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Pre-Loss Grief in Caregivers of Older Adults with Dementia with Lewy Bodies

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Abstract

Background: Pre-loss grief increases as dementia advances. Caregivers who experience pre-loss grief face risks to their own physical and psychological health.

Objective: The study examined factors associated with pre-loss grief in caregivers of older adults with dementia with Lewy bodies (DLB) to determine whether overall caregiver experiences differ based on the stages of DLB in care recipients. The study also compared pre-loss grief in caregivers of DLB patients with that in caregivers of patients with Alzheimer's disease (AD) and other dementias.

Method: Using a cross-sectional design, 714 caregivers of older adults with dementia (488 DLB, 81 AD, 145 other dementia) completed an online survey on pre-loss grief. Multivariate linear regression identified risk factors associated with pre-loss grief and analysis of variance examined whether pre-loss grief in caregivers differed significantly based on type of dementia or stage of DLB.

Results: Being the caregiver of a spouse, lower level of caregiver well-being, lower psychological well-being of the caregiver, and higher level of burden were associated ($p < 0.005$) with increased pre-loss grief in caregivers of older adults with DLB. There was no significant difference in caregiver burden, well-being, or depression according to the various stages of DLB (mild, moderate, severe, deceased) in the care recipients. There was no significant difference in pre-loss grief in caregivers of DLB care recipients compared to caregivers of patients with other dementias.

Conclusion: Assessment of DLB caregivers and appropriate interventions should be conducted to reduce their burden and emotional distress to decrease the incidence of pre-loss grief.

Keywords

Alzheimer's disease; burden; caregiver; dementia; dementia with Lewy bodies; pre-loss grief; prolonged grief; well-being

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INTRODUCTION

Dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) comprise Lewy body dementia (LBD), the second most common form of neurodegenerative dementia in older adults, after Alzheimer's disease (AD) [1], accounting for 20% of those with dementia [2]. It has been estimated that approximately 1.4 million people in the United States have LBD [1]. Although DLB shares features such as cognitive impairment with AD, DLB is characterized by a unique symptom profile, including fluctuating cognition with pronounced variation in attention and alternateness, recurrent visual hallucinations, rapid eye movement (REM) sleep behaviors disorder, Parkinsonism, and autonomic dysfunction [3]. Because psychiatric and behavioral features are similar to those observed in psychotic disorders, such as schizophrenia, DLB is often under-detected and initially misdiagnosed [4]. Thus, DLB, compared to AD, is often poorly understood and many DLB patients, caregivers, and providers are less knowledgeable about the disease and all its manifestations [5].

Given the complex clinical phenotype with cognitive, psychiatric, motor, and autonomic symptoms, persons living with DLB face a number of unique challenges. Persons living with DLB have prominent and early behavioral symptoms [1, 3], have long delays in diagnosis [5], have difficulty in finding healthcare providers who are knowledgeable about the diagnosis and management of DLB [4, 5], and are more likely to be hospitalized than patients with AD or other dementias [6]. Thus, DLB caregivers are also likely to experience unique challenges and burden due these complex symptoms. One such challenge is the experience of grief.

Grief is an emotional reaction by caregivers to actual or perceived loss [7]. Dementia caregiver grief often results from perceived loss over the trajectory of the person living with dementia, comprising physical, emotional, and behavioral characteristics [8, 9]. These symptoms often include sadness, yearning, crying, changes in sleep and appetite, frustration, and trouble concentrating [9]. Prolonged grief is a clinical condition with specific grief reactions, including daily symptoms of longing and yearning for the deceased, significant emotional suffering, behavioral symptoms, and difficulty in accepting the loss and moving on without the deceased [10, 11]. The symptoms associated with prolonged grief persist for at least 6 months after the actual loss [11]. People who suffer from prolonged grief are more likely to have adverse health conditions [12].

Complicated grief associated with dementia caregiving can be categorized as pre-loss grief (loss over the entire trajectory of illness) or pre-death grief (experience of loss in the terminal stages of disease) or bereavement (i.e., post-loss grief) [13]. As grief can extend from the time of diagnosis until after death of the person with dementia, it can be a prolonged and clinically significant issue for caregivers. It has been estimated that 47% to 71% of family caregivers of people with dementia have experienced pre-loss grief [14] and can experience negative symptoms such as depressive symptoms [15] and caregiver burden [16]. Many caregivers experience withdrawal from the painful emotions associated with pre-death grief [17, 18].

Caregivers of persons with dementia are likely to exhibit a high prevalence of stress, grief, and depression even before the physical death of the individual [19]. Caregivers of persons with dementia often begin grieving long before the physical death of the care recipient [20, 21]. Pre-loss grief refers to the presence of grief symptoms while the care recipient with a terminal illness is alive [22, 23]. Pre-loss grief includes a wide range of emotional and physical responses by the caregiver in reacting to the perceived loss of the care recipient over the course of DLB and before the death of the care recipient [24].

Caregivers of older adults with dementia often grieve for their care recipient long before the recipient's death and may even experience the recipient's death as a relief [25]. Pre-loss grief can lead to caregiver burden, depression, and other mood disorders; social isolation; and maladaptive coping [26, 27], as well as a desire to institutionalize the person living with dementia [27]. Pre-loss grief increases as dementia advances [14] and caregivers who experience pre-loss grief are likely to experience their own health complications after the loss [14, 22, 28]. Current research suggests that pre-loss grief can affect the caregiver's experience and the caregiver's ability to make post-loss adaptations [29].

Family caregivers experience a variety of emotional distress, starting with the diagnosis and continuing to the death [24]. This pre-loss grief often results from (a) the care recipient's psychological death; (b) a long and ambiguous disease trajectory as the care recipient may remain present physically but become absent psychologically; (c) compromised communication between the caregiver and care recipient; and (d) changes in roles, relationships, and caregiver freedom [24]. Pre-loss grief is a main predictor of post-loss complicated grief in dementia caregivers [19, 30]. Higher levels of pre-loss grief are likely to lead to complicated grief after death [31], estimated to occur with 1 in 10 caregivers [24].

Grief can have a complicated nature in dementia caregiving due to the uncertain trajectory of the disease, disrupted communication, and lost opportunity for social and productive activities. Furthermore, severe pre-loss grief symptoms have been found to predict strongly complicated grief, which refers to severe grief that impairs caregiver functioning for more than 6 months after the loss [28].

DLB caregivers may experience burden and grief at earlier stages than do caregivers of persons with other dementia types [5], particularly the construct of heartfelt loss and sadness. When persons with DLB or AD at similar cognitive stages are compared, DLB patients typically experience more behavioral features with a higher frequency of hallucinations, apathy, and appetite changes. The caregivers of persons with DLB report higher caregiver distress than do caregivers of persons with AD, and high distress is associated with delusions, hallucinations, anxiety, and apathy [5, 20, 32, 33]. However, in a direct comparison of DLB, PDD, and AD caregivers, constructs of caregiver burden, grief, and quality of life were similar, with reported differences more likely due to caregiver characteristics and care recipient symptoms than to specific dementia diagnoses or stages of disease [34].

Previous studies have examined caregiver stress and burden in caring for a recipient with AD; however, such experience of pre-death grief is not always recognized and there is limited research on the challenges and burdens facing caregivers of care recipients with DLB [4, 5]. Previous research showed that pre-loss grief was associated with physical or emotional impairment in caregivers, who were likely to consider admission of the recipient to long-term care [35, 36]. The limited research on pre-loss grief has focused on examining pre-loss grief as a predictor of prolonged grief disorder, which is a broad spectrum of grief-related symptoms starting at least 6 months post loss [23].

No studies have examined pre-loss grief in caregivers of DLB patients. Compared to caregivers of persons with other dementias, DLB caregivers may experience pre-loss grief from the ambiguous disease trajectory and the lack of a specialist in DLB who can diagnose and provide treatment options and prognosis [4, 5] for family member to psychologically prepare them for the eventual death and prepare for funeral and family members' adjustment after the death of the DLB care recipient. No specific factors associated with pre-loss grief in DLB caregivers have been identified, nor have any comparisons of pre-loss grief in DLB versus caregivers of persons with other dementias been conducted. In the current study, we focused on caregivers of DLB patients. Specifically, we examined factors associated with pre-loss grief in caregivers of older adults with DLB and compared their pre-loss grief with that of caregivers of persons living with AD and other dementias. We also sought to determine whether overall caregiver experiences differed according to the stages of the care recipient with DLB. Finally, we compared pre-loss grief between caregivers of living recipients and former caregivers of recently deceased recipients. Five research questions guided the study.

1. Are there differences in pre-loss grief in caregivers of care recipients with DLB, compared to that in caregivers of persons with AD or other dementias?
2. Are there differences in caregiver's pre-loss grief according to the stages of DLB (mild, moderate, severe) in the recipient?
3. Are caregivers' experiences of well-being and depression different according to the stages of DLB (mild, moderate, severe, deceased) and caregiver's burden based on the three stages of DLB (mild, moderate, severe)?
4. What factors are associated with pre-loss grief in caregivers of persons with DLB after controlling for caregiver age, gender, primary caregiver status, relationship with the care recipient, and living with the recipient?
5. Is pre-loss grief different between caregivers of living recipients and former caregivers of recently (<6 months) deceased recipients?

METHODS

Participants and study procedure

The current study was approved by the New York University Langone Medical Center Institutional Review Board as an exempt protocol since data were collected without any personal identifiers. Data was stripped of internet protocol (IP) addresses prior to any analyses for complete de-identification. Potential respondents were contacted with the assistance of the Lewy Body Dementia Association and several partner caregiving organizations. Recruitment information was sent out to individuals on caregiver emailing lists of these organizations and was listed on their webpage and in their social media sites. The email provided potential participants with information about the study and instructions on how to participate. Interested individuals were invited to participate in the study by following a link to the online survey. Eligible participants accessed the survey via an emailed link with no time limit to complete (participants could save and return to the survey later). The criterion for eligibility was a caregiver of a person with DLB or another dementia, including AD and PDD. Although DLB and PDD are both under the larger umbrella of LBD, in this study the groups were separated to determine whether different symptom presentations may influence pre-loss grief. A survey was available online for 3 months (2012-2013), using SurveyMonkey™ (http://www.surveymonkey.com, Palo Alto, CA).

Data collection

Sociodemographic variables—In the survey, participants were asked for information about social and demographic characteristics of the caregiver and their care recipient and the frequency and severity of dementia-related symptoms.

Care recipient's disease stage—The Quick Dementia Rating System (QDRS) was used to determine the presence of impairment and, if present, the stage or level of severity [37]. The QDRS has high correlation with gold-standard clinical assessments and neuropsychological testing and has high reliability (α: 0.86 to 0.90) [37]. The QDRS rates cognitive function in 10 domains: memory and recall, orientation, decision-making and problem-solving abilities, activities outside the home, function at home and hobbies, toileting and personal hygiene, behavior and personality changes, language and communication abilities, mood, and attention and concentration. Participants answer questions pertaining to the care recipient's level of functioning, with scores ranging from *0* (indicating no impairment) to *3* (indicating greater impairment), with higher total scores indicating more significant cognitive and functional impairment (i.e., later disease stage and greater severity). Care recipients were staged as mild (QDRS scores 2.0 to 12.5), moderate (QDRS scores 13.0 to 20.5) or severe (QDRS scores 21.0 to 30.0). In the current study, omega reliability (i.e., McDonald's ω), using Hayes' OMEG macro with SPSS, was 0.92 [38, 39].

Prolonged grief—The Prolonged Grief-12 (PG-12) is a 12-item self-report questionnaire for measuring pre-loss grief (pre-death grief). It measures the risk of prolonged grief by an assessment of 11 symptoms that have occurred in the previous month [40]. The scale describes the presence and frequency of common grief symptoms. Respondents are asked to rate on a 5-point Likert-type scale (1 = *almost never* to 5 = *always*) how often they have experienced distressing grief symptoms of yearning, bitterness, or interpersonal disengagement in the previous month.

The scale includes the sum of the score for each of the 11 grief symptoms, ranging from 11 to 55, with higher scores indicating a greater level of pre-loss grief. The final question asks whether the respondent has had a reduction in social, occupational, or other important area of functioning. The scale has shown good internal consistency, with Cronbach's alpha of 0.88 [41]. The internal consistency in the current study was 0.89, showing high reliability. In the current study, McDonald's ω was 0.90.

Caregiver burden—A 12-item brief version of the Zarit Burden Interview (ZBI) [42] was used to assess caregiver burden, using a 5-point Likert-type scale ranging from 0 (*never*) to 4 (*nearly always*). Scores range from 0 to 48, with higher scores indicating higher perceived caregiver burden. The scores from 0 to 10 indicate no burden or mild burden, scores from 10 to 20 indicate mild to moderate burden, and scores greater than 20 indicate severe burden [43]. The ZBI showed high reliability ($\alpha = 0.86$) in aprevious study [43], which is similar to the reliability score ($\alpha = 0.87$) in the present study. McDonald's ω in the current study was 0.87.

Perception of caregiver well-being—The Perceived Change Index (PCI) was used to measure the caregiver's self-appraisal of the levels of improvement or decline in well-being related to being a caregiver [44]. Caregivers rated each item on a 5-point Likert-type scale (1 = *much worse*, 2 = *somewhat worse*, 3 = *stayed the same*, 4 = *somewhat better*, 5 = *much better*). Scores range from 13 to 65, with higher scores indicating higher perceptions of well-being [44]. The previous result from the psychometric testing that the PCI is valid and reliable with Cronbach's $\alpha = 0.90$ [44]. McDonald's ω of the PCI in the current study was 0.89.

Psychological well-being—The Ryff Psychological Well-Being Scale (PWB) was used to measure psychological well-being in the caregivers. The scale contains six subscales: (a) self-acceptance, (b) positive relationships with others, (c) autonomy, (d) environmental mastery, (e) purpose in life, and (f) personal growth. Each subscale is operationalized by means of a 3-item scale in response to negative and positive assertions [45]. In the current study, the revised 24-item PWB scale used a 5-point Likert-type scale (1 = *strongly disagree* to 5 = *strongly agree*). Scores range from 24 to 120, with higher scores indicating higher levels of psychological well-being [45]. In the current study, McDonald's ω was 0.91, indicating high reliability.

Caregiver depression—The Patient Health Questionnaire 2-item Depression Scale (PHQ-2) was used to measure caregiver depression. The PHQ-2 includes the first two questions of the PHQ-9, which was designed as a screening tool for unipolar depression [46]. The 4-point Likert-type response scale ranges from *not at all* to *nearly every day*. Scores range from 0 to 6, with higher scores indicating a greater frequency of symptoms. The current study obtained a Cronbach's α of 0.84, which is satisfactory.

Investigator-generated questions—To further characterize pre-loss grief, we concluded the survey with three investigator-generated questions: (a) Have you experienced the above feelings (e.g., emotional pain, sorrow, bitterness) for at least 6 months (answer choices: *Yes* = *1* or *No* = *0*), (b) To what extent are you prepared (were you prepared [deceased recipient]) for your loved one's eventual death (answer choices: *Not at all = 1*, *Somewhat = 2*, *Very Much = 3*), and (c) In some way, do you think that you will be relieved by your loved one's eventual death (were you relieved by your loved one's death [deceased care recipients]) (answer choices: *Not at all = 1, Somewhat = 2, Very Much = 3*).

Data analysis—Statistical analyses were conducted using SPSS v27 (IBM, Armonk, NY). Descriptive statistics were performed to describe mean and standard deviation (*SD*) or frequency for each of the demographic characteristics. One-way analysis of variance (ANOVA) was conducted to examine group differences based on the type of diagnosis (DLB, AD, and other dementias) for continuous variables, while Pearson's Chi-square tests were used to examine group differences for categorical variables. Assumptions for use of ANOVA were verified: (a) homogeneity of variance using Levene's test for assumption of homogeneity of variance, (b) normality (each sample was taken from a normally distributed population), and (c) independence (each study participant was drawn independently of the other samples). In the normality, Shapiro-Wilks test of normality in SPSS program was conducted to check whether each sample was taken from a normally distributed population. The results of the Shapiro-Wilks test confirmed normal distribution based on a p-value >0.05 and a review of the Q-Q plot. Conditions for the use of one-way ANOVA were met for all analyses: the independent variable should be nominal level with at least three levels (groups) and the dependent variable should be continuous (ratio or interval).

One-way ANOVA was performed to examine whether pre-loss grief in caregivers was significantly different based on the type of dementia (Research Question 1). The three types of dementia were entered as an independent variable: DLB, AD, and other dementias (e.g., PDD, vascular dementia, frontotemporal degeneration). Pre-loss grief, as a dependent variable, was continuous. One-way ANOVA was conducted to examine whether the mean scores of pre-loss grief were significantly different according to stages of DLB (Research Question 2). The stage of DLB, as an independent variable, was nominal level with three stages: mild, moderate, or severe. (The status *deceased* was excluded in the stage of DLB for examining pre-loss grief.)

To address Research Question 3, One-way ANOVA was used to calculate the mean of caregivers' experience (burden, well-being, depression) according to the four stages of DLB: mild, moderate, severe, and deceased. (The status of *deceased* was included for comparing experiences of caregivers of living care recipients with various stages of DLB and former caregivers of recently deceased recipients). However, for caregiver burden, three stages of DLB (mild, moderate, severe) were added because caregiver burden no longer exists once the care recipient is deceased. Burden, well-being, and depression, as a dependent variable, was continuous and the stages of DLB, as an independent variable, was nominal with either three or four stages.

To address Research Question 4, multivariate linear regression with hierarchical data entry was conducted to identify risk factors associated with pre-loss grief after controlling for caregiver's age, caregiver's gender, financial costs of caregiving, relationship with the care recipient, and living with the recipient. A hierarchical analysis of a set of independent variables—stage of DLB, care recipient's disturbing symptoms, caregiver well-being, psychological well-being, and caregiver burden—produced coefficients that were analyzed to address the research questions. The controlling variables of care recipient's age, care recipient's gender, financial costs of caregiving, relationship with the caregiver, and living with the caregiver were entered into the regression equation as Step 1, followed by independent variables in Step 2. The results of the analyses identified predictors associated with pre-loss grief among caregivers of patients with DLB.

To address Research Question 5, an independent t test was performed to assess whether the care recipient's status (living versus deceased) was significantly different in caregiver's prolonged grief as measured by the three investigator-generated questions. Care recipient's status was entered as an independent variable (*living* = 1, *deceased* = 0) and the total score for the three questions was entered as a dependent variable.

Power analyses and sample size calculation—Power analysis indicated a minimum sample size of 159 for one-way ANOVA for Research Questions 1 and 2 (G*Power, 3.1) [47], with power of 80%, a medium effect size of 0.25 (*Cohen's f*), with three groups, and a significance level of 0.05 [48]. Power analysis indicated a minimum sample size of 180 for one-way ANOVA for Research Question 3, with power of 80%, effect size of 0.25, with four groups, and a significance level of 0.05. Power analysis indicated a minimum sample size of 92 for multiple regression for Research Question 4, with 80% power, a medium effect size of 0.15 (Cohen's f^2), with four groups, and a significance level of 0.05. This study utilized a sample of 488 for DLB and 714 for DLB, AD, and other dementias, exceeding the minimum sample size of 159 calculated by power analysis.

RESULTS

Sample characteristics

Caregiver characteristics are presented in Table 1. The 488 caregivers of care recipients with DLB were compared to caregivers of care recipients with AD (n = 81) and other dementias (n = 145). There were no significant differences in caregiver characteristics, other than marital status.

Of the 488 DLB caregivers, the majority were women (88.3%, n = 431) and 81.1% (n = 396) were married. Most participants were non-Hispanic White (95.7%, n = 467). The mean age of the caregivers was 60.1 years (SD = 11.0) and the mode was 60 years, which indicates that a significant number of caregivers were also older adults. Regarding the relationship with the care recipient, 43.6% (n = 213) were wives, followed by daughters (34%, n = 166); only 12.7% (n = 62) were husbands of the care recipients. As the highest level of education, 65.4% (n = 319) of the caregivers had completed college or post-college education. The majority of the caregivers (84.8%, n = 414) reported that they defined themselves as the primary caregiver and 64.5% (n = 315) lived with the care recipient. Daughters reported the highest level of pre-loss grief (M = 28.5, SD = 10.3) and burden (M = 28.2, SD = 8.5), while friends reported the lowest levels of caregiver burden (M = 24.2, SD = 7.0) and the lowest level of pre-loss grief (M = 24.0, SD = 9.7).

Regarding the caregiver's health, more than half of the participants rated their physical health as good (56.8%, *n* = 277), 50% (*n* = 244) rated their mental health as good, and 41.0% (*n* = 202) reported that their energy level was fair. In terms of household chores, 38.7% (*n* = 189) of the caregivers reported that they were able to do household chores or similar activities.

For the three investigator-generated questions, a majority of the DLB caregivers (68.9%, *n* = 336) reported having experienced prolonged grief for at least 6 months, 75.6% (*n* = 369) reported that they were prepared for the care recipient's eventual death, and 66.5% (*n* = 306) reported that they would be relieved by the care recipient's eventual death. Of the caregivers who had experienced grief for at least 6 months (prolonged grief), 96.4% (*n* = 322) of their care recipients were still living.

The care recipient characteristics are presented in Table 1. The mean age of the care recipients was 75.3 years (*SD* = 9.4; range 47 to 98 years), and 64.1% (*n* = 313) of the care recipients were male. A majority of the care recipients (71.5%, *n* = 346) were married while 21.3% (*n* = 104) were widowed. In terms of the stage of DLB using the QDRS, more than half of the recipients with DLB were at the moderate stage (53.9%, *n* = 263), 33.4% (*n* = 163) at the severe stage, and 6.6% (*n* = 32) at the mild stage. In addition, 5.7% (*n* = 28) of the care recipients were deceased and 0.4% (*n* = 2) did not report the stage of DLB.

The caregivers reported that the most disturbing symptoms that care recipients displayed were cognitive (38.9%, *n* = 190), followed by behavioral (16.8%, *n* = 82). The mean DLB caregiver burden score (ZBI) was 26.4, indicating moderate to severe burden. Among DLB caregivers, 26% (*n* = 131) reported that they *nearly always* were burdened in caring for the care recipient, and 29.3% reported feeling burdened *quite frequently*. Of the DLB caregivers, 67% (*n* = 328) reported they had experienced a significant reduction in their social, occupational, or other important areas of functioning.

Research Question 1: Caregivers' pre-loss grief based on types of dementia

We compared caregivers' pre-loss grief scores by type of dementia in the care recipient. ANOVA identified that no significant difference in the caregivers' pre-loss grief, measured by PG-12, based on the type of dementias was identified, *F*(2, 625) = 1.1, *p* = 0.32. Levene's test for assumption of homogeneity of variance was conducted [49]; the result was *p* = 0.33. Although statistical significance was not reached, caregivers of DLB patients tended to show the highest grief score (*M* = 28.3, *SD* = 10.2), followed by other dementias (*M* = 27.7, *SD* = 10.1); caregivers of AD patients showed the lowest level of prolonged grief (*M* = 26.4, *SD* = 10.3).

Research Question 2: Caregivers' pre-loss grief based on stage of DLB

ANOVA Analyses showed no significant difference in caregivers' pre-loss grief according to the three stages of DLB, *F*(2, 409) = 1.3, *p* = 0.26. The assumption of homogeneity of variance was met at *p* = 0.65. Although the overall model indicated no statistical difference based on stages of DLB, caregivers of recipients with severe DLB tended to show the highest pre-loss grief score (*M* = 29.2, *SD* = 10.8), while those of care recipients with mild DLB showed the lowest pre-loss grief score (*M* = 26.6, *SD* = 11.3).

Research Question 3: Caregivers' overall experience and care recipients' stages of DLB: burden, well-being, and depression

ANOVA identified no significant difference in caregiver burden by stage of DLB (mild, moderate, severe), $F(2, 407) = 1.4$, $p = 0.24$. Although no significant difference in caregiver burden was related to stages of DLB, caregivers of severe DLB care recipients had the highest burden score ($M = 27.2$, $SD = 8.67$), followed by caregivers of moderate DLB care recipients ($M = 26.3$, $SD = 8.1$), and caregivers of mild DLB care recipients ($M = 24.5$, $SD = 9.8$).

There were no significant differences in caregiver well-being or depression by stage of DLB (mild, moderate, severe, deceased), $F(3, 427) = 1.2$, $p = 0.32$. There were no significant differences in caregiver's depressive symptoms according to the four stages of DLB, $F(3, 449) = 0.5$, $p = 0.64$. The caregivers of recipients with severe DLB showed the highest depression scores ($M = 2.1$, $SD = 1.7$), while those with deceased care recipients showed the lowest depression score ($M = 1.9$, $SD = 2.0$).

There was no significant difference in caregiver well-being (PCI) according to the stage of DLB, $F(3, 449) = 1.4$, $p = 0.22$; however, former caregivers of deceased care recipients showed the highest well-being scores ($M = 36.3$, $SD = 12.0$) and those of care recipients with severe dementia had lowest well-being scores ($M = 33.2$, $SD = 8.1$).

Research Question 4: Risk factors associated with pre-loss grief in caregivers of DLB care recipients

The overall linear regression model conducted to predict caregivers' pre-loss grief was significant, $F(8, 398) = 62.2$, $p < 0.005$, accounting for 56.1% of the variance in caregiver pre-loss grief (dependent variable) by the set of independent variables: stage of DLB, care recipient's disturbing symptoms, caregiver well-being (PCI), general psychological well-being (PWB), and caregiver burden, after controlling for caregiver's age, caregiver's gender, financial costs of caregiving, and the relationship to the patient (Table 2). Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Regression analysis indicated that the caregiver's relationship to the person living with dementia, caregiver well-being, general psychological well-being, and caregiver burden were significantly associated with the caregiver's pre-loss grief, while caregiver's age, caregiver's gender, financial cost of caregiving, stage of DLB, and the care recipient's disturbing symptoms were not statistically significant predictors of pre-loss grief. Being a spouse caregiver ($\beta = -0.11$, $p = 0.007$), and having lower level of caregiver well-being ($\beta = -0.13$, $p = 0.001$), lower psychological well-being ($\beta = -0.08$, $p < 0.005$), and higher level of burden ($\beta = 0.45$, $p < 0.005$) were associated with increased caregiver pre-loss grief (Table 2). Of the 460 caregivers, 70.4% ($n = 324$) reported that they had experienced the 12 grief symptoms for at least 6 months (Table 2).

Research Question 5: Comparison of prolonged grief between caregivers of living care recipients and former caregivers of deceased recipients

An independent-samples t test indicated no significant difference in mean prolonged grief scores for caregivers of living care recipients ($M = 5.3$, $SD = 1.2$) and scores for former caregivers of recently deceased recipients ($M = 5.5$, $SD = 1.5$), $t(605) = 0.63$, $p = 0.53$. Although no significant difference in prolonged grief was identified between the caregivers, former caregivers of deceased care recipients had slightly higher grief scores than those of living care recipients.

DISCUSSION

This study was the first to identify factors associated with the DLB caregiver's pre-loss grief. Based on the results, being the spouse of the care recipient, lower levels of caregiver well-being, lower psychological well-being, and higher levels of burden were associated with increased caregiver pre-loss grief. Being the spouse caregiver, compared to being an adult child or other family member, was highly associated with pre-loss grief. This finding is consistent with previous findings [50] that indicated that spouses were more likely to experience pre-loss grief. Spouse caregivers tend to have longer and more intimate bonds with care recipients and may have more pre-loss grief reaction. These results suggest that psychoeducation interventions may include conversations about pre-loss grief with caregivers in support groups, encouraging adaptive ways of coping with loss, and exploring new ways to remain connected with older adults living with DLB, even involving other family members in exploration of pre-loss grief [27].

In the current study, the caregivers' perceived ability to provide care and be mindful of their own well-being (e.g., ability to sleep through the night, energy level, ability to manage day-to-day caregiving, ability to understand the care recipient's behavior) was associated with pre-loss grief. As DLB progresses, caregivers often face increasing complexity of multiple care challenges, including changes in their own well-being [27] and health-related quality of life [51], which also refers to a measure of perceived well-being related to being a caregiver and perceived ability to provide caregiving [27].

The current study indicated that lower psychological well-being was associated with pre-loss grief. Providing care to family members with dementia could significantly influence the psychological well-being of the caregiver [52]. Stress from caregiving encompasses psychological and emotional reactions to the demands of caregiving, as caregivers feel isolated in the caregiving role [53]. Studies have examined the association of caregiver stress and psychological well-being, indicating that higher stress is associated with lower well-being. Family caregivers have significant changes in responsibilities as a result of the care recipient's diagnosis, which often increases caregiver burden and decreases their own physical and mental health [54]. Caregivers of dementia patients are likely to assist with daily living activities and experience burden and physical strain, resulting in poor physical and emotional health [55]. Caregivers observe changes in older adults with DLB that are so significant that the recipient is no longer the person whom the caregiver knew previously, which may trigger a grief process before the DLB patient actually dies. In particular, placing someone with DLB in a care home or nursing home can be a significant loss and may be intensely distressing for the caregiver [56].

A higher level of caregiver burden in DLB caregivers predicted pre-loss grief. DLB caregivers (67.6%) reported severe caregiver burden, which is highly associated with pre-loss grief. This result confirms findings in a concurrent and prospective study [55] in which greater burden was associated with greater pre-loss grief at baseline. However, that study reported that level of burden predicted greater pre-loss grief symptoms at the 1-month follow-up. The study provided evidence for the role of caregiver burden in contributing to pre-loss grief in family members of patients with dementia or cancer [55]. Singer et al. [55] also compared rates between caregivers of dementia patients and caregivers of cancer patients; the caregivers of dementia patients were significantly than caregivers of patients with cancer to have severe levels of pre-loss grief. That study also examined factors associated with pre-loss grief in both sets of caregivers. Higher caregiver burden and being a female caregiver were associated with greater pre-loss grief at 1-month follow-up, controlling for baseline pre-loss grief; age and depressive symptoms were not significantly associated with pre-loss grief at follow-up.

DLB caregivers are often stressed and emotionally drained from caregiving and increased caregiver burden, which are associated with increased caregiver grief. The caregiver’s health deteriorates, and the sense of burden increases as pre-loss grief increases when dementia symptoms deteriorate [14].

In a previous study [57], caregiver burden was greater among adult child caregivers, associated with depression, physical illness, and decreased quality of life, while caregiver grief was greater in spouse caregivers as disease severity increased. However, little attention has been paid to pre-loss grief, although it can lead to concerns about the health of the caregiver. Studies indicate that high pre-loss grief is associated with depressive symptoms and post-loss grief [57]. Behavioral and emotional symptoms presented by dementia patients are often considered to be the most stressful aspects of caregiving [43].

The results of the current study regarding pre-loss grief provide evidence of significant issues of loss inherent in caring for older adults with DLB. The caregivers of DLB patients are socially isolated and often feel guilty because they are unable to manage the care recipient’s behavioral and cognitive symptoms [4]. It also takes a substantial time to establish a DLB diagnosis, with long delays requiring multiple visits to multiple physicians and frequent changes in diagnoses until DLB is confirmed [5]. Caregivers are challenged to cope with the stressful needs and demands of a care recipient who can no longer provide self-care [36] and may be behaviorally challenging to provide care. Caregivers may reduce burden and improve psychological well-being through education and caregiver support groups to reduce pre-loss grief.

Previous studies have produced conflicting findings about the association between demographic characteristics and pre-loss grief. For example, while caregiver age and gender were not associated with grief in this study, other studies have reported that association. Age and gender have been found to be associated with bereavement outcome, with female caregivers having significantly greater psychological distress than male caregivers [55, 57]. Also reported is a greater mortality risk in a younger bereaved caregiver who lost a spouse [28].

The current study determined that the caregivers' pre-loss grief was not associated with the stage of DLB in the care recipients. This finding is consistent with a recent study examining dementia caregiver grief in DLB, PDD, and AD [34]. Regardless of the stage of DLB, the caregivers faced challenges early in their caregiving role [5], marked by relatively higher levels of pre-loss grief symptoms in early stages, than did caregivers of patients with AD or other dementias. Caregivers' pre-loss grief for severe DLB patients was similar to that of caregivers of those with moderate or mild levels of DLB. This finding is consistent with the caregiver literature indicating that the extent of behavioral and emotional problems [42], as well as sleep disturbance [4] presented by the DLB patient, were associated with higher rates of caregiver distress and grief [43].

Caregivers' pre-loss grief was not significantly different from that of grief reported by caregivers of recipients with AD or other types of dementia. Although statistical significance was not reached, caregivers of DLB patients tended to show the highest amount of pre-loss grief and caregivers of AD patients showed the lowest level of pre-loss grief. It is possible that DLB caregivers are much more burdened than those of care recipients with AD or other dementias or that the initial presentation of neuropsychiatric, motor, and sleep symptoms, in addition to cognitive symptoms, may be overwhelming to DLB caregivers. The DLB caregivers reported higher levels of caregiver burden and distress than did AD caregivers [5, 32, 58], while in other studies the level of burden was similar but more directly related to caregiver characteristics and care recipient symptoms [34]. These challenges may lead to pre-loss grief in DLB caregivers, who generally have more severe behavioral and emotional symptoms, such as recurrent hallucinations, delusions, sleep disorders, and functional limitations at disease onset than are seen in AD [59].

No significant difference in caregiver burden, caregiver well-being, or caregiver depression based on stage of care recipient's DLB was identified consistent with previous reports [34]. In those reports, constructs were associated with the symptoms that the caregiver found most disturbing at the time of survey completion (e.g., sleep disturbance, behavior). In two studies [4, 5], DLB caregivers reported high levels of burden due to demands associated with providing care and monitoring persons with DLB. Unlike persons with AD, those with DLB present with REM sleep behaviors and psychiatric and autonomic symptoms, even in the earlier stages. Thus, DLB caregivers often experience burden due to such complex symptoms early in the progression of the disorder, which could result in burden, poor quality of well-being, and depression, regardless of the stage of DLB [3-5]. However, when comparing DLB directly with AD, no differences in burden were reported [34].

Unlike most of the studies that focused on prolonged grief for the care recipient after the recipient's death [31, 50], the current study focused on pre-loss grief in living patients but also captured data from caregivers of recently deceased care recipients. We also examined novel questions regarding the length of time pre-loss grief was experienced and whether the passing of the care recipient diminished the perception of pre-loss grief. It was unexpected that 96.4% of the DLB caregivers who reported having experienced pre-loss grief for at least 6 months reported that the care recipient was still living.

DLB caregivers with higher pre-loss grief are connected to complicated grief outcomes and prolonged grief [60]; however, a majority of the studies on prolonged grief examined caregivers' grief after the care recipient's death. Recently, researchers have started to look closely at the impact of the pre-loss grief on dementia caregivers' experience and connect that impact with the caregiver's prolonged grief and ability to make post-loss adaptation [55, 57]. A majority of caregivers whose care recipient was still alive reported they would be relieved by the care recipient's eventual death.

Limitations, strengths, and implications

Several limitations are acknowledged. The cross-sectional design did not allow inference of causality in the relationship between the variable factors and pre-loss grief. Future longitudinal studies could examine how DLB caregivers experience pre-loss grief, how that grief changes over time, and how pre-loss grief affects post-loss grief. This study was done in a convenience sample of caregivers who responded to a call to complete a survey about their experiences providing care for an individual living with dementia. While convenience samples do limit generalizability to an extent, for topics such as caregiving grief it is an advantageous way to gain broad and diverse responses from caregivers of persons with dementia diagnoses such as DLB. While the responses obtained were consistent with the clinical experience of the senior author in a transdisciplinary dementia care clinic, there is no way to know the responses of caregivers who did not heed the call to complete the survey. This study focused on dementia caregiving; however, future studies could compare and contrast pre-loss grief across different conditions. The caregiver participants were predominately White, Internet users, and generally comfortable about their household income, which may limit generalizability. Ethnically and culturally diverse caregivers and those from various socioeconomic statuses should be included in future studies to assure that cultural belief, economic resources, and access to services are accounted. Although the recruitment e-mail was sent to caregivers through the Lewy Body Dementia Association and several relevant organizations, no medical records were provided to verify the diagnosis of DLB or other forms of dementia. DLB is a challenge to diagnose and caregivers report that it is difficult to find a provider knowledgeable about the diagnosis, staging, or treatment [4, 5]. Likewise, it may be difficult for caregivers to accurately provide disease staging. However, to overcome this we used validated, informant-based staging tools (i.e., the QDRS) to provide the most accurate assessment available for survey collection [37]. Finally, as the data set is now several years old, future research could focus on newly collected data. However, the measures used in this study are validated scales in wide use at the time of the survey and continue to be widely used now to address questions about the caregiving experience.

Despite the study limitations, this study contributed to the current literature by examining DLB caregivers' pre-loss grief, identifying factors associated with pre-loss grief in those caregivers, comparing their overall experience with that of caregivers of persons with other dementias and exploring whether the perception of pre-loss grief might be relieved after the death of the care recipient. This foundation may lead to developing preventive interventions to reduce pre-loss grief in caregivers of persons living with dementia.

Interventions that can reduce levels of burden and stress in DLB caregivers are necessary to decrease the level of pre-loss grief. Although there are services designed to assist caregivers, including caregiver training programs or respite care services [61], interventions have not sufficiently addressed the feelings of sadness and guilt that caregivers experience before the physical death of the person living with dementia [61].

Early assessment and diagnosis will allow DLB caregivers to learn about the disease and specific and expected symptoms, to plan for expected cognitive decline and behavioral and functional impairment, begin early advanced care planning, to arrange for timely therapeutic intervention, and to obtain information about community resources and support [4] so they can prepare for reducing caregiver burden and improving physical and psychological well-being in order to reduce pre-loss grief. Assessment of DLB caregivers should be conducted to address their burden and emotional distress and to identify appropriate interventions for their well-being. Psychoeducational interventions for DLB caregivers, such as programs focused on improving understanding of DLB and caregiver support groups, have been shown to produce positive results [58]. Due to the increased burden associated with DLB patients' behavioral symptoms, it is recommended that virtual support groups and online-based educational materials and resources be provided [4].

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Table 1

Demographic Characteristics of the Caregivers and Care Recipient by Type of Dementia

Variable	**DLB** **(*n* = 488)**	**AD** **(*n* = 81)**	**Other** **(*n* = 145)**	***p***
Caregivers				
Age(y) *M(SD)*	60.1 (10.9)	59.1 (10.6)	60.9 (10.6)	0.51
Gender (%)				0.72
Female	88.7	88.8	91.0	
Male	11.3	11.2	9.0	
Race (%)				0.02
White	96.7	91.1	97.9	
Other race	3.3	8.9	2.1	
Education (%)				0.10
Less than high school/high school	10.9	13.6	4.8	
Partial college or college	55.6	56.8	54.5	
Post college	33.5	29.6	40.7	
Marital Status (%)				0.02
Married	81.6	64.2	77.9	
Widowed	3.3	6.2	4.8	
Divorced/separated	6.2	16.0	6.9	
Never married/member of unmarried couple	8.9	13.6	10.3	
Living w/partner (%)				0.56
Yes	65.1	63.0	69.2	
No	34.9	37.0	30.8	
Primary caregiver (%)				0.72
Yes	86.6	88.9	85.1	
No	13.4	11.1	14.9	
Care Recipients				
Age (y) *M* (*SD*)	75.3 (9.4)	79.9 (8.9)	72.6 (8.8)	0.005
Gender (%)				<0.001
Female	35.3	92.5	98.6	
Male	64.7	7.5	1.4	

Variable	**DLB** **(*n* = 488)**	**AD** **(*n* = 81)**	**Other** **(*n* = 145)**	***p***
Race (%)				0.08
White	95.2	92.5	98.6	
Non-White	4.8	7.5	1.4	
Education (%)				0.005
Less than high school/high school	34.5	52.5	23.1	
Partial college or college	41.9	31.3	45.5	
Post college	23.6	16.3	31.5	
Marital status (%)				0.005
Married	71.5	48.8	70.9	
Widowed	21.5	43.8	17.0	
Divorced/separated	6.0	6.3	8.5	
Never married/member of unmarried couple	1.0	1.3	3.5	

DLB, Dementia with Lewy bodies; AD, Alzheimer's disease; Other, other dementias.

Table 2

Linear Regression Analysis for Pre-Loss Grief of Dementia with Lewy Bodies Caregivers ($N = 399$)

Variable	*B*	*SE*	*β*	*t*	*p*	*95% CI*
Model 1. $R^2 = 0.103$						
Caregiver Age	−0.14	0.05	−0.15	−2.68	0.008	[−0.25, −0.03]
Caregiver Gender	0.95	1.61	0.02	0.58	0.56	[−2.23, 4.13]
Financial Costs of Caregiving	2.97	0.52	0.27	5.63	<0.001	[1.93, 4.00]
Relationship to the patient	−0.66	0.40	−0.09	−1.65	0.09	[−1.45, 0.12]
Model 2. $R^2 = 0.563$						
Caregiver Age	−0.01	0.03	−0.01	−0.31	0.75	[−0.08, 0.06]
Caregiver Gender	0.96	1.15	0.02	0.83	0.40	[−1.30, 3.22]
Financial Costs of Caregiving	0.13	0.40	0.01	0.34	0.73	[−0.65, 0.92]
Relationship to the patient	−0.77	0.28	−0.11	−2.70	0.007	[−1.33, −0.21]
Stage of DLB	1.00	0.59	0.05	1.69	0.09	[−0.16, 2.18]
Disturbing Symptoms	−0.26	0.19	−0.04	−1.33	0.18	[−0.64, 0.12]
Caregiver Well-Being	−0.19	0.05	−0.13	−3.35	0.001	[−0.30, −0.08]
Psychological Well-Being	−0.23	0.03	−0.29	−7.43	< 0.001	[−0.29, −0.17]
Caregiver Burden	0.54	0.05	0.45	10.09	< 0.001	[0.43, 0.65]