Comparison of the Caregiving Experience of Grief, Burden, and Quality of Life in Dementia with Lewy Bodies, Alzheimer's Disease, and Parkinson's Disease Dementia

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Abstract

Background: Caregivers of persons living with Alzheimer's disease (AD), dementia with Lewy bodies (DLB), and Parkinson's disease dementia (PDD) are faced with numerous challenges. However, little is known about the caregiving experience across different dementias.

Objective: The aims of this cross-sectional study were to examine the differences in the caregiver experience between DLB, PDD, and AD.

Methods: Respondents were caregivers (N = 515; 384 DLB, 69 AD, 62 PDD) who completed a 230-question survey including sociodemographics, disease severity, neuropsychiatric symptoms, and measures of grief, burden, depression, quality of life, social support, well-being, care confidence, and mastery/self-efficacy.

Results: There were no differences in caregiver age, sex, race, or education, or in the distribution of disease severity between diagnostic groups. Constructs were highly intercorrelated with positive attributes (caregiver QoL, care recipient QoL, social support, well-being, mastery and care confidence) being inversely correlated with negative attributes (burden, grief, and depression). Across dementia etiologies, no differences were reported for quality of life, social support, depression, well-being, psychological well-being, mastery, care confidence, burden or grief. Instead, we found that the caregiver's experience was dependent on caregiver characteristics, person living with dementia characteristics and their most disturbing symptom, with behavior, personality changes, and sleep having the greatest effect on constructs.

Conclusion: Caregiver ratings of psychosocial constructs may be more dependent on care recipient-caregiver dyad characteristics and the current symptoms than the underlying cause of

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those symptoms. Interventions to improve the caregiving experience should be developed to address specific psychosocial constructs rather than focusing on disease etiology or stage.

Keywords

Alzheimer's disease; caregiver burden; caregiver grief; caregiving; dementia with Lewy bodies; depression; Parkinson's disease dementia; quality of life; social support

INTRODUCTION

Caregivers of persons living with Alzheimer's disease (AD) [1], dementia with Lewy bodies (DLB) [2], and Parkinson's disease dementia (PDD) [3] are faced with numerous challenges that may be associated with depression, anxiety, and physical health problems [4–6]. However, little is known about the caregiving experience across different dementias as few papers have compared the caregiving experience between diseases. Most of the extant literature has focused on caregivers of persons living with AD with fewer papers focusing on caregivers of persons living with DLB or PDD. The clinical features of AD, DLB, and PDD have both unique and overlapping aspects, with more overlap between disorders in the latter stages of disease [7]. The main distinctions appear in the initial presentation, with AD characterized by early episodic memory deficits [1], PDD characterized by early motor impairment followed by cognitive decline [3], and DLB characterized by features overlapping with AD and PDD, and well as unique features of cognitive fluctuations and early pronounced neuropsychiatric symptoms [2]. Differences in disease presentation and progression may impact caregivers' subjective experience of burden, grief, depression, and quality of life, or in what factors may alter, exacerbate, or alleviate these experiences. For example, social support may be a protective factor against the deleterious effects associated with caregiving, as having the perception of good social support is related to greater life satisfaction [8, 9] and fewer depressive symptoms in caregivers [10].

Caregiver burden is associated with poorer outcomes for caregivers such as depression, physical illness, and decreased quality of life [4, 5, 11]. Self-reported caregiver burden is frequently related to the severity of neuropsychiatric symptoms exhibited by the person living with dementia [11–14] and reflects their level of dependency on the caregiver [4]. Caregivers of persons living with DLB or PDD have reported higher levels of stress and burden than those caring for persons living with AD and vascular dementia [15, 16] and less than those persons living with frontotemporal dementia [14]. DLB and PDD may have more compromised functional abilities when compared with AD [16], which may lead to greater dependence on the caregiver early in the disease course [17–19]. The distinctive dementia profiles of DLB, PDD, and AD [7] may alter the caregiver experience of burden.

Caregiver grief in AD is associated with an increased risk of mortality and decrements in physical and mental health [15, 21] for caregivers. Little is known about the grief reactions of those caring for someone living with DLB or PDD. Studies of AD caregivers have shown that grief increased as the disease course progressed, and the care recipient's functional decline increased [22–24]. Neuropsychiatric symptoms may be the strongest determinant of grief among caregivers—even more so than disease stage or time spent on caregiving

duties [12, 14]. Due to the frequency and severity of neuropsychiatric symptoms and more compromised functional abilities seen at early stages in the disease in DLB and PDD, caregivers may experience grief at earlier stages in the disease course.

Caregiving has been associated with having more depressive symptoms and a poorer self-reported quality of life [26], while having the perception of good social support has been shown to be related to greater life satisfaction [8, 9] and fewer depressive symptoms in caregivers [10]. A meta-analysis found that caregivers report more depression than non-caregivers [6]. Reports suggest that DLB and AD caregivers self-report a similar frequency of depression [27] and may be similar between DLB and PDD [20]. The presence of cognitive and noncognitive symptoms (e.g., neuropsychiatric features, extrapyramidal features, autonomic and sleep features) and functional deficits may have a negative impact on the quality of life of dementia caregivers [20, 26–29]. Caregivers of persons living with DLB have reported a lower quality of life than caregivers of persons living with AD [29].

It should be noted, however, that much of the caregiving literature presents negative aspects of caregiving, without ample discussion of positive appraisals, benefits, and rewards [9]. Caregivers can report feelings of family togetherness, satisfaction with helping, improved relationships, serving as a role model, or an enhanced sense of purpose. These positive appraisals could be captured separately in scales that assess self-efficacy, quality of life, and psychological well-being or could be captured in a global rating scale [9].

The aims of this cross-sectional study were to examine the differences in the reported experience of burden, grief, depression, self-efficacy, well-being, and quality of life between caregivers of persons living with DLB, PDD, and AD. We used the Sociocultural Stress and Coping Model [30, 31] as a theoretical framework. Negative caregiving consequences may be mediated by the appraisal of burden, coping styles, and social support. This model also considers cultural/ethnic differences between caregivers, accounts for behavioral problems as a major stressor, and provides paths to explain poorer mental and physical health outcomes. Caregivers' appraisal process determines the interpretation and reaction to environmental demands and stressors [32]. These reactions are mediated by culture, social support and the caregiver's past experiences and responses [30–32]. The Sociocultural Stress and Coping Model was used to guide the choice of constructs chosen for this study; however, the goal of this paper was not to explicitly test this framework. Rather, we hypothesized that due to presence of early neuropsychiatric symptoms in DLB that DLB caregivers would experience more grief and burden, particularly earlier in disease compared with AD caregivers. Due to overlap between DLB and PDD [33], we posited that the caregiver experiences would be similar. Because studies have suggested that social support and self-efficacy can serve as mediators to grief and burden [34], we were further interested in testing whether these constructs would be associated with less depression and higher caregiver quality of life and psychological well-being.

MATERIAL AND METHODS

Participants

Potential respondents were contacted with the assistance of the Lewy Body Dementia Association to recruit DLB and PDD caregivers. We solicited assistance from several other partner organizations including the Alzheimer Foundation of America, Family Caregiver Alliance, Alzheimer's Daily News, Parkinson's Disease Foundation, and the National Institute on Aging Alzheimer Disease Center Program to recruit caregivers of other disorders. Information about the study was sent out to individuals on caregiver e-mailing lists of these organizations and was listed on their webpages and social media sites. The e-mail provided potential participants with information about the study and instructions on how to participate by following a link to the online survey. A 230-question survey was created by the senior author based on the literature and prior research [13, 17–19, 34, 35] and reviewed for content and clarity by the staff at the Lewy Body Dementia Association. The survey was available online for 3 months using Survey Monkey (http://www.surveymonkey.com, Palo Alto, CA) and details were previously published [35]. As this was an anonymous survey, the only eligibility requirement was to be a caregiver of a person living with dementia. Participants accessed the survey via an e-mailed link with no time limit to complete (i.e., participants could save and return to the survey later). Only current caregivers of persons living with DLB, AD, and PDD were included in this study. After the first 25 responses, the survey was reviewed to assure that respondents answered all questions and that no negative comments were entered into open-text fields. All collected personal health information remained confidential and all data was deidentified during analyses. This study was considered exempt and approved by Institutional Review Board at the New York University Langone Medical Center.

Measures

Caregiver characteristics—Respondents were asked to provide information about their social and demographic characteristics including age, sex (Male = 1, Female = 2), race (White = 1, African American = 2), ethnicity (Non-Hispanic = 1, Hispanic = 2), education, relationship to care recipient (Spouse = 1, Adult child = 2), marital status, frequency of contact with care recipient, and geographic locale.

Care recipient characteristics—Respondents were asked to provide information about the person living with DLB, AD, or PDD including age, sex (Male = 1, Female = 2), race (White = 1, African American = 2), ethnicity (Non-Hispanic = 1, Hispanic = 2), education, marital status, living arrangements, diagnosis, duration of disease, presenting symptom, and most disturbing symptom. Symptoms were presented as seven categories with exemplars provided: Cognitive (e.g., memory, thinking), Motor (e.g., movement, slowness, tremor), Behavioral (e.g., seeing things, false beliefs), Language (e.g., word-findings, comprehension), Personality Changes (e.g., irritable, disinhibited), Mood (e.g., depression, anxiety, apathy), and Sleep (e.g., bad dreams, nightmares).

Disease stage severity—The caregivers completed the informant-version of the Quick Dementia Rating System (QDRS) [36] to determine the presence of cognitive impairment

and, if present, rate its severity. The QDRS covers 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. QDRS scores range from 0–30 with higher scores representing more impairment. The QDRS has a high correlation with the Clinical Dementia Rating (CDR) [37] and can be used to generate the CDR and its sum of boxes (CDR-SB) in a valid and reliable fashion [36]. There were no CDR 0 (i.e., no dementia) individuals in this study. CDR 0.5 and 1 were combined to represent mild dementia, CDR 2 represented moderate dementia, and CDR 3 represented severe dementia. Former caregivers for deceased individuals were not included in the analyses.

Neuropsychiatric symptoms—The overall frequency of neuropsychiatric symptoms was assessed using the Revised Memory and Behavioral Problems Checklist (RMBPC) [38]. The RMBPC contains 24 statements. Respondents answer questions pertaining to the frequency of caregiver observed memory and neuropsychiatric symptoms in the person living with dementia. Questions are answered using a 5-point Likert Scale. Higher scores indicating greater severity of symptoms.

Caregiver grief—The Marwit-Meuser Caregiver Grief Inventory Short Form (CGI) [39] was used to assess caregiver grief. The CGI has 18 statements using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) providing a total score and three factors: *personal sacrifice and burden; heartfelt sadness and longing, and worry and feelings of isolation*. The possible range of scores is 18–90 with higher scores indicate higher levels of grief.

Caregiver burden—A 12-item abridged version of the Zarit Burden Interview (ZBI) [40] was used to characterize caregiver burden using a 5-point Likert-type scale ranging from 0 (never) to 4 (nearly always). The possible range of scores is 0–48 with higher scores signifying higher perceived caregiver burden.

Caregiver depression—Caregiver depression was measured using the Patient Health Questionnaire 2-item Depression Scale (PHQ-2). The PHQ-2 comprises the first two questions of the PHQ-9 that was designed as a screening tool for unipolar depression [41]. Participants respond using a four-point Likert scale ranging from *not at all* to *nearly every day*. The possible range of scores is 0–6 with higher scores indicating a greater frequency of symptoms.

Quality of life—The caregiver was asked to rate their quality of life and the person living with dementia's quality of life using the Quality of Life in Alzheimer's Disease (QoL) scale [42]. The scale is comprised of 13 items that provide a global assessment of quality of life. Questions are answered using a four-point Likert scale ranging from *poor* to *excellent*. The possible range of scores is 0–56 with higher scores indicate a higher perceived level of quality of life.

Social support—The Medical Outcome Study Social Support (MOS-SS) was used to measure level of social support [43]. There are five dimensions of social support in this scale: (a) tangible support, (b) emotional support, (c) affectionate support, (d) information support, and (e) positive social interaction. The self-report instrument contains 19 items asking the respondent to rate the current level of social support on a 5-point Likert-type scale ranging from 1 (none of the time) to 5 (all of the time). The possible range of scores is 19–95 with higher scores indicating a higher perception of social support.

Caregiver well-being—The Perceived Change Index (PCI), a 13-item scale that measures appraisals of self-improvement or decline in distinct areas of well-being related to being a caregiver. The possible range of scores is 13–65 with higher scores signifying higher perceptions of well-being [44].

Psychological well-being—The Ryff Psychological Well-Being Scale (PWB) was used to measure more general psychological well-being in the respondents [45]. 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. The 24-item PWB scale used a 5-point Likert-type scale of 1 = strongly disagree to 5 = strongly agree. The possible range of scores is 24–120 with higher scores indicating higher levels of psychological well-being.

Care confidence—The respondent's confidence in their ability to provide care to the person living with dementia was measured using 4 investigator-generated questions that have been used in prior studies [9, 46] and were adapted from the Dementia Care Confidence scale [47]. The questions were scored on a 4-point Likert Scale of 4 (strongly agree) to 1 (strongly disagree). The possible range of scores is 4–16 with higher scores relating to higher caregiver confidence in their ability to provide care to the person living with AD, DLB, or PDD.

Mastery and self-efficacy—Caregiver mastery and self-efficacy were measured using 12 investigator-generated questions that have been used in previous studies [9, 34, 46]. Questions were scored on a 4-point Likert scale of 4 (strongly agree) to 1 (strongly disagree). The possible range of scores is 12–48 with higher scores indicating a higher sense of mastery and self-efficacy.

Data analysis—Statistical analyses were performed using SPSS v26 (IBM, Armonk, NY). Distributional assumptions were tested to identify outliers; no respondents were removed from the analyses due to extreme scores. Six respondents were removed because they did not complete the survey beyond the demographic information section. Descriptive statistics were used to compare care recipient and caregiver characteristics, care recipient symptoms and ratings, and caregiver-reported outcomes by diagnostic group and by most disturbing symptom. Analysis of variance (ANOVA) was used to examine group differences for continuous variables while Chi-square test were used to examine group differences for categorical variables. *Post-hoc* differences were examined with Tukey's honestly significant differences. Spearman correlation coefficients were used to examine the strength of association between caregiver and care recipient characteristics and study outcomes. As

statistical significance is dependent on sample size, the magnitude of correlation coefficients was grouped into effect sizes for small ($\rho = 0.10$), medium ($\rho = 0.30$), and large ($\rho = 0.50$) effects. Correction for multiple comparisons was performed using the Bonferroni correction based on the number of constructs evaluated.

RESULTS

Sample characteristics

A total of 515 respondents completed the survey: 384 DLB, 69 AD, and 62 PDD caregivers. Caregiver and care recipient characteristics are presented in Table 1. There were no differences in caregiver age, sex, race, education, or reports of being the primary caregiver between diagnostic groups. PDD caregivers were more likely to be spouses, while AD caregivers were more likely to be adult children ($p < 0.001$). AD caregivers reported the least amount of weekly contact with the care recipient ($p = 0.009$). Consistent with prior research, persons living with AD were older ($p < 0.001$) while the DLB and PDD groups had more men ($p < 0.001$). The DLB group had a shorter duration of disease than the AD and PDD group ($p = 0.002$). The PDD group was more likely to reside with the respondent ($p = 0.03$). There was no difference in distribution of disease severity between the three diagnostic groups by the QDRS, CDR-SB, or RMBPC. The median stage for the three groups was consistent with moderate dementia (mean CDR 1.8 ± 0.9, median CDR 2.0).

Relationship between study outcomes

Caregiver constructs were highly intercorrelated (Table 2) with positive attributes (caregiver QoL, care recipient QoL, social support, well-being, mastery and care confidence) showing moderate to large correlations with each other. Negative attributes (burden, grief, and depression) and neuropsychiatric disturbances showed moderate to large correlations with each other. Positive attributes were inversely correlated with negative attributes and neuropsychiatric disturbances.

Study outcomes by dementia etiology

When comparing study outcomes across dementia etiologies (Table 3), no differences in reported caregiver or care recipient quality of life, social support, depression, caregiver well-being, psychological well-being, mastery, care confidence, caregiver burden or total caregiver grief were detected. A marginal difference in the grief construct of *heartfelt sadness and longing* was reported by DLB caregivers but this did not remain significant after correcting for multiple comparisons (data not shown).

Relationship between sample characteristics and study outcomes

Although we had hypothesized differences in outcomes by dementia etiology based on reports in the literature, we did not find this to be true. To further explore the caregiving experience in AD, DLB, and PDD, we re-examined study outcomes looking the strength of association with caregiver and care recipient characteristics in Table 4. Positive attributes (caregiver QoL, care recipient QoL, social support, well-being, mastery and care confidence) were more likely to be associated with higher education of the caregiver and less severe disease in the care recipient. Caregiver and care recipient QoL were higher in spouse

caregivers while social support was higher in adult child caregivers. Caregiver age was positively correlated with QoL, social support, and well-being, while caregiver education was associated with care recipient QoL, caregiver well-being and mastery. Negative attributes (burden, grief, and depression) were more likely to be associated with younger age of the caregiver, being an adult child caregiver, younger age of the care recipient, and severity of disease.

Relationship between care recipient symptoms and study outcomes

We next examined the distribution of presenting symptoms and most disturbing symptoms across the three disorders (Table 5). As expected, there were significant differences in the first symptom reported by the caregiver based on diagnosis (χ^2=112.9, $p < 0.001$) with AD most commonly presenting with cognitive symptoms, PDD most commonly presenting with motor symptoms, and DLB have several different initial presentations including cognitive, motor, behavior, and sleep symptoms. However, when asked about the most disturbing symptoms at the time of survey completion, the distribution of symptoms was not different between the three disorders ($\chi^2 = 13.9$, $p = 0.30$) with cognitive symptoms being the most disturbing symptoms for all three groups. Therefore, we re-examined the study outcomes by most disturbing symptom (Table 6). Although cognitive symptoms were reported as the most disturbing symptoms by caregivers of AD, DLB, and PDD, the correlations for nearly every construct with cognitive symptoms were amongst the highest for positive attributes (e.g., QoL, well-being) and lowest for negative attributes (e.g., grief, burden), perhaps suggesting that caregivers were better equipped to handle these symptoms. A similar pattern was seen for motor, language, and mood symptoms. A different set of responses was seen when personality, behavior and sleep symptoms were the most disturbing suggesting that caregivers were not as well prepared to deal with these symptoms. Caregiver QoL was most affected by personality and sleep symptoms. Caregiver well-being was lowest when care recipients had disturbing behavior and personality symptoms and psychological well-being was lowest when care recipients had disturbing personality symptoms. Although not reaching significance after correction for multiple comparisons, caregiver burden showed a trend to being higher when behavior and personality changes were the most disturbing symptom, caregiver grief tended to be highest for personality and sleep symptoms, and care recipient QoL was rated as lowest when personality and sleep symptoms were most prominent.

DISCUSSION

Studies of caregiver outcomes in dementia have largely been within-group designs that have focused on caregivers of one disease at a time (caregivers of DLB, PDD, or AD) or on one construct at a time. There have been few studies that have compared caregivers of persons living with DLB, PDD, and AD across a range of psychosocial constructs in the same study. Based on cross-study comparisons [13, 16, 17–19, 48], we had hypothesized that caregivers for one form of dementia (i.e., DLB) might experience more burden or grief, or report lower levels of well-being than caregivers of a different dementia (i.e., AD). However, we found that caregivers of those with DLB, AD, or PDD collectively reported similar quality of life, depressive symptoms, social support, mastery, care confidence, well-being,

and a sense of grief and burden regardless of the care recipient's diagnosis or stage of disease as measured by the QDRS and CDR. Our findings that all three groups of dementia caregivers experience disease similarly across multiple constructs and by multiple stages is novel in that it disagrees with what has been generally reported. We found that with more greater dementia severity there is more burden, grief and lower quality of life in caregivers as a whole. We also found that the caregiver's experience was dependent on caregiver characteristics (age, education, relationship to care recipient), care recipient characteristics (age, sex, duration of disease, and severity of disease), and the most disturbing symptom (particularly behavior, personality changes, and sleep) at the time of survey completion. Last, we found that caregivers across dementia etiologies reported positive appraisals of caregiving (self-efficacy, well-being, quality of life) similarly and these positive appraisals were inversely related to negative (burden, grief, depression) appraisals. This is consistent with other reports that highlight that caregivers note both positive and negative aspects of caregiving [9, 20].

Clinicians may expect differences in the caregiving experience across AD, DLB, and PDD based on their knowledge of the clinical and pathological differences between DLB, AD, and PDD but perhaps to caregivers, those differences are not so important—rather it is the individual caregiver traits, the stage of disease, and the manifestations of disease at a given moment that drives their experience. Caregivers may have few internal referants to evaluate or compare their own caregiving experience against a perceived "norm." They may also have few external referants of what is like to be a caregiver for a different individual, or for someone with a different form of dementia. Instead, completing a survey on different psychosocial constructs appears to capture a caregiver's threshholded experience at that particular timepoint, regardless of the clinical diagnosis.

However, our findings are consistent with many reports in the literature that neuropsychiatric symptoms are among the most stressful aspects of caregiving [11, 13, 14, 15, 26] and that the frequency and severity of neuropsychiatric symptoms exhibited is associated with the amount of self-reported dementia caregiver burden [11–14]. Caregivers facing more challenging symptom profiles likely have a very different lived experience than caregivers of individuals that do not exhibit prominent neuropsychiatric symptoms. This likely needs to be taken into account when initiating caregiver interventions (e.g., group-based or individual psychosocial supportive therapies).

Although disease severity was similar across DLB, AD, and PDD, disease duration was shorter in DLB by approximately 1 year. We found that disease severity was associated with greater caregiver grief and burden, and with lower quality of life for the caregiver and care recipient while disease duration was associated with lower quality of life in the care recipient. Shorter durations of disease may suggest less time for the caregiver to adjust and cause more distress. While this was not reflected in caregiver self-ratings of positive or negative attributes, it may have been captured in the caregivers rating of the care recipient's quality of life.

Consistent with the literature, we found that social support was inversely correlated with burden, grief, and depression suggesting that it may act as a buffer against the deleterious

effects of caregiving. The Sociocultureal Stress and Coping Model [30, 31] suggests that negative caregiving consequences could be mediated by different coping styles, self efficacy, and the available social support for the caregiver. In a recent study examing mediating effects of self-efficacy and social support [34], self-efficacy mediated caregiver burden to improve psychological well-being, while social support mediated the association between caregiver grief and psychological well-being. These results are interesting because they suggest that higher self-efficacy may provide some resilience to caregiver burden and increased social support may protect against the effects of caregiver grief, providing novel targets for intervention.

This line of research may promote the development of new caregiver interventions that could be effective across neurodegenerative dementias that focus on specific caregiver characteristics and care recipient symptoms rather than being based on the specific diagnosis. We previously found that spouse and adult children experience DLB caregiving very differently [35] with adult children reporting worse quality of life and higher burden despite also reporting more social support and marginally greater social networks. Other studies have examined the role of dyadic communication and quality of intimate relationships between caregivers and care recipients [49]. Findings such as these provide further support that psychosocial constructs may be more dependent on care recipient-caregiver dyad characteristics and the current symptoms than the underlying cause of those symptoms, and align with caregiver interests in expanding research topics in DLB, PDD, and AD [50].

Our study has several limitations. Respondents were largely female and White. Male caregivers may experience these constructs in very different ways [9, 51]. Further, different racial and ethnic groups may have different attitudes and beliefs about caregiving and would have responded in a different fashion [9, 52]. The authors acknowledge that DLB participants were over sampled compared with AD and PDD; thus it is recommended that these results be interpreted with caution. The respondents caring for AD or PDD may be different from the broader caregiving community in ways that are not captured in this survey. The cross-sectional nature of the survey limits the ability to infer causality and given the most disturbing symptoms appear to have the greatest influence on negative attributes (depression, grief, burden), the results should be interpreted with caution. Disturbing neuropsychiatric and sleep symptoms can be cyclical and thus the survey completed at a different time might have revealed different findings. Longitudinal evaluations of how these constructs change should be a focus of future research. However, the consistency of responses across different dementia etiologies and the fact that cognitive, motor, and language symptoms appeared not to cause as much distress suggests that early symptom recognition can help clinicians provide better support to caregivers. There may be other constructs (e.g., personality traits, strength of dyadic relationships, communication styles) that can help explain caregiver responses that were not captured in the current study.

The cognitive, functional, and behavioral decline experienced by individuals diag-nosed with AD, DLB, PDD, or related dementias can be severe and debilitating, leading to a significant need of support from formal and informal caregivers beginning early in the course of the disease [53]. As such, there may be an increasing sense of strain, stress,

and burden to caregivers, as spouses and adult children often take on a multitude of new responsibilities previously managed by the person living with dementia. This may occur even before a formal diagnosis and continue through transitions to skilled nursing facilities [17–19]. In conjunction with increasing burden, there is often an accompanying sense of grief and loss as the disease progresses [9, 23]. Although caregiver stress, strain, burden, depression, and grief have been extensively studied in caregivers of persons living with dementia [9, 53], little is known about how these constructs influence other psychological and emotional constructs such as self-efficacy and psychological well-being [34, 54] and positive aspects of caregiving are rarely considered [9]. Many extant studies capture only a few caregiving constructs at one time, often leaving unanswered questions about how other caregiving domains may be influenced or impacted by a proposed intervention [9]. For example, although increasing social support and self-efficacy have been shown to decrease caregiver depression [55] or burden [35], no information was available to assess how other constructs may change. In prior work, we found that negative appraisals of caregiving were related to caregiver and care receiver characteristics while the positive appraisals of caregiving were only associated with caregiver characteristics [9].

The experience of burden and grief associated with caregiving was universally distressing regardless of the dementia etiology. Being a caregiver for those with any form of dementia is a significant challenge, and we found that caregivers report these challenges similarly. While there are differences in the individuals symptoms that affect care recipients across cognitive, behavioral, motor, mood, personality and sleep domains, the caregiving experience across broader constructs of quality of life, mood, social support, grief and burden appear to be strikingly similar. Of all dementia symptoms, behavioral and personality changes were the most disturbing and ellicited the greatest responses in the psychosocial constructs. This would suggest that interventions to improve the caregiving experience should be developed to address specific psychosocial constructs and care recipient symptoms, and be tailored towards the characteristics of the caregiver rather than focusing more broadly on disease etiology or stage.

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Table 1

Sample Characteristics by Dementia Etiology

Variable	DLB (n = 384)	AD (n = 69)	PDD (n = 61)	p
Caregiver Characteristics				
Age, y	60.8 (10.5)	59.5 (10.4)	63.3 (10.0)	0.10
Sex, % Women	89.5	88.2	95.2	0.34
Race, % White	97.1	92.5	96.7	0.03
Education, % High School Graduate	99.2	98.5	98.4	0.39
Relationship, % Spouse	62.5	40.6[a]	80.6[c]	**< 0.001**
Primary caregiver, %	88.1	89.9	88.3	0.91
Frequency of contact, % > 4x/wk	84.5	64.5[a]	73.9[c]	0.009
Care Recipient Characteristics				
Age, y	75.1 (9.3)	79.3 (9.0)[a]	72.9 (7.4)	**< 0.001**
Sex, % Men	67.9	38.2[a]	86.9	**< 0.001**
Race, % White	96.1	92.8	98.4	0.25
Education, % High School Graduate	87.2	81.1[a]	95.1	0.03
Lives with Respondent, %	68.6	62.7	77.0[c]	0.03
Duration of Disease, y	3.7 (2.5)[b]	4.7 (2.9)	4.8 (2.9)	**0.002**
CDR Sum of Boxes	10.5 (4.3)	10.1 (4.5)	9.2 (4.0)	0.11
QDRS	16.2 (6.7)	15.1 (6.9)	14.5 (6.3)	0.11
RMBPC Total	21.4 (14.8)	18.9 (12.9)	20.6 (14.9)	0.40
Stage of Disease (CDR)				0.16
Mild, %	32.8	50.8	40.4	
Moderate, %	28.4	29.5	29.7	
Severe, %	38.8	19.7	29.9	

Means (SD) or % DLB, dementia with Lewy bodies; AD, Alzheimer's disease; PDD, Parkinson's disease dementia; CDR, Clinical Dementia Rating; QDRS, Quick Dementia Rating System; RMBPC, Revised Memory and Behavioral Problem Checklist **Bold** *p*-value signifies significance after correction for multiple comparisons (corrected *p*-value < 0.007 for caregiver characteristics, and corrected *p*-value < 0.005 for care recipient characteristics). Notes on *Post-hoc* analyses:

[a] AD different from DLB and PDD;

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[b]DLB different from AD and PDD;

[c]PDD different from AD and DLB.

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Table 2

Correlation Between Caregiver Outcomes and Care Recipient Memory and Behavior Severity

	CG QoL	CR QoL	Social Support	PCI	Well-Being	Mastery	Care Confidence	RMBPC	PHQ2	Grief	Burden
Caregiver QoL	1										
Care Recipient QoL	0.377 ***	1									
Social Support	0.379 ***	0.147 **	1								
PCI	0.415 ***	0.244 ***	0.199 ***	1							
Well-Being	0.637 ***	0.216 ***	0.405 ***	0.349 ***	1						
Mastery	0.464 ***	0.205 ***	0.274 ***	0.304 ***	0.661 ***	1					
Care Confidence	0.283 ***	0.263 ***	0.311 ***	0.253 ***	0.404 ***	0.475 ***	1				
RMBPC	-0.281 ***	0.464 ***	-0.104 *	-0.404 ***	-0.184 ***	-0.171 ***	-0.141 **	1			
PHQ2	-0.613 ***	0.283 ***	-0.187 ***	-0.474 ***	-0.534 ***	-0.368 ***	-0.175 ***	0.277 ***	1		
Grief	-0.526 ***	-0.328 ***	-0.401 ***	-0.448 ***	-0.521 ***	-0.451 ***	-0.321 ***	0.378 ***	0.488 ***	1	
Burden	-0.547 ***	-0.327 ***	-0.234 ***	-0.529 ***	-0.484 ***	-0.414 ***	-0.349 ***	0.506 ***	0.503 ***	0.708 ***	1

Spearman correlation coefficients

*
$p < 0.05$,

**
$p < 0.01$,

***
$p < 0.001$.

Bold p-value signifies significance after correction for multiple comparisons (corrected p-value < 0.0045). CG, caregiver; CR, care recipient; RMBPC, Revised Memory and Behavioral Problem Checklist; QoL, Quality of Life; PHQ-2, Patient Health Questionnaire; PCI, Perceived Change Index.

Table 3

Study Outcomes by Dementia Etiology

Variable	DLB (*n* = 384)	AD (*n* = 69)	PDD (*n* = 61)	*p*-value
Caregiver Quality of Life	35.5 (7.5)	34.9 (8.4)	37.1 (7.3)	.23
Care Recipient Quality of Life	26.0 (5.8)	27.7 (5.9)	27.1 (5.6)	.05
Social Support	60.9 (19.3)	61.1 (20.1)	57.9 (18.4)	.69
PHQ-2	2.1 (1.7)	2.2 (1.5)	2.0 (1.9)	.85
Perceived Change Index	33.9 (7.2)	34.9 (6.3)	32.2 (7.2)	.08
Psychological Well-Being	82.6 (12.6)	82.4 (13.4)	84.0 (12.2)	.69
Mastery	30.8 (4.0)	30.7 (4.3)	31.2 (4.1)	.74
Care Confidence	12.2 (2.1)	12.7 (1.8)	12.1 (2.1)	.13
Caregiver Burden	25.5 (8.4)	25.0 (8.5)	25.9 (8.3)	.82
Grief	61.8 (12.9)	58.4 (14.3)	60.9 (11.2)	.13

Means (SD) KEY: DLB = Dementia with Lewy Bodies; AD = Alzheimer's Disease; PDD = Parkinson's Disease Dementia; PHQ-2 = Patient Health Questionnaire.

Table 4

Correlations Between Caregiver and Care Recipient Characteristics and Study Outcomes

Construct	Caregiver Age	Caregiver Sex	Caregiver Education	Caregiver Relationship	Care Recipient Age	Care Recipient Sex	Duration of Disease	CDR-SB
Positive Attributes								
Caregiver QoL	**0.273** ***	−0.083	0.089	**−0.243** ***	−0.072	−0.068	−0.033	**−0.158** ***
Care Recipient QoL	0.009	0.055	0.115 **	**−0.120** **	−0.084	**−0.123** **	**−0.161** ***	**−0.571** ***
Social Support	−0.081	0.064	0.047	**0.204** ***	**0.165** ***	**0.119** **	−0.012	−0.015
Perceived Change Index	**0.207** ***	−0.029	0.073	−0.100 *	0.099	−0.010	−0.021	−0.041
Psychological Well-Being	**0.146** ***	−0.064	0.134 **	−0.083	0.014	−0.039	0.030	−0.077
Mastery	0.079	−0.101	0.104 *	−0.015	−0.053	0.019	−0.057	−0.064
Care Confidence	0.011	−0.021	0.029	−0.006	0.036	0.001	−0.006	−0.098 *
Negative Attributes								
PHQ-2	**−0.171** ***	0.098	−0.064	**0.128** **	−0.017	0.039	0.039	0.025
Grief	−0.095 *	0.035	−0.021	−0.071	**−0.140** **	−0.040	0.030	**0.188** ***
Burden	**−0.193** ***	0.088 *	0.039	**0.123** **	−0.030	0.042	−0.028	**0.122** **

Spearman correlation coefficients

*
$p < 0.05$,

**
$p < 0.01$,

***
$p < 0.001$.

Bold *p*-value signifies significance after correction for multiple comparisons (corrected *p*-value < 0.007 for positive attributes, and corrected *p*-value < 0.017 for care recipient characteristics) CDR-SB, Clinical Dementia Rating Sum of Boxes; QoL, Quality of Life; PHQ-2, Patient Health Questionnaire.

Table 5

Distribution of Presenting and Most Disturbing Symptoms by Dementia Etiology

Symptom, %	First Symptom			Most Disturbing Symptom		
	DLB	AD	PDD	DLB	AD	PDD
Cognitive	41.0	68.1	24.2	31.9	40.6	49.2
Motor	13.6	5.8	58.1	19.1	11.6	14.8
Behavior	15.9	7.2	1.6	21.5	20.3	14.8
Language	4.3	3.2	2.9	9.9	11.6	3.3
Personality	3.1	7.2	0.0	6.3	7.2	6.6
Mood	6.3	7.2	6.5	7.1	7.2	9.8
Sleep	17.2	0.0	6.5	7.1	7.2	9.8
Chi-Square	$\chi^2 = 112.9$, $p < 0.001$			$\chi^2 = 13.9$, $p = 0.30$		

DLB, dementia with Lewy bodies; AD, Alzheimer's disease; PDD, Parkinson's disease dementia.

Table 6

Comparison of Study Outcomes by Most Disturbing Symptoms

Rating Scale	Cognitive (n = 179)	Motor (n = 90)	Behavior (n = 105)	Language (n = 48)	Personality (n = 33)	Mood (n = 38)	Sleep (n = 18)	p-value (Omnibus F Test)
Caregiver QoL	36.5 (8.0)	36.1 (6.6)	35.0 (7.6)	36.6 (7.1)	31.5 (8.2)**	36.1 (6.0)	31.1 (8.4)	**0.002** [a]
Care Recipient QoL	27.1 (6.2)	26.3 (5.0)	25.9 (5.6)	27.3 (5.9)	24.1 (5.4)	25.7 (5.0)	24.2 (6.4)	0.05
Social Support	59.9 (18.4)	62.8 (17.9)	60.4 (19.5)	63.2 (20.6)	53.9 (23.3)	66.0 (16.6)	49.4 (20.9)	0.02
PHQ-2	2.1 (1.8)	2.0 (1.6)	2.1 (1.8)	1.7 (1.4)	2.6 (1.7)	1.8 (1.4)	1.8 (1.7)	0.27
Perceived Change Index	34.7 (6.8)	34.5 (5.9)	31.8 (8.0)	36.4 (6.2)	31.3 (8.9)	32.7 (5.8)	34.5 (6.7)	**0.001** [b]
Psychological Well-Being	83.8 (12.7)	82.1 (11.2)	82.6 (12.8)	84.5 (11.7)	74.9 (14.6)	86.7 (12.2)	78.0 (12.0)	**0.002** [c]
Mastery	30.9 (3.9)	30.5 (4.0)	30.7 (4.5)	31.7 (3.5)	29.7 (4.50	31.8 (4.2)	30.6 (3.8)	0.26
Care Confidence	12.3 (1.9)	12.6 (1.7)	12.1 (2.2)	12.6 (1.6)	11.7 (2.9)	12.6 (2.0)	11.4 (2.2)	0.13
Grief	61.2 (13.4)	59.0 (11.9)	62.8 (13.5)	61.0 (12.3)	65.3 (13.7)	57.9 (10.1)	64.6 (13.2)	0.08
Burden	24.8 (8.7)	24.5 (7.5)	26.9 (8.5)	24.4 (8.1)	29.4 (7.7)	25.7 (7.1)	25.1 (9.9)	0.03

Mean (SD) **Bold** p-values are significant after correction for multiple comparisons (corrected p-value < 0.005) Notes on *Post-hoc* analyses:

[a] Personality and Sleep symptoms are different from other disturbing symptoms, but not different from each other.

[b] Behavior is different from cognitive, motor, and language; Personality is different from cognitive, motor, and language.

[c] Personality is different from other symptoms except sleep. Sleep is different from mood. QoL, Quality of Life; PHQ-2, Patient Health Questionnaire.