



## Frequency of suicidal ideation and associated clinical features in Lewy body dementia

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### ARTICLE INFO

#### Keywords:

Lewy body disease  
Lewy Body Dementia  
Suicide  
Suicidal ideation

### ABSTRACT

**Introduction:** Neuropsychiatric disturbance is common in individuals with Lewy body dementia (LBD). Despite this, there is minimal research regarding suicide risks in this population.

**Methods:** This study was a retrospective review of a prospectively-collected database at a tertiary movement disorders clinic. Database participants with an LBD diagnosis at their most recent visit and at least one complete Beck Depression Inventory-II (BDI-II) were included. Additional measures included demographics and measures of cognition, psychiatric symptoms, motor function, and the Parkinson Disease Questionnaire-39. The frequency of suicidal ideation was assessed using question 9 of the BDI-II. Features associated with a BDI-II score greater than zero were assessed using logistic regression.

**Results:** The database included 95 individuals with LBD and at least one BDI-II (visit years 2010–2020). Most participants were older men who identified as white. Eighteen individuals (18.9%; 95% CI 12.3%–28.0%) reported thoughts of killing themselves without an intent to carry them out (BDI-II = 1). No participants reported a desire or plan to kill themselves. The presence of SI was associated with measures of depression, anxiety, and emotional well-being, but not with demographics, measures of disease severity, or other psychiatric concerns.

**Conclusion:** These findings emphasize the importance of routine screening for psychiatric symptoms in LBD and intervention when such concerns are identified. Interventions could include pharmacologic (e.g. depression treatment) and non-pharmacologic (e.g. firearm screening) approaches. More research is needed to assess suicidal ideation and suicide risks in large and more diverse LBD populations. Prospective studies should include measures of additional potential contributors to suicidality.

### 1. Introduction

Lewy body dementia (LBD) is the second-most common neurodegenerative dementia after Alzheimer disease (AD) dementia [1]. It is an umbrella term including dementia with Lewy bodies (DLB) and Parkinson disease dementia (PDD) [2]. Individuals with LBD have symptoms including dementia, behavioral changes, parkinsonism, falls, sleep disturbance, and autonomic findings [2]. Despite the fact that several of these features (e.g. behavioral symptoms) associate with an increased risk of suicidality in older adults, relatively little research has investigated suicide risk in this population.

A study from the Department of Veterans Affairs National Patient Care Database and National Suicide Prevention Applications reported suicidal ideation (SI) in <2% of individuals with LBD and a suicide plan or attempt in <0.1% of individuals with LBD in 2012–2013 [3]. However, the study likely underestimated true prevalence due to reliance on healthcare provider reports to the National Suicide Prevention Applications tracking system. In research using a large United Kingdom hospital database, the occurrence of non-accidental self-injury was significantly higher in individuals with DLB (3.1%) than individuals with AD dementia (0.7%) in 2006–2013 [4]. In a 2017 survey of family and friends of individuals who died with DLB, almost 1% (5/646) of

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<https://doi.org/10.1016/j.parkreldis.2021.07.029>

Received 8 March 2021; Received in revised form 23 July 2021; Accepted 27 July 2021

Available online 29 July 2021

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deaths were attributed to suicide [5]. A 2021 assessment of suicide risk in the first year after dementia diagnosis using Medicare data reported that LBD accounted for 1.8% of the new dementia diagnoses but 2.3% of the deaths by suicide in the first year, with a suicide mortality rate of 32.41 per 100,000 person-years. The rate of non-fatal suicide events in the first year after LBD diagnosis was 0.84 per 10,000 person-years [6].

In 2020, the Lewy Body Dementia Association commissioned a working group to examine research regarding suicide in LBD, suggest best practices surrounding suicide and care in LBD, and identify opportunities for further research [7]. Because of the paucity of research regarding suicide and LBD, the working group made recommendations for care based on PD and dementia literature [7]. The group also identified 7 specific areas needing further research, starting with investigating the prevalence of SI and suicide attempts in individuals with LBD and identifying clinical and psychosocial risk factors for SI and suicide behaviors. The current study thus aimed to use a single-center database to identify the frequency of SI in LBD at a specialty movement disorders clinic and factors associated with SI in this population.

## 2. Methods

### 2.1. Study design

This study was a retrospective review of a prospectively-collected longitudinal database at the University of Florida (UF). Over 90% of patients receiving care at the UF movement disorders clinic agree to participate. Individuals who provide informed consent complete scales at each clinical visit (for clinical and research purposes) and agree to have clinical documentation (e.g. examination findings) included in the database. The database is approved by the UF Institutional Review Board (IRB201501166). The current analysis was approved as exempt (IRB202002696).

### 2.2. Population

The current study included all database participants with a diagnosis of LBD (DLB, PDD, or unspecified) and completion of at least one Beck Depression Inventory-II (BDI-II). The database started collecting the BDI-II in 2010 and the data query occurred in January 2021. Diagnosis was assigned by a fellowship-trained movement disorders specialist. As diagnoses can change over time, the most recent diagnosis was used to assign participants to a diagnostic group for the current analysis. Database participants with other primary diagnoses were excluded.

### 2.3. Measures

The presence or absence of SI was assessed using BDI-II question 9, where a response of 0 indicates “I don’t have any thoughts of killing myself, 1 indicates “I have thoughts of killing myself, but I would not carry them out,” 2 indicates “I would like to kill myself,” and 3 indicates “I would kill myself if I had the chance.” The BDI is one of the validated and recommended scales for assessing depression in PD for both screening and severity [8]. The BDI-II is the current BDI version and overlaps considerably with the original BDI, with high correlation between the two versions [9].

Demographic and historical information collected includes age, self-identified gender, self-identified race/ethnicity, diagnosis, and disease duration (years since symptom onset, years since diagnosis). The database does not routinely collect level of education, medications, or medical comorbidities. In addition to the BDI-II, intake forms completed by the patients/caregivers include the Unified Parkinson Disease Rating Scale (UPDRS) part I (assessing mentation, behavior, and mood, including presence of psychosis) and II (activities of daily living) [10], Beck Anxiety Inventory (BAI) [11], Apathy Scale (AS) [12], and Parkinson’s Disease Questionnaire (PDQ-39) [13]. The database includes UPDRS part III (motor function) ratings [10], with clinicians noting if

the patient was in the “off” or “on” state at the time of the assessment. Database participants do not routinely complete cognitive screening, but clinical assessments of cognition use either the Mini Mental State Examination (MMSE) [14] or the Montreal Cognitive Assessment (MoCA) [15]. The clinic largely switched from MMSE to MoCA use in 2015, but clinicians select cognitive testing approaches.

### 2.4. Analysis

Baseline demographics were assessed using baseline visit results for each participant (baseline visit: first visit with BDI-II completion in a person with an LBD diagnosis at the most recent visit). Descriptive statistics were performed using frequencies and medians with interquartile ranges. The frequency of SI (any visit) was assessed across LBD diagnostic groups, as was SI frequency across multiple visits. Confidence intervals for frequencies were calculated using Wilson’s method [16]. Frequencies between diagnostic groups were compared with a chi-square analysis. To assess factors associated with SI, data were used from the most recent visit (in the cases of individuals with SI, the most recent visit with SI). For cognitive screening, scores were used from the same visit if available. Otherwise, the most recent cognitive screening score was included, regardless of date of administration, as cognitive screening is not performed at every clinical visit. Logistic regression assessed variables associated with SI in both univariate models and multivariable models adjusting for age and gender. Post-hoc, correlations between significant variables were assessed using Pearson’s method and a logistic regression was conducted using the main significant variables. Missing data were handled by noting the “n” for any given analysis.  $P < 0.05$  was considered significant. Statistics were performed using IBM SPSS Statistics Version 27.0 (IBM SPSS Statistics for Windows, Version 27.0 [2020]. Armonk, NY: IBM Corp).

## 3. Results

The database included 95 individuals with LBD and at least one complete BDI-II. Visits ranged from 2010 to 2020. Most of the included individuals were older men who self-identified as white (Table 1).

### 3.1. Frequency of suicidal ideation

Eighteen individuals (18.9%; 95% CI 12.3%–28.0%) with LBD reported thoughts of killing themselves without an intent to carry them out (BDI-II question 9 = 1). The remainder of respondents denied SI. No one stated that they wanted to kill themselves or would kill themselves if they had the chance (BDI-II question 9 score 2 or 3; 0%, 95% CI 0%–3.9%). Of the 18 individuals with LBD endorsing SI, 10 had a database diagnosis of DLB (10/67, 14.9%), 8 had a database diagnosis of unspecified LBD (8/22, 36.3%), and none had a PDD diagnosis (0/6, 0%) ( $p = 0.04$ ). Four of the 18 individuals with LBD endorsing SI only had a single visit with a BDI-II completed. Of the remaining 14 individuals, 6 (43%) endorsed SI over multiple visits (range 2–5 visits with SI; range 2–11 visits total where a BDI-II was completed). This corresponded to persistent SI in 6.3% of the total population studied (6/95; 95% CI 2.9%–13.1%) or 9.1% of the study population with at least 2 visits with a completed BDI-II (6/66; 95% CI 4.2%–18.5%). Of the 18 individuals who endorsed SI on the BDI-II during at least one encounter, 5 were lost to follow-up (no information since at least 2018), 11 were still living at the time of last available information, and 2 had died. One individual died on hospice. No information was available regarding the death of the second person.

### 3.2. Factors associating with suicidal ideation

In the univariate analysis, depression (total BDI-II score), anxiety (total BAI score), and emotional well-being (PDQ-39 emotional well-

**Table 1**  
Participant demographics at first visit.

	DLB (n = 67)	PD dementia (n = 6)	LBD unspecified (n = 22)	Total (n = 95)
Age, years	72 (68–76)	73 (72–73)	71 (66–78)	72 (68–76)
Male sex (%)	52 (77.6%)	4 (66.7%)	14 (63.6%)	70 (73.7%)
White (%)	60 (89.6%)	6 (100%)	17 (77.3%)	83 (87.4%)
Years since symptom onset (n = 51)	3 (2–6)	11 (1–11)	4 (2–5)	4 (2–6)
Years since diagnosis (n = 39)	2 (1–3)	5 (1–10)	2 (1–2)	2 (1–3)
H&Y stage	Off 3 (2.5–4) (n = 19) On 2.5 (2–3) (n = 16)	Off 2 (2–2) (n = 1) On 2.8 (2.5–3) (n = 2)	Off 3 (3–5) (n = 5) On 3 (3–3) (n = 5)	Off 3 (2.5–4) (n = 25) On 3 (3–3) (n = 23)
UPDRS I – total (range 0–16) (n = 54)	6 (3–7)	7.5 (4–9) (n = 6)	6.5 (5–8) (n = 18)	6 (4–8) (n = 78)
UPDRS I.2 – thought disorder (response, %) (n = 54)	0: 18 (26.9%) 1: 8 (11.9%) 2: 15 (22.4%) 3: 14 (20.9%) 4: 0 (0.0%) Missing: 12 (17.9%)	0: 0 (0.0%) 1: 3 (50.0%) 2: 1 (16.7%) 3: 2 (33.3%) 4: 0 (0.0%) Missing: 0 (0.0%)	0: 5 (22.7%) 1: 2 (0.09%) 2: 8 (36.4%) 3: 3 (13.6%) 4: 0 (0.0%) Missing: 6 (27.3%)	0: 23 (24.2%) 1: 13 (13.7%) 2: 24 (25.3%) 3: 19 (20.0%) 4: 0 (0.0%) Missing: 16 (16.8%)
UPDRS II – total (n = 56)	15 (9.5–21)	16.5 (10–24) (n = 6)	15 (12–19) (n = 17)	15 (10–21) (n = 79)
UPDRS III – total <sup>a</sup> (n = 29)	Off 35 (29–42) On 30.5 (24.5–34)	Off 25 (25–25) On 46 (19–52)	Off 35.5 (27–46) On 24.5 (21–38.5)	Off 35 (26–43.25) On 30 (23–36)
H&Y stage (n = 19)	Off 3 (2.5–4) On 2.5 (2–3) (n = 16)	Off 2 (2–2) (n = 1) On 2.8 (2.5–3) (n = 2)	Off 3 (3–5) (n = 5) On 3 (3–3) (n = 5)	Off 3 (2.5–4) (n = 25) On 3 (3–3) (n = 23)
MMSE (n = 13)	22 (11–25)	N/A	19 (25–25) (n = 8)	21 (11.5–25) (n = 21)
MoCA (n = 14)	15 (6–20)	9 (5–14) (n = 4)	20 (15–23) (n = 4)	15 (6–20.5) (n = 22)

Variables presented as median (interquartile range) except for sex, race (n, percent). “N” in parentheses reports the number of participants with each of these scales in each group. For UPDRS question 1.2, the response options are: 0 = none, 1 = vivid dreaming, 2 = “benign” hallucinations with insight retained, 3 = occasional to frequent hallucinations or delusions, without insight, could interfere with daily activities, and 4 = persistent hallucinations, delusions, or florid psychosis, not able to care for self.

<sup>a</sup> UPDRS-III total “off” and “on” scores reflect the state in which the patients were examined in clinic and do not imply off/on assessments for individual patients.

being subscale) associated with SI (Table 2). These associations remained statistically significant when adjusting for age and gender in multivariable analyses (adjusted models: total BDI-II  $p < 0.001$ , total BAI  $p = 0.02$ , PDQ-39 emotional well-being subscale  $p = 0.001$ ). The association between SI and the BDI-II total score remained when excluding question 9 about SI from the total score ( $p < 0.001$ ). Other assessments did not associate with the presence of SI (Table 2). Across study visits (i.e., not limiting to the visits with SI alone), BDI-II and BAI scores were highly correlated (0.80,  $p < 0.001$ ), as were emotional well-being and both the BDI-II (0.71,  $p < 0.001$ ) and BAI (0.66,  $p = 0.001$ ). A multivariate logistic regression model including BDI-II and BAI total scores performed with the 28 individuals with complete a BAI was not significant ( $p = 0.972$ ), potentially due to the small sample size.

**Table 2**  
Features Associated with Suicidality (BDI-II score >0) in Individuals with Lewy Body Dementia.

	LBD without SI (BDI-II Question 9 = 0) (n = 77)	LBD with SI (BDI-II Question 9 = 1) (n = 18)	P-value (univariate analysis)
Age	73 (69–78.5)	72 (68.5–77.25)	0.42
Male gender (%)	57 (74.0%)	13 (72.2%)	0.88
White race (%)	66 (85.7%)	17 (94.4%)	0.65
Years since symptom onset (n = 61)	5 (3–6)	5 (3–8)	0.81
Years since diagnosis (n = 47)	3 (1–4)	3 (2–5)	0.90
MMSE (n = 35)	21 (15–25)	23 (23–23)	0.66
MoCA (n = 31)	15 (13–20)	13 (6–22)	0.54
BDI-II total score	15 (10–21)	31 (22.75–37.25)	<b>&lt;0.001</b>
BAI total score (n = 22)	16 (10.75–23.35)	28 (20.5–33.75)	<b>0.02</b>
AS total score (n = 64)	22 (17.25–28)	20.5 (19–25.75)	0.88
UDPRS part I total (n = 55)	7 (5–8)	7.5 (6.5–8.75)	0.33
Psychosis (UPDRS 1.2 score >0) (n = 56)	47 (83.9%)	7 (70%)	0.30
Psychosis (UPDRS 1.2 score >1) (n = 56)	37 (66.1%)	6 (60%)	0.71
UPDRS part II total (n = 55)	17 (12–22)	14 (12–31)	0.27
UPDRS part III total - OFF (n = 16)	32 (25.25–48.75)	29 (13.5–54)	0.79
UPDRS part III total - ON (n = 39)	34 (26–44)	36 (22.5–40)	0.66
PDQ-39 mobility (10 items) (n = 65)	57.5 (32.5–87.5)	75 (48.75–87.5)	0.19
PDQ-39 ADLs (6 items) (n = 66)	45.8 (25–80.2)	54.2 (37.5–81.25)	0.42
PDQ-39 emotional well-being (6 items) (n = 63)	25 (16.67–54.2)	58.3 (41.67–75)	<b>0.002</b>
PDQ-39 stigma (4 items) (n = 66)	12.5 (0–25)	16.67 (0–25)	0.11
PDQ-39 social support (3 items) (n = 65)	8.33 (0–25)	16.67 (0–25)	0.16
PDQ-39 cognitive impairment (4 items) (n = 66)	50 (37.5–75)	50 (40.63–68.75)	0.92
PDQ-39 communication (3 items) (n = 66)	37.5 (16.67–66.67)	41.67 (29.17–58.33)	0.62
PDQ-39 bodily discomfort (3 items) (n = 67)	41.67 (25–58.33)	41.67 (33.33–62.5)	0.41

Variables presented as median (interquartile range) except for sex, race, and categories of responses to the psychosis question on the UPDRS Part I (n, percent). “N” in parentheses reports the number of participants with each of these scales in each group.

MMSE: Mini-Mental State Examination, MoCA: Montreal Cognitive Assessment, BDI-II: Beck Depression Inventory-II, BAI: Beck Anxiety Inventory, AS: Apathy Scale, UPDRS: Unified Parkinson’s Disease Rating Scale, PDQ-39: Parkinson’s Disease Questionnaire-39.

Bold: Statistically significant results.

#### 4. Discussion

In this study of individuals with LBD receiving care at a specialty movement disorders center, 18/95 (18.9%) reported SI without an intent to carry out a plan. No participants reported a desire or plan to kill themselves. The presence of SI was associated with depression, anxiety, and emotional well-being but not with demographics (e.g. age, gender), measures of disease severity (e.g. cognition, motor symptoms, function), or other psychiatric concerns (psychosis, apathy).

The finding that 18.9% of database participants with LBD described thoughts of killing themselves is higher than prior studies reporting SI in <2% of individuals with LBD [3] and non-accidental self-injury in 3% of individuals with DLB [4]. This likely reflects how SI was measured. In the current study, a score of 1 on the BDI-II suicidality question was considered sufficient for SI, but this indicates thoughts of killing oneself without an intent to carry the thoughts out. The SI reported in prior studies involved healthcare provider reporting to the National Suicide Prevention Applications tracking system [3] or hospitalization for non-accidental self-injury [4], both of which indicate a higher level of concern than was measured in the current study. While no individuals in the current study endorsed wanting to kill themselves or an intent to kill themselves if they had the chance (BDI-II question 9 score 2 or 3), the confidence interval for this (0%–3.9%) was consistent with the frequency of more severe SI reported previously.

The current study did not compare the frequency of SI in individuals with LBD to individuals with other diagnoses (e.g. PD without dementia or other dementias). A 2019 systematic review identified that most studies reported SI frequency in individuals with PD to be around 30% [17]. Subsequently published studies reported SI present in 23–31% of individuals with PD [18,19]. When considering suicide rates in dementia, a Denmark population-based study found that 0.2% of individuals with dementia died by suicide (569/243022; incidence rate 57.7 per 100,000 person-years) [20]. A 2017 survey of family and friends of individuals who died with DLB found that almost 1% (5/646) of deaths of individuals with DLB were attributed to suicide [5]. Most recently, a Medicare analysis of deaths in the first year after a dementia diagnosis found that suicide accounted for 0.03% of all deaths in the first year, with LBD having the second-highest suicide morality amongst dementia types after frontotemporal dementia [6]. The current study's finding that there was a statistical difference in SI frequency between DLB, unspecified LBD, and PDD should be interpreted with caution given the small sample size in each group.

In the current analysis, a score of 1 on the BDI-II suicidality question was associated with depression (higher total BDI-II scores when assessed with and without the suicide question included), anxiety (higher total BAI scores), and worse emotional well-being (PDQ-39). This is consistent with prior research showing that SI and suicide risk in PD associate with overall non-motor symptom severity (e.g. relating to mood, sleep, fatigue, urination, and cognition) [18,19], depression [17,18], anxiety [17,18], psychosis [17,18], and other psychiatric disorders [18]. Most studies of suicide risk in PD excluded individuals with dementia, however [17]. Suicide in dementia is also associated with psychiatric comorbidity, including depression, anxiety, and psychosis [6,21–23].

Older age and male gender are known risk factors for SI and suicide in older adults [24], but these were not associated with SI in the current cohort. This could potentially relate to the facts that the age dispersion was fairly narrow (median 72 years; IQR 68–76) and almost three-quarters of participants were men, consistent with studies suggesting that LBD is more common in men [25]. Similarly, SI in the current study did not associate with disease duration, cognition (MMSE, MoCA, or PDQ-39 cognitive impairment subscale), motor symptoms (motor UPDRS, PDQ-39 mobility subscale), function (UPDRS ADL scale, PDQ-39 ADL subscale), other psychiatric concerns (UPDRS psychosis score, AS total score), or measures of social aspects of disease (PDQ-39 stigma subscale, PDQ-39 social support subscale). Interpretation of this should be approached with caution, however, given the sample size, retrospective analysis, and use of a single center cohort. In addition to older age, male gender, and psychiatric disturbance, risk factors for suicidality in older adults include disease-related factors (e.g. medical illness, multi-morbidity, pain), disability (e.g. functional impairments, dependency), social disconnectedness (e.g., loneliness, isolation, feeling like a burden), and access to deadly means [24,26–28].

Whether degree of cognitive impairment is a risk factor for suicidality is uncertain. One study identified that individuals with PD who died by suicide (versus “natural causes”) had higher (less impaired)

mean MMSE scores (25.75 vs. 21.36) [29], but most studies of suicide risk in PD exclude individuals with dementia [17]. The relationship between motor symptom severity and suicide risk in individuals with PD is also unclear, with studies showing conflicting results [17,29].

This study used a database to assess the frequency of SI as reported on the BDI-II. However, the best way to query the presence of SI is unknown [7] and frequency may be different if using other approaches. Additionally, suicide-related ideation can be casual, transient, passive, active, or persistent [30]. Active or persistent SI is easier to capture at clinic visits, but suicidal behaviors may be impulsive in individuals with LBD and occur without pre-meditation [7]. Other study limitations include the fact that this database analysis relies on standard collection of measures. Thus, while the analysis could assess the relationship of SI and many potentially associated factors (e.g. depression, anxiety, motor function), other potential contributors (e.g. fluctuations, medications, medical comorbidities) had limited or no corresponding database measure. The database also does not capture whether intake forms were patient- or caregiver-completed, which could affect response interpretation, particularly for individuals with dementia where caregivers likely assisted with form completion. Database measures are skipped by patients at some visits and can be incomplete, limiting sample size for some analyses. It is uncertain whether respondents are attentive to measure instructions (e.g. completing the BDI-II according to how they were feeling over the past two weeks). Variables collected as part of routine clinical care also have inconsistencies in completion (e.g. cognitive screening is at the discretion of the clinician and switched from the MMSE to the MoCA in 2015, the UPDRS is typically completed in the “off” state at first visit and “on” thereafter, but this varies by patient and medication regimen). Available cognitive scores are likely an overestimate of cohort cognition, as cognitive screening is often not attempted or is aborted for the most severely affected patients. The cohort of individuals with PDD is under-represented in the current study as the database only recently started systematically collecting the progression of PD to PDD. The cohort represents patients at a single tertiary care movement disorders center, so results may not fully generalize to other populations. Finally, the current study does not compare SI frequency in LBD to that of other diagnoses because the focus of the current analysis is on LBD alone, to guide care of individuals with LBD.

While the current study has limitations, it also has important strengths. This is one of only a few studies to systematically assess the frequency of SI in LBD. Additionally, this is the first identified study to assess risk factors for SI in individuals with LBD. The finding that depression, anxiety, and emotional distress associate with SI emphasizes the importance of routine screening for these features and treatment when psychiatric disturbance is identified. American Academy of Neurology dementia quality measures require screening and management of neuropsychiatric symptoms at least annually [31]. However, given the high frequency of neuropsychiatric symptoms in LBD, clinicians should likely ask about psychiatric/behavioral symptoms at every routine follow up clinic visit, with development of a treatment plan for identified symptoms [7]. Whether screening for SI in LBD should occur regularly is uncertain [7], but the dementia quality measures recommend safety screening (e.g. for risk to self or others) with individuals with dementia and their caregivers at least annually [31]. In addition to treating identified psychiatric symptoms in individuals with LBD, addressing other potential contributors to suicide in older adults is important, such as connecting individuals with LBD and caregivers to social support and providing counseling regarding safety measures such as removing firearms from the home [7].

In conclusion, the current study identified that 18.9% of individuals with LBD in this single-center cohort endorsed SI without an intent to follow through. Risk factors for SI included depression, anxiety, and emotional distress. More research is needed to assess SI and suicide risks in other LBD populations (e.g. from different referral sources) with larger sample sizes. Prospective studies should include measures of additional potential contributors to suicidality (e.g. other LBD features

such as fluctuations and executive dysfunction; social connectedness). Additionally, qualitative studies are needed to understand the experiences of individuals with LBD with SI with and without self-harm. Ultimately, research is also needed to inform optimal screening approaches and strategies for addressing and preventing SI in LBD populations, including interventions that can be implemented at diagnosis and when SI is identified.

### Declarations of interest

M. J. Armstrong: Dr. Armstrong receives research support from the NIA (R01AG068128, P30AG047266), the Florida Department of Health (grant 20A08), and as the local PI of a Lewy Body Dementia Association Research Center of Excellence. She receives royalties from the publication of the book *Parkinson's Disease: Improving Patient Care*. K. Moore: The University of Florida Movement Disorders Fellowship Program has received support for the fellowship of Dr. Moore that is paid directly to the University. Dr. Moore has no direct conflicts of interest or industry disclosures to report. C. E. Jacobson: None. N. Bedenfield: None. B. Patel: Dr. Patel received a training grant from the American Brain Foundation and Mary E. Groff Charitable Trust. She received compensation for a consultation to Medtronic. J. L. Sullivan: None.

### Acknowledgements

No direct funding was received for this study. Lewy body dementia research at the University of Florida is supported by the University of Florida Dorothy Mangurian Headquarters for Lewy Dementia and the Raymond E. Kassar Research Fund for Lewy Body Dementia.

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