

REVIEW

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

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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 Knafel, 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

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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.

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,

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

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

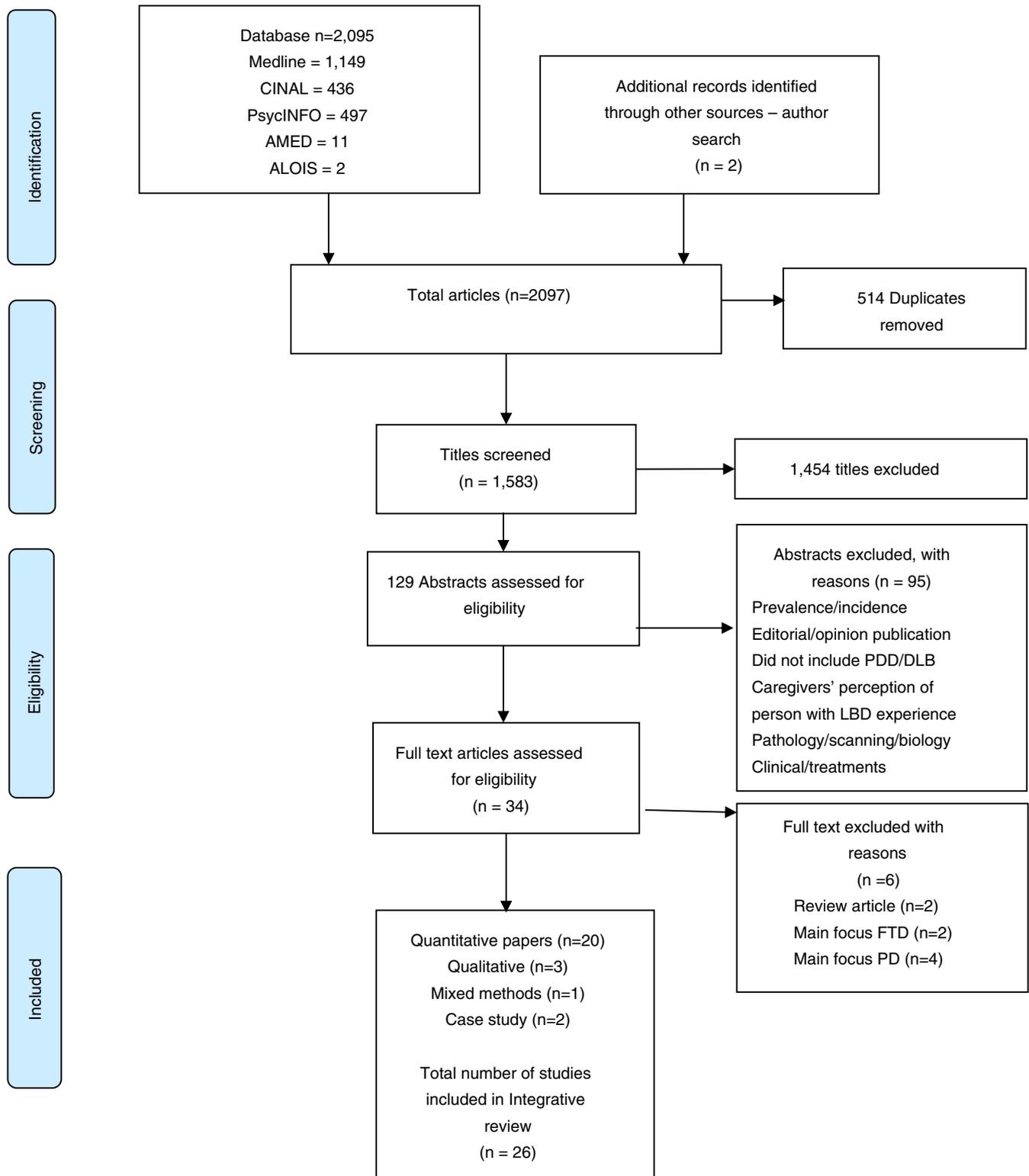


FIGURE 1 PRISMA Flow diagram of literature searches and selection, March 2020

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; Whittmore & 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)
Kurusu 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).

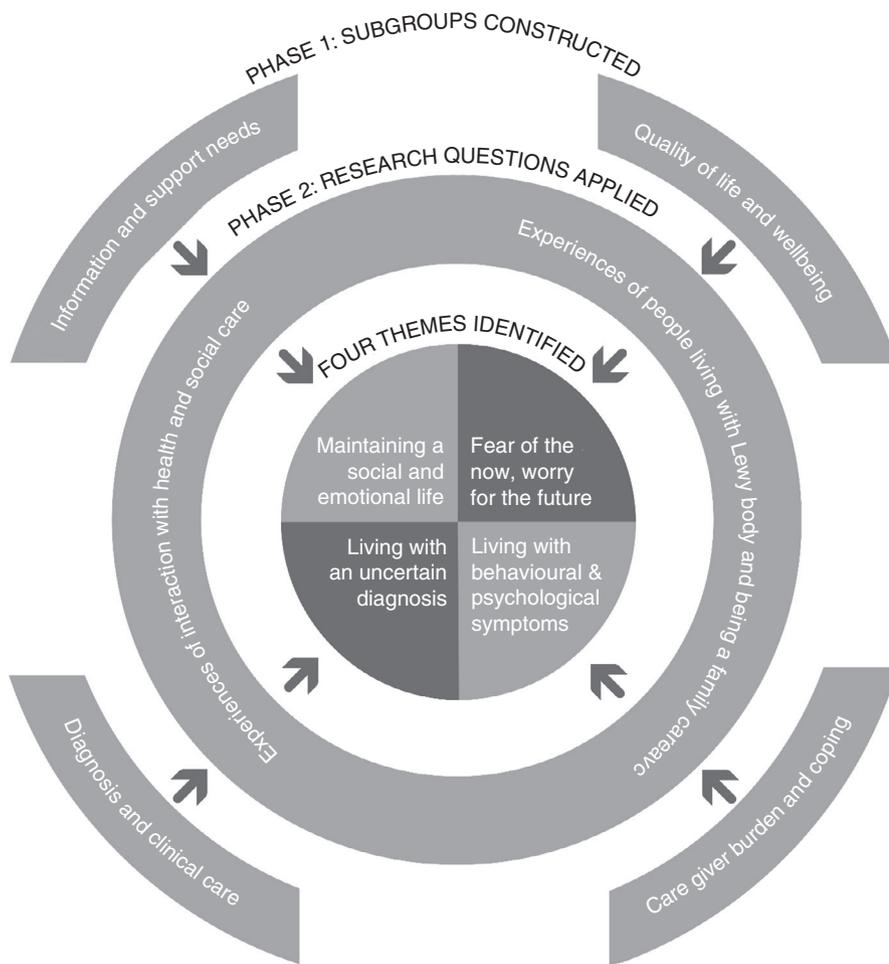
The papers were initially sub-grouped according to their predominant focus of caregiver burden and coping, quality of life and well-being, diagnosis and clinical care, and information and support needs (Figure 2). Eleven papers focused on caregiver burden and were of a cross-sectional design (Galvin 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.

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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.

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