OPEN LETTER

Widening the scope of social science research on the dementias: the importance of Lewy Body Dementia

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Abstract

Lewy Body Dementia (LBD) is an umbrella diagnostic label which includes both Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD). Research on LBD has overwhelmingly adopted a biomedical, clinical perspective, while the field of dementia studies has often orientated towards singular, monolithic understandings of dementia. Accordingly, diagnostic categories, sociotechnical constitution, or lived experience of dementia subtypes of have not been adequately disaggregated and conceptualised. The heterogeneity of LBD's aetiology, presentation, and management - located across historically constituted medical specialities underscore the need to build, critique, and extend conventional social sciences approaches to neurodegenerative illness and health, with the aim of ultimately improving health and care. Here we review existing social science literature regarding LBD, and propose an agenda for interdisciplinary research on the condition. First, we map the social arena of research on LBD and its relationship with existing Dementia and Parkinson's Disease research. Second, we examine the clinical and service barriers and facilitators to diagnosis and management of LBD.

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Third, we analyse the role lived experience might play in informing social science research on LBD. We conclude by highlighting 10 key priorities around which a social scientific, and in particular a sociologically-informed, approach to LBD might coalesce.

Plain English Summary

Lewy Body Dementia (LBD) is used to describe two illnesses; Dementia with Lewy Bodies and Parkinson's Disease Dementia. Most research on LBD focuses on medical and biological aspects of the illness, with less attention paid to how people live with the condition. When social scientists do think about dementia, we often don't tend to think about how the different types of dementia can affect people in different ways. LBD is different to other types of dementia. As well as affecting people's memory and thinking, LBD also affects people's movements, and can cause people to see things that aren't there. However we haven't tended to think specifically about how LBD affects people's lives.

This paper argues that we need a better understanding of LBD that includes people's real-life experiences, social factors, and their experience of diagnosis and care. It's symptoms and treatment vary widely, and the condition sits between different areas of medicine—like neurology and geriatrics—which can make care harder to manage.

In this article we review what social science research already exists on LBD, and suggest how future research can do more to connect medical knowledge with people's experiences of living with LBD. We look at how current services help or fail people with LBD, and how understanding their personal stories can help shape better research and care. We finish by suggesting how medical professionals and social scientists can work together to improve our understanding of, and support for people with LBD.

Keywords

Lewy Body Dementia. Dementia. Dementia with Lewy Bodies. Parkinson's Disease Dementia. Biopolitics

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Introduction

Lewy Body Dementia (LBD) is an umbrella diagnostic label which includes both Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD). In UK clinics, DLB accounts for around 5% of all cases of dementia, while PDD occurs in 9.7% of PD cases[1]. There is, however, evidence that LBD is underdiagnosed and is likely to be sub-optimally managed[2]. The core clinical diagnostic symptoms of DLB include fluctuating cognition, recurrent visual hallucinations, REM sleep behaviour disorder, and one or more spontaneous features of parkinsonism[3]. Diagnostic criteria for PDD include an established diagnosis of Parkinson's disease, decreased global cognitive function, and impairment in more than one cognitive domain and activities of daily living[4]. Such symptoms differentiate LBD from more common forms of dementia such as Alzheimer's disease, which are characterised by a more general decline in cognitive function.

In this paper, we critically review the existing social science and related literature with regards to LBD. Following this, we propose an agenda for future social scientific - and particularly sociological - research on this condition. In the context of an ageing population and increased social visibility of dementia, we hope that this will also inform the wider field of social science research on the dementias. Our point of departure is the relative neglect that LBD has experienced in biomedicine, dementia studies, and in social research on illness and health. This is underscored by a lack of recognition of the heterogeneity of lived experience across dementia conditions within much research. Furthermore, we suggest that LBD presents a unique, timely and important topic for establishing an approach where the sociotechnical process of disease categorisation in the laboratory and clinic is seen in close relationship with professional and non-clinical practices of illness management. We thus also provide an analytical overview of the scientific and technological framing of LBD, identifying historically emergent epistemic and institutional tensions within Alzheimer's and Parkinson's disease research. Further, we detail clinical and service organisation barriers and facilitators to diagnosis and management of LBD and how these might interact with social determinants of health. Finally, we consider the everyday aspects of living with LBD, particularly the impact of symptoms including cognitive fluctuations and visual hallucinations on quality of life. In our conclusion, we draw on our key findings to outline a research agenda for social science research on LBD. We also argue that people with lived experience of LBD should play a salient role in developing and refining this agenda.

Diversifying dementia within social science research

Until relatively recently, dementia had historically been positioned within biomedicine as a 'Cinderella' illness, receiving relatively little attention or funding when compared to conditions such as cancer and heart disease[5,6]. Yet, since the turn of the millennium, and accelerating over the last decade or so, the prevention and treatment of dementia has grown significantly as a priority within the health and social policy spheres of a range of countries. This has driven increased funding for dementia research and a greater focus on dementia services within clinical care[7]. In the United Kingdom, for instance, the 2010s saw significant political attention paid to dementia, including through the then Prime Minister David Cameron's Challenge for Dementia[8]. This collectively led to significant raising of the profile of dementia, as well as dramatic increases in public and private sponsorship of dementia research - growing from £28m in 2009–2010 to £83m in 2017–2018[9].

Subsequently, Dementia slipped somewhat down the political agenda, although the Dementia 'Moonshot' proposed the investment of £1.6bn in dementia research over ten years from 2021[10]. However, at the time of writing this investment has not been forthcoming. The wider investment in dementia research has also driven the creation of several dedicated dementia funding streams across multiple UK research councils, alongside the establishment of the UK Dementia Research Institute in 2017. The rise in the profile of dementia has been accompanied by a policy drive towards increasing dementia diagnosis rates and provision of post-diagnostic support services[11,12], although in practice continuing austerity in health and social care has constrained the expansion of dementia care services. Accordingly, although it is arguable as to whether this growth has met its aims of developing effective pharmacological treatments, and while it continues to be underfunded compared to diseases such as cancer, the profile of biomedical dementia research has undoubtedly grown significantly[9].

Coinciding with the growing profile of biomedical research within dementia has been the growth since the early 1990s of the field of dementia studies. This discipline has been inspired by a disparate literature that includes nursing, social care and social work, psychology, sociology, social gerontology, and the wider social sciences. Dementia studies has subsequently evolved as an alternative field of inquiry regarding dementia, its lived experience, and associated care practices. Given the comparative lack of attention and status historically given to dementia, dementia studies emerged as a critique of the failure of medicine to provide effective dementia care. In doing so, it has advocated for person-centred and subsequently relationship-focused and rights-based approaches to dementia[9]. Those in the discipline engage with people living with dementia as holistic persons in all their biopsychosocial complexity. While lacking funding when compared to biomedical dementia research, dementia studies has led to significant transformations in dementia care practice[13,14].

With the foundations of the field lying in the person-centred approaches advocated by Kitwood[15], more recently research in dementia studies has explored the potential of relationship-centred care[16]. It has also embraced a rights and citizenship informed approach to people with dementia and dementia care practice. Drawing on social studies of disability, rights-based approaches in dementia studies acknowledge the person living with dementia as a citizen possessing the full gamut of human rights, and as such possessing the same standing in relation to research and practice in health and social care as any other citizen[6,12,17,18]. Recent years have also seen the growth of critical dementia studies, developing a lens

configured through feminist, disability and queer studies. Critical dementia studies argues that both biomedical approaches to dementia and care-based approaches in dementia studies have paid too little attention to the biopolitics of dementia[9,19]. In contrast, critical dementia studies considers questions such as how framings of and interventions for dementia too often elide the role of wider, intersectional social inequalities in differentially influencing experiences of dementia[9,19–22].

Outwith dementia studies per se, social science has, in the past three decades, focused overwhelmingly on how biomedical models of dementia should be replaced with social, psychosocial or biopsychosocial models. Work situated at the interface of medical sociology and the interdisciplinary field of science and technology studies (STS) has often sought to critique and challenge solely biomedical conceptions of dementia by tracing changes in the scientific and technological framing of Alzheimer's disease. Of particular focus has been the move to a 'preventative paradigm' and the expansion of diagnostic framing of Mild Cognitive Impairment (MCI) as both an explicit disease category and prodromal step in the dementia trajectory[7,23,24]. With their origins in the social sciences, both dementia studies and sociological inquiries have implications for framings of persons experiencing cognitive impairment[25], the wider conceptualisation of dementia as disease category, and the professional cultures and practices of illness management, as well as the position of dementia in the popular imagination[26].

A recent example of the implications of the biopolitics of dementia for those living with the condition, is the representation of people with dementia in fundraising campaigns in 2024 by the Alzheimer's Society, a major UK research charity. This campaign, called 'The Long Goodbye', was described as an attempt to demonstrate 'the unvarnished truth' of living with dementia to generate a public response. The campaign was also launched during a period when decisions were being made in the UK about whether a new generation of anti-dementia drugs (Lecanemab and Donanemab) should be licenced for NHS use[27], alongside debate within the UK parliament regarding the introduction of legislation to legalise assisted dying. However, the campaign was met with significant criticism. In presenting an outdated construction of dementia as the sole reality of living with the disease, the campaign rejected several decades of work in dementia studies problematising such monolithic constructions - as well as over a decade of activism from dementia advocacy groups (including from within the Society itself). The campaign led to a complaint to the UK Advertising Standards Agency from these groups, which was subsequently rejected[28]. The campaign demonstrates the relevance of the continuing biopolitics of dementia, its representation, and its impacts on both care practices and the lives of people with dementia[9].

As noted above, the disparate bodies of work across sociology and dementia studies have been critiqued for a lack of substance in how they engage with each other, for essentialising the heterogeneity of the dementia experience[29] and for ignoring the biopolitics of dementia[9]. Such work could also be critiqued for refraining from adequately disaggregating and attending to the various subtypes or diagnostic categories constitutive of the dementia syndrome: i.e., vascular dementia, mild cognitive impairment, and - the focus of this paper - LBD. A singular approach to dementia that is too often based on the aetiology, pathology, and subjective experience of AD has not yet fully acknowledged that different dementia conditions entail significantly different lived experiences, and involve diverse subjectivities deployed around these subtypes in specific social, sociotechnical contexts, each with their own distinct biopolitics[30]. For the remainder of this paper, we begin to consider what such a critical approach, when applied to LBD, might look like.

Making LBD

Lewy bodies – particular clumps of protein found within brain cells - were originally identified by Fritz Heinrich Lewy in the early twentieth century through the same methods of 'laboratory medicine' used by Alois Alzheimer to characterise the cell inclusions found in brains of Alzheimer's disease patients[31]. However, it was only in the 1970s and 80s that research focused specifically on Lewy bodies as a distinct neuropathological marker associated with cognitive impairment, including neuropsychiatric as well as motor symptoms[32]. Interest in the characterisation of this aetiology led to a proliferation of proposed diagnostic labels, with Perry *et al.*[33] suggesting "senile dementia of the Lewy body type", and Hansen and colleagues[34] proposing the term "Lewy body variant of Alzheimer's disease" to add to Kosaka's earlier 'Lewy Body Disease'[35]. In 1995, a consensus workshop led to clinical and pathological guidelines for diagnosis and treatment of 'Dementia with Lewy bodies'[36]. A detailed investigation of this history remains to be conducted.

The establishment of LBD as a diagnostic category has not been straightforward, leading to conflicting disease definitions, diagnostic criteria, and treatment pathways. Multiple diagnostic definitions for LBD exist based on their association with either Parkinson's disease or Alzheimer's disease; LBD researchers have had to negotiate the position of the condition in relation to the more established fields dedicated to Parkinson's disease and Alzheimer's disease, as well as differentiation in diagnostic categories prioritising Parkinson's disease dementia (PDD) over Dementia with Lewy bodies (DLB)[37,38]. The prevalence of Lewy Body pathology at autopsy within between a third and half of people diagnosed with Parkinson's disease and 60% of cases of Alzheimer's disease also suggests significant overlap between these conditions[37,39].

The process of establishing LBD as a diagnostic category can also be considered the result of interactions between the physiological changes and embedded professional and institutional commitments, reinforced by the technological and economic networks that support research on those conditions. An example of how such dynamics have contributed to the determination and revision of diagnostic criteria in LBD occurred in 2005, which introduced a temporal standard (the 'one year

rule') distinguishing DLB from PDD[40]. Despite continuing controversy about this distinction, both DLB and PDD have been included as separate categories in the 2013 edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the most recent edition of the International Classification of Diseases (ICD-11). Understanding the dynamics of conflict, competition, cooperation, and exchange within the social arena of biomedical research on neurological disease is a priority. This should include mapping of the collaborative links between researchers in the subfields, and their connections to key research funding, regulatory, and classificatory institutions.

The importance of the relatively recent recognition of the LBD category by key diagnostic classifications should not be underestimated. Standardised diagnostic classifications facilitate coordination between professional practice, bureaucratic procedure, epidemiological surveillance, and biomedical research[41]. To adopt the idiom of STS: they make LBD 'doable'[42] as a research and administrative target within the complex socio-material networks in which people living with LBD manage their illness. This means that transformation of the classificatory infrastructure of diseases - including ongoing shifts in the ontological orientation of the DSM[43,44] - might have consequences for how LBD is managed, investigated, and lived with. Further, current efforts to validate biomarkers for LBD are expected to consolidate the status of the illness within biomedical and clinical worlds of practice[38]. However, these developments also provide a critical time-sensitive opportunity to explore the social and ethical dimensions of LBD's enhanced profile.

Managing LBD

A key challenge for the clinical management of LBD is that its characteristic constellation of symptoms falls between different specialities of clinical medicine and health service organisation. This fragmentation of treatment pathways contributes to the varying trajectories experienced by people living with LBD. For example, Kane *et al.*[1] show that despite Lewy bodies being detected in 20% of cases of dementia at post-mortem, only 4.6% of referrals to specialist dementia services were diagnosed with dementia with Lewy Bodies - suggesting that there is significant under-diagnosis of people with LBD.

Despite the increased recognition of the dementias in biomedicine, and the consensus around the need for an integrated approach, this has not yet been implemented in the organisational structure of associated health services. In the UK and the Netherlands, for instance, a key issue is the lack of shared care pathways despite the multi-system nature of the condition, leading to a considerable burden of treatment[45] linked to multiple appointments across different specialties[46,47]). Work to determine the effectiveness of different approaches to managing LBD patients is ongoing[38,46,48–51]. We regard this as an important line of research with broader implications for managing disorders presenting across specialisms or associated with multiple morbidities. This, in turn, is likely to affect capacity to diagnose LBD and recognise its prevalence in the community. These developments also will require sociological scrutiny: how, for instance, is 'effectiveness' imagined and synthesised, and how are the perceived ontologies of LBD reconfigured through the making of 'effective' treatments?

Little is known about the biosocial epidemiology of LBD, except its higher incidence amongst men[1,52] and the fact that it is not so closely correlated with chronological age as other forms of dementia[1]. These factors in themselves serve to differentiate LBD from the typical epidemiology of Alzheimer's disease and therefore the assumed epidemiology of dementia, which has a higher incidence among women and is more common with increasing age. It is imperative to investigate the relationship between the onset of LBD and conditions such as education, socio-economic status, and life-course events, as well as contextual local factors. This imperative becomes increasingly salient given that these factors are clearly distinctly different in LBD from both the symptomal and psychosocial experience and social inequalities associated with dementia as currently conceptualised.

Within the UK context, there is also significant geographical variation in services, with the organisation of specialised services seemingly highly influenced by clinicians' special interest in LBD rather than necessarily by patient need. This geographical inequity is compounded by the route through which patients come to experience LBD symptoms and thereby seek a diagnosis. Those initially presenting with movement problems are diagnosed and treated through Parkinson's disease pathways: through movement disorder clinics and ongoing support from neurologists/geriatricians and specialist nurses, with patients only receiving a PDD diagnosis upon the onset of cognitive impairment. In contrast, those presenting with cognitive symptoms first may receive a diagnosis of DLB leading to their being placed on a diagnose and discharge memory service such as a memory clinic[46], before then falling under the remit of social care. Finally, the onset of affective symptoms, followed by psychotic features prior to the onset of DLB may lead to patients entering treatment from a mood disorder or acute psychosis pathway[53]. Research suggests that knowledge and skill levels regarding LBD differ significantly across staff within these different treatment pathways, with movement disorder clinic staff having much greater levels of awareness regarding its pathology and treatment[46]. Such a difference also reflects the longstanding underfunding of mental health services in comparison with physical health. The management of symptoms in isolation by this wide range of specialists with often different approaches to clinical management has meant that high quality care for people with LBD has frequently been difficult to achieve in practice - and that focusing on a single solution, intervention, or pathway may not be a suitable response[46].

The importance of service organisation for obtaining a timely diagnosis and appropriate management also pertains to the infrastructure and support instruments available to health care practitioners. We argue that as well as interventions to raise awareness of LBD in health and social care professionals, it is necessary to understand the clinical effectiveness and social

effects of emerging tools for diagnosis and treatment of LBD[54]. Detailed ethnographic explorations of the forms of action that such tools enable is required to understand how they help build (or not) arrangements of care for persons living with LBD. We recognise that the structure of medical consultations have significant effects in identifying issues relevant to patients and carers, but uncertainty remains in relation to the form this should take in LBD, as well as how that should be decided, and by who.

Living with LBD

Any approach that considers the various diseases and syndromes categorised as dementia needs to consider the implications of this heterogeneity in disease expressions as well as the lived experience of these conditions and their social effects. When compared to Alzheimer's disease and many other dementia sub-types, LBD is associated with significantly greater functional disability[55], significantly worse quality of life[56,57], and shorter survival time[58]. There are a variety of factors that might contribute to this. Spontaneous parkinsonism hinders the performance of ordinary activities, in profound and acutely embodied ways[59]. Marked cognitive fluctuations and significant variation in ability and understanding impact upon strategies of equilibrium and normalisation that are associated with the ways through which individuals living with chronic illness manage their symptoms. Visual hallucinations further limit the realm of activity of persons living with LBD; for example, by impacting on practices of daily living or by impeding activities such as driving[60,61]. Further, REM sleep behaviour disorder can disrupt longstanding patterns of rest, with implications for care work[62]. These symptoms are compounded by a widespread clinical lack of familiarity and awareness about LBD[47,63], with the condition being frequently likened to both Alzheimer's disease and Parkinson's disease, yet falling outside of the expected frame of behaviour linked to either condition.

Research exploring the personal lives and perspectives of people with LBD is comparatively rare, but qualitative analysts have identified specific difficulties that are likely to be associated with its lived experience[64]. Studies into the related conditions of Alzheimer's disease and Parkinson's disease have demonstrated that both diseases have uniquely distinct disruptive effects for a person's sense of self and identity, while their ability to respond to their illness in ways that maintain a coherent self-identity become severely constrained as symptoms worsen[59,65–67]. Those living with LBD face an uncertain diagnosis and prognosis, often receiving multiple alternative diagnoses prior to being diagnosed with LBD, depending on their routes through the various clinical pathway(s)[68]). Post-diagnostic support offers also differ, with a lack of specific resources for people with LBD meaning they may face significant difficulties in accessing services or in co-ordinating care appropriate to their specific needs. LBD's symptoms will also inevitably lead to significant difficulties maintaining a social and intimate personal life, with the stigma and social isolation experienced in LBD being over and above that experienced by those with more common forms of dementia[69]. Those living and/or caring for people with LBD also face declining opportunities for social relationships or ability to access social or emotional support, leading to loneliness, isolation, and reduced quality of life[64].

To illustrate the lived effects of LBD's symptomal expression we discuss two elements which serve to both characterise LBD and differentiate LBD from the other dementias: visual hallucinations and the iatrogenic effects of pharmacological antiparkinsonism therapies. While relatively uncommon among the wider dementia conditions, visual hallucinations are a core feature of LBD, affecting between 60% to 80% of cases[36,70,71]. People experiencing hallucinations in LBD face greater impairment in daily activities, and higher levels of anxiety and depression. They are, therefore, a key area to be explored from an interdisciplinary perspective. Visual hallucinations may last several minutes and are often well formed, typically featuring people, children, or animals[3]. While there is some understanding of the aetiological basis of visual hallucinations in LBD[72], there is room to investigate its relationship with the cognitive neuroscience of hallucinations in the visual and other modalities and the phenomenology of altered sensorial experience. Visual hallucinations have been associated with poorer outcomes, particularly when they are associated with psychosis[73]. Previous qualitative research on the experience of hallucinations among people with Parkinson's disease shows that while some people have insight into their hallucinations, others may keep them to themselves - often for fear of the stigmatisation that may result[67,74,75]. People with LBD and their carers find hallucinations stressful and burdensome[76,77]. Given both their impact on people with LBD, and the relative paucity of information about both their lived experience and management, identifying ways of supporting persons living with LBD and their carers in coping and dealing with hallucinations remains an important research focus[78].

Another important characteristic of LBD is increased sensitivity to neuroleptics and other medications, making the therapeutic regimes managed by persons living with LBD critical[38]. Pharmacological interventions for LBD are still of limited clinical effectiveness, and considerable effort is needed to develop and evaluate non-pharmacological interventions[48]. Research regarding the pharmacological treatment of LBD is less developed than the related conditions of PD and AD, but research suggests that the condition can be treated by therapies with efficacy for both conditions. This, though, comes with the caveat that medications to improve some LBD symptoms, such as drugs used to treat parkinsonism, come with significant iatrogenic effects.

Qualitative research regarding the therapies used to treat the related condition of PD has illustrated the embodied complexity that living with these therapies brings[67]. Many treatments may well make cognitive symptoms worse[3]. Gibson[67] suggests that among people living with Parkinson's disease, low adherence to medications should be viewed through the lens of embodiment. Parkinson's therapy, including both drugs and more intrusive neurosurgical procedures such as Deep Brain Stimulation, can lead to a dramatic improvement in symptoms; however, they

frequently give rise to changes in motor response in the form of peak dose dyskinesias and 'on-off' fluctuations. These fluctuations, which can be as hard to live with as the underlying disease pathology, create a fluctuating embodiment distinct both from 'normality' and from their previous experience of Parkinson's disease[79,80]. Little is known about the meanings and practices of medicine for LBD more generally, such as how far motor fluctuations common in Parkinson's disease therapy may occur for those with LBD – given both the overlap between the two aetiologies and the use of the same therapies to treat both conditions. This is particularly pertinent because medications to manage hallucinations can make mobility worse whilst medications to improve mobility can worsen hallucinations, requiring clinicians and carers to work with the patient to find an appropriate balance. Given a fluctuating bodily state caused by the intersection between LBD's aetiology and its pharmacological treatment, understanding how those living with LBD and clinicians make meaningful decisions about their therapy is a necessary element of unpicking the biopolitics of LBD.

Towards a social science agenda for LBD

Constructive rapprochements and engagements between neurology, psychiatry, sociology, and dementia studies can inform a wider socially-informed body of work, which turns a critical lens towards both the construction of dementia within society (including biomedicine) and how alternative conceptualisations of dementia can inform both theory and care practice[19]. This form of scholarship would also scrutinise how different dementias, their diagnosis, and their treatment(s) are constituted and experienced in medicine and health and social care - and how they inter-relate with wider social structures, such as class, ethnicity, sexuality, or gender. Different dementia subjectivities, which stem from specific structural, institutional, and cultural locations, will affect the delivery of person-centred care, the social participation of people with dementia in the context of wider social structures, and their experience of inequalities which differentially confer or restrict citizenship and human rights. It might once have been necessary to strategically aggregate the diversity of somatic and psychosocial experiences associated with different forms of dementia to catalyse dementia studies as a distinct canon of work, and to orient policymakers to the salience of dementia. But it is now worth considering how a specific if still heterogeneous condition differentially interacts with the expanding institutions and practices of biomedicine, healthcare, and wider society.

We suggest that LBD provides an opportunity to combine a conventional social science approach to illness with research that is "interested in the dialectic interaction between social life and specific diseases"[81]. Given its linked aetiologies with other dementias and Parkinson's disease, LBD raises key questions with regards to, for instance: how conceptualisation of distinct disease categories transition across the pathophysiology of specific disease processes; how such diseases come to be defined as distinct disease entities at different times and by different professional disciplines (e.g., movement disorders, neurology, or geriatric psychiatry), leading to different care trajectories and treatment regimens; how LBD is managed across the differing groups involved in dementia care, including clinical medicine, the allied health professions and social care; and, finally, its subjective and embodied experience among the heterogeneous groups of people living with LBD (both singly and in comparison to other dementia subtypes such as Alzheimer's disease) and how these experiences are shaped by pre-existing social structures and dynamics of inequality. Our contention is that such work could represent a distinctive social scientific research agenda that could only progress in close, yet also reflexive and critical, collaboration with biomedicine[82]. Such an ambitious programme of research will necessarily foster interdisciplinarity: between the biomedical disciplines of clinical neurology and geriatric psychiatry, the allied health professions, dementia studies, social gerontology, and the sociology of health and illness.

On the one hand, LBD enables the exploration of wider issues of lived experience, social identity, the organisation of medicine, and the management of illness in complex social networks. Its particular combination of symptoms defies the historically constituted configuration of specialities within medicine, leading often to fragmented illness trajectories. This has been reinforced by the dominance exerted by the two more established diseases – Alzheimer's disease and Parkinson's disease – in the 'social arena[s]' of biomedical research on neurological diseases[83]. Cognitive fluctuations and hallucinations present exemplars of the challenges to how LBD is defined and managed as a form of dementia within medicine, and the strategies used by people living with LBD, their carers, and by health care professionals to stabilise a sense of self that is normatively adequate. LBD consequently represents an important case illness for the sociology of health and medicine, concerned with the relationships between groups with specific disease identities, their relationships with social actors such as health or care services, and the relationships between illnesses, bodies and physical and social spaces that these bodies occupy. Through contributing to general social theory, analyses of LBD might thus also enhance healthcare and experiences of illness across other categories of disease as well.

Equally, LBD can be investigated as a combination of biological, social, and epistemic processes in its own right. From this perspective, it is possible to explore the arrangement of concepts, instruments, and techniques that led to (for instance) the emergence of LBD as a diagnostic category. Similarly, we can aim to identify the practical skills, knowledge, and service organisation structure that are required for a clinical diagnosis of LBD, and how this diagnosis facilitates (or not) transformation of bodies and identities. Attention to the material, everyday aspects of living with LBD - such as taking medicines and booking clinical appointments - should provide further insight into the complexity of the trajectories of this disease. In turn, these investigations should enable us to identify and map the various norms – of health, wellbeing, and so on – that are enacted

in those practices, and ultimately contribute to the care and wellbeing of people with LBD.

Working towards inclusion

In mapping out an explicitly 'academic' approach above, we are mindful of what is relatively absent in our reflections: most notably, people with LBD themselves. In this section, we want to consider how inclusive and collaborative research practices could further enhance and propel a social scientific research agenda regarding LBD. One of the strengths of recent developments within dementia studies has been its now decades-long engagement with people living with dementia, their perspectives and experiences, and more recently in their inclusion as co-producers of knowledge and practice.

The impetus for co-produced approaches in dementia studies has been common since its inception; for example, Wilkinson's significant text, *The Perspectives of People with Dementia*[84], discusses how to engage people with dementia as co-contributors to research, including through chapters written by people living with dementia. More recently, projects such as the Dementia Enquirers[85], as well as recent work by Ashworth *et al.*[86], provide guidance produced with and by people with dementia about how to effectively engage people with dementia into the research enterprise. Since then, the greater emphasis on co-produced approaches in dementia studies has been informed by the growth of a wide range of self-organised, independent, and autonomous organisations and groups of people living with dementia and their carers. These have become long established, prominent, and powerful features of the dementia policy, practice, and research landscape[87–90]. Such groups are frequently led by people with dementia, with several people - such as Agnes Houston[91], Kate Swaffer[92], the late Wendy Mitchell[93,94], and many others - becoming prominent advocates for people with dementia, both among health and care researchers and within the public sphere.

In LBD, research is underway to develop and evaluate the efficacy, feasibility, and acceptability of deploying a support and information group in clinical settings, a 'needs gap' identified by people with LBD and caregivers[77,95]. The co-production of knowledge and practice regarding LBD treatments, using a combination of clinical information with 'experiential expertise'[96] built with those with lived experience, might contribute to increasing quality of life. The production of such resources illustrates how people living with LBD can make meaningful contributions to wider debates about LBD and its treatment, if supported to do so. However, this is an area which remains under-researched, therefore supporting people living with and affected by LBD to lead in such discussions - including research - should be a key priority.

Nevertheless, the shift towards greater inclusion of people living with all types of dementia has not been without its issues. The various disciplines involved in dementia research have seen much debate, often occurring at different points of each invested discipline's evolution, about whether and how people can be effectively involved in the research process, and how to ensure collaboration is not tokenistic and is inclusive of the needs of people living with dementia[97,98]. Questions have also been posed about how far existing prominent advocates or dementia advocacy organisations reflect or represent the wider diversity of people living with dementia and their symptomatology[99]. As part of a nascent social science research agenda, deep consideration is required regarding how best to support people with LBD to join already existing communities, built around advocacy and activism among people with dementia. This includes support to access and learn from the range of dementia support organisations, particularly in relation to activism and research, as well as recognising what their specific needs might be.

Sociologically informed researchers can also engage with these groups to co-develop research agendas which place commitments such as the rights of people with LBD equally, alongside the wider dementias. Killen and colleagues' work regarding information and support needs among people living with LBD[77] prompts questions about the wider role of patient and carer organisations in shaping the research agenda and information infrastructure in LBD. Such organisations include Lewy Buddies UK, a self-funded, volunteer led organisation which provide peer to peer support to people living with LBD[100].

Again, the dominance exerted by Alzheimer's disease and Parkinson's disease and related absence of explicit LBD advocacy in the field of health activism is a significant challenge. This may be compounded by the barriers to diagnosis discussed above, hindering the development of a collective identity. Examples where people with LBD and their families have come forward to express their voice - such as Susan Schneider Williams, the widow of comic actor Robin Williams who died with LBD[63] - illustrate how those affected can enrich research. It would be fruitful to explore how LBD organisations' focus on supporting research could be combined with a more active role in collecting and disseminating experiences to reinforce a shared identity and raise public and professional awareness of the illness[101]. Seeking to explicitly engage with people living with LBD within this agenda can only serve to further enable people with LBD to articulate their specific experiences and concerns about living with their condition. Such work reveals both powerful lived experiences which have been under-recognised across the treatment of LBD. Further, it demonstrates the potential of people living with LBD to be involved in setting the research agenda and driving knowledge exchange and practice development.

Conclusion

Based on our analysis, we identify the following 10 priorities which should be considered in any social science informed research programme into LBD (Box 1):

1. Understand and map the dynamics of the social arenas of biomedical research on LBD from the late 1970s.
2. Examine how changes in approach to diagnostic classification could impact on the clinical management of LBD.
3. Identify and characterise the clinical and service organisation barriers and facilitators to the diagnosis and management of LBD.

4. Explore how social determinants of health interact with the structure of service organisation to support management of LBD.
5. Develop, test, and introduce interventions to raise awareness of LBD in health and social care professionals.
6. Examine the structure of consultations, and the use of diagnostic and management tools and their effects in identifying and addressing issues relevant to patients and carers.
7. Investigate the phenomenology of visual hallucinations in LBD
8. Examine the meanings and practices of medicine-taking in LBD.
9. Determine the role of non-pharmacological interventions in patients' trajectories and identities.
10. Explore ways of including people with LBD in further defining the LBD research agenda and co-producing research in relation to LBD.

A sociologically informed research agenda for LBD is both necessary and overdue. We suggest that this agenda should combine established approaches to the social study of health and illness, with a more interdisciplinary approach that investigates how specific diseases are conceptualised, managed, and interact with social life. Importantly, any such agenda should seek to include people living with LBD as co-producers and co-creators of this research agenda. Initial priorities for this nascent agenda include the scientific and technological framing of LBD, the clinical and organisational challenges presented by the disorder (including their implications for health and social care practice), and the everyday aspects of living with LBD - including promoting participation and advocacy of people with LBD within and across dementia activism.

Disclaimer

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Data availability statement

No data are associated with this article.

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