instructions]	1.0	20 August 2018
Summary CV for Chief Investigator (CI) [CV CI v1.0 14.6.18]	1.0	14 June 2018
Summary CV for student [Research CV PhD student]	1.0	20 August 2018
Summary CV for supervisor (student research) [CV 2018 Supervisor C Walshe]	1.0	14 June 2018
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance exclusions]	1.0	19 July 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Living with Lewy body dementia flow diagram]	1.0	20 August 2018

Statement of compliance

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

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

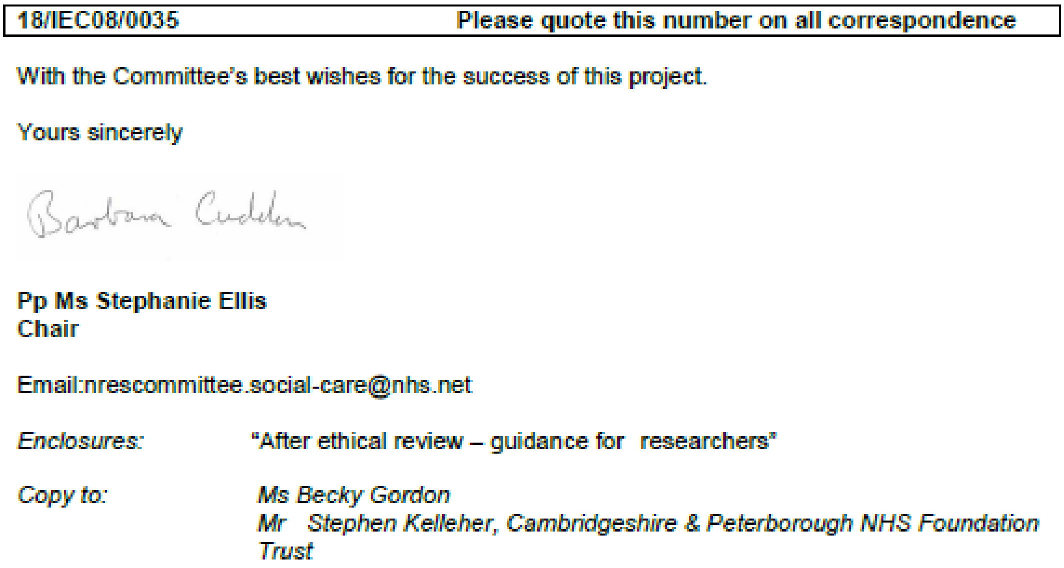
The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/



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

Yours sincerely

Barbara Cudden

Pp Ms Stephanie Ellis
Chair

Email:nrescommittee.social-care@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Becky Gordon*
Mr Stephen Kelleher, Cambridgeshire & Peterborough NHS Foundation Trust

Appendix 13: Interview topic guide

Person with dementia:

1. I want to find out what it's like to live with Lewy body dementia. I know it might not be easy to describe. To get us going – if I ask you what it's like to live with Lewy body dementia, what's the first thing that comes into your mind?
2. Probe answer – then What else comes to mind?
3. Repeat until topic exhausted.
4. What are the main difficulties for you of living well with Lewy body?
5. What gets in the way of doing things you want to do?
6. What helps?
7. Tell me about something you enjoy?
8. Thinking about a nice day out you have had, or a holiday
    a. What made it good
    b. What could have made it better

Family Carer:

1. If I were to ask you what it's like to live with someone who has Lewy body, what's the first thing that comes into your mind?
2. Probe and repeat as above.
3. What is a typical day like for you and your husband/mother/father…/?
4. How much freedom do you have to pursue your own activities and interests?
5. What gets in the way of you doing things you would like to do yourself? The two of you together?
6. What/ who helps make life easier?
7. How have things changed over time?

Appendix 14: Published methods article

Regular Article

International Journal of Qualitative Methods
Volume 20: 1–8
© The Author(s) 2021
DOI: 10.1177/16094069211060653
journals.sagepub.com/home/ijq
SAGE

Applying an Analytical Process to Longitudinal Narrative Interviews With Couples Living and Dying With Lewy Body Dementia

Allison Bentley[1,2], **Yakubu Salifu**[2], **and Catherine Walshe**[2]

Abstract

Narrative research methods invite people to share their experiences via storytelling. There is increasing interest as to how qualitative narrative inquiry can provide greater understanding into the lived experience around health and illness, particularly within the field of dementia. Narrative research is concerned with how humans make sense of and engage with the changes and disruptions of everyday life. However, narrative research is an emerging and evolving field with no single clearly defined approach to data analysis. In this article, we provide a methodological exemplar by applying Murray's four levels of narrative analysis to longitudinal narrative interviews completed with couples living with Lewy body dementia. We describe how to analyse connections between the four levels and how to articulate this across different interview time points. This analysis process contributes to methodological knowledge by providing a strategy to connect the personal, interpersonal, positional and societal levels of analysis. The time taken for in-depth analysis of a co-created, dyadic longitudinal narrative approach requires careful consideration, but ultimately, it can provide a richer understanding of the lived experience, allowing for deeper social, clinical and academic insight.

Keywords

qualitative analysis, dyadic, longitudinal, personal narratives, narrative psychology, Lewy body dementia

Introduction

Narrative research methods invite people to share their experiences via storytelling. This may occur through oral, written or visual accounts (Andrews et al., 2013). There is increasing interest as to how qualitative narrative inquiry can provide greater understanding into people's experiences of health and illness (Wang & Geale, 2015), although this method is less explored within the field of dementia. However, narrative research is an emerging and evolving field with no single, clearly defined approach to data analysis (Meraz et al., 2019). The approach taken is said to depend on researcher perspective, other literature in the field and the underlying theory used to guide the choice of research topic and questions (Woolf & Silver, 2017). These conceptual perspectives and traditions form the framework for the analysis process and provide the foundation to assess the validity of narrative research (Riessman, 2008). This research is set within an interpretivist, phenomenological experience-centred approach.

The aim of this article is to provide an analytical example by applying Murray's (2000) levels of narrative analysis in health psychology to longitudinal narrative data gathered with couples living with Lewy body dementia. Lewy body dementia is a common neurodegenerative dementia which can give rise to an array of physical and cognitive symptoms such as fluctuation attention, visual hallucinations, falls and motor features of Parkinsonism. These complex symptoms can result in particular psychosocial challenges specific to people living with Lewy

---

[1] Cambridgeshire and Peterborough NHS Foundation Trust, Cambridge, UK
[2] Faculty of Health and Medicine, Health Innovation One, Lancaster University, Lancaster, UK

Corresponding Author:
Allison Bentley, Windsor Research Unit, Cambridgeshire and Peterborough NHS Foundation Trust, Fulbourn Hospital, Cambridge CB21 5EF, UK.
Email: allison.bentley@cpft.nhs.uk

body dementia and their families (Killen et al., 2021). Murray's (2000) four analytical levels include the personal, interpersonal, positional and societal (Murray, 2000). We explore how this application can reveal a richer understanding of the lived experience and gain deeper insight into these complex issues. Finally, we discuss how this process addresses the two aspects of validity considered to be important within narrative research: 'The story told by the research participant,' and 'the story told by the researcher' (Riessman, 2008, p. 184).

Living and Dying With Lewy Body Dementia: Demonstrating Narrative Analysis

To demonstrate the analysis process, data are drawn from a PhD project exploring day to day experiences of couples living with Lewy body dementia. Experience-centred approaches acknowledge personal narratives may be fluid, incorporating past, present or future stories, both real and imagined (Squire et al., 2014). Using a longitudinal narrative approach couples were interviewed three times over a six-month period. The qualitative data collection stage consisted of in-depth, open-ended interviewing which was conversational in nature. The stories of one couple are chosen to illustrate the analytical process rather than the overall study results. The study received ethical approval (Social Care Research Ethics Committee: London REC 18/IEC08/0035 November 30, 2018) and names and places have been changed to preserve anonymity. Interviews were audio-recorded and transcribed verbatim for analysis. ATLAS. ti. (version eight) qualitative data analysis software was used to organise and structure the longitudinal narrative data collected (Woolf & Silver, 2017).

To ensure methodological rigour and trustworthiness of the study, longitudinal interviews with the same participants (triangulation of data sources) were collected (Caldwell, 2014). Repeated listening to the audio recordings and re-reading of transcripts allowed for familiarisation of both structure and content of the narrative accounts (Davidsen, 2013). The study data were initially organised into an overarching descriptive narrative for each couple. This helps to get a sense of the whole before going into more detail of the main chapters and stories. This was followed by the application of Murray's (2000) four levels of narrative analysis, which seeks to illuminate the complexity of health and illness narratives by articulating the personal, interpersonal, positional and societal levels at work in stories (Table 1: Murray's four levels and related analytical questions). The final stage involved applying the research questions and connecting the levels to provide more in-depth understanding of the experience of Living with Lewy body dementia.

Developing an Overarching Descriptive Narrative

An overarching narrative in the form of a short descriptive profile was completed. This enables familiarity with the key characters, features and content of the longitudinal interviews (Murray & Sools, 2015). A single coherent narrative also helps 'to preserve the flow of the story as a whole,' and is considered important when the raw data may be disjointed (Bazeley, 2013, p. 115). At the time of the interviews, Joan was in her early seventies and living with Lewy body dementia at home with her husband Peter. They had been married for over 45 years and the final interview was carried out nine months before Joan died (Box 1: Short descriptive profile).

BOX 1: Short Descriptive Profile

Joan, a retired teacher first noticed changes to her mobility about five years previously and was given a diagnosis of Parkinson's which she found "*depressing*". Following a long hospital stay she found herself "*much more dependent on other people,*" especially Peter. Joan had some problems with her memory, and "*started to see children and other people in the garden*" which she said were "*unsettling.*" She was diagnosed with Lewy body dementia. "*Well dementia with Lewy body has been mentioned, Parkinson's with dementia, I don't think anyone's absolutely certain.*" Before the second interview at their home Joan had a fall. This resulted in another hospital admission with a fractured hip and recurrent pneumonia where "*things went from bad to worse.*" Joan's condition deteriorated, and she was discharged home for end of life care with carers four times a day under NHS Continuing Healthcare funding. This resulted in a lot of medical equipment in the house and frequent visits from community staff. Peter found it difficult to adjust his role as husband and carer and what palliative and end of life care meant for them. For the final visit, Joan's physical and mental condition had improved slightly and she was able to re-call some of her hospital admission and talk about the changes and frustrations for her.

Level 1: Identifying Personal Stories

The personal level of analysis narratives closely relates to the phenomenological approach within narrative psychology, where stories are considered to have therapeutic functions, providing shape and order to peoples experiences (Davidsen, 2013). Most commonly this occurs in the reassessment of identity (Frank, 2013) and making sense of the chaos caused by the disruption of illness (Bury, 1982). Within Murray's (2000) approach, stories told by the research participants at the personal level were analysed intact, rather than breaking down into themes. The aim was to ensure the stories remain authentic and 'visible' to aide transparency of the analytical

Table 1. Murray's Four Levels and Related Analytical Questions (adapted from Murray, 2000; Murray & Sools, 2015).

Level	Health and Illness Narratives	Narratives Portrayed as:	Analytical Considerations/Questions
1	Personal	Expressions of the lived experience of the narrator.	What stories are being told? Which particular events are noted? Who are the main characters and sub-characters in the story? Where/what is the setting (physical or psychosocial) for the story? Are there divergent perspectives in dyads experience of same story? Which stories reoccur and change over time? What is the underlying narrative thread of the stories?
2	Interpersonal	A dialogue which is 'co-created' and structured between participants and interviewer.	In what context does the interview take place? How does couple interactions/relationships influence the storytelling? How is it determined which stories fade, or dominate and get told? Is there an indication that the stories are told with an intention to be read or heard? How do the participants articulate which are important stories? Are there messages to be conveyed?
3	Positional	The differences in social position between the narrators and researcher/listener.	Within the interview interaction what roles and social characteristics are known or emerge? How may the characteristics (gender, age, health status, background, role, etc.) of the researcher affect the storyline? How do the interviewers' questions, responses and behaviour influence the story?
4	Societal/ideological level	Shared stories that are shaped by the social context and ideological assumptions within which we live.	How does the social, cultural and historic context influence the stories? What broader societal (or community based) assumptions, (thoughts, practices and language) are evident?
	Connecting the levels	An integration of the 4 different levels of narrative analysis	Is there a connecting underlying narrative woven through each level? What is the narrative thread evident at each level, and what does it represent? What new evidence does it offer?

Table 2. Example Personal Stories: Longitudinal Analysis Matrix (adapted from Grossoehme & Lipstein, 2016).

Story Title	Interview 1	Interview 2	Interview 3
	Narrative Meaning	Narrative Meaning	Narrative Meaning
Healthcare interactions	Advocacy	Frustration	Restrictive, rigid system
Relationship changes	Marital disconnection	Loneliness	Adjusting to being apart
Becoming a carer	Learning through experience	Guilt	Adapting and accepting

process (Riessman, 2008). Dyadic interviewing allowed for prompting, corroboration and modification of the narrative interactions. Conducting three interviews with the same participants over time also allows for clarification of stories and personal interpretation (Caldwell, 2014). Collecting dyadic longitudinal data can support the trustworthiness of the analysis process, and subsequent findings (Bjørnholt & Farstad, 2014). The setting, plot, characters and main event of each storyline were identified and a title was applied to capture the main focus of the story (Murray & Sools, 2015). Within each story the underlying narrative was then identified as 'a means of viewing experiences' (Puplampu et al., 2020, p. 881). Grossoehme and Lipstein's (2016) trajectory approach was applied (Grossoehme & Lipstein, 2016). This was to observe if experiences changed over the three interviews, by applying a time ordered sequential matrix (Table 2: Example personal stories: longitudinal analysis matrix).

The dominant stories for Peter involve his changing relationship from husband to carer and interactions with healthcare professionals. Peter talks about his relationship in terms of being 'divorced' and missing their shared interactions:

> PETER: "*it's again adjusting to our relationship because I said to some people when they'd asked me, it feels like we've in a way been divorced, but not, but still living together, because it's a different feeling between us isn't it, which is not your fault at all..... I miss what we had, a lot [laughter]. I don't think it necessarily has quite the same impact in Joan.*" (Story – Relationship changes: Interview 1).

And the sense of frustration this causes:

> PETER: "*I suppose the other frustrations are um there's nothing from Joan, it's not her fault I know that but she's much more receptive to the carers and things than she is to me....//... I suppose the other things I miss most is just the companionship really, that's hardest because we're not sharing anything in the sense of other than me putting a spoon in her mouth, that's it now really. That's the only actual interaction we've got....*"(Story– Relationship changes: Interview 2).

Peter and Joan also talk of frustration with interactions with the community teams and the situation they find themselves in:

> PETER: "*...part of this healthcare is occupational therapy, and she's quite adamant that she doesn't think it will do Joan any good to move out of the bed at this stage. INTERVIEWER: Did she say in what way? PETER: Because they measured Joan's blood pressure. Now again that was relatively low, although Joan's had low blood pressure for years but I understand they have a protocol. I find it quite annoying that they're not prepared to see how it goes rather than say we can't do it..... Anyway I got angry, ... they said we're not going to be able to move Joan for the foreseeable future, so we're stuck really. But I said well I'm not prepared to accept that long term....So that's frustrating,...*" (Story-Healthcare interactions: Interview 2)

Joan expresses this situation as a loss of independence with the use of metaphors with particular reference to the feeling of being a prisoner, of being kept captive in her hospital bed:

> JOAN: "*I was capable of being able to walk, whereas now I'm mostly being prisoner here. INTERVIEWER: Prisoner here, you mean in bed? JOAN: Mmm. I have all my um meals... JOAN: It's frustrating...Unfortunately she [The occupational therapist] concluded that I wasn't ready to be released.*" (Story - Healthcare interactions: Interview 3)

Peter and Joan both described her illness within the context of constant change and interruptions 'where the structures of everyday life and the forms of knowledge which underpin them are disrupted' (Bury, 1982, p. 169).

> PETER: "*...the thing I miss most is it's difficult to do things together as we would have done before, to get out would be lovely I mean I can but obviously Joan can't but um I think that's what we miss most isn't it, just to go places and do things together.*" (Story – Relationship changes: Interview 3).

Peter is able to reflect and adjust over the interviews, and by the final interview, Peter has adapted his approach to communicating with the community team:

> PETER: "*I think I told you we had a little bit of a run in the first time [laughter], I got a bit upset, and um shouldn't have done, but this time I kept very calm and I sort of anticipated the outcome anyway, 'cos I thought they're not going to give us the go ahead.*" (Story - Healthcare interactions: Interview 3).

Analysing dyadic interviews at the personal level allows for a deeper understanding of divergent and convergent views on a shared experience (Polak & Green, 2016). However, it is important to observe whose story gets told, and this becomes more apparent when analysing at Murray's (2000) interpersonal level.

Level 2: Exploring Co-Created Stories at the Interpersonal Level

The interpersonal level of analysis is one that is 'co-created in dialogue' and as such is the result of a joint enterprise (Murray, 2000). This level is important in understanding the context, structure and participant roles within which narrative accounts are produced (Wong & Breheny, 2018). It is said that co-created stories can provide a common reflective space that produces rich data, both in terms of expanding and corroboration of a story, and by highlighting differences and disagreements (Bjørnholt & Farstad, 2014).

Peter and Joan were predominantly interviewed together; therefore, the stories are portrayed as shared expressions of their lived experience to acknowledge the *'interdependent relationship between individuals.....as a source of information rather than attempting to control for it'* (Caldwell, 2014, p. 488). Peter is the key narrator, who is keen to tell his story. When analysing which stories fade or dominate it can be seen that Peter influences the direction of the stories:

> PETER: "*Tell [researchers name], you had a visit from an occupational therapist, can you tell her about that? That was last Wednesday wasn't it. Do you remember what she came for? JOAN: Oh she came to see if whether I could sit in a chair, and do various other. PETER: What conclusion did she come to? JOAN: Unfortunately she concluded that I wasn't ready to be released.*" (Story – Healthcare interactions: Interview 3).

Peter admits that he "*sometimes takes over, and that isn't sort of right.*" This was apparent when Peter interjects:

> INTERVIEWER: "*Can you tell me a bit.... PETER: Sorry, no I was going to say, once the diagnosis had come through, that gave you some access then to a Parkinson's nurse didn't it. JOAN: That's right.*" (Story – Healthcare interactions: Interview 1)

Peter says he "*find it quite difficult to hear Joan at times.*" and Joan does have difficulty in getting her voice heard in the interview setting. By the final interview, she does make the point that "*the idea is to have a two way conversation*" when talking to Peter about her respite carer:

> INTERVIEWER: "*Do you find those visits [from the respite carer] helpful? JOAN: Yes, except Katie is so good at talking. PETER: That's an understatement. JOAN: Try to get a word in sometimes. PETER: I can imagine [laughter].JOAN: But the idea is to have....Two* " (Story - Becoming a carer: Interview 3)

The challenge to 'get a word in sometimes' may be due to the physical and cognitive changes associated with Lewy body dementia, differing personalities or Joan being viewed in the role of 'patient' or 'cared for' person. It highlights the disadvantages of joint interviewing, when the interaction may have the effect of silencing an individual's account (Polak & Green, 2016). However, the couple's intimate knowledge of each other may serve as an advantage in expanding conversations:

> PETER: "*Not so easy for you though with youngsters is it. INTERVIEWER: I was going to say how is that when [the grandchildren] come? JOAN: Well I enjoy having them but find I can't, play with them so much because I can't get down and get up, I need some help. PETER: Do you find you miss that? JOAN: Yes.*"

One of the strengths of analysing Murray's interpersonal level with dyadic interviews is it enables greater understanding of how couple interactions and relationships influence the storytelling and whose story gets told.

Level 3: Understanding Social Positions at the Positional Level

Social characteristics and roles are relevant at the positional level of analysis; in particular the role of the researcher, where the issue of power relations is of principal concern in narrative enquiry (Clandinin & Connelly, 2000). Challenges to the integrity of the research can be addressed by considering how perspectives might be influenced by personal, historical, cultural and academic experiences (Creswell & Creswell, 2018). We have backgrounds in community nursing, palliative care and dementia research. To reduce potential medical influences and improve the credibility and quality of the analytical process, people with lived experience of Lewy body dementia were involved in shaping and testing the open-ended questions. Professional socialisation is considered unavoidable (Salisu et al., 2019), so within this analysis the researcher remains 'visible' by retaining the interviewer dialogue within the stories. When analysing how the interviewers' questions, responses and behaviour influence the story there is some evidence of the natural orientation toward the clinical interview with the 'probing' questions. For example, when Joan mentions her memory "*can you tell me more about....*" and when they talked about speech and language therapist:

> PETER: "*....she was first brought in to look and see whether Joan was having swallowing difficulties. INTERVIEWER: I was going to say do you find that's a bit of a problem, swallowing? PETER: Not too bad is it,*" (Story – Healthcare interactions: Interview 1).

It seems that Peter does not view the researcher in a clinical context, but more of a 'confident' of his frustrations with healthcare professionals "*But um so no we will quietly - I'd like this to be treated confidentially [laughed]....*"

He predominantly uses the research as a vehicle to discuss their relationship and feelings:

> PETER: "*it's me trying to adjust to what our life is now like. And starting to and I think I am, realising that we're never going to do as much as we used to do or but I think the things I miss most are those, it's been nice today, you've talked a lot about how you feel, but we really don't do that hardly at all, ……The way our minds work and when they go wrong you can't talk like that and we've really never talked about really have we Joan your condition as such, it's very difficult to say if I start trying to explain what I think is happening, that's not really very kind …*" (Story - Relationship changes: Interview 1).

As a retired professional, he gives methodical and articulate accounts in his stories. He takes on particular roles, for example, as research participant, questioner and advocate speaking for Joan. Analysing the positional level at different time points can highlight how the roles for researcher and participants may change and evolve as they become more acquainted. This can show differing perspectives of the same experiences adding to the quality, depth and richness of the data.

Level 4: The Societal Level

Societal level of analysis is concerned with the socially shared stories that are characteristic of certain communities or societies (Murray, 2000). Community-based assumptions were considered within cultural, social and linguistic dimensions as this allows for broader understanding of the narrative (Andrews et al., 2013). Peter describes his experience of Joan's hospital admission which is essentially the start of his caring role.

> PETER: "*… so many different people turning up, different doctors, you couldn't tell necessarily who would be the best person to talk with. And er I probably I think it's always difficult if you start to challenge the service, I think at that the other patients basically were going to be there and be accepting of what was going on, I wasn't [laughter]. I felt it was important to alert them to what Joan's needs were, I don't think I made myself very popular but er…….If you don't shout, no one listens.*" (Story – Healthcare interactions: Interview 1).

Peter starts to learn the language of medicine and says he has been "*looking things up.*" and is particularly concerned about the effects and interactions of the medications Joan is on – "*my biggest worry is the interaction of medication which all seem to pinpoint the same part of the synaptic join if you like.....*" Words such as 'medicines' and 'brain' are frequently drawn on to frame and discuss dementia in the media and can influence shared beliefs and influences surrounding health and illness (Bailey et al., 2019). Peter's advocacy and caring roles develop over the three interviews. As Joan's condition deteriorates the couple's role of husband and wife move as Joan becomes a 'patient' and Peter a 'carer' and advocate for Joan. By the final interview, his caring skills involve becoming part of the 'medical' team he initially challenged.

> PETER: "*… we've had a doctor or a paramedic come and then an ambulance once or twice but then after consideration it's been felt more appropriate to try and help Joan here.... they're quite keen not to take us to A&E which I'm quite happy about - and they've often said that with the consultation of the doctor and then me we'll give you antibiotics here and that's worked. And in fact one of the paramedics that came after my call to the surgery, told me that his actual job was to try and keep as many of 65 year olds and above out of hospital, …*" (Story – Healthcare interactions: Interview 3).

The final stage of analysis involves connecting and articulating Peter and Joan's stories across the four levels (Murray, 2000). Evaluating how these levels work together can allow for a deeper understanding of human experience and enhance 'coherence' of the data, (Riessman, 2008). It can lead to a greater depth of analysis and contribute to the wider social narrative (Wong & Breheny, 2018).

Connecting the Levels of Analysis

Finding the connections between these different levels is complex; however, by doing so, it becomes possible to challenge the dominant narrative and 'develop a new story that enhances alternative knowledge' (Murray, 2000). It is at this stage the data is analysed 'though a researcher's lens with the purpose of understanding the experiences, aided by research and theoretical literature' (Loh, 2015, p. 6). All authors were involved in data analysis as a means of corroboration and of establishing trustworthiness of the interpretation process. (Loh, 2015).

To connect Murray's four levels, this stage of analysis involved applying the following research questions to the data:

- What are the everyday life experiences of people with Lewy body Dementia?
- How do family/informal carers describe the experience of living with someone who has Lewy body dementia?
- Are there similarities in content (what story is told), experience and meaning between person living with Lewy body dementia and the family carer?

Joan and Peter find many aspects of living with Lewy body dementia frustrating. Underpinning the frustrations, the main connecting narrative was identified as 'communication'. The importance of clinician-family communication (Armstrong et al., 2019) and communication between couples (Vatter et al., 2018) has been previously noted for people living with Lewy body dementia. However, applying Murray's levels allowed for deeper insight into the complex issues around communication from theoretical, academic and clinical perspectives. Intercultural communication theory places importance of the processing of identity (personal, relational, enacted and community) through interactions (Gudykunst, 2005). Communication is key to this process; therefore, by applying Murray's levels of narrative analysis, communication 'gaps' for Peter and Joan were more readily identified.

Personal level stories highlighted the relationship between communication style, competence and message strategies, which is important clinically. This was evident when Peter is communicating with the therapy team:

> PETER: "*Anyway I got angry, then they started treating me like an infant, why do all these people speak so loudly, this is my question, I didn't say that to them, and then they speak to you as if "are you alright, do you need to sit down*"……(Story – Healthcare interactions: Interview 2).

Communication gaps may also be observed within the couple's relationship:

> PETER: "*I suppose the other frustrations are um there's nothing from Joan, it's not her fault I know that but she's much more receptive to the carers and things than she is to me….*" (Story-Relationship changes: Interview 2).

And in relation to physical features of Lewy body dementia, whereby the voice gets quieter as the condition progresses. This makes communication between Peter and Joan more difficult. Peter says "*I find it quite difficult to hear Joan at times, But Joan was never a loud person….you've got quieter and quieter haven't you?' JOAN: Yes.*" By the second interview, he misses what conversation they did have: *PETER:* "*I never get a smile, I never get a um, I don't get any reciprocal……it might be my fault I don't know, but there's not much conversation going on at all, 'it's me that ends up doing the talking…*" (Story – Relationship changes: Interview 2).

Analysis at the positional level reveals how the research interview acts as an avenue to open up communication between the couple, "*it's been nice today, you've talked a lot about how you feel, but we really don't do that hardly at all,….. we've really never talked about really have we Joan your condition as such,..*"

Exploring societal and cultural perspectives and can illuminate tensions between self, disability and communities (Riessman, 2008). As Peter adjusts to Joan's deteriorating condition, interactions with healthcare professionals became more equal with shared decision making. Peter says they have "*had one or two scares about er pneumonia coming back'* but he monitors Joan's condition – *'I've got monitors and things, I can check her oxygen saturation, I can check blood pressure.*" (Story – Healthcare interactions: Interview 3). Communication between Peter and the community healthcare teams improves as they work together to prevent hospital admissions, which may not be considered appropriate at the end of life (Robinson et al., 2016).

Conclusion

A dyadic longitudinal narrative approach offers deeper clinical and academic understanding of the personal experiences of people living with Lewy body dementia. Applying Murray's four level approach enables a transparent analysis process to reflect the multitude of influences which in turn can strengthen the validity of findings. Two levels of validity are considered important within narrative analysis: the story told by the research participant, which relates to Murray's descriptive stage, and the story told by the researcher, or the analytical stage. The interviewer remains visible within the text which enables transparency of the analysis process to clarify and confirm the story told by the researcher. To enhance coherence of the story told by the research participant, the stories were kept intact rather than breaking into themes, and by completing longitudinal couple interviews, some member checking occurred naturally. How people relate their experiences to others is complex, and this approach attempts to integrate the content, structure and composition of dyadic narrative interviews in a flexible way. This paper provides a structured transparent example of how to connect and integrate Murray's levels of analysis and contributes to the growing body of analytic methods for interpreting stories.

Acknowledgements

The authors thank the Lewy Body Society for funding this work and all the participants and family members who kindly agreed to take part. Grateful thanks also to Iliana Rokkou, Manager of the Cambridgeshire and Peterborough NHS Foundation Trust Service User and Carer Research Group, and the members involved with designing and supporting the research project.

Author Contributions

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: AB, CW and YS. Involved in drafting the manuscript or revising it critically for important intellectual content: AB, CW and YS. Given final approval of the version to be published: AB, CW and YS. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: AB, CW and YS.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The first author collected this data for a PhD at Lancaster University which is funded by the Lewy Body Society, UK, Grant LBS/003/2020.

ORCID iDs

Allison Bentley https://orcid.org/0000-0001-9673-580X
Yakubu Salifu https://orcid.org/0000-0001-5523-3010

References

Andrews, M., Squire, C., & Tamboukou, M. (Eds.), (2013). *Doing narrative research* (2nd ed.). SAGE.

Armstrong, M. J., Alliance, S., Taylor, A., Corsentino, P., & Galvin, J. E. (2019). End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former caregivers. *PLOS ONE*, *14*(5), e0217039. https://doi.org/10.1371/journal.pone.0217039.

Bailey, A., Dening, T., & Harvey, K. (2019). Battles and breakthroughs: Representations of dementia in the British press. *Ageing and Society*, *41*(2), 362–376. https://doi.org/10.1017/S0144686X19001120.

Bazeley, P. (2013). *Qualitative data analysis: Practical strategies*. SAGE.

Bjørnholt, M., & Farstad, G. R. (2014). 'Am i rambling?' On the advantages of interviewing couples together. *Qualitative Research*, *14*(1), 3–19. https://doi.org/10.1177/1468794112459671.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, *4*(2), 167-182. https://doi.org/10.1111/1467-9566.ep11339939.

Caldwell, K. (2014). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, *14*(4), 488–507. https://doi.org/10.1177/1468794113490718.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE.

Davidsen, A. S. (2013). Phenomenological approaches in psychology and health sciences. *Qualitative Research in Psychology*, *10*(3), 318–339. https://doi.org/10.1080/14780887.2011.608466.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). The University of Chicago Press.

Grossoehme, D., & Lipstein, E. (2016). Analyzing longitudinal qualitative data: The application of trajectory and recurrent cross-sectional approaches. *BMC Research Notes*, *9*(1), 136. https://doi.org/10.1186/s13104-016-1954-1.

Gudykunst, W. B. (Ed.), (2005). *Theorizing about intercultural communication*. Sage.

Killen, A., Flynn, D., O'Brien, N., & Taylor, J.-P. (2021). The feasibility and acceptability of a psychosocial intervention to support people with dementia with Lewy bodies and family care partners. *Dementia*, (June), 147130122110285. https://doi.org/10.1177/14713012211028501.

Loh, J. (2015). Inquiry into issues of trustworthiness and quality in narrative studies: A perspective. *The qualitative report*, *18*(23), 1–15. https://doi.org/10.46743/2160-3715/2013.1477.

Meraz, R. L., Osteen, K., & McGee, J. (2019). Applying multiple methods of systematic evaluation in narrative analysis for greater validity and deeper meaning. *International Journal of Qualitative Methods*, *18*(January), 160940691989247. https://doi.org/10.1177/1609406919892472.

Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, *5*(3), 337–347. https://doi.org/10.1177/135910530000500305.

Murray, M., & Sools, A. (2015). Narrative research. In P. Rohleder, & A. C. Lyons (Eds), *Qualitative research in clinical and health psychology* (pp. 133–154). Palgrave Macmillan.

Polak, L., & Green, J. (2016). Using joint interviews to add analytic value. *Qualitative Health Research*, *26*(12), 1638–1648. https://doi.org/10.1177/1049732315580103.

Puplampu, G. L., Caine, V., & Clandinin, J. D. (2020). Sustaining hope: A narrative inquiry into the experiences of hope for nurses who work alongside people living with HIV in Ghana. *Nursing Open*, *7*(3), 879–886. https://doi.org/10.1002/nop2.465.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage Publications.

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2016). The 'problematisation' of palliative care in hospital: An exploratory review of international palliative care policy in five countries. *BMC Palliative Care*, *15*(1), 64. https://doi.org/10.1186/s12904-016-0137-0.

Salisu, W. J., Dehghan Nayeri, N., Yakubu, I., & Ebrahimpour, F. (2019). Challenges and facilitators of professional socialization: A systematic review. *Nursing Open*, *6*(4), 1289–1298. https://doi.org/10.1002/nop2.341.

Squire, C., Andrews, M., Davis, M., & Esin, C. (Eds.), (2014). *What is narrative research?* Bloomsbury.

Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., McCormick, S. A., & Leroi, I. (2018). A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age & Ageing*, *47*(4), 604–610.

Wang, C. C., & Geale, S. K. (2015). The power of story: Narrative inquiry as a methodology in nursing research. *International Journal of Nursing Sciences*, *2*(2), 195–198. https://doi.org/10.1016/j.ijnss.2015.04.014.

Wong, G., & Breheny, M. (2018). Narrative analysis in health psychology: A guide for analysis. *Health Psychology and Behavioral Medicine*, *6*(1), 245–261. https://doi.org/10.1080/21642850.2018.1515017.

Woolf, N. H., & Silver, C. (2017). *Qualitative analysis using ATLAS.ti: The five-level QDA® method* (1st ed.). Routledge. https://doi.org/10.4324/9781315181684.

Appendix 15: Overarching descriptive narrative for each couple

Couple 01 Patrick and Sue

Interview 1: timepoint 0 53 mins
Interview 2: timepoint 2 months 106 mins
(66 mins life story work Patrick, 40 mins Sue alone)
Interview 3: timepoint 4 months 58 mins

Patrick and Sue are in their early 70's and Patrick was diagnosed with deentia with Lewy bodoes around a year before the first interview. Patrick's early career was as a scientist before becoming a teacher before he retired (**Story: Working Life "an organised scientist").** He enjoyed being part of a band which played at his wedding to his wife Sue of 36 years (**Story: Music –"it was just a bit of fun".)** Patrick first noticed things were changing when he started to have difficulty adding up at a quiz night and his leg was not quite right. As time went on he realised there was 'something badly wrong' and took himself off to the doctors **(Story: getting a diagnosis)** and was eventually diagnosed with Lewy body dementia a year ago. He had to give up golf and decided to stop driving - a particularly difficult decision as he has owned an old classic car for many years **(Story: Driving** "I really couldn't go out and kill a few people".). His family have stepped in to help by **(Story: friends and family).** Both Patrick and Sue are struggling with the medication regime that has come with the diagnosis (**Story: Pills and potions** "all of a sudden having to take all these pills") and are having difficulty finding a health professional who can help "manage both sides of the condition" (**Story: Interactions with healthcare professionals** *"they are under pressure".*). Sue is finding some of the symptoms of Lewy body difficult to manage particularly when Patrick mistakes her for someone else such as family members or the gardener **(Story: mistaken identity – "**at the beginning it was really quite distressing,"). The issues around bladder and bowel incontinence are becoming increasingly difficult **(Story: Bowels and bladder).** Sue says it is starting to affect Patrick's quality of life and the ease at which they can socialise **(Story:Maintaining a social life),** but Patrick has adjusted – he has taken up playing music again and is sorting through his collections **(Story: Collecting things).** Sue has family sit with Patrick whilst she does her volunteer work or meets friends, and they have formed a new social group with other couples they met at a dementia group.

Story Title (Couple 01)	Underlying narrative		
	Interview 1	Interview 2	Interview 3
Getting a diagnosis	Piece together	-	-
Maintaining a social life	Forming new friendships	supportive	Struggling to maintain
Working life	Being organised	Experimenting	
Driving	Giving up	Working out solutions	constricting
Friends and family	Supportive	Back-up	
Pills and potions	Difficult to manage	Balancing act	unsupported
Interactions with professionals	variable	looking for the right help	Frustrated with the system
Music	-	Reconnecting to music	Coping
Bowels and bladder	-	Quality of life	restrictive
Mistaken identity	Distressing	upsetting	-
Being a collector (life story work)	-	Linking to the past	Reminiscing

Couple 02 Ken and Kathleen

Interview 1: Timepoint 0 1 hr 10 mins (life story work Kath only)

Interview 2: Timepoint 2 months 39 mins

Interview 3: Timepoint 6 months 20 mins

Kathleen and Ken had been married for many years after they met at work which Kathleen recalls as being an enjoyable period in her life. She has had a Lewy body diagnosis for around six years **(Story: Getting a diagnosis),** which started with disturbing hallucinations which resulted in her being admitted to hospital **(Story: hospital admissions).** She feels they have been less frequent since starting medication **(Story: Medication ‘a wonder drug’)** and has since learnt to manage them **(Story: Dreams and hallucinations).** She has regular contact with her GP and occasionally sees a neurologist, Parkinson’s nurse or member of the mental health team **(Story: Interactions with healthcare professionals).** Kath likes to keep busy and pushes herself to keep going. Ken says Kath does *‘push’* herself but is *‘her own worst enemy’* which he finds frustrating. If things become tense Kath takes herself into the garden **(Story: Garden)** as it’s her ‘retreat’. She says the social services carer helps her keep doing the things she wants to do **(Story: Social carer)**. Two mornings a week they go shopping, to garden centres and have coffee **(Story: Getting out).** She finds it frustrating that her mobility is getting worse **(Story: Mobility ‘frustrating’)** and has started to have falls which takes a while to recover from **(Story: Falls ‘shook me up’).** Her daughter brough her a ‘wheeler’ to help get around, which up-set her greatly ‘I said to her - I’m 72 not 82’ **(Story- Family).** Kath reports “*it’s just been a slow progression and I do fight it, very much so, ‘cos I won’t let it get hold of me,”* During lifestory work decribed how liberating it was to be able to have independence on a ferry trip where she felt able to go exploring on her own. She has problems with bowels and bladder and has a radar key to access disability toilets when out **(Story: Toilets)** and is starting to think about adaptations to the house **(Story: Bath and showering).** By the final interview, and another hospital admission Kath is feeling weary and tired.

Story Title (Couple 02)	Underlying narrative		
	Interview 1	Interview 2	Interview 3
Getting a diagnosis	Frightening	-	-
Social Carer	Getting out and about	Companionship	Supports independence
Hospital admissions	Due to hallucinations - frightening	Due to fall – Not with it, feeling strange	Exhausting
Family	Advising - Equipment	Feeling indebted	supportive
Medications	A wonder drug	Balancing act	Taking control
Interactions with professionals	Variable	Waiting in the system	draining
Mobility	Frustrating	resisting need for equipment	pushing
Falls	Shaken up	Tiring	Denial
Toilets	Difficult accessing	-	-
Hallucinations	Learn to manage	-	-
Garden	Retreat/sanctuary	-	Hobby
Getting out	Social support	Not giving in	Slowing down/tiring
Eating and Drinking	Difficulty swallowing	Importance for socialising	-
Bath and showering	Difficulty getting in and out – needing help	Family organising alterations	Organising and paying for adaptions

Couple 03 Peter and Joan

Interview 1: Timepoint 0 64 mins

Interview 2: Timepoint 2 months 1 hr 42 mins (60 mins with Carer only)

Interview 3: Timepoint 6 months 67 mins

Joan, a retired teacher first noticed changes to her mobility about five years previously and was given a diagnosis of Parkinson’s which she found ‘depressing’ . **(STORY - Getting a diagnosis 'it was depressing')** Following a significant car crash and a long hospital stay she found herself ‘much more dependent on other people’, especially Peter **(Story- Driving).** Peter describes his experience of the hospital admission and essentially the start of his caring role. **(STORY - Hospital - 'if you don't shout, no one listens').** She was determined to maintain some independence but felt the equipment in the home (**STORY – Equipment – ‘Useful, but…**), and visits from the grand-daughters were a constant reminder of the things she now cannot do. 'I enjoy having them but find I can’t, with them playing so much because I can’t get down and get up, I need some help’. **(STORY - Grandchildren 'I can't join in'). Joan** also finds it difficult to speak and be heard due to the physical voice changes often associated with Lewy body dementia.**(STORY – Voice changes – ‘difficult to hear Joan at times’). Joan** had some problems with her memory, and ‘started to see children and other people in the garden’ which she said were ‘unsettling’. **(Story- Dreams and delusions).** She was diagnosed with Lewy body dementia. ‘ Well dementia with Lewy Body has been mentioned, Parkinson’s with dementia, I don’t think anyone’s absolutely certain’. He has been looking things up and is particularly concerned about the effects and interactions of the medications **Joan** is on - 'my biggest worry is the interaction of medication.....I suppose it’s dangerous to keep reading but it does seem that it’s very very difficult to pinpoint why this happens’. **(STORY - Medication 'my biggest worry’).** Peter says he finds aspects of his caring role difficult 'I'm learning as I go'. **(Story – Becoming a carer ‘learning as I go’).** Before the second interview at their home **Joan** had a fall. This resulted in another hospital admission with a fractured hip and pneumonia where ‘things went from bad to worse’. **Joan**’s was discharged home for end of life care **(Story - Palliative Care)** with carers four times a day under NHS Continuing Healthcare funding **(Story- NHS funding).** Peter finds it frustrating interacting with the local community health teams **(Story-Interactions with community services).** He finds it difficult to find activities to stimulate **Joan (Story-Hobbies & Interests)** and knowing what soft foods to prepare **(Story – Eating & drinking).** He struggles 'trying to adjust to what our life is now like’ and starts to pursue activities on his own **(Story- Relationship changes).** For the final visit, **Joan**’s physical and mental condition had improved slightly and she was able to re-call some of her hospital admission and talk about the changes and frustrations due to lack of mobility and being ‘prisoner’ in bed **(Story- Mobility).**

Story Title (Couple 03)	Underlying narrative		
	Interview 1	Interview 2	Interview 3
Getting a diagnosis/prognosis	Understanding	Uncertainty	Stasis
Driving	Trauma	Realisation	Resignation
Hospital	Advocacy/Speaking out	Responsibility	Re-focus of care
Equipment	Conflictions	Disruption	Security safety
Grandchildren	Physical loss	Tiring	Re-engaging
Voice changes	Being heard	-	Talking back
Dreams and delusions	Fear of separation	Distressing	Suspicion
Becoming a carer	Learning through experience	Performance anxiety/guilt	Adapting accepting
Medication	Worry about treatment & side effects	Roles and responsibility	Taking control
Hobbies & Interests	Becoming dependant	Motivation (Lack of motivation for **Joan**, and Introjected for Peter, ie feels the tension of guilt)	Carer re-connecting with own hobbies
Interactions with Community services	Connecting	Frustration	Restrictive, rigid system
Relationship changes	Marital disconnection	Loneliness & Guilt	Adjusting to not being together
Mobility	Fear of falling	Being vigilant	Worry about inactivity
NHS Continuing Care	-	Learning the system	New friends
Eating & Drinking	-	Learning by experience	Problem solving
Palliative care	Living well	Decision making responsibility	Supportive

Couple 04 Jack and Linda

Interview 1: Timepoint 0 - 40 mins (joint interview couple)

Interview 2: Timepoint 3 months - 41 mins (separate interviews)

Interview 3: cancelled due to COVID

Jack and Sue are in their late 60's and Jack says he was a chemist who had a smallholding in semi-retirement (**Story: working and retirement**). Linda reports Jack was successful and intelligent in his career and neither understood way he was struggling at work, and as a result Linda encouraged Jack to retire.They had to move from their small holding 3 years ago when Jack had his diagnosis **(Story: Living with a diagnosis),** as it was quite isolated and Jack was finding it difficult walking **(Story: walking).** Jack decided to give up driving due to hallucinations **(Story- Driving).** Jack says he has to give up many of his previous hobbies but Jack's family have set up a weekend rota so he and Linda can continue with interests and have a break. They enjoy holidays, spending time by the sea and with family **(Story – friends and family).** They try to 'keep busy' and maintain links with thier smallholding self-sufficiency groups **(Story: smallholding, growing),** as well as forging new links with couples who are living with dementia. Linda and Jack are reliant on the local mental health services for medication advice, but find it distressing talking about and being reminded of his condition. Linda says they go "over stuff you know, we don't need to be told that Jack imagines the chairs are an animal, we know that, I don't need to be told, it's quite annoying as you can see" **(Story: interactions with community services).** They are having trouble getting the right medication and doses "so I was insistent that he would meet this consultant 'cos I thought that's not ok….that was the big thing about the medication". **(Story: medications)** They like to have something planned to do each day. **"**You don't want to define yourself by your ailments do you". **(Story: planning and organising).** and Linda uses a day by day diary now for their activities as it reduces Jack's anxiety **(Story: Planning and organising)** However, Jack does admit that hallucinations **(Story: hallucinations),** anxiety, juggling medications and subsequently not been able to drive has been particularly difficult. Although pragmatic about living with the condition Linda doesn't like watching dementia related programs on the TV *"you don't want it to be in your face, I tend to turn it off".*

Story Title (Couple 04)	Underlying narrative		
	Interview 1	Interview 2	Interview 3
Living with a diagnosis	Worrying	Disconcerting	
Walking	Importance for Independence	Adapting	
Friends and family	support	Providing care	
Smallholding	Giving up	Holding on	
Hobbies and interests	Changing lifestyle	Letting go	
Planning and organising	reduced motivation	Keeping busy	
Hallucinations	Learning to live with	-	
Medication	Struggling to find support	Side effects/ QoL	
Interactions with community services	Discord	distressing	
Driving	Resigned	dependent	
Working and retirement	Giving up	Struggle	

Couple 05 Doug and Gayle

Interview 1:	Timepoint 0	61 mins	
Interview 2:	Timepoint 2 months	63 mins	
Interview 3:	Timepoint 4 months	69 mins	(also with adult daughter)

Doug and Gayle both come from farming backgrounds and have been married for 49 years. (**Story – Working rural life – “I thought I was going to have a retirement with old tractors on the drive**”). Dogs form a big part of their lives - they had *“quite a few sheep dogs as well and Doug trained them to work the sheep and the gun dogs”.* (**Story – dogs –*“really misses the shooting and the dogs*”).** They always remember the date of Doug’s Lewy body diagnosis as one of their dog *“had her puppies the day before he was diagnosed, that was the last time he drove anywhere”.* **(Story – driving –*“he’d been having odd incidents”).*** They like to keep busy with activities during the week (**Story – Activities and groups -*“we have to make more effort to be active and run into people”*)** with a farming group and singing sessions providing new interests (**Singing & Music – “I’m determined to keep my singing going”).** In order to maintain her own hobbies and interests Gayle tries to plan ahead and use respite care **(Story – Respite care –“all a headache”).** They have tried live-in care, respite in a care home, but this often breaks down at the last minute, and as Doug can’t be left alone this proves challenging for the family **(Story – caring roles –“all the time you’re having to think about the cover”).** They have three adult children. The daughters help take Doug to groups and sit when Gayle goes out. Together with “a bank of friends” they provide support, ‘back-up cover,’ and advice (**Story – Friends and family – “He’s got my back”**). Finding the right cover is difficult due to Doug’s variable condition **(Story – diagnosis/ prognosis -*“it’s a bumpy ride”*)** and problems with swallowing **(Story – Eating and drinking -“scared he was going to choke”)** and incontinence **(Story – toileting –“we get through a lot of washing”.).** They have some support from local health professionals but have paid for physiotherapy to try and help with Doug’s stooped neck **(Story – interactions with health professionals – “so poorly resourced these days”).** Gayle has difficulty understanding Doug “Sometimes I can’t understand what Doug’s saying at all and it gets frustrating for both of us”. Doug goes to music therapy to help with voice strengthening and they have a speech therapist but at the moment they think “the problem is um more in the brain than in the vocal muscles”. By the final interview Doug is almost aphasic and the family have started to look at care homes with Doug’s involvement. They are particularly keen on homes who integrate with the local community and are allowed dogs.

Story Title (Couple 05)	Underlying narrative		
	Interview 1	Interview 2	Interview 3
Dogs	Companionship	Socialising	Important to visit care homes
Music/singing	New interests	Voice strengthening	Family take to music therapy
Driving	Carers relief when told to stop (Gayle)	Being a passenger (Doug)	Frightening & worrying experience
Farming/rural life	Maintaining links	Socialising	Reminiscing
Respite care	Challenging/difficult	-	Keep safe
Groups and activities	Keeping up social interactions	Struggling to maintain	Going separate
Friends and family	Teamwork	Keeping a sense of humour	Emotional and practical support
Interactions with healthcare professionals	Takes time lack of resources	Problem solving	-
Eating and drinking	Difficult to manage	Way to meet people	Importance as a social activity
Caring roles	Constraining & constricting	dependent	Strain of responsibility
Toileting	restricting	-	Holding onto self respect
Diagnosis/prognosis	uncertain	‘Bumpy ride’	Looking for care homes

Appendix 16: The language of loss - table

Physical Loss:	Quotes
Loss of energy	Patrick: "*It does take energy out of me, but I think I, I could do two hard days".* Linda: *Well motivation's an issue isn't it with this dementia isn't it.* Jack: *I'm not always motivated.* Patrick: *Tired. I was tired this morning and I'm definitely tired now, but I've felt tired for.* Sue: *Well we've been away as well.* Kath: *I went out with my carer yesterday…I said I'd love to go out, you know. But I was I was tired, I needed to get back if you know what I mean, we had coffee, I said I need to get back now, I felt like I'd had enough.* Ken: *"Kath just won't give in to anything, and then next day you know she's tired and and wants to spend the day in bed so she's her own worst enemy in that respect".* Kath: *"I am tired. That's how I feel, um at the moment, um".* Linda: "*I couldn't understand it. I never thought you know it was that [Lewy body], he was just tired,…"* Sue: "*I said oh I'm Sue, oh yes yes that's right, so no I'm tired, difficult week".* Sue: *"….he often falls asleep once his brother's been here which is fine 'cos it's tiring,"* Gayle: *"Sunday he slept a huge amount but then we had been out quite late the evening before so he was really tired but there's no real pattern to it, he just nods off".*
Loss of voice	Patrick: *"It was deemed I think that, the we didn't need um um, sorry I'm thinking of the wrong words".* Patrick: *Just constricted. Not like I'm free like a bird….Um, there the situation I'm in is, can't think of the word…..I'm not locked up but there is a certain constrictment, getting around.* Patrick: *"I mean my vocabulary is mixed, it's gone from being quite high level to um mumble. I lost my voice early on, then it came back. I mean thinking about it it is down, definitely up and down".* Gayle: *"Sometimes I can't understand what Doug's saying at all and it gets frustrating for both of us. And sometimes he's quite clear….*

	Peter: “ *I find it quite difficult to hear* ***Joan*** *at times, But* ***Joan*** *was never a loud person….you’ve got quieter and quieter haven’t you?* ***Joan****: Yes* *Peter: “….it might be my fault I don’t know, but there’s not much conversation going on at all, “it’s me that ends up doing the talking,...”* Jack: *I’m distressed today.* Linda*: Yeah talking about it isn’t.* Jack: *Talking about it is the worst thing going.*
Loss of memory	Jack: “*….there was one other thing I was going to say to you, which I can’t remember, I really do suffer from a lousy memory…. I’m sure that if I could just bridge my mind it would come up with all interesting things. But I can’t bridge my mind I’m afraid”.* Gayle: “*I suddenly find something you can’t do or can’t find or can’t remember, but you could remember, did know the day before. But on the day in question you might not know it at all and you can’t anticipate, so it tries your patience rather a lot. And other days he’s brighter and chattier and you know, it’s the fluctuation I think makes it challenging”.*
Loss of mobility	Kath: “*Um mobility at the moment is quite frustrating for me now”.* Kath: *My daughter got [the walker] for me and I was a bit upset, you know, and I wouldn’t even think about it. But now I know myself mobility is is getting worse,.. I cried….And I just I couldn’t talk to her until the next day and I said to her I’m 72, not 82.* *Kath: “My balance is very um especially after the fall yesterday I had that shook me up quite a lot actually. I still don’t feel quite right”*
Loss of swallow	*Gayle: “…poor Doug kept getting his nose in the cream, it was very sad, um……Sometimes, he can’t get to the bottom of the cup, um but that’s the problem, he was trying to swallow his pills the other day with just about an inch of drink left in the bottom of the glass and couldn’t get it up to you know….”* *Gayle: “I was really scared he was going to choke, and I’m not so anxious about that now so”.*
Loss of continence	Sue: *“he does a poo but doesn’t know he’s done it, which I’ve no problem, bodily functions don’t phase me at all. I keep him clean, he tries to keep clean, so I said to him I’m going to give you some CosmoCol to sort of pull it together….”* *Sue: “I find it frustrating, I just said to him I want his quality of life what’s best for him, I don’t mind clearing up, I really don’t mind, but it doesn’t make him happy and very comfortable…”*

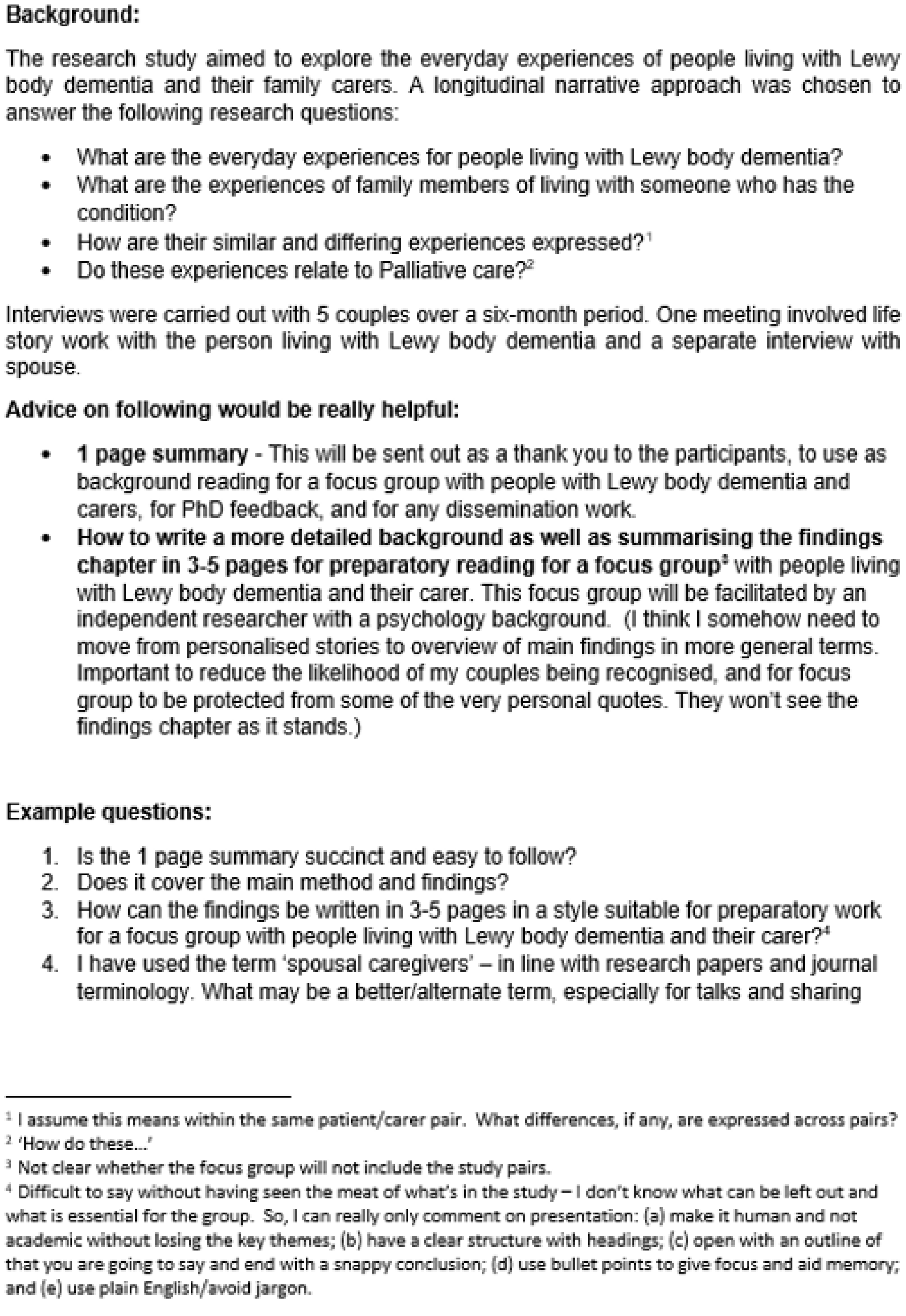
	Gayle: "*We had the continence advisor came out about a year ago with a range of techniques, but none of them suited,…. they tried everything else and none of the other stuff, gadgets work, it's too complicated you know, we can never manage a sheath without a lot of assistance, he didn't like the feel of it and all of that so, and pads that you stick them on the pants you've got to be able to manage getting them off and putting new ones on if you're going to have any independence and self respect, so it's pull up pants….that's eased it a bit".* Gayle: *"I might sound cowardly but I'm frightened, I'd be worried that we'd have an incident like we had on the motorway last Summer. There was an accident and a very long hold up, we were stationary for about an hour. He'd got his paddy pants on, but he insisted on getting out of the car. and he's trying to open the door, and in the end we tried tearing up another pear of padded pants and stuffing them down his trousers and that didn't help, we couldn't do it, and we hadn't got a bottle with us then".* Gayle: *"Just I get more and more exasperated. Around the situation you know, um getting a bit, we just sit down and just start a meal and he pops out to the loo or something".* *Linda: "….he's also struggled 'cos they've changed his medication, he's on medication for sort of depression, anxiety, which gave him diarrhoea, he couldn't go out anywhere…"*
Social/ emotional loss	
Loss of confidence	Sue: *"he's not quite as confident and I don't know whether I'm overhelping him because I don't want to him to lose his confidence or his independence um but".* Gayle: "*The bad winter two years ago he fell over on the ice and um lost his confidence [walking the dogs], he did have a pendant alarm with GPS on it which was good 'cos, it gave him a bit of independence…"* Jack: *"Well if it is Lewy whatever it is, then um it's very off putting, it's um and it's worrying and you wish it would go away but it ain't going to".*
Loss of social life	Gayle: *"Um it's quite sad really 'cos it's mostly the women who make an effort to go and chat……I think the men just don't know what to talk about".* Gayle: *"we had a nice lunch and then we had um hot chocolate, it had a whirl of cream on the top, and poor Doug kept getting his nose in the cream, it was very sad, um".*

	Sue: *[I said] "do you want to come shopping, 'cos we usually go together, and it's to do with if he makes a mess. I want him to be able to go out and he has incontinence pads which he wears at night but he doesn't like wearing them during the day, which is understandable".* Jack: *"I mean I think we, Linda more than me, are pretty good at socialising, considering that I haven't got a car, I can't drive".* Sue: "*I just cannot plan anything, I mean a group of friends went to the cinema last week, I can't you know I can't do it, not during the week,"* Gayle: *"I like to contribute to the village and I can't you know as much…., so I don't get the social contact that I used to. Um I just can't do all the things I like to do,"*
Loss of agency/independence	Patrick: "*there's a certain sort of sense of er being pinched in a bit, but they're looking after me.* Interviewer: *How do you mean pinched in a bit?* Patrick: *Just constricted. Not like I'm free like a bird….Um, there the situation I'm in is, can't think of the word…..I'm not locked up but there is a certain constrictment, getting around…. but I can't go out and go driving or anything like that".* **Joan**: *"I was capable of being able to walk, whereas now I'm mostly being prisoner here. Unfortunately she [The occupational therspist] concluded that I wasn't ready to be released".* Gayle: *"Constricting now, because he needs somebody here, I might nip down to the shop and back, about half an hour, but um ……you know all the time you're having to think about the cover. I've got friends in the village who very kindly offer to help, but because of the loo business, not everybody you can ask to do that".* Gayle: *"it does constrain my lifestyle and I know his lifestyle's not really…."* Kath: *"it's just been a slow progression and I do fight it, very much so, 'cos I won't let it get hold of me, but I do notice the change in me, what you know things that are happening. Um so um… I just I push myself,.."* Peter: *I understand they [therapists] have a protocol. I find it quite annoying that they're not prepared to see how it goes rather than say we can't do it….. Anyway I got angry,… they said we're not going to be able to move* ***Joan*** *for the foreseeable future, so we're stuck really. But I said well I'm not prepared to accept that long term….So that's frustrating,…"*

	***Joan**: It's frustrating…Unfortunately she [The occupational therspist] concluded that I wasn't ready to be released".* Sue: *"he's not quite as confident and I don't know whether I'm overhelping him because I don't want to him to lose his confidence or his independence um but".*
Mutual/ couple loss	
Loss of roles/identity	*Jack: "I mean like most folk in my position you know they're very dedicated to their jobs aren't they, you know but er I need to give up the job, I mean that's something else major that I had to give up, June didn't have to but I had to, I just realised that I couldn't do what I was trying to do".* Sue: "*I think the thing is John's personality is there but it um you know it's I want to say it's changed,…"*
Loss of driving	Jack and Linda decided to move *"because it was out of the way, there's no pavements or anything and Jack doesn't drive".* Jack says not being able to drive *"is a real bummer".* Jack: *"I gave up voluntarily 'cos I could see the way it was going, and I thought the thing is to get used to. Well I realised I'd got, or it was highly likely that I had this [Lewy body dementia]. June: It's the hallucinations that's the issue, if you're driving a car it's seeing [things]".* Patrick: "*…. The bottom line about that is that er it's not necessarily your vision being changed, the thing that's more dangerous is you might have a black out. You can't predict it. So that's what stops you, and I really couldn't go out and kill a few people. But it's the vision you know, it's a serious thing. And it does happen apparently".* Gayle: *Yeah that was the last time you [drove] wasn't it….*Doug: *Sadly I can't do it anymore".*
Loss of purpose	Peter: *"I think the other thing you get this guilt. I suppose it's guilt, you feel I should be, 'cos I don't feel I've ever I'm not really doing anything with any particular purpose, does that make sense, the purpose is keeping the day going but not actually doing anything of any substance really,"* Linda: "….*he just struggled and I thought this is really funny, you know he can't get a grip on this new [job role], and it was quite complex but normally he wouldn't have struggled with it but he really seemed to be struggling.…"*
Loss of shared sense of reality	Peter finds most difficult is that **Joan** thinks he is having affairs with other women and says *"sadly the most I ever talk to **Joan** about are things which aren't real anyway".*

	Linda: “They were quite scary images weren’t they. Jack: They were scary and um yeah but we did get over it and things gradually improved”. Sue:….. *we had a lovely day, and then about quarter to ten he said to me when’s Sue coming back? Then I got upset, I try not to ‘cos it doesn’t help. ….and I said oh I’m Sue, oh yes yes that’s right, so no I’m tired, difficult week”.* *Sue: ….at the beginning it was really quite distressing, um but er you know I will sit and he’ll suddenly say where’s the nice lady that made the tea.* Patrick: *I can’t explain that.* Sue:*…. “I don’t know what’s from one day to the next, I mean it’s the most horrendous um I was going to say medical condition, I think I told you my mother had cancer, John’s mum had dementia and they both decided that having cancer was better than having dementia. Although my mother knew she was very ill, at least she had all her - you know she knew what was happening, whereas sometimes he doesn’t*,..”
Being a couple/anticipated future	Peter:….*the thing I miss most is it’s difficult to do things together as we would have done before, to get out would be lovely I mean I can but obviously* ***Joan*** *can’t but um I think that’s what we miss most isn’t it, just to go places and do things together*”. Gayle: *“it does constrain my lifestyle and I know his lifestyle’s not really but I thought I was going to have a retirement with old tractors on the drive being repaired, ‘cos he and a friend used to do up some vintage tractors a few years back…”.* *Kath: “I find that, things when things get difficult between Ken and me ….I go out into the garden and that has become my retreat”*
Loss of companionship/ loneliness	Peter: “*I suppose the other things I miss most is just the companionship really, that’s hardest because we’re not sharing anything in the sense of other than me putting a spoon in her mouth, that’s it now really”.* *Gayle: “if you’re long periods with somebody who can’t be left on their own and they’re asleep it gets quite lonely,”* Peter: *“I suppose the other frustrations are um there’s nothing from* ***Joan****, it’s not her fault I know that but she’s much more receptive to the carers and things than she is to me. I never get a smile, I never get a um, I don’t get any reciprocal ….”* Sue: **“***I suppose it is down to me, I was cross and I was frustrated and of course I suppose that reflects,”*

Appendix 17: Local patient and public involvement feedback



Background:

The research study aimed to explore the everyday experiences of people living with Lewy body dementia and their family carers. A longitudinal narrative approach was chosen to answer the following research questions:

- What are the everyday experiences for people living with Lewy body dementia?
- What are the experiences of family members of living with someone who has the condition?
- How are their similar and differing experiences expressed?[1]
- Do these experiences relate to Palliative care?[2]

Interviews were carried out with 5 couples over a six-month period. One meeting involved life story work with the person living with Lewy body dementia and a separate interview with spouse.

Advice on following would be really helpful:

- **1 page summary** - This will be sent out as a thank you to the participants, to use as background reading for a focus group with people with Lewy body dementia and carers, for PhD feedback, and for any dissemination work.
- **How to write a more detailed background as well as summarising the findings chapter in 3-5 pages for preparatory reading for a focus group**[3] with people living with Lewy body dementia and their carer. This focus group will be facilitated by an independent researcher with a psychology background. (I think I somehow need to move from personalised stories to overview of main findings in more general terms. Important to reduce the likelihood of my couples being recognised, and for focus group to be protected from some of the very personal quotes. They won't see the findings chapter as it stands.)

Example questions:

1. Is the 1 page summary succinct and easy to follow?
2. Does it cover the main method and findings?
3. How can the findings be written in 3-5 pages in a style suitable for preparatory work for a focus group with people living with Lewy body dementia and their carer?[4]
4. I have used the term 'spousal caregivers' – in line with research papers and journal terminology. What may be a better/alternate term, especially for talks and sharing

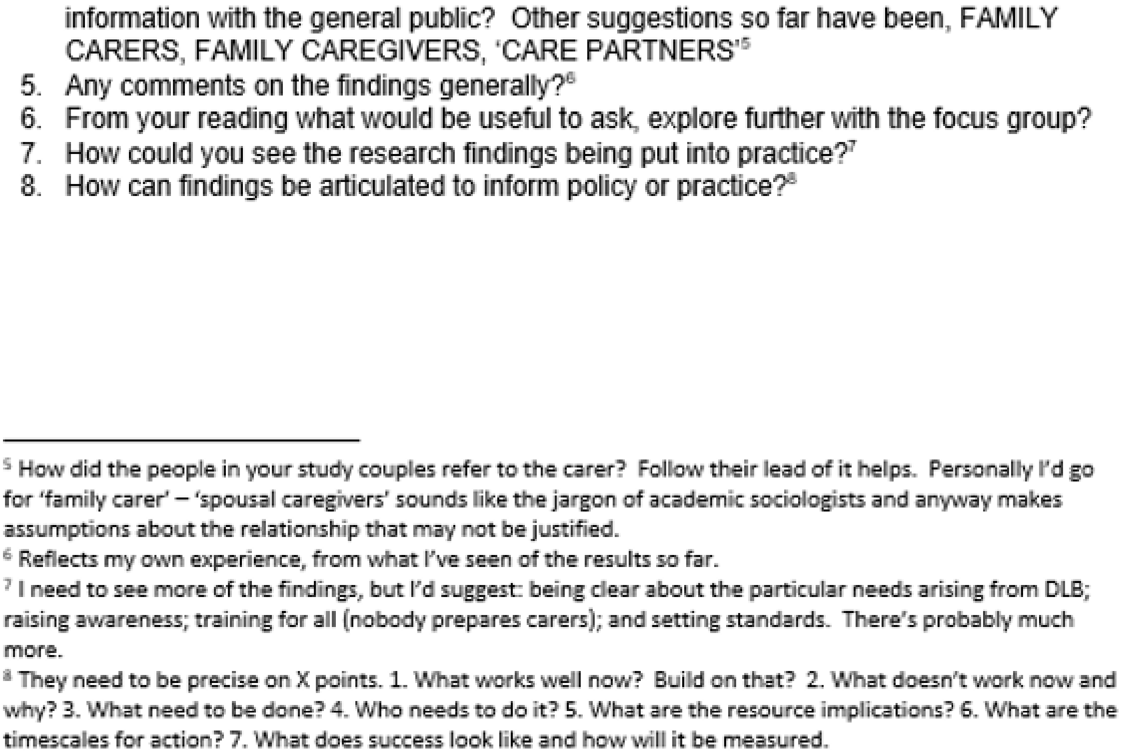
---

[1] I assume this means within the same patient/carer pair. What differences, if any, are expressed across pairs?

[2] 'How do these...'

[3] Not clear whether the focus group will not include the study pairs.

[4] Difficult to say without having seen the meat of what's in the study – I don't know what can be left out and what is essential for the group. So, I can really only comment on presentation: (a) make it human and not academic without losing the key themes; (b) have a clear structure with headings; (c) open with an outline of that you are going to say and end with a snappy conclusion; (d) use bullet points to give focus and aid memory; and (e) use plain English/avoid jargon.



information with the general public? Other suggestions so far have been, FAMILY CARERS, FAMILY CAREGIVERS, 'CARE PARTNERS'[5]

5. Any comments on the findings generally?[6]
6. From your reading what would be useful to ask, explore further with the focus group?
7. How could you see the research findings being put into practice?[7]
8. How can findings be articulated to inform policy or practice?[8]

---

[5] How did the people in your study couples refer to the carer? Follow their lead of it helps. Personally I'd go for 'family carer' – 'spousal caregivers' sounds like the jargon of academic sociologists and anyway makes assumptions about the relationship that may not be justified.

[6] Reflects my own experience, from what I've seen of the results so far.

[7] I need to see more of the findings, but I'd suggest: being clear about the particular needs arising from DLB; raising awareness; training for all (nobody prepares carers); and setting standards. There's probably much more.

[8] They need to be precise on X points. 1. What works well now? Build on that? 2. What doesn't work now and why? 3. What need to be done? 4. Who needs to do it? 5. What are the resource implications? 6. What are the timescales for action? 7. What does success look like and how will it be measured.

Appendix 18: Plain English summaries

Why this research is important:

Lewy body dementia is a complex condition with a wide range of symptoms and problems, from memory issues and hallucinations, to features associated with Parkinson’s. As the condition progresses many of the caring and nursing duties fall to families. At present, however, little is known about how people with Lewy body and their families are affected by day-today by the condition. The aim of this research was to fill this gap by exploring couples’ experiences of living with Lewy body dementia and how this changes over time.

How I carried out the research:

I carried out in-depth interviews with five married couples three times over a six month period. One of the meetings involved interviewing the care partner on their own followed by a life story work session with the person with dementia. The overall aim was to gain both individual, and joint insights into their experiences over time. Couples were recruited from the Join Dementia Research register and memory clinics within East Anglia, England. Information was collected by asking open ended questions to explore each couples experiences. The information was then analysed by looking at the individual personal stories as well as the stories that emerged as the couples interacted with each other. I then considered if couples had shared, or differing experiences of the same stories. The stories were then compared across couples, and with wider society.

What I found:

When the stories were compared the overarching narrative was the importance for couples of ‘social connectedness’ or connecting with others, feeling part of a network or group. Analysis showed that the person with Lewy body dementia and their care partner did not always have the same experience, and experiences change over time. The findings around ‘social connectedness’ highlighted the importance of relationships. Support from adult children, friends and an overall supportive environment enabled social connections to continue and new ones to be established, but physical changes, communication challenges and difficulty connecting to health and social care, could result in a social and marital disconnection for the couples.

Conclusion:

My research revealed that gaining access to clinicians was patchy while information, support, and formal care were difficult to access at the right time, and availability was inconsistent across couples. The stepwise approach can provide guidance for more targeted healthcare interventions and support for management of Lewy body dementia.

Plain English long summary

Couple experiences of living with Lewy body dementia: A study of experiences over time.

Origins of my research:

As a community nurse I had supported several people living with Lewy body dementia, and I came to realise how difficult it was to manage the many symptoms which occur with this condition. An opportunity came up to be a research nurse. The local university was setting up a study looking to improve the diagnosis and management of Lewy body dementia, so I applied to join the team. The result was that over the next four years I met many people living with Lewy body dementia, their families and clinicians. I then realised that within research there was very little written about the day to day lived experience of this condition.

Why this research is important:

Lewy body dementia is a complex condition with a wide range of symptoms and problems. These include memory issues, changes in personality and behaviours, sensory challenges such as hallucinations and delusions, and features associated with Parkinson's. Initial signs, and symptoms are varied and often difficult to detect. This makes it difficult to diagnose, and as a result many people do not receive the best possible management. Following a diagnosis of Lewy body dementia most people are likely to be discharged from memory clinics and mental health teams after a short period. As the condition progresses many of the caring and nursing duties fall on their families. The result is that little is known in detail about how people with Lewy body and their families are affected by the condition on a day-to-day basis.

At the start of the PhD, I looked at what research was published in journals around the experience of living with Lewy body dementia. The review of this literature highlighted a gap in our understanding of what it is like to live with Lewy body dementia, and what it means for a person with dementia and their family carer. I thought it was important to fill this gap by exploring couples' experiences of living with Lewy body dementia and how this changes over time.

Aim

The overall aim of this study is to explore the experience of everyday life for both people living with Lewy body dementia, and their family carer.

Broader objectives

- To explore physical, psychological, social, spiritual aspects of everyday life with Lewy body dementia.

- To understand similarities and differences between the experiences of people with Lewy body dementia and those of their care partner.
- To explore if the stories allow wider social and clinical insight to help improve knowledge and care.

How I carried out the research:

Three narrative interviews with people living with Lewy body dementia and their family carer, were conducted flexibly over 6 months between August 2019 and March 2020. *Narrative research* involves collecting interviews and then analysing the accounts people give in describing their experiences. Narrative interviewing provides an in-depth way to gather stories. To assist with this the local carers advisory group helped devise 5-7 broad open questions. The advantage of encouraging storytelling, rather than direct questioning in an interview is:

- It can encourage a more natural conversation.
- People express stories and events important to them when taking the lead in conversation.
- Looking at these events or small stories can help make sense of experiences.

In order to encourage the opening up of converstaions and stories I also carried out a life story work' session with the person with Lewy body dementia at one of the interviews. People with Lewy body dementia sometimes need help to communicate important aspects of their day-to-day lives – like background, interests, who and what is important to them. This may be due to problems with memory loss, word-finding difficulties, and decreased voice volume, for example. Life Story work is an activity in which the person with dementia is supported to gather objects, photos, and mementos as an 'aide-memoire' and review their past life events for discussion or build a personal biography. Within this project it was used to help the person to remember and share their past experiences about what they enjoyed, how they have coped with events in their life, and what they may now find difficult.

Once all the information was collected, it was then analysed by looking at the individual personal stories as well as the stories that emerged as the couples interacted with each other. I then considered if couples had shared or differing experiences of the same stories. The stories were then compared across couples, and with wider social political, policy and media influences on dementia generally. Analysis showed that the person with Lewy body dementia and their care partner did not always have the same experience, and experiences change over time. However, when the stories were compared the importance of 'social connectedness' was found to be the overarching narrative (the main story that included and affected everyone).

What I found:

Being socially connected was seen as in important. Connecting with each other, to friends and family, and the need to feel part of a commnity network or group was particularly important. The findings around 'social connectedness' can be seen as different stages the couples that took part in the research met with:

- Maintaining social connections (keeping up long term hobbies, friendships, clubs)
- Developing new connections together – such as with people in similar situaltion (dementia groups etc)
- Social disconnections - trying to maintain independence
- Changes in connecting with adult children - as they stepped in to help
- Marital changes - from marriage partnership to becoming a 'carer'
- Connecting to health and social care - challenges of finding right person/team at the right time.
- Marital 'disconnection' - living togther but feeling an emotional, physical distance

Maintaining social connections

Continuing with hobbies, having fun and companionship were important for the couples. However, the person with Lewy body said this became more difficult due to voice and memory changes. They found a slowness in retrieving words, loss of words, word linking, and poor memory which was challenging for them.

Developing new connections together

The couples started to meet people at cognitive stimulation and dementia groups, where they formed new friendships and 'break away groups' with people they felt had something in common. Meeting people in a similar situation also provided an opportunity to try and find out more information and tips about the condition. As this was also a time of of worry, frustration, and confusion they were able to gain some support from each other. At this point they felt *"we've had to rely on each other to a considerable extent".* But the family member started to talk about their individual experiences of becoming an advocate, of seeking information and needing to learn new skills to help their partner as their condition changed.

Social disconnections

The person with Lewy body struggled with tiredness, fatigue and eventually a lack of motivation. This could be a time of tension for the couples as they tried to maintain activities as a couple and keep busy, but the person with Lewy body dementia found they needed to pace. Memory, psychological and physical changes such as tiredness, hallucinations, delusions, word finding difficulty, incontinence resulted in the person living with Lewy body dementia reducing their social activities and interactions and the care partner starting to go out alone. This was essentially the start of loss of independence, freedom, and spontaneity for everyone, particularly when the person with Lewy body dementia had to give up driving.

Changes in connecting with adult children

The couples sought help from outside, in the first instance from friends and family. The couples in this study received a great deal of support from adult children. The ones not living locally provided financial advice, paid for equipment, alterations, helped with paperwork and organised visiting rotas. Children who lived locally would take the person with Lewy body to physiotherapy, groups, appointments, and act as sitters for the care partner, so they could maintain their own interests and attend to their own health.

Marital relationship changes

Maintaining the social, physical and emotional aspects of the mariage became difficult for the couples. They talked of the loss of companionship, and going out. They had to adjust to an ever changing relationship, as a shift occurred from marital partnership to becomng a ‘carer’. This came at a time when they were looking to access community health and social care services.

Establishing connections with health and social care

The couples were in contact with a wide range of community services. They talked about their experiences both positive and negative. They had difficulty finding the right people at the right time and they said services were often under-resourced and under pressure. Findings highlighted *“balancing”* medication and management of incontinence as particularly challenging for all couples. Medications caused diarrhoea, and constipation and at worst one person reported having a ‘psychotic attack’. Stories around bowel and bladder problems highlighted the impacted this had on their physical and psychological aspects of daily living, social activities, and quality of life. They waited ages for advice and had to go through the system-a variety of assessments and criteria checks before accessing NHS services and products.

Marital ‘disconnection’

The feeling of a marital disconnection was made more difficult if the person with Lewy body dementia had personality changes that involved mistaking the care partner for someone else, or had more challenging behaviour. In addition to continuing their everyday tasks the care partner also had to take on additional roles that their partner traditionally completed, such as cooking, driving, finances and maintenance.

Conclusion:

Physical changes, communication challenges and personality and behavioural difficulties undermined the established social connections. Help from adult children, friends and a supportive environment enabled social connections to continue and new ones to be established. Access to information, and to health and social care professionals who understand this complex condition was difficult for all couples. Providing earlier advice on dealing with tiredness, continence and behavioural symptoms may improve quality of life and help maintain supportive connections for longer. The social stages identified in this research can provide guidance for more targeted healthcare interventions and support for management of Lewy body dementia.

Appendix 19: External patient and public involvement discussions Held March/April 2022 (Part 1)

Jill (wife and former carer of David who had DLB)

General thoughts

I didn't know what or how a narrative interview was different from other interviews. She said that to help you should have five to seven broad, open questions and thinking of David and open questions I'm not sure you'd get an answer. I think you'd have to be quite specific rather than having open questions because I'm not sure that he would have been able to talk about the things you necessarily wanted him to talk about. I thought to myself now we couldn't have done that, and I couldn't have got David to talk really like that I'd have had to keep saying 'and what happened then?' and you know 'why did that happen?'

The life story work, which I know is a sort of standard thing and which we did a very short one with David when I was going to another group, and he liked doing it. He contributed to his own story, just photographs, telling me who they were and what happened, and so on.

Do you feel the 7 areas identified in the research are common/ uncommon experiences for people and families living with Lewy body? Do they 'ring true of your experiences and with of others you know?

- **Maintaining social connections (keeping up long term hobbies, friendships, clubs)**

The things we had done before we would continue to do, such as we always would go to the theatre, David liked watching sport, he continued listening to music. And we continued social life with friends in a more limited way, not in the same way much more limited.

He would never have initiated any of those things. I had to initiate everything and say, 'shall we?' If there was something coming on at the theatre, I'd say shall we go and see it and he'd always say yes because I knew what he liked. And, shall we go to the football match which he loved and he'd say yes or he'd just get his coat on but he would never have initiated any of those things. Even from the very beginning and, in fact one of the signs that I picked up before he was diagnosed was the fact that he had lost interest in the things we had done previously.

What do you mean by lost interest?

He always had his radio in the car and for example he would often come in at night and say I was listening to the radio, and this is going on or this is going to happen, shall we get tickets. And it was something I had never heard about or seen or thought about and he'd get tickets. And he'd say I was talking to someone today and they said they had been to so and so, and it might be a holiday or something, and it was good shall we have a look at it? Now all of that stopped and even just saying shall we just go out for a meal tonight, instead of cooking, all of that had stopped and so you just thought gosh he's losing interest, and that was before he was diagnosed.

Once David became more impaired, you said you did things in a more limited way, so how did that change in your friendship groups? How did you change what you did with them previously?

I'd be careful if I was going out for a meal with people, I would have to think no I don't think that would be suitable for David. It would have to be a sort of user-friendly restaurant. You wouldn't have gone to a grand restaurant; you'd go somewhere user friendly where you could get up and just wander outside and the staff would understand, and you'd come back in time for the next course you know. He would find it too long sitting if the meal was taking a long time. He would get sort of a little bit agitated, and if it was somewhere we knew I would just get up and say we'll have a walk. So, you had to think about where you're going.

We never stayed with friends overnight, that wouldn't necessarily been a good thing. He would have been a strange place and that might have disturbed him. We could go on holiday, and he was all right, as long as he could see me. When he couldn't see me that’s when he would get upset, even though he didn't know me.

Were there benefits in keeping up activities?

I don't know what you'd have done if you hadn't kept them up. Because he didn't go to a day centre until maybe the last six months of his life so he wasn't going out meeting other people in that sense, and I don't know what we would have done. And because I could drive, I could take him places which I think was an advantage. And because we had a garden, he could sit and watch me in the garden, and now and again, he’d wander out and say, ‘should I help you?’ And he was quite content, he wasn't wanting to be entertained because I think there's a tiredness as well. You know people with Lewy body dementia can get very tired. You can't be sort of dashing here, there and everywhere.

At the time, how would you have known whether David was enjoying an activity or not, would you have known?

I would know because he was quite content. And because when there was a goal scored, he would jump out with everybody else, whether that was automatic or not I don't know. If there was music, he would sort of keep in time to the music so if people were jigging about, he could do that. He gave the impression that he was enjoying it and he would laugh at the right times, or you know if something funny happened. But if you asked about it when he came home, he might tell you particularly about the match, he would tell me he had been to the much even though I’d been with him and I would say ‘Oh that was good’ and he would tell me maybe incidents that had happened, but which hadn't happened. He told me told me about things which he had seen but they hadn't happened. And he wouldn't have necessarily been able to tell me the correct score he wouldn't have known that and he wouldn't necessarily have known who they were playing, although he knew beforehand. When he was telling me about it, he was loving it even though it wasn't an accurate version, so it had benefits, because he was happy. When she talks about talking to the carers on one hand and the patient, on the other and whether their narratives were the same if she’d talked to David immediately after a match and then talked to me, she’d have got two different stories.

- **Developing new connections together – such as with people in similar situation (dementia groups etc)**

We only ever went to one group, I’ve forgotten the person who was leading it and he was a psychiatrist, and it was interesting while we were there, and he was quite happy to go but we didn’t maintain any connections. We didn't make any new connections with people in a similar group.

We went to a group at the very beginning, after David had been diagnosed. It was a camera club, and it would be the new cameras had come out, you know the digital cameras. I had bought one for David and we couldn't work it. I saw the course and I thought we could go on that so we both went. And we would learn a new skill each week and then we'd have to go out and take photographs demonstrating that skill. He loved going to that club, and he didn't do any work. We each had a computer, and I would set his up and I would set mine up, and we would have been out the previous week and taking photographs and we took those photographs, along with us, so he chose his photographs to take with him from the ones I had taken. And he didn't really converse with the other people in the group, but he liked looking at their photos on their screens. At the end of the course, we had to present our workbooks and David got a credit and I got a pass because I did the notes and then I’d say right now, you copy those notes, and he would copy the notes out in his own hand and he could do that then and he was willing to do it and he chose which photographs he would put in his file.

- **Social disconnections - trying to maintain independence**

  Trying to maintain independence is hard. David couldn't drive from the very beginning, so he lost his independence for driving, he wouldn't have been safe, He'd been a driver, since he was 17 or 18 and he missed that very much. And one time when he was quite advanced and I came onto the drive with a car, and he said, ‘will you let me put it away?’ And he just wanted to drive it into the garage which would have been the last place you’d have let him drive. You couldn't have let him drive on the road, because you wouldn't have been safe you couldn't have done it and he really missed his car.

  One of the things about independence you've got to know that they're going to be safe, while they’re independent. He could walk from the house to the shops, but I always would time him, so I’d know if he was going to be too long. He never got lost, sometimes he took longer, and I was sort of anxious and keeping an eye. He wouldn't have gone on a bus on his own. He knew he’d lost his independence and that was sad. I don't know how he could have kept his independence and been safe. He just would say ‘I can't do anything on my own’ and I thought, no you can't.

  I would invite people here and quite a number of my friend who were not necessarily joint friends, would always invite David and they knew what had happened, and they knew his situation, and they would always invite him, and their husbands were always very kind, they would take him out for a drink or something like that, so he wasn't excluded but you always had to think of that.

- **Changes in connecting with adult children - as they stepped in to help**
  (No children)

- **Marital changes - from marriage partnership to becoming a ‘carer’**

  He couldn't have done jobs around the house which he had done previously. And with financial things I could do those anyway, and I would just tell him what I’d done, and he was quite happy with that. He wasn't a man who was concerned about money and that kind of thing you know so I would take on that. I suppose I took on the care of the house where previously it would have been shared and we’d have discussed things whereas sometimes I had to make decisions when I couldn't really talk about it with him.

  It was a loss because he couldn't always contribute ideas and before you could sort of work things out between you and I might suggest that and he’d say yes, but would it be better if you did it this way or that way, or instead of doing that why don't we do this? So, you didn't have that second opinion all the time which you would have had. I think that is possibly more difficult than it would be just to do it, you can be quite capable of organizing with the gas people to get a new gas boiler but if you had been able to talk about it with David and say, ‘when we get the new gas boiler do you think we should change some radiators as well’, you couldn't have done that.

- **Connecting to health and social care - challenges of finding right person/team at the right time.**

  We were very different from most people. Once David was diagnosed, he was immediately asked if he would take part in studies, which I think there were a cohort of five studies. So, from then on, it might be sort of every three months, we might have been going and seeing this person or that person or the other person depending which branch of the study was involved at the time.

  People were saying ‘why do you bother? David enjoyed it, I think he felt he was still contributing something, so he felt useful and that's one thing to the credit of everyone, we dealt with, they made him feel worthy, which was lovely. So we didn't have this time when we were finished with anyone to do with dementia, and maybe, just had an annual check which might have been five minutes or 10 minutes, we never had that

We had the care manager who came to visit us, she must have come I think at first maybe every three months, she came to the house and then she came every month, and you got to know her, and David liked her, and I think she liked David and she was invaluable. In the last 16 weeks of David's life, we needed care, full time care and she just organized it all. I didn't have to try and find carers, or should I go to social services or should I go to care in the community or Age Concern, it was all done by her. The kind of things she would say I think David should be seeing more people I think we'll get to the occupational therapist, and so the occupational therapist came and was devising things that she would do with David and another time David was having trouble with the shoulder and she said we'll get the physiotherapist. I didn't have to do any of these things.

- **Marital 'disconnection' - living togther but feeling an emotional, physical distance**

When we had carers all his carers were called Jill. They weren't me they were Jill. He would say that the carer Jill was here today, and he didn't know it was me. You can't always describe it, can you, their disconnection? I think it had happened beforehand before that, I don't know that you always knew, because he would respond to me if I was suggesting something and he wasn't at this stage, having lengthy conversations, so you weren't having deep meaningful conversations anyway at that time and I don't think you always recognized that he hadn't recognized you.

Based on your own experience what 3 things would, or could have made a difference to you as a family carer?

1. More knowledge about Lewy body dementia, I'd never heard of it so for knowledge things like even the fluctuations that you get. There was a time when I queried whether David had been misdiagnosed because I thought he's fine, and it wasn't just one or two days ago it was a while and I thought he's made a mistake here, and so I actually queried it.

2. When someone has a major illness, you don't always recognize that everything you can't put down to Lewy body dementia. He could maybe have a tummy upset which would have nothing at all to do with Lewy body dementia. You have to be careful that you didn't just attribute everything to Lewy body dementia.

3. Practical advice and the importance of power of attorney. If I had died first David would have been on his own, so I had to appoint people who would manage his care does not take over his care, but make sure he was cared for. Attendance allowance could make a big difference to people, you can get a disabled badge for the car because, you can park near a doorway, and you can ask for assistance at the airport and ask for assistance on the train. So, I can keep hold of him while someone else sorts out cases, and all of that's available, but I don't know if people know that.

Thinking about interactions relationships with health and social care professionals and services:

a) What was your best experience of services?/ b) What made it a good experience?

- Taking part in study trials.
- I don't know if everyone realizes the benefits of them. I mean David knew it would make no difference to him in the long term it wasn't going to find a cure for him, but I think he felt useful. In fact, in the short term it did have benefits for him. We would have felt much more isolated I think if we hadn't been involved in study trials.

- David had botox injections in his neck which stopped the saliva because it froze the glands. And so, he would go back every two months, three months and have and it meant he didn’t have a saliva problem, and while it didn't cure his Lewy body dementia it improved his quality of life.

c) What was the most frustrating? / d) Why was that do you think?

- The last six months David went to the day centre, and I had frustrations there

- I think they weren't very well trained. It would have paid them to just observe, just sit and watch the people in the room but they weren’t trained to observe, to notice, to be aware and I think there could be more observation in the training, and it wouldn’t take a lot of money.

e) What would you like to see improved, made better?

More flexibility and common sense

How useful would this information be for people living with Lewy body dementia more generally? For professionals? For managers in charge of services?

I think with the steps at least if you have an awareness of what might be, you might know what to look for so I think it would be useful. The more information you have, the better you are at judging what is happening. The more information you have, the more knowledge you have, the better you are dealing with just even everyday basic things.

You can go on a level plane, and you think great David’s not getting any worse then suddenly I think it goes down it's not on a slope like that. It would be very, very like a plateau and then a sudden drop.

I don't necessarily think that because a person deteriorates in a step model that your connections will necessarily step as well. I think it's only maybe afterwards when you reflect on your experience. At the time it may well be that you're too busy doing what you have to do to have time to reflect.

- The ‘separated but living together’ step

I don't think I felt like that, no, I think, as long as David was there, he was there, even though he wasn't sometimes mentally there or psychologically there. He was just David and whether he could do it, or he couldn't do it, you know it didn't make that much difference, as to how you thought about him, I didn't look upon him as a patient, he was just David.

What type of interventions should be recommended for clinical practice and further research?

(Unsure)

What type of support should be recommended for clinical practice and further research?

(Unsure)

Summarised transcript of focused discussions held March/April 2022 (Part 2)

Dawn, wife and former carer of Greg with DLB
Jan, wife and former carer of Lewis with DLB
Millie, wife and current carer of Jack who is living with DLB
Grace, daughter of Mike who is living with DLB in residential care

General thoughts

I agreed with a lot of what she was saying (Millie)
I found a lot of it I agreed with some of them were more relevant than others but overall, it tied in with my experience (Jan)

Do you feel the 7 areas identified in the research are common/ uncommon experiences for people and families living with Lewy body? Do they ‘ring true of your experiences and with of others you know?

- **Maintaining social connections (keeping up long term hobbies, friendships, clubs)**
  We tried very, very much to continue with social interaction, but Greg’s cognitive ability was such that as the disease progressed, he didn't cope so well with larger numbers, and he was better in a in a calmer environment with fewer people. One of his classic things that he would say was ‘too many people, too many people’. His verbalisation was massively reduced and even with that, that was something that he said a lot ‘too many people’. (Dawn)

  Instead of going out for food, for a meal we’d go for ice cream or coffee, because that was enough for him. He might need to have physical help and he was either embarrassed or got too tired, or he would need the toilet and his mobility wasn't great or he couldn't find the toilet. So, keeping social connections is vital, but you have to adapt to their ability as things progress. (Dawn)

  The biggest change in Lewis because he'd always been very outgoing very much an extrovert loved being with people and he was in a lunch group for retired Librarians which he loved to go to normally and he started not wanting to go and he felt uncomfortable he couldn't hear properly. And that was one of the first things before he was diagnosed, I sent him off for a hearing test, I thought, he was going deaf. The hearing test was fine, we later found out it was the Lewy bodies that was causing the hearing problem. He also was acutely aware of his condition and embarrassed by it, so that was a barrier for him as well, so increasingly he preferred to be just with me really or in very, very small groups. (Jan)

  Dad got forcibly retired so he didn't really pick up any hobbies and my dad was quite extrovert but actually I think he suffered because he didn't pick up anything after he retired. (Grace)

  It became very obvious quite quickly that he would struggle to keep up conversations if there were too many people talking at the same time, so mum and dad did keep up some sort of social interactions, but it was done so on a much smaller kind of scale, so trying to make it more one on one. If we were organizing a group, we kind of started briefing people beforehand and just saying you know when you are talking to dad can you just make sure you're looking at him and all that kind of stuff. You had to adapt situations to try and help him more and help him feel more comfortable in that situation. (Grace)

I find Jack doesn't like when there's a lot of people there. If there's about four of us there then he can follow the conversation but even then, if he wants to say something he is about 10 minutes behind. We try to go up on a Sunday for Sunday lunch to the golf club and we get a table for four of us or six of us and he's quite happy with that. They're people that he does know, although he'll turn round to me and he'll say, 'who was that?' but they know him and they know what's wrong and they'll come over for a chat and they understand if he doesn't recognize them and he enjoys that interaction (Millie).

Organizations helping to maintain social connections

He's not got his membership to the golf club anymore. The Secretary phoned me, she says it's not worth the money, he's hardly played last year, it's a lot of money for you to pay out so she's agreed that on a Wednesday which is a ladies morning i'm only going to do, nine holes and if I want to take them with me then she says, you can go out you don't have to pay just take him so the golf club has been very good. (Millie)

- **Developing new connections together – such as with people in similar situation (dementia groups etc)**

  I have a friend, whose husband has dementia, and we meet up for coffee and we go to a club which is for people that have got mental disablement of some sort and there's always a carer that sits with them whatever they're doing if it's arts and crafts or pottery there's somebody else there so that we can communicate with them, rather than the whole table. (Millie)

  I think the new connections we made were more for mums benefit than dads. Dad was very much about wanting to make sure that mum was going to be okay and less about himself and there were a couple of groups for people with dementia to go along to and do little sport kind of activities and I found a local one to me, a memory group they both went to for a while and enjoyed going to but it was more for my mum being able to talk to other carers and other people going through the journey that she was going on, and dad did chat to people because he was always like that anyway but those new kind of connections that they made with people in similar situations were much more about mum's benefit. (Grace).

  We went to the xx group which was supported with volunteers, and they had a carer or a volunteer that would do one to one with Greg and that would enable me to get an hour to go and have a walk into town and go and have a coffee, on my own or with one of the other wives which was wonderful. (Dawn).

We had a living with memory loss course which we both went on in a group all with various different types of dementia no one else had Lewy body. And that was that was quite helpful, and they organized some outings there was a boat trip one time and a movie and he enjoyed those, because I was with him. (Jan)

I got a lot of love from the situation I got a lot of connections with a lot of people who gave us an awful lot of care and support and brought a lot of love and a lot of joy to our house that we wouldn't have seen if Greg health had been different, so it wasn't all bad it really wasn't all bad. People don't want to be dragged down with this it's all bad and it's all hopeless and it's only going to get worse. I can't pretend it's not hard, but we had some lovely times and some lovely joyful memories that are lovely to hang on to. (Dawn)

- **Social disconnections - trying to maintain independence**
  He’s often said I’ll take the dog out and I’ll say no the dog’s too strong, for you, you won't be able to hold him and I don't want you getting pulled over and he’s kind of accepted it. (Millie)

  When it when it was eventually evident that he really shouldn't be driving he wasn't happy at all, and I said look I can take you anywhere, you want to go anytime you don't need to drive it would just be awful if there was an accident, because you didn't see something quick enough or you didn't you find the right gear You just don't need that risk. He didn't like it, and he took a massive hump with me for many months over the driving, and I mean not in the other parts of our life, but that was definitely a sore spot for a long time. (Dawn).

  By the time Lewis got was diagnosed his first question after asking what his prognosis was his second question was ‘should I still be driving?’ and the consultant just shook her head. And I think he knew that really and I must admit I’d been up until then trying to sort of let him keep that level of independence, but I was becoming a more and more nervous passenger. But he was embarrassed about it, and he kept mentioning it every time we saw someone he'd say, ‘I can't drive anymore’. (Jan)

- **Changes in connecting with adult children - as they stepped in to help**
  I was having discussions about advanced decisions and about what he wanted for his future care and all those kinds of things that you never think you’re going to have to sit down and talk to your father about.
  Dad and I were always close, but if something was going on, he used to keep it very close to his chest, so I guess there was a bit of a change there in terms of him needing somebody to kind of help and support him, and some of the things that he had to kind of try and think about. (Grace)

  My boys were incredible, one was in Australia, and he travelled regularly to visit, and x was in London and he came up at least one weekend a month. And it was more to give me some support than anything else, but they’d come, and they’d taken him to football and things and I just took care of all of the admin and appointments and bills and stuff like that, but my boys were absolutely my rock. The Lewy body journey that we took made for some much, much closer connections with both of our boys, then I think we probably would have had if things have been different. (Dawn)

I find that my eldest son, he is more supportive for me on the financial side. If I have a problem, I can speak to him about it and he'll advise and help me out that way. My youngest son, who lives close by is more supportive on the mental health side and he's very good with Jack, he calms him down straight away. (Millie)

- **Marital changes - from marriage partnership to becoming a 'carer'**
  My mum really struggled to start with, and she was talking about the fact she couldn't do this, and she can't be with him anymore and it was a real internal battle that she was having that this wasn't what she'd signed up for when they got married, this was not what the plan was for their later years, for their retirement years. She didn't want this; she didn't want her life to end because she was going to have to be this carer of dad and that went on for quite a long time. I had to support her quite heavily to kind of get her through that period and I think she was probably going through kind of cyclic grief because she kind of has come out the other side of it. And it is really very much about I'm doing whatever I need to do to try and make dad's life better and she'll go in to visit him, she's cutting his hair and she bought herself a new engagement ring from a jeweller that they visited once during one of their holidays and on one of dads more lucid days she asked dad to kind of marry her again. (Grace).

  It was over two years before Lewis was diagnosed, so it was a long time before I realized what the problem was anyway, but at first because we'd always been such equal partners and he'd always been so helpful, I really resented having to do more. He just wouldn't seem to notice; you know if I was clearing up after dinner. When he was well, he would say, 'can I do that? I'll clear up' and he would do ironing and things like that, and he would just wander into the room, as I was ironing and smile at me and wander out again and so it was difficult for me to accept that that was just beyond his control and it wasn't his fault really so there was a period of adjustment there. (Jan)

- **Connecting to health and social care - challenges of finding right person/team at the right time.**
  I took advantage of what was then Crossroads it's now part of Carers trust and they provided me with a sitting service and I had somebody who came once a week and I had a full afternoon or a full evening and I used to use it to go to my choir and that just meant that I was able to step away and know that Greg was safe and slowly he did build a relationship with the volunteers that came to sit with him. At first, he was a bit anti 'I don't want strange people coming in here'. They slowly built a rapport and build confidence and it got that they had a nice relationship with him, and that was absolute gold for me. (Dawn)

  It was really hard to work out where to go, there's so much information in some respects that it was difficult to know where to go to find out exactly what. Mum got some that of that help where somebody could come in for an afternoon so she could go out and just go do anything she wanted to do for a few hours And that took a while to kind of find that information, so it was quite a lengthy process. I felt like I was digging a lot to find stuff out that we needed to find out, and so I think it can be a challenge. (Grace).

- **Marital 'disconnection' - living togther but feeling an emotional, physical distance**
  Mum was kind of going through a kind of turmoil, I guess, is the best word I can come to describe it then she was feeling guilty because she promised to be with dad forever but equally they started sleeping in separate rooms, because she couldn't sleep in the bed with him because he kept kicking and lashing out in his sleep and so I think again, that was a bit of a process she went through with feeling detached but feeling guilty because she felt detached (Grace).

  Jack and I are in separate beds now because of the kicking and everything and there are times, where I find it really difficult with him, but yeah we're still together and that's fine. It's not what we planned for our retirement, but we've just got to accept it and make the best of it . We've been married for 55 years come this year and we knew each other for about three or four years before that so we're talking about nearly 60 years we've known each other and it's hard. We did everything together and if we were doing anything we'd discuss it first. It's very hard, now I've got to make all the decisions. He doesn't know what to do, he doesn't know how to do it.
  (Millie)

  I just feel that, yes, we're married but I feel I'm becoming more of a carer than his wife. He'll turn round and he'll say, 'Do you still love me?' I've had to take my rings off because I've got arthritis my hands and my fingers are swelling and I didn't want to get the rings cut off and he turned round to my sister and said 'she doesn't love me anymore because she's taken her rings off' (Millie)
  Greg and I were very close, and we were together from being very young and we had a great connection like close friendship. We'd been together over 40 years, and if that had been different if it had been a newer relationship, I don't know that I would have had the staying power that I did have. As it as it was, it was unconditional that's what he needs that's what I want to give and equally if it was me that had been unwell I'm sure that he would have been the same. If I had been in a new relationship, perhaps with a man for four or five years let's say and then this had got landed on my lap I don't know that I would have felt the same (Dawn)

  We lived together we worked together. We were together for 26 years but we used to joke that we probably spent more time in each other's company, than a lot of couples who had been together twice as long because we spent you know 24 seven together and we really enjoyed each other's company but then you become the carer, and I remember once Lewis saying to me 'you don't love me anymore' and it tore my heart and it wasn't true, of course, but it factored into the decision to put him into a care home (Jan)

Based on your own experience what 3 things would, or could have made a difference to you as a family carer?

There's no in-depth information about what you're entitled to and what the costs are, there's nothing. (Millie)

There isn't a service that listens to your needs, there's plenty there if you've got the savvy to find it really when you're dealing with so many other things you don't know where to turn. A support specialist to signpost. I think, for me, would be the one thing because there's plenty of excellence but you've got to know where. (Dawn)

You can find all of these things, but they're not joined up at all, and it's patchy, some of them are better than others, we saw lots of different people it would have been better and more efficient and more effective if there'd been one person with us throughout who could point us in the right direction. I don't think it's just a case of more money needed it just needs a different emphasis (Jan)

Thinking about interactions relationships with health and social care professionals and services:

a) What was your best experience of services? / b) What made it a good experience?

The challenging behaviour team were brilliant. Early on in the diagnosis the consultant suggested that we talk with them, and they came out and did lengthy sessions at home with us things like teaching me how to steer things, distractions, they were brilliant. They get the shining star badge from me. (Dawn)

The crisis team they were very good (Millie)

c) What was the most frustrating?

One of the difficulties from my experience anyway, is trying to find the right kind of support that you needed at the right time, it was incredibly time consuming and difficult and quite exhausting really. The fact that it does take so long to diagnose it's a difficult one to diagnose. And it was such a long time, and our GP who I got very cross with in the end just kept insisting that everything was okay, that it was just a normal part of aging. (Jan)

There was a lot of 'no everything's fine' and passing from pillar to post and getting nowhere and it wasn't until he got his confirmed diagnosis that things started to fall into place My social worker was hopeless, absolutely hopeless. The admin of like consent forms and things hadn't been processed, for months, which is no wonder things hadn't happened. They just kept fobbing you off and fobbing you off and you're waiting, you're waiting to find out you're waiting to hear and it's just not forthcoming it's very, very bad.
(Dawn)

d) Why was that do you think?

It's about giving them the right information, answering the right questions the right way. For example, I had never mentioned about Greg having what we later found out to be hallucinations, we just thought they were dreams, and it maybe that if the doctors and the consultants had had that piece of information, it would have been critical to them changing their opinion. It was just something that we just thought was a quirk of his. We never thought to mention that when they were doing an assessment about his memory. (Dawn)

e) What would you like to see improved, made better?
The more you understand, the more you can cope, the more you can manage it, the more you can let things go and say that's a symptom, that's the way it is. You have to learn, and you have to understand. For me, I had to know, and I read, and I trawled the internet and I asked questions and I wanted to understand as much as possible so that I could cope. (Dawn)

How useful would this information be for people living with Lewy body dementia more generally? For professionals? For managers in charge of services?
The nurses and doctors they should get a tutorial done on that (Millie) (*referring to the study findings*)

What type of interventions should be recommended for clinical practice and further research?
Unsure
What type of support should be recommended for clinical practice and further research?
Unsure

- Progression scale or steps? Are they different lengths or durations?
  Medically and socially and with fatigue everything was just a roller coaster you never knew what he would be like we'd have a few weeks of low and then be great again. So, not for me it wasn't a steady decline, it was a roller coaster for me. (Dawn)

  It was a gradual, very gradual and quite subtle decline, and then a big decline. Really dramatic one, and then it would sort of plateau again and then another big decline, so it was more of that sort of pattern. There were steps (Jan)

Appendix 20: External academic feedback

Thank you for the opportunity to provide academic feedback on this interesting and worthwhile study. This feedback is based primarily on many years' experience conducting research with people with Lewy body dementia and caregivers, but also time spent as a practitioner psychologist providing pre- and post-diagnostic support in a Lewy body disorders clinic.

The use of narrative-based analysis, a social constructivist approach which recognises narratives as constructed rather than representative of any single reality is highly credible as the theoretical approach for this project, and well-suited for researching the lived experience of the population in question. This methodology offers a holistic perspective on the lives of the participants and how their stories unfold over time. It adds emotional and experiential depth to the project beyond the thematically identified findings.

Longitudinal data from the Lewy body dementia/caregivers cohort has previously been limited with interview-based studies often involving cross-sectional designs or based on specific pre and post intervention evaluations. Through use of a longitudinal approach in the current project, the student skilfully demonstrates the evolution of the narrative both across successive interviews and between participants. This reveals how various core and noteworthy features of the condition escalate and gain new meaning over time.

The student capably signposts towards overarching narratives of connectedness and communication. The social model of disconnection provides a valid interpretation and while for some there may be elements of counterbalance to this deterioration e.g., increased physical connection through caregiving tasks, it vividly conveys the challenges of living with Lewy body disease. The model illustrates the widespread disruption of a disease such as dementia on previously anticipated narratives of later life, particularly a dementia widely acknowledged as rapidly progressing in comparison with the more common dementia subtype of Alzheimer's disease.

On reading and subsequent discussion with the student, it is evident that Murray's four stage approach is well suited to the analysis, with the key findings spanning and connecting the four levels. To further justify their theoretical approach, the student gives substantial weight to the co-creation of the narrative between the couples. Recognition of the significance of the person with lived experience/caregiver relationship; its co-creation, increasing centrality and changing nature, is a particular strength of this work. The project proficiently recognises the importance of this dyadic relationship in the context of the complex nature of Lewy body dementia with its notable neuropsychiatric, cognitive, and physical features, and highlights the inherent tension between the caregiver as both an enabling and dominating voice.

The data extrapolated from the interviews and life story work offer credible representations of the lives of people in various stages of Lewy body disease. Whilst details of individual experiences are necessarily unique, the quoted words are highly plausible. The direct participant voice provides enlightening instances of the many ways in which people with this diagnosis are affected and the burdensome nature of much of the caregiving role. These accounts show coherence and resonate strongly with similar trajectories shown by many such couples I have encountered. The interpretation by the student can therefore be viewed as trustworthy and believable.

The perspective of the student reaches beyond the academic to encompass their wide and varied experience as a healthcare professional. The mutual acceptance of the student as an appropriate person to elicit significant health care information from the participants may have stemmed from this. Their skills have enabled effective collaboration with participants whose story-telling voices were severely limited by dementia and constructing meaning from these narratives offers unparalleled insights beyond what may have otherwise been obtained.

Much of the project narrative is visibly situated within the social structures of the health and social care system. Narratives can be a mobilizing impetus for therapeutic purposes or for empowering others who share an identity with the participants, and a further strength is therefore the potential for future application. This may include focussed interventions at various stages of the Lewy body disease journey. For example, the need for social connectedness is fundamental to the human state and the model of changes in connectedness and communication developed by the student graphically illustrates the pathway followed by the spousal couples with respect to this. Whilst any model is generalised and not everyone will follow a linear route or pass through each stage, this may provide a useful tool for raising awareness of where, and in what way social disconnection might be anticipated to increase. Findings will consequently be of interest not only to academics, but also to health and social care professionals, and dementia charities working to improve their quality of life of people with this complex condition and their caregivers.

Dr A K
Chartered Psychologist & HCPC registered practitioner psychologist