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

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 to 2020.

Review Methods: Twenty-six articles from twenty studies were synthesised (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: Lewy body dementia, Parkinson's disease dementia, dementia with Lewy bodies, integrative review, experience, caregivers, carer, informal care, family, nursing

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 24-31% (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 under, 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 people with Lewy body dementia have poorer survival time compared to 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 upon to manage and coordinate many aspects of dementia care including physical, social, and medical needs (WHO, 2012).

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 in 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.

THE REVIEW

Aims:

The aim of this integrative review was to synthesise 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 health care professionals?

Methods

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 a number of 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 are no specific reporting guidance for integrative reviews (Toronto & Remington, 2020).

Search method

To ensure the maximum number of eligible primary sources were identified Whittemore & 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 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) . 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: Inclusion and exclusion criteria).

[INSERT BOX 1: Inclusion and exclusion criteria]

Medline, CINAHL, PsycINFO, and AMED databases were searched for English language publications occurring between 1995-2020. 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.

[INSERT BOX 2: Search strategy]

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’ also emerged 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.

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 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 PRISMA Flow diagram of literature searches and selection, March 2020).

[INSERT FIGURE 1: PRISMA flowchart]

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

Quality appraisal

The included studies were evaluated for their methodological quality, and overall relevance to the review questions by applying the 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) Supplementary 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 achieved. A summary of characteristics of included studies and quality appraisal information is provided in Supplementary table S1. It was decided to retain all articles for synthesis, regardless of methodological quality as they offered different perspectives on personal experience (Table 2: Summary of included studies).

[INSERT TABLE 2: Summary of included studies]

Data extraction

Data was extracted using the headings: study aims; research questions; participants 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: Supplementary table S1). ATLAS.ti 8 software was used for organisation of data extraction, coding, and synthesis of the data.

Data analysis and synthesis

Data analysis and synthesis involved three iterative phases: (a) papers were ordered and categorised according to their primary focus (Toronto & Remington, 2020; Whittemore & Knafl, 2005); (b) a convergent integrated design was applied to convert quantitative data to qualitative (qualitising) (Noyes et al., 2019, p.9). ‘Qualitising’ was achieved by identifying words or phrases related to frequent and recurring descriptive statistics in the results sections. Examples of ‘qualitising’ 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 presented diagrammatically (FIGURE 2: Display of findings - the experiences of people living with Lewy body dementia and their family carers).

[INSERT FIGURE 2: FIGURE 2: Display of findings - the experiences of people living with Lewy body dementia and their family carers.]

RESULTS

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., 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., 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 & 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 on-line surveys. (Armstrong et al., 2019; Galvin et al., 2010a; Killen et al., 2016; Leggett et al., 2011, 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% - 100%, and most participants were female carers (62% -

100%). 3,342 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 et al., 2020; Vatter et al., 2018a). The Zarit Caregiver Burden Interview (Zarit et al., 1986) was frequently applied with the Neuropsychiatric Inventory (NPI) which found 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 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 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). Quality of life experiences were measured using the EQ-5D (Boström et al., 2007; Shin et al., 2012; Vatter et al., 2020; Vatter et al., 2018a), 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 was 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 & Chappell, 2019; Wu et al., 2018).

Experience of diagnosis, clinical care, support and information needs were predominantly represented by on-line surveys (Armstrong et al., 2019; Galvin et al., 2010b; Killen et al., 2016) qualitative (Armstrong 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 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).

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 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.

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 regarding disease course and prognosis, available community resources, referrals to appropriate services and difficulty coordinating care across healthcare professionals (Armstrong et al., 2019 a; Armstrong et al., 2019b; 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 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 dementias and carers also report the importance of establishing a collaboration between themselves and health care 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 found to be important at the end of life, where 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).

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 et al., 2018a). 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 et al., 2018b). 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).

Theme 3: Living with behavioural and psychiatric symptoms

The papers highlighted 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 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 & 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 were 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., 2017; 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 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).

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 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 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 et al., 2018a). 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 (Vatter et al., 2018a; Galvin et al., 2010b), 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 et al., 2020; Vatter et al., 2018b; Wu et al., 2018).

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 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 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, 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 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 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). 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, in order to address the complex physical, cognitive and psychosocial needs those with Lewy body dementia may require life-long tailored support and services (Capouch et al., 2018).

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 synthesising 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.

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 limited 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 experiences may change and fluctuate, there is a need to incorporate a longitudinal approach in future research.

Implications for practice

Increase 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, is designed to provide 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 optimise 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 are considered important factors when developing carer support services.

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 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.

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.

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.

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.

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.

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.

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.

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 Br?n, 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.

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*(1), e024983.

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. *International Journal of Geriatric Psychiatry*, *28*(2), 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*(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.

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*, 10.1212/WNL.0000000000004058. 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–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.

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. *BMJ 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 in Aging*, *3*(3), 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.

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.

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. (2017). 'Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease': Corrigendum. *International Journal of Geriatric Psychiatry*, *32*(4), 470.

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.

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.

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. (2018a). Multidimensional care burden in Parkinson-related dementia. *Journal of Geriatric Psychiatry and Neurology*, *31*(6), 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 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

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).

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