

UC San Diego

UC San Diego Previously Published Works

Title

Research Priorities of Individuals and Caregivers With Lewy Body Dementia: A Web-based Survey.

Permalink

<https://escholarship.org/uc/item/3jb6t7mj>

Journal

Alzheimer Disease and Associated Disorders, 37(1)

Authors

Schwilk, Chris

Fleisher, Jori

Duda, John

et al.

Publication Date

2023

DOI

10.1097/WAD.0000000000000545

Peer reviewed



Published in final edited form as:

Alzheimer Dis Assoc Disord. 2023 ; 37(1): 50–58. doi:10.1097/WAD.0000000000000545.

Research priorities of individuals and caregivers with Lewy body dementia: A web-based survey

Samantha K. Holden, MD, MS¹, Noheli Bedenfield, MHA², Angela S. Taylor³, Ece Bayram, MD, PhD⁴, Chris Schwilk, PhD³, Jori Fleisher, MD, MSCE⁵, John Duda, MD⁶, Holly Shill, MD⁷, Henry L. Paulson, MD⁸, Kelly Stacy, PhD, MHA, RN⁹, Julia Wood³, Pamela Corsentino³, Sharon J. Sha, MD, MS¹⁰, Irene Litvan, MD⁴, David J. Irwin, MD⁶, Joseph F. Quinn, MD¹¹, Jennifer G. Goldman, MD, MS¹², Katherine Amodeo, MD¹³, John-Paul Taylor, PhD¹⁴, Bradley F. Boeve, MD¹⁵, Melissa J. Armstrong, MD, MSc²

¹Department of Neurology, University of Colorado School of Medicine, Aurora, CO

²Department of Neurology, University of Florida, Dorothy Mangurian Clinical-Research Headquarters for Lewy Body Dementia, Gainesville, FL

³Lewy Body Dementia Association, Lilburn, GA

⁴Department of Neurosciences, University of California San Diego, San Diego, CA

⁵Department of Neurological Sciences, Rush University Medical Center, Chicago, IL

⁶Department of Neurology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

⁷Department of Neurology, Barrow Neurological Institute, Phoenix, AZ

⁸Department of Neurology, University of Michigan, Ann Arbor, MI

⁹College of Nursing, University of Cincinnati, Cincinnati, OH

¹⁰Department of Neurology and Neurological Sciences, Stanford University, Stanford, CA

Corresponding Author: Samantha K. Holden, MD, MS, University of Colorado School of Medicine, Department of Neurology, Sections of Behavioral Neurology and Movement Disorders, 12469 E 17th Place, Mail Stop F429, Aurora, CO 80045, Office 303.724.8225, Voicemail 303.724.1940, Fax 303.724.4082, samantha.holden@cuanschutz.edu.

Conflicts of Interest and Sources of Support: This project was conceived and executed by the Community Engagement Working Group of the Lewy Body Dementia Association Research Center of Excellence program. SKH has received research support from the Michael J. Fox Foundation for Parkinson's Research and NIH and has received honoraria from the American Academy of Neurology. HLP has received research support from NIH/NIA (P30AG 072931). JGG has received research support from Acadia, Michael J. Fox Foundation, Parkinson's Foundation, serves as a consultant for Worldwide Med, and has received honoraria from American Academy of Neurology, Davis Phinney Foundation, International Parkinson and Movement Disorders Society, Medscape, and Parkinson's Foundation. IL has received research support from NIH (2R01AG038791-06A, U01NS100610, U01NS80818, R25NS098999; U19 AG063911-1, 1R21NS114764-01A1) the Michael J Fox Foundation, Parkinson Foundation, Lewy Body Association, CurePSP, Roche, Abbvie, Biogen, Centogene. EIP-Pharma, Biohaven Pharmaceuticals, Novartis, Brain Neurotherapy Bio, and United Biopharma SRL-UCB. IL was a member of the Scientific Advisory Board of Lundbeck and is a Scientific Advisor for Amydis and Rossy Center for the Progressive Supranuclear Palsy University of Toronto. IL receives her salary from the University of California San Diego and as Chief Editor of Frontiers in Neurology. DJI receives research funding from NIH (R01-NS109260, P01-AG066597, U19-AG062418, U01-NS100610), Penn Institute on Aging. DJI is a member of the scientific advisory board of Denali Therapeutics. J-PT reports grants from the UK National Institute of Health Research (NIHR), non-financial support from Axovant and personal fees from GE Healthcare. BFB reports personal fees for scientific advisory board membership from the Tau Consortium, grants from GE Healthcare, National Institutes of Health, Mangurian Foundation, and Axovant, MJA receives research support from the NIA (R01AG068128, P30AG047266), the Florida Department of Health (Grant 20A08). MJA serves on the data safety monitoring boards (DSMBs) for ACTC/ATRI and ADCS. MJA receives royalties from the publication of the book Parkinson's Disease: Improving Patient Care. MJA serves on the level of evidence editorial board for Neurology and related publications (uncompensated).

¹¹Department of Neurology, Oregon Health and Science University, Portland, OR

¹²Shirley Ryan AbilityLab, Parkinson's Disease and Movement Disorders Program, Northwestern University, Chicago, IL

¹³Department of Neurology, Westchester Medical Center- MidHudson Regional Hospital, Poughkeepsie, NY

¹⁴Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

¹⁵Department of Neurology, Mayo Clinic, Rochester, MN

Abstract

Introduction: Lewy body dementia (LBD) is common, yet under-recognized and under-researched. To plan studies with the highest impact, engagement of the community personally affected by these conditions is essential.

Methods: A web-based survey of people living with LBD and current and former caregivers of people with LBD queried research priorities through forced ranking and exploration of burden of LBD symptoms. Specific caregiving needs in LBD and perceptions of research participation were also investigated.

Results: Between 4/7/2021–7/1/2021, 984 responses were recorded. Top research priorities included disease-modifying therapies and improved disease detection and staging. People with LBD were interested in pathophysiology and more bothered by motor symptoms; caregivers were interested in risk factors and symptomatic therapies and more bothered by neuropsychiatric symptoms. Few available LBD treatments and resources were rated as helpful, and many valuable services were never received. Previous participation in LBD research was infrequent, but interest was high.

Discussion: People with LBD and caregivers highlighted the need for research across all aspects of LBD, from pathophysiology and disease modification to prognosis, education, symptomatic treatments, and caregiver support. Funders should increase support of all aspects of LBD research to target the many needs identified by individuals and families living with LBD.

Keywords

Lewy body dementia; research priorities; caregiving; community engagement; survey

Introduction

Lewy body dementia (LBD) is the second most common cause of neurodegenerative dementia and the most misdiagnosed^{1,2} and costliest³ form of dementia. LBD is an umbrella term including Parkinson's disease dementia (PDD) and dementia with Lewy bodies (DLB)⁴, which are clinically differentiated by timing of onset of parkinsonism versus dementia. There is much work needed to better understand pathophysiology, diagnostic capabilities, and effective treatments in LBD, but research funding and resources are limited. Therefore, prioritizing the areas of greatest need and potential impact is vital to guide research efforts in LBD for the near future.

The Advisory Council on Alzheimer's Research, Care and Services recommends that people with LBD and their caregivers be engaged as research partners at all stages, including priority-setting.⁵ The 2017 and 2020 *National Research Summits on Care, Services, and Supports for Persons with Dementia and Their Caregivers* also highlighted the need to understand what outcomes are important to individuals living with dementia and to engage individuals with dementia and caregivers as part of research teams.^{6–8} This is important as studies suggest that the priorities of patients, families, clinicians, and researchers can differ⁹ and interventions for dementia will be impactful only when they make a difference on patient- and caregiver-reported outcomes.¹⁰ Yet, little research directly investigates the priorities of people living with dementia and their caregivers, particularly in LBD. In addition, barriers for engagement for people with dementia and caregivers,¹¹ which may vary for different types of dementia, need to be recognized and addressed through this work.

In a single-center interview study of people living with LBD and caregivers, numerous perceived gaps were identified, including the need for more focused research on quality of life and daily function, caregiver support, and understanding of LBD disease progression.¹² Although these findings offer invaluable insight to the perspectives of people with LBD, the data was collected at a single tertiary care referral center, which limits the generalizability of the findings. Given that the community affected by LBD is not a monolith – different backgrounds, education, races and ethnicities, locations, symptomatic presentations, and disease severities must be appreciated and included – what is prioritized by some may not be important to all. Accordingly, the current study aimed to solicit the opinions of a broader group of community members affected by LBD to identify the research priorities of people with LBD and LBD caregivers.

Methods

Study design

The study was conceptualized and designed by the Lewy Body Dementia Association Research Centers of Excellence (LBDA RCOE)¹³ Community Engagement Working Group. This working group consists of RCOE site directors and staff, LBDA staff, and an individual living with LBD. One focus of the working group is to better understand the current needs and opinions of people with LBD and their caregivers. To this end, working group members and other collaborators designed and implemented a web-based survey to identify research priorities of people personally affected by LBD. Reporting of the study results was guided by the published criteria for web-based survey research (Supplemental File 1).¹⁴

Survey development

One working group co-chair (MJA) drafted the initial survey based on findings of the previous single-center interview study.¹² Iterative rounds of revisions occurred with feedback the LBDA Community Engagement Work Group leadership (SKH, AT), additional working group members, LBDA staff, people with LBD, current and former caregivers, and co-chairs of the Clinical Trial (DJI, JFQ), Industry Engagement (SJS, IL), and Professional Education (JGG, KA) Working Groups of the LBDA RCOE program. The resulting survey

was then pilot tested using a cognitive interviewing approach (NB) with three people with LBD, two current caregivers, and two former caregivers, followed by further revisions.

The final survey (Supplemental File 2) was comprised of up to 7 total webpages depending on respondent type. Branching logic separated questions for individuals living with LBD and current and former caregivers. All respondents answered 18 demographic and clinical feature questions on page 1 of the survey. Additional questions included a forced choice ranking of respondents' top five research priorities from a list of 18 topics. Gaps in care to inform research needs were queried by asking respondents to describe the burden of LBD symptoms in daily life and the helpfulness of available treatments and resources using 5-point Likert scale response options. Caregiver respondents provided their interpretation of their loved one's experience with common LBD symptoms as well as their own symptom-related caregiving burden. Caregiver respondents also answered an additional page of questions on the frequency of specific caregiving concerns (e.g., managing behavioral symptoms, financial planning, identifying disease progression). The final survey page included a yes/no question querying general interest in research participation, with a free text space to explain or provide any additional comments on the theme of LBD research.

Population and recruitment

Invitations to participate in this open web-based survey were distributed through the LBDA electronic mailing list (current subscribers: 25,300), which includes people with LBD, caregivers, family, and friends interested in LBD and who have agreed to receive information regarding the disease and ongoing research opportunities. Email survey invitations were sent a total of three times at monthly intervals, starting on 4/7/2021. Additional recruitment was solicited through a banner ad on the LBDA landing page and through official LBDA social media posts. Inclusion criteria were: (1) someone with diagnosis of LBD (either DLB or PDD) OR a current or former caregiver for someone with a diagnosis of LBD (either DLB or PDD) and (2) ability to complete an English online survey. Participants were recruited as individuals and not as person with LBD/caregiver dyads; therefore, responses were not directly compared by respondent type.

Regulatory approvals and consent

The University of Florida institutional review board provided approval (IRB202100414). A waiver of documentation of informed consent maintained anonymity. Individuals accessing the online survey received a description (e.g., inclusion/exclusion criteria, number of questions) and embedded link to view the informed consent form (PDF). If individuals proceeded with the survey, consent was assumed. All survey responses were voluntary and anonymous, and no incentives were offered.

Data collection and analysis

Web-based survey responses were automatically collected and managed using REDCap electronic data capture tools hosted at the University of Florida.^{15,16} REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated

export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. The survey did not contain steps for respondents to review their answers, nor methods to prevent multiple entries. Cookies were not collected. Estimated survey completion time was 15–20 minutes. Responses were not required to advance. Analyses were descriptive (frequency, median) and included all responses for each question (whether the entire survey was complete or incomplete). Responses were grouped by respondent type. The purpose of this work was to gain a broad overview of the needs and priorities of people personally affected by LBD, so no specific groupwise comparisons were made.

Results

Demographic and clinical characteristics

A total of 984 responses were recorded during the survey period (4/7/2021–7/1/2021); 818 complete surveys and 166 partially complete surveys. There were 296 survey views with no responses entered. One hundred thirty-one (13%) respondents identified as a person with LBD and 832 (85%) identified as a caregiver for a person with LBD (Table 1). Of these, 550 (66.3%) were current and 280 (33.7%) were former caregivers. Twenty-one (2%) respondents did not identify as a person with LBD or a caregiver (an optional response); these respondents were not asked questions on symptom burden or helpfulness of treatments/resources, as this branching logic depended on respondent type.

Most respondents were 60–79 years old (64.9%), identified as white (93.3%), were married or in a domestic partnership (72.5%), and were highly educated (>85% with some college education) (Table 1). The majority (90.1%) of respondents were U.S.-based, though there was at least one respondent from each inhabited continent. Respondents were most likely to live in a suburb of a large city (36.6%). People with LBD were more often male (64.9%). Caregivers were usually female (76.6%) and the spouse or partner of the person with LBD (63%). Most participants indicated a DLB diagnosis (74.9%), as opposed to PDD (10.8%).

Research priorities of people living with LBD

When ranking their top five priorities in research and identifying areas that require additional study, people with LBD focused primarily on understanding what is happening in the disease and how it progresses, developing tests to diagnose and track LBD progression, and developing disease-modifying therapies (Figure 1). Many respondents also ranked less traditional research areas within their top five, including complementary and alternative treatment approaches (25.4%), quality of life focused work (23%), and better understanding and improving care for end-of-life in LBD (18.3%).

Bothersome symptoms that people with LBD rated as occurring ‘frequently’ or ‘all the time or almost of all of the time’ included parkinsonism, fatigue and sleepiness, and cognitive impairment (Figure 2). The only group of symptoms for which >50% of people with LBD felt treatments were at least “somewhat helpful” was non-psychosis psychiatric symptoms (provided examples in survey: depression, anxiety, lack of interest, anger). For every other symptom, available treatments were rated as “not helpful at all” (28–58% of responses)) or

only “slightly helpful” by most respondents (Table 2). High proportions of people with LBD reported never receiving important resources, such as social work services (46.3%), advance care planning (43.2%), rehabilitative therapies (37.9%), and disease education (36.4%) (Figure 3). Among all potential services and resources listed, clinical care from an LBD specialist was most likely to be ranked as helpful by people with LBD (58.7% reported as at least “somewhat helpful”).

Research priorities of LBD caregivers

The top LBD research priority for caregivers was disease-modifying therapies (Figure 1). Three of the five top research priorities were shared between current and former caregivers, including disease-modifying therapies, development of diagnostic tests, and better understanding the pathophysiology of LBD. Current caregivers were more likely to prioritize symptomatic treatments for LBD (47.1% vs 33.9% for former caregivers) and defining LBD disease progression or stages (45.6% vs 25.7% for former caregivers) within their top five priorities. Former caregivers endorsed more interest in understanding risk factors for LBD (47.1% vs 22.4% for current caregivers), as well as more interest in improving LBD education for healthcare providers (41.1% vs 26.4% for current caregivers). Compared to individuals with LBD, all caregivers reported more interest in research on symptomatic treatments (44%), as well as studies focused on risk factors (31.8%) end of life (21.7%) and reducing hospitalizations (8%).

Cognitive and behavioral symptoms, including cognitive fluctuations, were more frequently rated as bothersome by caregivers than by people with LBD (Table 2). Motor symptoms were not as bothersome to caregivers as they were to people with LBD. Like people with LBD, very few available treatments or resources were rated as helpful by caregivers (1.5–12.5%, Table 2) and many had not received important services at all (14.7–64.3%, Figure 3). Caregivers most frequently ranked clinical care from LBD specialists as helpful (60.5% reported as at least “somewhat helpful”), like people with LBD, along with patient education resources (53.8%) and rehabilitation services (50.5%).

Participation in Research

Almost 80% of survey respondents reported no prior participation in LBD research. Reasons for non-participation (respondents could choose all reasons that applied) differed between people with LBD and caregivers: people with LBD (n=18) cited distance from research centers and need to travel (44.4%), worry about side effects or other risks of participation (33.3%), and concerns about receiving a placebo instead of active treatments (33.3%). Caregivers (n=290) were also concerned with travel requirements (26.6%), as well as lack of time (23.8%) and their loved one being too impaired to participate (19.3%). People with LBD endorsed some mistrust of research overall (11.1%), as well as mistrust of pharmaceutical companies (27.8%); fewer caregivers reported these concerns, though 5.9% also mistrust pharmaceutical companies. Misperceptions of research participation, including perceived financial costs to the participant (33.3% of people with LBD and 4.8% of caregivers) or negative effects on the quality of medical care (33.3% of people with LBD and 8.3% of caregivers), were also present.

Over half (58.4%) of respondents reported interest in future LBD research participation, though 25.3% were unsure and 16.2% were not interested. Interest in research participation was higher among people with LBD (83.5%) than caregivers (54.9%). Free text comments regarding lack of interest in research participation from caregivers centered on the fact that caregivers did not have LBD themselves, reflecting limited awareness or outreach regarding caregiver-focused research.

Discussion

This survey aimed to engage those personally affected by LBD at the foundational stages of LBD research by identifying their research priorities. People with LBD and caregivers of people with LBD highly ranked understanding what is happening in the brain in LBD, tests to help diagnose LBD, defining progression and identifying stages, and developing disease-modifying therapies. People with LBD also prioritized development of tests to track disease progression, while caregivers highly ranked development of symptomatic therapies. Overall, there were broad and diverse research interests among survey respondents, with each of the 18 presented research topics collectively represented within top five priorities. Considerable proportions of people with LBD and caregivers of people with LBD prioritized more complementary and alternative medicine, palliative and end-of-life care, and caregiver-focused research. The most commonly ranked research priorities from people with LBD and caregivers largely align with priorities identified by the National Institutes of Health and a previous interview-based study,¹² including understanding pathophysiology, biomarker development for diagnosis and monitoring disease progression, and development of disease-modifying and symptomatic therapies.¹⁷ Both people with LBD and caregivers also prioritized defining the course of how LBD progresses over time and identifying LBD stages. This is consistent with recommendations from the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers for research to understand different dementia trajectories.⁶ This is an area, however, receiving relatively little attention from funders of dementia research.

Burden of LBD symptoms

Cognitive changes were the most bothersome symptom to all respondents, both in terms of how they affected the person with LBD and how they affected the caregiver personally. Cognitive fluctuations and psychosis were generally more bothersome to caregivers than to people with LBD. This could reflect that respondents with LBD were at relatively earlier stages of disease, that people with LBD have less insight into these symptoms, or that people with LBD are simply less bothered by these symptoms themselves. Very few available LBD treatments and resources were rated as helpful and many existing LBD resources were reported as never received. Even prior to new research studies, then, efforts should be made to ensure adequate access and awareness of existing services for people with LBD and their caregivers.

The low ratings of helpful treatment options by both people with LBD and caregivers illustrates the vast needs for this patient population and many areas of potentially impactful scientific advancements. There are no FDA-approved medications for DLB and

all pharmacological treatments are therefore off-label. Non-pharmacological treatments and support services are a mainstay of LBD treatment, but respondents also highlight limited helpfulness and access. For example, 32.4% of our survey respondents reported they had not received any specific patient education on LBD. Provision of educational resources, either in person or through direction to specific literature or websites, is an essential component of LBD care.¹ Further work is needed to increase access and awareness of resources for LBD, as well as expansion and improvement of these tools and supports. Considerable progress could be made in the care of LBD through improved utilization of existing resources (e.g., the Lewy Body Dementia: Information for Patients, Families, and Professionals freely available booklet from the National Institutes on Health¹⁸). Barriers to such utilization, including awareness, limited time with clinicians, confusing or inconsistent terminology, and insurance coverage, must be identified and eliminated.¹⁹

Caregiving research in LBD

Given the reliance of the U.S. healthcare system on informal caregivers for chronic disabling conditions, focused research on caregiving in LBD is essential.^{5,10} The voices of LBD caregivers should be elevated within research planning and execution, leveraging their expertise and direct knowledge of the disease.⁸ Not only can caregivers provide invaluable information regarding disease manifestations and progression, but they can also interpret the effectiveness of treatments. Additionally, research on caregiving in LBD specifically is also vital, given its unique clinical manifestations when compared to other forms of dementia. Our caregiver respondents identified major sources of caregiving concerns, including management of distinctive behavioral symptoms in LBD, such as psychosis and cognitive fluctuations, as well as a need to define LBD disease stages and progression milestones. A concerted effort to define stages of LBD, taking into account variable clinical presentations and prodromal forms (i.e., cognitive, delirium, or psychiatric²⁰) should be prioritized.^{7,12,19} The unique behavioral symptoms of LBD urgently require evidence-based targeted interventions, with direct input and involvement from the LBD community to ensure treatments are feasible and effective in real-world caregiving situations.

Perceptions of research participation in LBD

It is important to understand perceptions of research among the LBD community to build authentic partnerships between people with LBD, caregivers, clinicians, and scientists. The high proportion of non-participation in research among our respondents (79%) highlights the need to better engage this community. Common barriers to research participation reported by our respondents included the need to travel and lack of time, but also some troubling views emerged regarding mistrust of research and pharmaceutical companies, as well as perceived risks to health, safety, and quality of care with participation. These responses demonstrate the need to partner directly with people with LBD and caregivers from the earliest stages of research design, including developing research projects together, and building trusting, bidirectional relationships. With an intimidating amount of scientific work needed in LBD and multiple potential paths forward, these preparatory, collaborative efforts are essential. We can only accomplish more when working together in study design and interpretation, combining our unique expertise as clinicians, scientists, community members, disease advocacy groups, and policy makers.²¹⁻²⁴ These efforts will also serve to improve

study recruitment and retention, when potential participants are provided their “equal and active voices” in study design and resource allocation.^{7,25}

Strengths and limitations

Strengths of our study include recruitment through the Lewy Body Dementia Association, the largest LBD advocacy organization in the United States, reaching individuals from various backgrounds with and without LBD specialty care. Inclusion of individuals living with LBD (both DLB and PDD) and both current and former caregivers is also a strength. Despite the large number of respondents in our survey, however, the findings may not be representative of everyone affected by LBD. Most respondents were caregivers. Most of the respondents with LBD were at earlier disease stages (63% less than 2 years from diagnosis). As with many research studies, the higher rates of white and highly educated respondents likely bias the outcomes. Little is known about the disease features and specific needs of non-white ethnorracial groups,^{26–28} LGBTQ+ populations, and people from lower socioeconomic levels and without high levels of education. People with LBD from underrepresented groups may be at a higher risk of misdiagnosis, and likely to have even less access to education, research participation, and clinical resources. More directed outreach to broader communities is necessary.

Another important limitation in our study was the inclusion of more DLB respondents than those with PDD. This is perhaps in part due to the LBDA targeting more of the DLB community, in addition to people with PDD who have long-standing Parkinson’s disease not often identifying as having LBD and thus not connecting with the LBDA or LBD research efforts. Although there is an ongoing debate about the distinction between PDD and DLB, these diseases share many similarities and can be viewed as two dementia syndromes on the same spectrum.²⁹ Currently, the clinical distinction is based on the onset of parkinsonism relative to dementia and both conditions lack a disease-modifying treatment option. Therefore, more clarification and education in the LBD community can help people understand the diagnoses better and combining resources for the time being can be beneficial to address the needs in both dementias.

Conclusions

People with LBD and caregivers of people with LBD underscored the importance of understanding how the disease affects their brain now and in the future, as well as the development of effective treatment strategies. In addition to these more universal research priorities, respondents emphasized the need for research in less traditional areas, including identifying stages of LBD, caregiver-focused research, end-of-life issues, and complementary/alternative treatments, issues not reflected in the current NIH ADRD priorities.⁵ Funding opportunities prioritizing these research needs have immediate implications for people personally affected by LBD. The LBD community should be fully involved in all stages of research to ensure meaningful and practical outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

REFERENCES

1. Galvin JE, Duda JE, Kaufer DI, Lipka CF, Taylor A, Zarit SH. Lewy body dementia: the caregiver experience of clinical care. *Parkinsonism Relat Disord*. Jul 2010;16(6):388–92. doi:10.1016/j.parkreldis.2010.03.007 [PubMed: 20434939]
2. Surendranathan A, Kane JPM, Bentley A, et al. Clinical diagnosis of Lewy body dementia. *BJPsych Open*. Jun 16 2020;6(4):e61. doi:10.1192/bjo.2020.44 [PubMed: 32539875]
3. Chen Y, Wilson L, Kornak J, et al. The costs of dementia subtypes to California Medicare fee-for-service, 2015. *Alzheimers Dement*. 07 2019;15(7):899–906. doi:10.1016/j.jalz.2019.03.015 [PubMed: 31175026]
4. Barker WW, Luis CA, Kashuba A, et al. Relative frequencies of Alzheimer disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank. *Alzheimer Dis Assoc Disord*. 2002 Oct-Dec 2002;16(4):203–12. doi:10.1097/00002093-200210000-00001 [PubMed: 12468894]
5. PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2020 Recommendations Executive Summary. <https://aspe.hhs.gov/sites/default/files/private/pdf/259591/2018PubMemRec.pdf>
6. Gitlin LN, Maslow K, Khillan R. Research Summit on Dementia Care Building Evidence for Services and Supports: Main Summit Recommendations. 2017:
7. Rukes K, Fowler NR. Engaging Persons Living With Dementia in the Research Process: Best Practice Considerations From a National Dementia Meeting. *Am J Geriatr Psychiatry*. 04 2020;28(4):431–433. doi:10.1016/j.jagp.2019.11.008 [PubMed: 31839462]
8. Reuben DB, Wolff JL. The future of dementia care, caregiving, and services research. *J Am Geriatr Soc*. 07 2021;69(7):1752–1754. doi:10.1111/jgs.17268 [PubMed: 34245587]
9. Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch. *Res Involv Engagem*. 2015;1:2. doi:10.1186/s40900-015-0003-x [PubMed: 29062491]
10. Patel NK, Masoud SS, Meyer K, et al. Engaging multi-stakeholder perspectives to identify dementia care research priorities. *J Patient Rep Outcomes*. Jun 22 2021;5(1):46. doi:10.1186/s41687-021-00325-x [PubMed: 34156561]
11. Bethell J, Commisso E, Rostad HM, et al. Patient engagement in research related to dementia: A scoping review. *Dementia (London)*. Nov 2018;17(8):944–975. doi:10.1177/1471301218789292 [PubMed: 30373460]
12. Armstrong MJ, Gamez N, Alliance S, et al. Research priorities of caregivers and individuals with dementia with Lewy bodies: An interview study. *PLoS One*. 2020;15(10):e0239279. doi:10.1371/journal.pone.0239279 [PubMed: 33027276]
13. Peterson B, Armstrong M, Galasko D, et al. Lewy Body Dementia Association's Research Centers of Excellence Program: Inaugural Meeting Proceedings. *Alzheimers Res Ther*. 03 13 2019;11(1):23. doi:10.1186/s13195-019-0476-1 [PubMed: 30867052]
14. Eysenbach G Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *Journal of Medical Internet Research*. 2004-09-29 2004;6(3):e34. doi:10.2196/jmir.6.3.e34 [PubMed: 15471760]
15. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. Apr 2009;42(2):377–81. doi:10.1016/j.jbi.2008.08.010 [PubMed: 18929686]
16. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. *J Biomed Inform*. 07 2019;95:103208. doi:10.1016/j.jbi.2019.103208 [PubMed: 31078660]
17. Schneider J, Jeon S, Gladman JT, Corriveau RA. ADRD Summit 2019 Report to the National Advisory Neurological Disorders and Stroke Council. https://www.ninds.nih.gov/sites/default/files/2019_adrd_summit_recommendations_508c.pdf

18. Lewy Body Dementia: Information for Patients, Families, and Professionals. National Institutes on Health. 2022. <https://order.nia.nih.gov/publication/lewy-body-dementia-information-for-patients-families-and-professionals>
19. Armstrong MJ, Gamez N, Alliance S, et al. Clinical Care and Unmet Needs of Individuals With Dementia With Lewy Bodies and Caregivers: An Interview Study. *Alzheimer Dis Assoc Disord*. 2021 Oct-Dec 01 2021;35(4):327–334. doi:10.1097/WAD.0000000000000459 [PubMed: 34034295]
20. McKeith IG, Ferman TJ, Thomas AJ, et al. Research criteria for the diagnosis of prodromal dementia with Lewy bodies. *Neurology*. 04 2020;94(17):743–755. doi:10.1212/WNL.00000000000009323 [PubMed: 32241955]
21. Woolf SH, Zimmerman E, Haley A, Krist AH. Authentic Engagement Of Patients And Communities Can Transform Research, Practice, And Policy. *Health Aff (Millwood)*. Apr 2016;35(4):590–4. doi:10.1377/hlthaff.2015.1512 [PubMed: 27044956]
22. Frank L, Shubeck E, Schicker M, et al. The Experiences of Persons Living with Dementia Planning for a Dementia Research Meeting. Lessons Learned From the National Research Summit on Care, Services, and Supports for Persons With Dementia and Their Caregivers. *Am J Geriatr Psychiatry*. 04 2020;28(4):434–442. doi:10.1016/j.jagp.2019.10.015 [PubMed: 31767451]
23. Keogh F, Carney P, O’Shea E. Innovative methods for involving people with dementia and carers in the policymaking process. *Health Expect*. 06 2021;24(3):800–809. doi:10.1111/hex.13213 [PubMed: 33650760]
24. Nygaard A, Halvorsrud L, Bye A, Bergland A. It takes two to tango: carers’ reflections on their participation and the participation of people with dementia in the James Lind Alliance process. *BMC Geriatr*. 05 14 2020;20(1):175. doi:10.1186/s12877-020-01570-3 [PubMed: 32408893]
25. Frank L, Jennings LA, Petersen RC, et al. Participation of persons with dementia and their caregivers in research. *J Am Geriatr Soc*. 07 2021;69(7):1784–1792. doi:10.1111/jgs.17340 [PubMed: 34245586]
26. Babulal GM, Quiroz YT, Albeni BC, et al. Perspectives on ethnic and racial disparities in Alzheimer’s disease and related dementias: Update and areas of immediate need. *Alzheimers Dement*. 02 2019;15(2):292–312. doi:10.1016/j.jalz.2018.09.009 [PubMed: 30555031]
27. Kurasz AM, Smith GE, McFarland MG, Armstrong MJ. Ethnoracial Differences in Lewy Body Diseases with Cognitive Impairment. *J Alzheimers Dis*. 2020;77(1):165–174. doi:10.3233/JAD-200395 [PubMed: 32804137]
28. Damron L, Litvan I, Bayram E, Berk S, Siddiqi B, Shill H. Hispanic Perspectives on Parkinson’s Disease Care and Research Participation. *J Alzheimers Dis*. 2021;81(2):809–819. doi:10.3233/JAD-210231 [PubMed: 33843687]
29. Jellinger KA, Korczyn AD. Are dementia with Lewy bodies and Parkinson’s disease dementia the same disease? *BMC Med*. 03 06 2018;16(1):34. doi:10.1186/s12916-018-1016-8 [PubMed: 29510692]

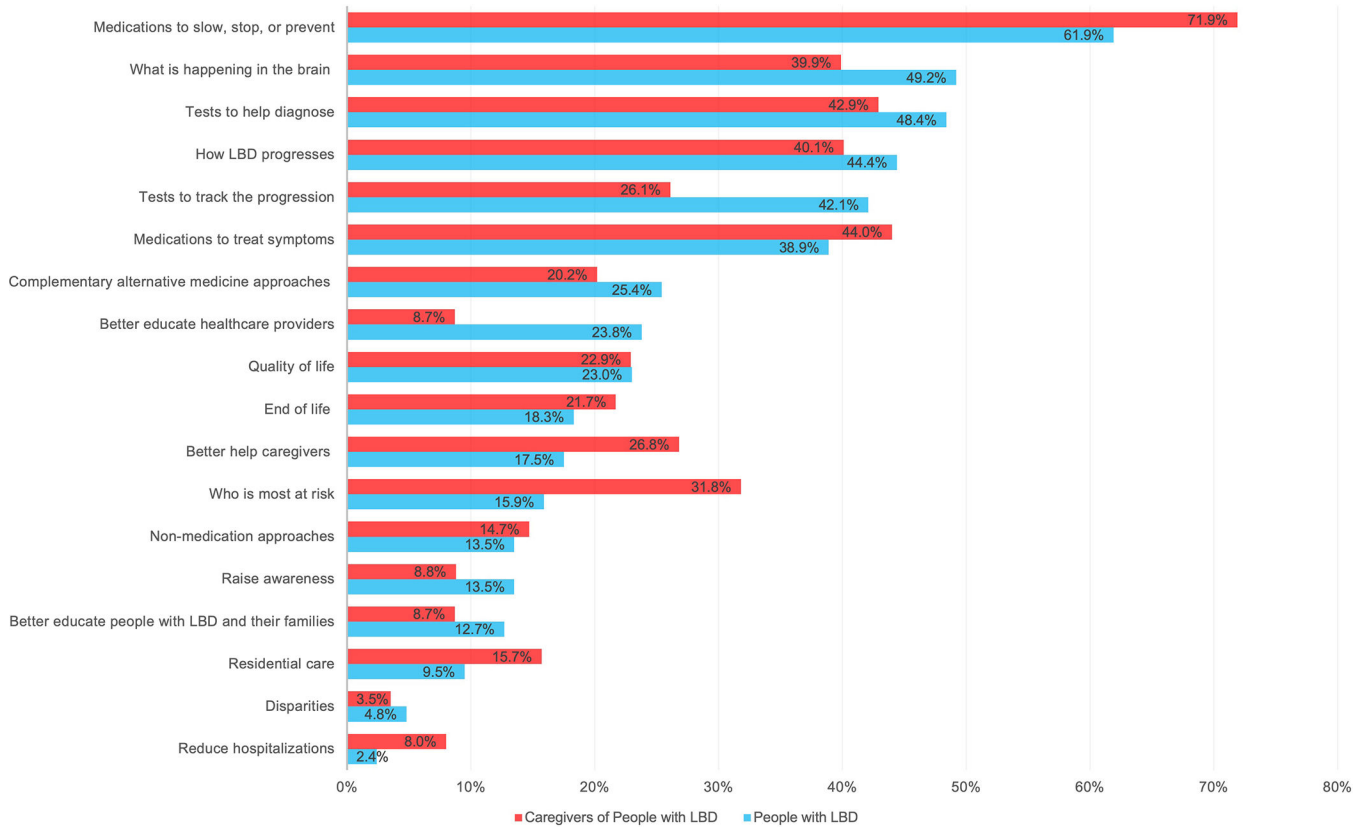


Figure 1:
Frequency of ranking research priorities within Top 5 by respondent type

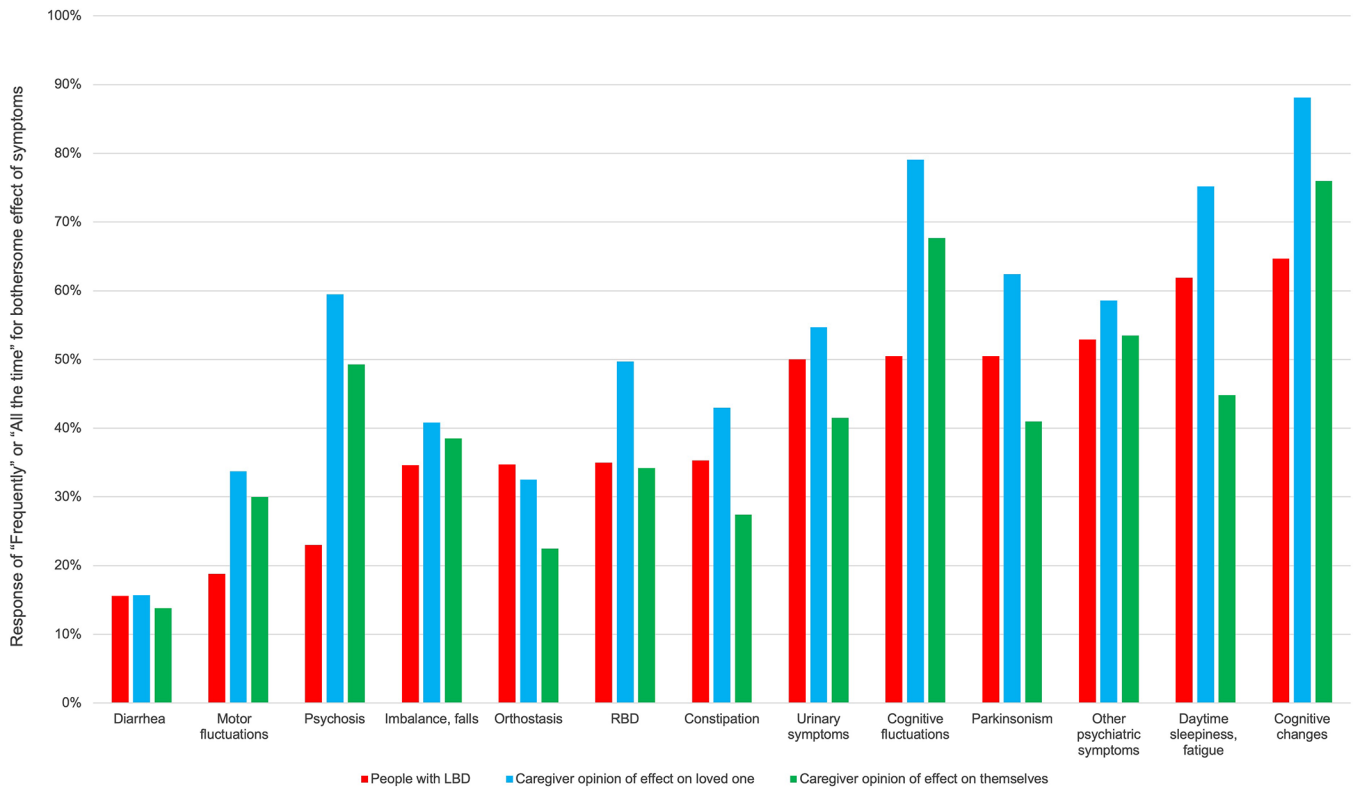


Figure 2: Symptoms rated as being bothersome “frequently” or “all the time” by respondent type

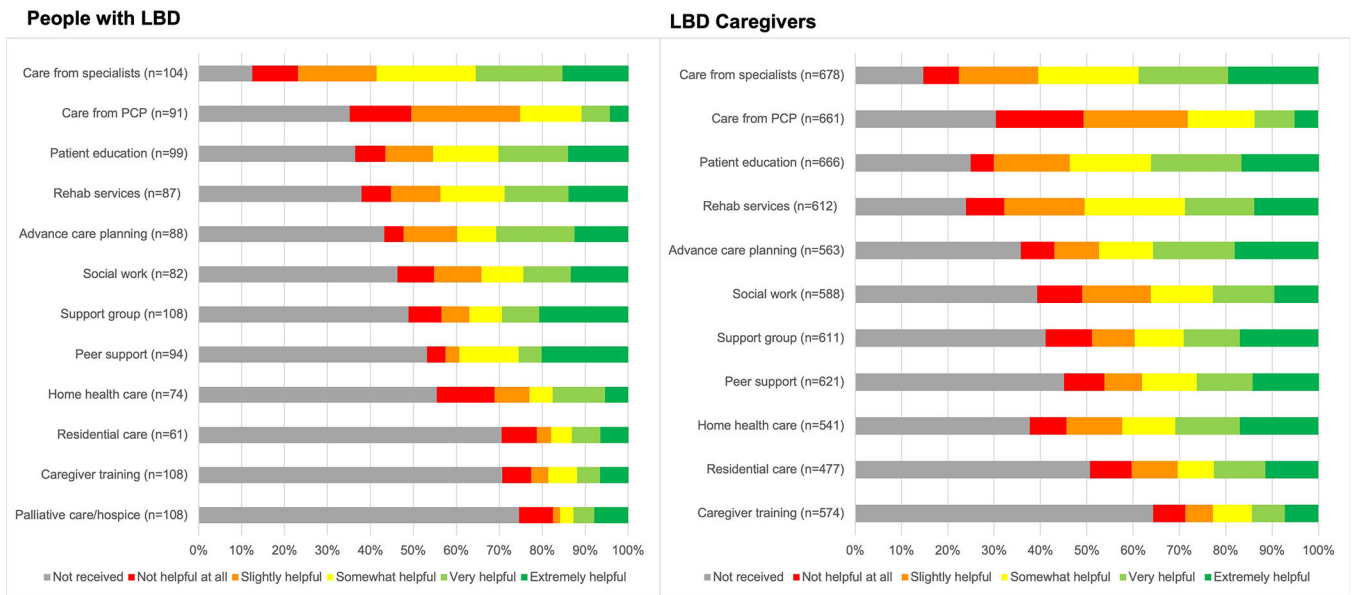


Figure 3:
Helpfulness of currently available services for LBD

Table 1:

Respondent demographic and clinical information

		Person with LBD (n=131)	Caregiver of Person with LBD (n=832)
Demographic Information			
Age	<50 years old	2 (1.5%)	82 (9.9%)
	50–59 years old	18 (13.7%)	154 (18.5%)
	60–69 years old	47 (35.9%)	243 (29.2%)
	70–79 years old	56 (42.7%)	279 (33.5%)
	80 or older	8 (6.1%)	74 (8.9%)
Gender	Male	85 (64.9%)	130 (15.6%)
	Female	44 (33.6%)	698 (84%)
	Transgender Male	1 (0.8%)	1 (0.1%)
	Transgender Female	-	1 (0.1%)
	Genderqueer or gender non-conforming	1 (0.8%)	-
	Other or prefer not to answer	-	1 (0.1%)
Race/Ethnicity <i>(Respondents could choose all that applied)</i>	White	121 (92.4%)	773 (93.4%)
	Black or African American	2 (1.5%)	14 (1.7%)
	Hispanic or Latino	2 (1.5%)	17 (2.1%)
	Asian	2 (1.5%)	12 (1.4%)
	American Indian or Alaska Native	3 (2.3%)	4 (0.5%)
	Native Hawaiian or other Pacific Islander	-	4 (0.5%)
	None of the above	3 (2.3%)	1 (0.1%)
	Prefer not to answer	3 (2.3%)	23 (2.8%)
Education	Up to 8th grade	1 (0.8%)	3 (0.4%)
	Some high school, no diploma	0	3 (0.4%)
	High school graduate or equivalent (GED)	10 (7.6%)	75 (9.1%)
	Technical school	8 (6.1%)	21 (2.5%)
	Some college coursework	25 (19.1%)	107 (12.9%)
	Associate's degree	14 (10.7%)	71 (8.6%)
	Bachelor's degree	34 (26%)	265 (32%)
	Master's degree or doctorate	39 (29.8%)	283 (34.2%)
Marital Status	Single	7 (5.4%)	59 (7.1%)
	Married or domestic partnership	103 (79.2%)	591 (71.3%)
	Widowed	5 (3.8%)	134 (16.2%)
	Divorced	12 (9.2%)	38 (4.6%)
	Separated	3 (2.3%)	7 (0.8%)
Geographic Location	USA	123 (93.9%)	740 (89.6%)

		Person with LBD (n=131)	Caregiver of Person with LBD (n=832)
	North America, not USA	1 (0.8%)	30 (3.6%)
	South America	1 (0.8%)	2 (0.2%)
	Europe	3 (2.3%)	41 (5%)
	Asia	1 (0.8%)	4 (0.5%)
	Oceania	2 (1.5%)	6 (0.7%)
	Africa	-	3 (0.4%)
Location Type	Large city	15 (11.5%)	152 (18.3%)
	Suburb near a large city	56 (43.1%)	295 (35.6%)
	Small city or town	38 (29.2%)	296 (35.7%)
	Rural area	21 (16.2%)	86 (10.4%)
Clinical Information			
LBD Diagnosis	DLB	97 (74.6%)	624 (75.8%)
	PDD	7 (5.4%)	97 (11.8%)
	Unsure	26 (20%)	102 (12.4%)
Relationship to Person with LBD	Spouse or partner	NA	521 (63%)
	Child (son or daughter)		220 (26.6%)
	Brother or sister		14 (1.7%)
	Friend		3 (0.4%)
	Other		69 (8.3%)
Length of LBD Diagnosis	<1 year	51 (39.2%)	175 (22.3%)
	1 to <2 years	31 (23.8%)	115 (14.7%)
	2 to <3 years	14 (10.8%)	123 (15.7%)
	3 to <4 years	10 (7.7%)	115 (14.7%)
	4 to <5 years	5 (3.8%)	76 (9.7%)
	5 to <6 years	5 (3.8%)	75 (9.6%)
	6 to <7 years	4 (3.1%)	40 (5.1%)
	7 to <8 years	5 (3.8%)	23 (2.9%)
	8 to <9 years	1 (0.8%)	15 (1.9%)
>10 years	3 (2.3%)	26 (3.3%)	
Current or Former Caregiver	Current	NA	549 (66.3%)
	Former		279 (33.7%)
Previous Participation in Research	Yes	31 (23.7%)	135 (16.3%)
	No	95 (72.5%)	663 (80%)
	Unsure	5 (3.8%)	31 (3.7%)

Table 2:

Helpfulness of currently available LBD symptomatic treatments by respondent type

	People with LBD					Caregivers of people with LBD				
	<i>Nothing helpful</i>	<i>Slightly helpful</i>	<i>Somewhat helpful</i>	<i>Very helpful</i>	<i>Extremely helpful</i>	<i>Nothing helpful</i>	<i>Slightly helpful</i>	<i>Somewhat helpful</i>	<i>Very helpful</i>	<i>Extremely helpful</i>
Urinary symptoms	46.5%	19.8%	16.3%	8.1%	9.3%	51.4%	20.0%	17.9%	5.6%	5.0%
Diarrhea	39.3%	24.6%	18.0%	11.5%	6.6%	45.6%	20.6%	21.1%	9.3%	3.4%
Psychosis	38.8%	18.8%	14.1%	21.2%	7.1%	38.7%	20.3%	20.5%	12.4%	8.1%
Daytime sleepiness, fatigue	37.2%	31.9%	17.0%	8.5%	5.3%	57.9%	23.0%	14.1%	3.5%	1.5%
Motor fluctuations	34.9%	26.5%	24.1%	10.8%	3.6%	42.5%	26.7%	22.2%	6.0%	2.6%
Cognitive fluctuations	34.3%	27.3%	25.3%	10.1%	3.0%	43.0%	22.4%	24.5%	5.8%	4.4%
Constipation	33.3%	32.1%	14.8%	12.3%	7.4%	28.4%	23.7%	27.7%	14.1%	6.0%
REM sleep behavior disorder	31.9%	23.1%	20.9%	15.4%	8.8%	42.7%	21.3%	19.7%	10.5%	5.8%
Orthostasis	31.8%	28.2%	23.5%	8.2%	8.2%	41.5%	23.8%	21.3%	9.7%	3.7%
Parkinsonism	31.4%	22.0%	33.7%	8.1%	4.7%	38.2%	26.9%	22.9%	8.6%	3.5%
Imbalance, falls	26.1%	27.2%	26.1%	13.0%	7.6%	45.7%	23.7%	19.9%	8.1%	2.6%
Cognitive changes	26.0%	25.0%	27.0%	18.0%	4.0%	36.0%	22.0%	27.0%	7.9%	7.1%
Other psychiatric symptoms	21.2%	24.0%	29.8%	17.3%	7.7%	28.5%	25.8%	28.3%	12.5%	4.9%