DIFFERENCES IN CAREGIVER GRIEF AND BURDEN BETWEEN DEMENTIA WITH LEWY BODIES, DEMENTIA OF THE ALZHEIMER'S TYPE, AND DEMENTIA ASSOCIATED WITH PARKINSON'S DISEASE

By

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Abstract

Background: Caregiving for dementia has been associated with increased grief and burden. Dementia with Lewy Bodies (DLB) is the second most common form of dementia; yet, extant studies have focused primarily on caregivers of people with Alzheimer's disease (AD). By result, the current state of the literature overlooks potentially important differences between caregivers of DLB and other dementia types. Caregivers of DLB face unique challenges early in their caregiving role; thus, it is likely that they experience grief and burden at earlier stages than other dementia types. The purpose of the present study was to examine the differences in the experience of grief and burden in caregivers of DLB versus caregivers of AD and Parkinson's Disease with Dementia (PDD) at different disease stages.

Method: Family caregivers of individuals with DLB (n = 415), AD (n = 71), or PDD (n = 66) completed a series of self-report online surveys.

Results: Caregivers of DLB reported significantly more grief at earlier stages in the disease course than caregivers of AD. No significant differences in grief were found between caregivers of DLB and PDD. Caregivers for people with DLB, AD, and PDD had very similar profiles for burden.

Implications: These findings support the hypothesis that there are differences in the experience of caregiving for those with DLB and other dementia types. More research is needed to investigate other potential differences in the caregiving experience for patients with DLB.

Key words: dementia, Dementia with Lewy Bodies, caregivers

Table of Contents

Abstract iii

Chapter 1: Relevant background 1

Dementia of the Alzheimer's type (AD) 2

Lewy Body Disease (LBD) 3

Parkinson's disease with dementia (PDD) 4

Dementia with Lewy Bodies (DLB) 5

Features of Dementia with Lewy Bodies 6

Psychiatric features in Dementia with Lewy Bodies 9

Caregiving in dementia 12

The present study 15

Chapter 2: Method 17

Participants 17

Procedures 18

Measures 19

Data analysis 22

Chapter 3: Results 23

Chapter 4: Discussion 25

References 32

Table 1. 44

Table 2. 45

Table 3. 46

Appendix A. 47

Appendix B. 49

Appendix C. 50

Chapter 1: Relevant background

With current medical advances, the number of people age 65 years and older living in the United States (U.S.) is expected to grow by 13% from 2010 to 2030, and make up approximately 20% of the total population (Vincent & Velkoff, 2010). As the number of older Americans grows, so too will the numbers of new and existing cases of dementia that will require caregiver assistance (Hebert, Weuve, Scherr, & Evans, 2013). The financial and emotional burden of caregiving for those with dementia is high (Alzheimer's Association, 2016). According to the Alzheimer's Association (2016), in 2015, 15.9 million caregivers provided an estimated 18.1 billion hours of unpaid care—valued at more than 221.3 billion dollars. The estimated cost of healthcare, long-term care and hospice for dementia patients in 2015 was 236 billion dollars (Alzheimer's Association, 2016). Caregivers also shoulder a lot of physical and emotional burden that lead to health care costs of their own; 59% of family caregivers of dementia patients rated the emotional stress of caregiving as high or very high (Alzheimer's Association, 2016). Caregiving for dementia has been associated with a decreased sense of well-being, depression, anger, anxiety, guilt, and other caregiver health and medical problems (Brodaty, & Donkin, 2009; Etters, Goodall, & Harrison, 2008; Pinquart & Sörensen, 2003).

There are several types of dementia—each with a different clinical presentation. Unique onset and disease course among dementia types likely affect caregivers differently. Yet, there are relatively few studies that examine potential differences among caregivers. Extant studies have focused primarily on caregivers of patients with Dementia of the Alzheimer's type (AD) and there are relatively few studies that examine the experience of caregivers of Dementia with Lewy Bodies (DLB) or Parkinson's Disease with Dementia (PDD). By result, the current state of the research overlooks potentially important differences between DLB and other dementia types.

This paper will focus on DLB as compared to AD and PDD. All three of these diseases share some overlapping symptoms. However, they have different underlying disease processes and different clinical presentations—AD is marked by memory loss, DLB has prominent psychiatric features and fluctuation cognition, and PDD presents with marked motor impairment. Each is described in greater detail below.

Dementia of the Alzheimer's type (AD)

Clinical symptoms of AD manifest concurrent with the aggregation of proteins in the brain—commonly referred to as plaques and tangles (Alzheimer's Association, 2016). The plaques are made of beta amyloid that builds up in the spaces between nerve cells and cause neural connection problems (Alzheimer's Association, 2016; Jack et al., 2011; National Institute of Neurological Disorders and Stroke (NINDS), 2015). The tangles are made of another protein called tau that builds up inside neurons and causes eventual cell death (Alzheimer's Association, 2016; Jack et al., 2011; NINDS, 2014).

AD is the most common form of dementia in the U.S.—affecting an estimated 5.2 million people in the U.S. (Alzheimer's Association, 2016). According to the Alzheimer's Association (2016), AD is typically diagnosed after age 65 and is more common in women—this is likely due to the fact that women tend to live longer than men. The average survival time following a diagnosis is 8 years. The most prominent feature of AD is memory loss. This loss is usually persistent and gradual; AD typically effects short-term memory first and then long-term memory. The early indicators of AD tend to be memory and thinking problems, while psychiatric problems tend to occur at later stages in the disease process (Alzheimer's Association, 2016; Jack et al., 2011).

The diagnostic criteria for probable AD (Alzheimer's Association, 2016; Jack et al., 2011) include deficits in two or more areas of cognition: (a) progressive worsening of memory, and (b) progressive worsening of other cognitive functions. The diagnosis of probable AD is supported by: (a) progressive deterioration of specific cognitive functions such as language (aphasia), motor skills (apraxia), and perception (agnosia); (b) impaired activities of daily living and altered patterns of behavior; (c) family history of similar disorders, particularly if confirmed; (d) biomarkers showing an elevation in a-beta amyloid and tau; and (e) exclusion of other non-AD causes of dementia.

Lewy Body Disease (LBD)

The pathological hallmark of PD, PDD and DLB is the aggregation of Lewy bodies (LBs) in the brain. LBs consist of abnormal neuronal accumulation of a protein called α – synuclein (Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015; McKeith, 2004; Meeus, Theuns &Van Broeckhoven, 2012; National Parkinson Foundation, 2015; Neef & Walling, 2006; NINDS, 2014). Amyloid plaques seen most commonly in AD may also be present in some cases of DLB, but 80-90% of DLB cases do not feature the tau protein neurofibrillary tangles that are typical of AD (McKeith, Burn, O'Brien, Perry, & Perry, 2002). While AD pathology and/or vascular changes may also be present in PD, PDD and DLB, it is not necessary for symptoms of dementia to occur (McKeith et al., 2005; NINDS, 2014).

While both PD and DLB share underlying pathology, the onset of PD is marked by motor impairment whereas the onset of DLB is marked by cognitive impairment and psychiatric problems (Alzheimer's Association, 2016). If cognitive symptoms appear within a year of movement problems, a diagnosis of DLB is typically made. If cognitive problems develop more than a year after the onset of movement problems, the diagnosis is PDD (Lewy Body Dementia

Association, 2015; McKeith et al., 2005; NINDS, 2014). Ballard, Kahn, & Corbett (2011) made the argument that DLB and PDD are essentially the same disease, but with differences in the presentation and disease course. This view is debated in the literature. The current "one year" rule may seem arbitrary, but it is currently the most accurate way to group DLB and PDD patients according to symptomology and disease progression.

Parkinson's disease with dementia (PDD)

An estimated 1 million people are affected with Parkinson's disease (PD; National Parkinson Foundation, 2015). A prior diagnosis of PD is necessary to obtain a diagnosis of PDD, but not all PD patients will transition to PDD. However, the rate of transition is high—with 50 to 80% of PD patients eventually being diagnosed with a form of dementia (National Parkinson Foundation, 2015). PD is usually diagnosed after age 60, and men are 50% more likely than women to develop it (NINDS, 2014; National Parkinson Foundation, 2015). In a recent large-scale study, the median survival time in PD from motor onset was 15.8 years (Forsaa, Larsen, Wentzel-Larsen, & Alves, 2010). Another study found that within 6 years of their PD diagnosis 71% of women and 67.5% of men were diagnosed with dementia; it was also found that having PD complicated by dementia was associated with a greater likelihood of death than having PD alone (Willis, Schootman, Kung, Bradley, Perlmutter, & Racette, 2012). In PD, movement problems are the primary symptom present at disease onset; memory and thinking problems, as well as psychiatric problems can appear or increase if a patient transitions to PDD (Forsaa et al., 2010; Lewy Body Dementia Association, 2015).

The diagnostic criteria for PDD, according to the Diagnostic and statistical manual of mental disorders (DSM-5; 5th ed., 2013), includes (a) evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (e.g., complex attention,

executive function, learning, memory, language, perceptual-motor or social cognition); (b) the cognitive deficits interfere with independence in everyday activities; (c) the cognitive deficits don't occur exclusively in context of a delirium, and are not better explained by another mental disorder; (d) the disturbance occurs in the setting of established PD; and (e) there is insidious onset and gradual progression of impairment. Associated clinical features of PD include: (a) cognitive features with impaired: attention, executive function, visuospatial function, memory; and language; and (b) behavioral features: apathy, changes in personality and mood (including depressive features and anxiety), hallucinations, delusions, and excessive daytime sleepiness.

Dementia with Lewy Bodies (DLB)

DLB is estimated to affect 1.3 million people in the United States (Lewy Body Dementia Association, 2015). DLB is the second most common form of dementia (Galvin et al., 2010a; Leggett, Zarit, Taylor, & Galvin, 2010; McKeith, 2004; Meeus et al., 2012). In DLB, the disease onset is typically between ages 50-83 and there is a slight male predominance (Lejbak & Haugrud, 2010). The average survival following a diagnosis is 5 to 7 years and the median age of death for a person with DLB is 78 (Lewy Body Dementia Association, 2015; Galvin et al., 2008; Williams, Xiong, Morris, & Galvin, 2006). DLB is also associated with a shorter time to institutional placement than AD (Tarawneh & Galvin, 2007).

Consensus diagnostic criteria for DLB (McKeith et al., 2005) include the presence of progressive cognitive decline that is severe enough to interfere with daily life in conjunction with at least two of the following three core features: (a) fluctuating cognition with pronounced variations in attention and alertness, (b) recurrent visual hallucinations, or (c) spontaneous motor features of parkinsonism. Supportive features include: frequent falls, the presence of delusions,

severe neuroleptic sensitivity, hallucinations, rapid eye movement (REM) sleep behavior disorder (RBD), and depression.

Features of Dementia with Lewy Bodies

DLB has many symptoms in common with psychiatric disorders and other dementia types (American Psychiatric Association, 2013); thus, DLB is frequently misdiagnosed as a psychiatric disorder or another type of dementia (Leggett et al., 2010; Tarawneh & Galvin, 2007). While DLB has many symptoms in common with other psychiatric disorders and dementia types, the onset and disease course of DLB is unique (Lewy Body Dementia Association, 2015; McKeith, 2004). Unique features of DLB include the early onset of recurrent visual hallucinations, RBD, and spontaneous alterations in concentration and attention (or fluctuating cognition; Lewy Body Dementia Association, 2015; McKeith, 2004; Tarawneh & Galvin, 2007). Moreover, these symptoms are often present when the care recipient receives a diagnosis of probable DLB, as opposed to AD where these problems usually do not appear until the latter stages in the disease process (Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015; McKeith, 2004; National Parkinson Foundation, 2015).

Difficulty diagnosing Dementia with Lewy Bodies. Caregivers of DLB report difficulty obtaining a correct diagnosis (Galvin et al., 2010a). As a result, DLB is likely underreported (McKeith, 2004). One of the reasons for the misdiagnosis of DLB is that it is a relatively new disease classification and is not nearly as common as AD or as easy to identify as PDD (due to motor impairment in PDD; Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015). It also shares many features with AD, PD, and PDD (Galvin et el., 2010a; Johnson, Morris & Galvin, 2005; McKeith et al., 2002). Another reason for the difficulty in obtaining a correct diagnosis of DLB is that DLB has many psychiatric features that are an integral part of

the disease process, and doctors often mistake these symptoms for a psychiatric disorder rather than DLB (Galvin et al., 2010a; Johnson et al., 2005; McKeith et al., 2002). Additionally, some key diagnostic symptoms may go unreported by the caregiver, because they may seem unrelated to what people think of as dementia (e.g., fluctuating cognition, delusions; Lewy Body Dementia Association, 2015). Thus, getting a probable DLB diagnosis can take several visits to different physicians, which can be frustrating, costly, and time consuming (Galvin et al., 2010a). Unfortunately, a delay in obtaining an accurate diagnosis can lead to the inappropriate administration of traditional neuroleptics for psychiatric symptoms; the use of neuroleptics can result in an increase in psychotic symptoms and death in DLB and PDD (Emre et al., 2007; McKeith et al., 2002; Neef & Walling, 2006).

REM sleep behavior disorder (RBD). RBD is a sleep disorder where the individual moves during their REM sleep cycle. RBD often appears months or years before there are any symptoms of dementia, which makes it a useful tool for identifying those at greater risk of conversion to a neurodegenerative disease (Donaghy, O'Brien, & Thomas, 2015; Lewy Body Dementia Association, 2015; McKeith, 2004). A recent longitudinal study found that the risk of developing a neurodegenerative disease from the time of idiopathic RBD diagnosis was 33.1% at five years, 75.7% at ten years, and 90.9% at 14 years (Iranzo et al., 2014). The risk of converting to DLB, PD, or PDD after being diagnosed with RBD is relatively high, and RBD has been found to be more common in DLB and PDD than in other types of dementia (Boeve et al., 2013; Chiba et al., 2012; Iranzo et al., 2014; Munhoz, & Teive, 2014; Murray et al., 2013; Nagahama et al., 2007; Postuma et al., 2015; Suárez-González et al., 2014; Thaipisuttikul, Lobach, Zweig, Gurnani, & Galvin, 2013).

RBD is one of the supportive features in the diagnostic criteria of DLB. RBD differs from night terrors in that RBD occurs during REM sleep (while our bodies are normally paralyzed) and is associated with LB pathology, whereas night terrors tend to occur during periods of deep sleep (i.e., the first third of nocturnal sleep) and can happen in healthy individuals (American Psychiatric Association, 2013; WHO, 1992). RBD can result in kicking, spitting, swearing, and hitting of nearby people while the affected acts out their dream (McKeith, 2004). This sleep disorder can prove dangerous for the individual and caregivers, especially spouses sleeping in the same bed with the care recipient (Lewy Body Dementia Association, 2015). It is also emotionally taxing, as the experiences can be frightening for both the individual and their caregivers (Boeve, Silber, & Ferman, 2004).

Fluctuating Cognition. Fluctuating cognition is a cardinal feature of DLB with a frequency of 80-90% (McKeith, 2004, McKeith et al, 1996). Bonanni et al. (2008) found that few PDD patients presented with the symptom of fluctuating cognition at disease onset. Those with a diagnosis of AD report periodic fluctuations in memory problems that are distinguishable from the fluctuations seen in DLB (Bradshaw, Saling, Hopwood, Anderson, & Brodtmann, 2004). Fluctuating cognition includes the following features: daytime drowsiness and lethargy, daytime sleep of two or more hours, staring into space for long periods, and episodes of disorganized speech (Lewy Body Dementia Association, 2015). Caregivers describe these fluctuations as having a spontaneous, periodic, transient quality that appear to interrupt the ongoing flow of awareness or attention (Bradshaw et al., 2004). This symptom can be distressing to caregivers, because of the unpredictability of the episodes. The individual with DLB can be lucid at one moment and then confused or non-responsive the next. This makes planning events and other activities very difficult for the caregiver (McKeith, 2004). It also necessitates a greater level of

supervision for some activities, as the DLB the care recipient's alertness may change over the course of minutes, hours, or days (McKeith, 2004).

Psychiatric features in Dementia with Lewy Bodies

Psychiatric symptoms in DLB tend to occur at disease onset and remain stable across the disease course (McKeith et al., 2005; Tarawneh & Galvin, 2007). Comorbid psychiatric symptoms are a defining feature of DLB, and set DLB apart from the other dementia types. Patients often present with psychiatric problems like hallucinations, delusions, depression, and paranoia at disease onset (Alzheimer's Association, 2016; Galvin et al., 2010b; Lewy Body Dementia Association, 2015; McKeith, 2004; McKeith et al., 2005).

When individuals with DLB experience hallucinations and delusions it can be very distressing for their caregivers, because of the tangible change in their loved one's behavior and the unpredictable and unexpected nature of the changes. Patients can even become violent or difficult for the caregiver to manage. Another challenging aspect of caregiving for people with DLB is the personally changes that are seen from disease onset and through the progression of the disease. For instance, the DLB the care recipient may demonstrate diminished emotional responsiveness, resign hobbies, progressive apathy, and purposeless hyperactivity (Galvin, Malcom, Johnson, & Morris, 2007; Leggett et al., 2010). Each of the psychiatric comorbidities in DLB is discussed below in further detail.

Visual hallucinations (VH). Hallucinations and misperceptions are common in DLB. Their occurrence is associated with LB pathology in the amygdala, parahippocampus and inferior temporal lobe, and may involve disrupted cortical connections between the occipital and temporal lobes (Harding et al., 2002). According to the Lewy Body Dementia Association (2015), 43% of DLB cases present with hallucinations at disease onset—with VH being the most

common. VH are a core diagnostic feature of DLB and are the most common psychiatric feature in DLB (McKeith, 2004; Nagahama et al., 2007; Onofrj et al. 2013; Thaipisuttikul et al., 2013). VH have also been shown to be more common in DLB than in any other types of dementia and it is often argued that this symptom is the most effective at differentiating DLB from other dementia types (Auning et al., 2011; Bjoerke-Bertheussen, Ehrt, Rongve, Ballard, & Aarsland, 2012; Delli Pizzi et al., 2014; Erskine et al., 2015; Fujishiro et al. 2008; Yokoi, et al., 2014). Tiraboschi et al. reported an 83% positive predictive value of VH in distinguishing DLB from AD. VH in DLB can be simple (seeing objects move when they are actually still) or complex (seeing people and items that are not present; Teeple, Caplan, & Stern, 2009). Patients may or may not have insight into their hallucinatory content (Teeple et al., 2009).

Treating VH in DLB has proven difficult. DLB and PDD patients have an antipsychotic sensitivity to neuroleptics (McKeith et al., 2002; Neef & Walling, 2006). Unfortunately, the administration of traditional neuroleptics for psychiatric symptoms is common, and if administered to those with DLB or PDD, can result in an increase in psychotic symptoms and death (McKeith et al., 2002; Neef & Walling, 2006). If the VH are left untreated, symptoms persist and can markedly impair quality of life of the patient (Boström et al., 2007a; McKeith et al., 2002; Neef & Walling, 2006), and significantly increase caregiver distress (Ricci et al., 2009). Cholinesterase inhibitors are the preferred treatment for DLB, and can improve cognitive function and reduce psychotic symptoms (Galvin et al., 2008; McKeith et al., 2002). However, this treatment often exacerbates parkinsonian symptoms. Because of the difficulties in treating DLB, McKeith, Burn, O'Brien, Perry, & Perry (2002) liken the management of symptoms to walking a tightrope with the outcome "a compromise between a relatively mobile but psychotic patient and a nonpsychotic but immobile patient" (p. 1310).

Delusions and misidentifications. Delusions are common in DLB at all stages of the disease (McKeith, 2004). While AD and PDD patients also experience delusions, these symptoms usually do not appear until the later stages of AD and PDD (Alzheimer's Association, 2016; National Parkinson Foundation, 2015). Thus, delusions are more common at early stages of DLB than in other dementia types (Bjoerke-Bertheussen et al., 2012; Boström, Jönsson, Minthon, & Londos, 2007b; Kao et al. 2009; Suárez-González et al., 2014; Thaipisuttikul et al., 2013). Delusions often present as paranoid delusions or delusional misidentifications (Suárez-González et al., 2014). There is some debate in the literature whether misidentifications are delusions or hallucinations. According to a factor analysis done by Nagahama, et al. (2007), misidentifications loaded onto a factor separate from visual hallucinations. For the purpose of this paper, they will fall under the category of delusions.

Misidentifications can occur in neurodegenerative diseases, psychiatric disorders and brain injuries (e.g., stroke, traumatic brain injury; Harciarek, & Kertesz, 2008). A recent study found that misidentifications were identified in 16.6% of DLB cases, 15.8% of AD cases, and 0.0% of PD cases in their sample (Harciarek, & Kertesz, 2008). There are several types of misidentifications, but the most common in DLB is Capgras syndrome (Harciarek, & Kertesz, 2008). This is the delusion that an identical-looking impostor has replaced a spouse, friend, parent, or other close family member. This delusion is particularly troubling for caregivers, as they are often the object of the delusion (Thaipisuttikul et al., 2013) and patients can become resistant to care, violent, abusive and difficult to control when they believe that the caregiver is not who they say they are (De Pauw & Szulecka, 1988; Silva, Leong, Weinstock, 1992; Silva, Leong, Weinstock & Boyer, 1989). Unsurprisingly, the presence of Capgras has been shown to significantly increase caregiver burden and caregiver reported depressive symptoms

(Thaipisuttikul et al., 2013). Delusions and misidentifications can occur at any point in the disease course for DLB patients (McKeith, 2004). They can also occur in AD and PDD, but typically not until later stages of the disease course (Alzheimer's Association, 2016; National Parkinson Foundation, 2015).

Depression. The Lewy Body Dementia Association (2015), reported that 37% of DLB cases present with depression. Epidemiological studies have found that depression is the most commonly diagnosed illness prior to the diagnosis of DLB (Boot et al., 2013; Fereshtehnejad et al., 2014). Additionally, depression has been found to be more common in DLB at all stages of the disease than in other types of dementia (Auning et al., 2011; Bjoerke-Bertheussen et al., 2012; Boot et al., 2013; Chiba et al., 2012; Fujishiro et al. 2008; Sadak, Katon, Beck, Cochrane, & Borson, 2014; Thaipisuttikul et al., 2013; Yamane, Sakai, & Maeda, 2011).

Caregiving in dementia

With the progression of dementia, caregivers are increasingly responsible for providing assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL; Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015; National Parkinson Foundation, 2015; Tarawneh & Galvin, 2007). In DLB, PDD and AD caregiving typically includes assistance or oversight with self-care tasks and ADLs: bathing, dressing, grooming, feeding, and assisting with toilet use or managing incontinence (Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015; National Parkinson Foundation, 2015). Caregivers of DLB, AD and PDD typically manage instrumental activities of daily living (IADL): shopping for groceries, preparing meals, managing finances, completing household chores, providing transport, ensuring medications are taken, appropriate medical treatment obtained, and providing

supervision to prevent wandering (Alzheimer's Association, 2016; Lewy Body Dementia Association, 2015; National Parkinson Foundation, 2015).

As the functional needs of the care recipient increase, the caregiver is more likely to use external resources or institutionalize the patient, which results in greater cost of care. Those with DLB commonly have a shorter time to institutional placement and mortality than those with AD (Tarawneh & Galvin, 2007). The cost of care for those with DLB was significantly greater when compared to those with AD (Boström et al., 2007b). Functional decline in DLB is more rapid than in AD (Tarawneh & Galvin, 2007; Williams et al., 2006). DLB patients are also more functionally impaired in ADLs than patients with AD, even when their cognitive test scores are similar (Boström et al., 2007b). This is generally due to their visuospatial deficits, fluctuating cognition, early and severe executive dysfunction, and extrapyramidal symptoms (Galvin et al., 2010b; McKeith et al., 2006). In a recent study, the cost of care was shown to be significantly correlated with the dementia patient's dependency in IDALs (Boström et al., 2007b).

Caregiver grief. One painful aspect of being a caregiver of a dementia patient is the grief that goes along with watching your loved one functionally decline and eventually die. Grief results from perceived loss, and can manifest in psychological, physical, social, behavioral and affective forms (Ott, Reynolds, Matovina Schlidt & Noonan, 2006; Ott, Sanders, & Kelber, 2007; Marwit and Meuser, 2002; Rando, 2000). Symptoms of grief include sadness, yearning, crying, changes in sleep and appetite, anger, frustration and trouble concentrating (Ott et al., 2006; Ott et al., 2007). Behavioral and emotional problems exhibited by dementia patients is associated with higher rates of caregiver emotional distress along with poorer mental and physical health (Leggett et al., 2010; Schulz & Sherwood, 2008). Holley and Mast (2010) found

that behavior problems were the strongest determinant of grief among caregivers—even more so than disease stage or time spent on caregiving duties.

Ott, Sanders, & Kelber (2007) found that the amount of grief experienced by caregivers of dementia increased as the care recipient's disease course progressed. Similarly, Meuser & Marwit (2001) found that spousal AD caregivers experienced a significant increase in grief as the disease progressed and decline increased. An increase in grief intensity was also observed in caregivers when the care recipients were placed in nursing homes, despite the perceived decreases in stress and burden (Meuser & Marwit, 2001). However, both of these studies used AD caregiver samples, and may not provide information that is consistent with the experience of caregiving for other types of dementia. Additionally, caregivers of DLB often face these challenges early in the caregiving role, for example 43% of patients present with hallucinations at disease onset, and 37% with depression (Lewy Body Dementia Association, 2015).

Caregiver Burden. Behavioral and emotional problems exhibited by dementia patients are often considered to be among the most stressful aspects of caregiving; thus, they are viewed as main source of dementia caregiver burden in the literature (Leggett et al., 2010; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Schulz & Sherwood, 2008). The amount of behavioral and emotional problems exhibited by dementia patient is associated with the amount of self-reported burden (Holley & Mast, 2010; Leggett et al., 2010; Papastavrou, et al., 2007; Schulz & Sherwood, 2008). The unique dementia profiles of DLB, PDD, and AD may alter the caregiver experience of burden.

DLB patients generally have more severe behavioral symptoms and more compromised functional abilities at disease onset when compared with AD (Ricci et al., 2009). The presence of behavioral and emotional problems, such as recurrent hallucinations, delusions, sleep disorders,

and depression are prominent in DLB; the unpredictability of these symptoms add to caregiver stress (Leggett et al., 2010; Ferman et al., 2012; Ricci et al., 2009). Additionally, caregivers of DLB often face these challenges early in the caregiving role. Unlike in DLB, delusions, depression, and paranoia usually do not appear until the latter stages of AD (Alzheimer's Association, 2016; National Parkinson Foundation, 2015). In a recent study comparing caregivers of DLB and AD patients in early disease stages, high distress (caused by delusion, hallucinations, anxiety and apathy) was only observed in DLB caregivers (Ricci etal., 2009). As AD progress the burden placed on the caregivers increase, whereas the burden placed on DLB caregivers is relatively high at the onset and remains relatively stable across the disease course.

The present study

Extant studies have focused primarily on caregivers of patients with AD. There are relatively few studies that examine the experience of caregivers of DLB. By result, the current state of the research overlooks potentially important differences between DLB and other dementia types. The purpose of the present study was to examine the differences in the experience of grief and burden in caregivers of DLB versus caregivers of AD and PDD. Since early onset of psychiatric symptoms and fluctuating cognition are defining features of DLB, it was anticipated that the caregivers of DLB would perceive more mental health and behavioral problems in their loved ones at earlier stages in the disease course than caregivers of individuals with AD or PDD. Because the amount of behavior and emotional problems exhibited by the patient is associated with higher rates of caregiver distress and grief (and DLB patients often exhibit psychiatric symptoms at disease onset), it was anticipated that caregivers of DLB would experience grief at earlier stages than caregivers of AD or PDD. Finally, it was predicted that the reported subjective burden of caregiving for those with DLB would be greater at earlier stages in

the disease course than for caregivers of either AD or PDD, due to the high rates of psychiatric symptoms and fluctuating cognition exhibited by the patient at early stages in the disease course.

Chapter 2: Method

Participants

Potential participants were initially contacted with the assistance of the Lewy Body Dementia Association and sever partner organizations. Recruitment information was sent out to individuals on caregiver emailing lists of these organizations. The email provided potential participants with a link to the online study along with instructions on how to participate. There was no financial incentive for participation and participants provided their consent to participate prior to completing the survey. The participants who were selected for this study were either a spouse or an adult child caregiver of living individuals with a diagnosis of DLB, AD, or PDD.

Several chi-square tests of independence were performed—comparing disease types on caregiver and patient demographic characteristics. The following caregiver demographics did not yield a significant chi-square: sex, education and patient's disease stage. The chi-square comparing disease types on caregiver race was significant, χ^2 (10, N = 546) = 19.92, p = .03. This result was likely due to the fact that the majority of the sample identified as white and the cell counts for many of the other race types were small or zero. However, when race categories were collapsed into white and non-white categories, the chi-square was no longer significant, χ^2 (2, N = 546) = 3.34, p = .19. Because caregiver race was not influencing the variables of interest, it was decided not to use caregiver race as a covariate. The chi-square comparing disease types on the caregiver's relationship to patient was significant, χ^2 (6, N = 552) = 13.18, p = .04. To reduce group differences, the caregiver's relationship to patient was used as a covariate in the analyses.

The following patient demographic characteristics did not yield a significant chi-square: race, education, and the patient's disease stage. The chi-square comparing disease types on sex

of the patient was significant, χ^2 (2, N = 548) = 34.86, p = .001. To reduce group differences, sex of the patient was used as a covariate in the analyses.

Disease type by caregiver age and patient age was also examined for differences using ANOVAs. Caregiver age was not found to be significantly different among the disease types. Patient age was found to be significantly different among the disease types (F(1,482) = 12.58, p = .001). To reduce group differences, the patient age was used as a covariate in the analyses.

Since there were comparatively few respondents who were caregiving for a patient with a perceived disease stage of "Mild" (n=40), the perceived disease stage of "Mild" and the disease stage of "Moderate" (n=312) were collapsed into one category (n=352). This new category represents earlier perceived disease stages and was compared to the unchanged category representing the later perceived disease stage, "Severe" (n=200). The demographic frequencies by disease type of the new categories (earlier disease stages & later disease stage) can be found in Table 1.

Procedures

This survey was created and placed online using Survey Monkey (www.surveymonkey.com, Palo Alto CA). Eligible participants accessed the survey via an emailed link. The survey contained a total of 230 questions. Data was collected over a period of 12 months. There was no completion time limit on the survey, and participants could save and return to the survey at a later date. Upon completion of the survey, contact information was provided to the participants in the case of their requiring further assistance. All personal information was kept confidential and participant data has been deidentified. This study was

approved by Internal Review Board at the New York University's Medical Center to ensure the ethical use of archived data.

Measures

Socio-demographic. A total of 13 questions assessed caregiver (respondent) demographic characteristics and features of care. A further 14 questions assessed demographic characteristics of the care recipient.

Disease stage severity. Caregivers were asked to estimate the care recipient's disease stage by responding to the following question: "To the best of your knowledge, what stage of disease would you say the patient is in? 1) Mild; 2) Moderate; 3) Severe; 4) Deceased." Caregivers whose care recipient was deceased at the time of their participation in this study were not included in the analyses.

The care recipient behavior problems—Revised Memory and Behavior Problems Checklist (RMBPC). The RMBPC was used to assess the dementia care recipient's overall level of behavioral problems and the degree of behavioral dysfunction—including memory-related problems, depression, and disruptive behaviors (see Appendix A.; Teri et al., 1992). It also provides indexes of the caregiver's feelings of distress in response to the care recipient's behavior problems (Teri et al., 1992). However, since the Zarit Burden Interview (see below) was selected as the measure of burden for this study, these indexes were not looked at as they are redundant. According to Teri et al. (1992) the RMBPC has three first-order factors: Memory-Related Problems, Depression, and Disruption. Reliabilities of the overall scales of the care recipients' behavior and caregiver reaction were very high (.84 and .90). The subscale reliabilities indexes ranged from moderately high to very high (.67 to .89). The RMBPC also has both good concurrent validity and discriminant validity (Teri et al., 1992).

The RMBPC contains 24 statements, 1 total score and 3 subscale scores (memory-related, depression, and disruptive behaviors). Participants answer questions pertaining to the frequency of caregiver-observed behavioral problems in the patient. Questions are answered using a six-point Likert scale ranging from 0 (never occurred) to 4 (Extremely), and 9 (don't know/not applicable). Higher scores on the RMBPC referring to the care recipient's behavior problems indicate greater levels of perceived behavior problems in the care recipient by the caregiver.

Caregiver grief--Marwit-Meuser Caregiver Grief Inventory Short Form (MM-CGI-SF). The MM-CGI-SF was created from the original full-length version of the Marwit–Meuser Caregiver Grief Inventory (MM-CGI; Marwit & Meuser, 2002). Both versions were designed to measure grief in caregivers of persons with progressive dementia (Marwit & Meuser, 2002; Marwit & Meuser, 2005). The MM-CGI-SF (see Appendix B.; Marwit, & Meuser, 2005) is composed of 18 statements and assesses caregiver grief on three factors: 1) Personal Sacrifice Burden; 2) Heartfelt Sadness and Longing; and 3) Worry and Felt Isolation. Participants responded using a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate greater feelings of grief. The three factors can be looked at individually or as a sum score of all items.

The full-length version of the MM-CGI was developed using an exploratory factor analysis of 184 statements describing dementia caregiver grief and sadness (Marwit & Meuser, 2002). Of the original 184 statements 50 were retained. The analysis revealed three factors with high internal consistencies. The first factor, Personal Sacrifice and Burden, was designed to measure what caregivers view as sacrifices they have had to make to be a caregiver (α = .93). The second factor, Heartfelt Sadness and Longing, is intended to represent the "true grief factor" of the loss of the relationship with the care recipient and a longing for how life was before the

noticeable signs in illness in the care recipient. The third factor, Worry and Felt Isolation, was deigned to capture caregivers' uncertainty about the future and their feelings of being isolated from others. The sum score for all items was shown to have excellent internal consistency reliability (α = .96), and a split-half reliability of 0.91 (Marwit & Meuser, 2002). It was also shown to have a good test re-test reliability (Factor 1, r =.71; Factor 2, r = .73; Factor 3, r =.75; TG, r =.71; all ps < .01) and good convergent validity with measures covering similar content (Marwit & Meuser, 2002).

The same three factors that were used in the full-length version of the measure were also used in the short-form (Personal Sacrifice Burden; Heartfelt Sadness and Longing; and Worry and Felt Isolation; Marwit & Meuser, 2005). The authors selected six items per factor that they regarded as being the most representative of that factor in terms of content and coverage (i.e., good face validity). The three factors on the short form were shown to be highly correlated with the same factors on the long form (Factor 1, r = .915; Factor 2, r = .925; Factor 3, r =.928; all ps < .01; Marwit & Meuser, 2005), indicating good concurrent validity. Each of the three factors that comprise the 18-item MM-CGI-SF were also shown to have good internal consistency reliability (Factor 1, α = .83; Factor 2, α = .80; Factor 3, α =.80; Marwit & Meuser, 2005).

Caregiver Burden—Zarit Burden Interview (ZBI). The level of perceived caregiver burden was assessed using a 12 item abridged version of the ZBI (see Appendix C.). The ZBI is one of the most commonly used measures of caregiver burden, and was originally developed for use with caregivers of AD. The ZBI is comprised of questions asking caregivers about their experiences of emotional, physical, and social strains or difficulties that result from their role as a caregiver. Items include topics such as the degree to which their health has suffered due to being a caregiver, the degree to which being a caregiver affects their relationships with family

and friends, and how much burden they feel from the caregiving role. In the ZBI, participants respond to questions using a five-point Likert scale ranging from 0 (never) to 4 (nearly always). Higher scores indicate higher perceived levels of burden. The version used in this study was taken from a recent paper that chose ZBI questions that were deemed more likely to target the concerns of caregivers of DLB (see Appendix C.; Leggett et al., 2010). A similar version of the ZBI was shown to have a high combined reliability (α = .86; Bédard, 2001).

Data analysis

Data analysis was performed using a SPSS statistical package version 23. Distributions were examined and outliers were looked for and addressed in the data. Two participants were removed from the analyses due to extreme scores. An additional sixteen were removed for lack of completion of the survey—beyond the demographics section. To reduce group differences the caregiver's relationship to the patient, as well as the patient's age and sex were used as covariates. Demographic information can be found in Table 1. Over all differences between the experience of caregiving for individuals with DLB versus caregiving for individuals with AD or PDD were explored using a series of ANCOVAs (see Table 2.). Differences between the experience of caregiving for individuals with DLB versus caregiving for individuals with AD or PDD by stage (earlier stages vs. later stage) were also explored using a series of ANCOVAs (see Table 3.).

Chapter 3: Results

Caregiver reported patient behavioral problems. There were no significant overall differences on the RMBPC between dementia types and the caregiver perceived frequency of disruptive behavioral problems or the total frequency of behavioral problems (all *p*s > .05; see Table 2.). The overall reported frequency of depression (observed in the patient) on the RMBPC was significantly greater for those with DLB (*M* = 12.46, *SD* = 6.88) than for those with AD (*M* = 11.40, *SD* = 6.90; see Table 2.). The frequency of reported depression (observed in the patient) was significantly greater for those with DLB (*M* = 12.56, *SD* = 6.80) than for those with AD (*M* = 11.30, *SD* = 6.81) at earlier disease stages, while for the later stage there was no significant difference between the two diseases (see Table 3.). The overall reported frequency of memory related problems (observed in the patient) on the RMBPC was significantly greater for those with AD (*M* = 20.05, *SD* = 5.87) than for those with DLB (*M* = 17.48, *SD* = 6.78; see Table 2.). The frequency of reported memory problems (observed in the patient) was not significantly different between DLB and AD for earlier stages of the disease, while it was significantly greater for those with AD (*M* = 22.95, *SD* = 4.60) than for those with DLB (*M* = 17.80, *SD* = 7.77) at the later stage of the disease (see Table 3.).

Those caring for individuals with DLB (*M* = 17.48, *SD*= 6.78) reported significantly greater overall frequency of memory problems (observed in the patient) on the RMBPC than caregivers of those with PDD (*M* = 15.43; *SD* = 6.57; see Table 2.). Caregivers for those with DLB (*M* = 17.33, *SD*= 6.25) reported significantly more memory problems than caregivers for those with PDD (*M* = 14.51; *SD* = 5.49) at the earlier stages of the disease course, while for the later stage there was no significant difference between the two diseases (see Table 3.).

Reported Caregiver Grief. Caregivers of individuals with DLB (*M* = 22.46, *SD* = 4.93) reported significantly greater Heartfelt Sadness and Longing on the MM-CGI-SF overall than caregivers with AD (*M* = 20.71, *SD* = 5.58; see Table in 2.). Caregivers of individuals with DLB (*M* = 22.08, *SD* = 4.80) reported significantly greater Heartfelt Sadness and Longing than caregivers of AD (*M*= 19.37, *SD* = 5.26) at earlier stages of the disease course, while for the later stage there was no significant difference between the two diseases (see Table 3.). There were no other significant differences on the MM-CGI-SF between diseases (see Tables 2. & 3.).

Reported Caregiver Burden. No significant differences between the dementia types were found on the ZBI (all *p*s > .05; see Tables 2. & 3.).

Chapter 4: Discussion

Because of the early onset of psychiatric symptoms and fluctuating cognition associated with DLB, it was anticipated that the caregiver perceived frequency of patient overall behavioral problems and disruptive behavioral problems would be greater for caregivers of DLB at earlier stages in the disease course than for individuals with either AD or PDD; but, these dimensions were not significantly different between dementia types.

As expected, the frequency of caregiver reported depression symptoms (seen in the patient) was significantly greater for those with DLB than for those with AD. Depression is a supportive feature for the diagnosis of DLB, and is common at all stages of the disease (Auning et al., 2011; McKeith et al., 2005). Conversely, psychiatric symptoms tend to be less common until the later stages of AD (Alzheimer's Association, 2016). This lack of difference between DLB and AD at the later disease stage may be attributable to a caregiver perceived increase in depressive symptoms for those with AD, while the depression symptoms of those with DLB remain stable.

There was no significant difference between those with DLB and those with PDD in caregiver reported depression symptoms (seen in the patient). The lack of difference between caregiver reported depression symptoms (seen in the patient) for DLB versus PDD is not surprising. Depression is part of the diagnostic criteria for both diseases, and is a common feature of both (Aarsland, Påhlhagen, Ballard, Ehrt, Svenningsson, & 2012; Auning et al., 2011; DSM-5, 5th ed., 2013; McKeith et al., 2005).

As expected, the frequency of caregiver reported memory related problems (seen in the patient) was significantly greater for those with AD than for those with DLB; greater memory related problems in AD and DLB were anticipated because of the diagnostic criteria and typical

disease presentations of AD and DLB. Interestingly, the frequency of reported memory problems was not significantly different between DLB and AD at earlier stages of the disease. Memory deficits are a hallmark of AD at all stages of the disease (Alzheimer's Association, 2016; American Psychiatric Association, 2013), whereas, noticeable memory impairment may not be easily differentiated at early stages of DLB (but is usually evident with the progression of the disease; McKeith et al., 2005). Deficits and variation in attention, alertness, and executive function are more prominent and typical at early stages of DLB (Lewy Body Dementia Association, 2015; McKeith et al., 2005). This lack of difference at earlier stages may be attributable to caregivers of DLB conflating the symptom of fluctuating cognition and/or general cognitive decline with memory problems. Consistent with the disease expected presentations for DLB and AD, the caregiver perceived frequency of memory related problems at the later stage of the disease course was significantly greater for those caring for loved ones with AD than for those caring for loved ones with DLB.

Caregivers of those with DLB also reported significantly more (patient related) overall memory related problems than those with PDD. Caregivers for those with DLB also reported significantly more (patient related) memory problems than caregivers for those with PDD in the earlier stages of the disease course, though for the later stage there is no significant difference between the two diseases. While the common underlying pathology for DLB and PDD is the same (i.e., the aggregation of α –synuclein in the brain), they are still classified as different diseases because of differences in disease presentation and progression. To further complicate this picture, the amount of cortical LB pathology does not necessarily correlate with clinical dementia severity (Marui et al., 2002), and severe pathology can even be seen in the absence of clinically significant symptoms (Frigerio et al., 2011; Parkkinen, Pirttilä, & Alafuzoff, 2008).

The difference in memory problems found in this study may be attributable to differences in the localization, amount, and spread of LBs in addition to the comorbid aggregation of beta amyloid, neuronal atrophy, and/or vascular changes. Caregivers may also be conflating DLB patients' problems with cognitive fluctuations and executive function deficits as memory problems.

The overall reported Heartfelt Sadness and Longing was shown to be significantly greater for those caring for individuals with DLB than for those caring for individuals with AD. According to the creators of the MM-CGI, the factor Heartfelt Sadness and Longing is intended to represent the "true grief factor" of the loss of the relationship with the care recipient and a longing for how life was before the noticeable signs of illness in the care recipient (Marwit & Meuser, 2002). As anticipated, caregivers of individuals with DLB also reported significantly greater Heartfelt Sadness and Longing than caregivers for individuals with AD at earlier stages of the disease course, while for the later stage there is no significant difference between the two diseases. This finding supports the hypothesis that the early onset of psychiatric symptoms and fluctuating cognition associated with DLB leads to greater caregiver grief at early disease stages. This finding is also consistent with the caregiver literature indicating that the amount of behavior and emotional problems exhibited by the patient is associated with higher rates of caregiver distress and grief (Leggett et al., 2010; Schulz & Sherwood, 2008). The lack of difference between those with DLB and those with AD on the other two factors on the MM-CGI-SF (Personal Sacrifice and Burden & Worry and Felt Isolation) could be attributable to the overlap in difficulties that all caregivers face (e.g., making sacrifices to care for their loves one, worry about the future, feeling isolated from others).

Conversely, there were no significant differences between caregiver reported grief in DLB and PDD. This is lack of difference could be due to caregivers' grief over the PDD care

recipients' lack of mobility and decline in memory equating to the caregivers' grief in DLB over psychiatric problems and fluctuation cognition. Another important thing to consider may be that by the time someone is diagnosed with PDD they are experiencing greater cognitive deficits and they may also exhibit some of the same psychiatric problems seen in DLB.

Finally, it was anticipated that the reported subjective burden of caregiving for individuals with DLB would be greater at earlier stages in the disease course than for caregivers of either AD or PDD, because of the early onset of psychiatric symptoms and fluctuating cognition associated with DLB. However, little difference among caregivers was found. One caveat to this finding is that the measures used were developed primarily to assess the experience for AD caregivers; thus, they may not have adequately captured the unique facets of the DLB or the PDD caregiving experience. DLB caregivers face many unique demands and challenges that require the creation of new questionnaires that address the differences in the disease presentation and progression seen in DLB. Future studies addressing the caregiver experience between dementia types could make use of currently available tools that screen for symptoms that are more specific to DLB and less focused on memory deficits, which are not as common in DLB.

The early onset of psychotic behavior is something that sets DLB apart from other dementia types (Auning et al., 2011; Suárez-González et al., 2014) and causes caregivers of DLB a great deal of distress (Ferman et al., 2012; Galvin et al., 2010b; Leggett et al., 2010). Current questionnaires for caregivers do a relatively good job at identifying memory, orientation, and problem solving deficits in the care recipient based on caregiver reports, but they lack more in-depth questions about psychiatric problems. It would be beneficial to add questions that screen for this type of behavior into questionnaires assessing the caregiver experience. There are questionnaires available that have been primarily used in research and clinical settings that get at

some of these symptoms. Also, the creation of more specific questionnaires could help to further identify differences between caregiving for DLB versus AD, and potentially identify any possible differences between the caregiving for DLB versus PDD.

One common research tool that could be used is the Neuropsychiatric Inventory that screens for psychotic symptoms as well as other disturbances (Cummings et al., 1994). A recent study using a shortened form of this survey (NPI-Q) found that hallucinations and apathy occurred significantly more for those with DLB than those with other dementia types (Johnson, Watts, Chapin, Anderson, & Burns, 2011). Another study using the original full version of the NPI found that those with DLB had significantly more hallucinations, apathy, and a larger NPI summary score than those with AD (Boström etal., 2007b). Neither study was able to successfully differentiate DLB from other dementia types when comparing the incidence and severity of delusions; however, this may be due to the fact that these studies used participants at differing disease stages, and delusions have been shown to be more common at early stages of DLB than in other dementia types (Bjoerke-Bertheussen et al., 2012; Boström et al., 2007b; Kao et al. 2009; Suárez-González et al., 2014; Thaipisuttikul et al., 2013). Future studies could look at disease stage in conjunction with the psychiatric symptoms captured by the NPI.

RBD is another symptom that can be very distressing for caregivers and the care recipients. There are currently several measures that screen for RBD and other sleep disorders. Among them are the RBD screening questionnaire (RBDSQ; Stiasny-Kolster et al., 2007), RBDQ-HK (Li et al., 2010), and the Mayo Sleep Questionnaire (MSQ; Boeve et al., 2011). Because RBD is a supportive symptom in the DLB diagnostic criteria and has been shown to be more common in DLB than in other types of dementia (Chiba et al., 2012; Postuma et al., 2015; Thaipisuttikul et al., 2013), it would be useful to add questions that screen for sleep disorders to

questionnaires for caregivers as they may further differentiate the caregiving experience of DLB from other types of dementia.

Another prominent symptom of DLB that causes caregivers a lot of distress is fluctuating cognition. Since fluctuating cognition is a core feature of DLB, it might provide more insight into the difficulties of caring for an individual with these types of deficits if questions that capture these symptoms are included in questionnaires for caregivers. Unfortunately, studies show that fluctuations in cognition are difficult to define and capture consistently on assessments scales (Huang, & Halliday, 2013; Merdes et al., 2003; Verghese, Crystal, Dickson, & Lipton, 1999). Still, there are currently several questionnaires that screen for fluctuating cognition (The Cognition Assessment of Fluctuation, One Day Fluctuation Assessment Scale, The Mayo Fluctuations Composite Scale). The Cognition Assessment of Fluctuation is designed to be administered by a clinician and evaluates fluctuating confusion over the month prior to the interview; unfortunately, this scale has poor inter-rater reliability and requires administration by a trained clinician (McKeith et al., 2005; Walker et al., 2000). The One Day Fluctuation Assessment Scale evaluates fluctuating confusion over the 24 hours prior to the assessment and can be administered by a variety of trained staff (McKeith et al., 2005; Walker et al., 2000). The Mayo Fluctuations Composite Scale includes screening questions of symptoms that occur more frequently in DLB than in AD (McKeith et al., 2005). A recent systematic review of cognitive fluctuation in dementia by Lee, Taylor, & Thomas (2012) suggests that these tools require further evaluation for their reliability and validity. Future studies could examine the ability of each of these tools to identify fluctuating cognition in care recipient populations and how effective they are at differentiating between dementia types, as well as how these types of symptoms impact caregivers.

One limitation of this study is that caregivers were asked to estimate the care recipient's disease stage; thus, it is possible that they did not make accurate estimations. Additionally, the sample for this study exclusively contains individuals who were willing and able to participate using the internet; thus, the group may be younger, better educated, of a higher socioeconomic status, and more technologically savvy than those who did not participate. Also, respondents may not have felt comfortable providing answers that present themselves in an unfavorable manner. Finally, limitations of surveys in general also apply to this study.

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Table 1.

Table 1.
Caregiver and patient demographic frequencies by disease

	Caregivers				Patients			
	Patient Diagnosis				Patient Diagnosis			
	DLB *n* = 415	AD *n* = 71	PDD *n* = 66	Total *n* = 552	DLB *n* = 415	AD *n* = 71	PDD *n* = 66	Total *n* = 552
Age (*M* (*SD*))	61(11)	59(10)	63(10)		75(9)	79(9)	73(7)	
Sex								
Male	45	8	3	56	275	27	56	358
Female	386	62	63	493	138	43	9	190
Race								
White	400	64	36	527	396	66	65	527
Black or African American	5	2	1	8	8	2	1	11
Asian	4	0	0	4	5	0	0	5
Native Hawaiian or other Pacific Islander	2	0	0	2	1	0	0	1
American Indian or Alaskan Native	1	1	1	3	1	0	0	1
Other	0	2	0	2	2	3	0	5
Latino/a (collected separately)	7	2	0	9	7	2	0	9
Education								
Some high school or less	3	1	1	5	55	13	3	71
High school	41	9	3	53	90	22	10	122
Some college	94	20	15	129	72	9	10	91
College	133	21	19	173	97	15	17	129
Graduate school or professional training	144	20	28	192	100	12	25	137
Caregivers relationship to patient								
Husband	57	8	6	71				
Wife	198	21	46	265				
Son	13	2	1	16				
Daughter	147	40	13	200				
Disease Stage								
Earlier disease stages					267	48	37	352
Later disease Stage					148	23	29	200

Table 2.

Table 2.
Analysis of Covariance examining over all differences between caregivers on self report measures by diagnosis

	DLB vs. AD				DLB vs. PDD			
	df	*F*	*p*	ηp^2	*df*	*F*	*p*	ηp^2
Revised Memory and Behavioral Problems Checklist								
Total Behavioral Problems Frequency	1,453	.01	.92	.001	1,451	.79	.37	.002
Frequency of Disruptive Behavioral Problems	1,465	1.17	.28	.003	1,460	.05	.83	.001
Frequency of Depressive symptoms	1,470	5.20	.02*	.01	1,465	.14	.71	.001
Memory Problems Frequency	1,454	6.14	.01*	.01	1,452	3.99	.05*	.01
Zarit Burden Inventory	1,441	.43	.51	.001	1,436	.20	.66	.001
Marwit Meuser Caregiver Grief Inventory								
Total Caregiver Grief	1,448	1.97	.16	.004	1,441	1.37	.24	.003
Personal Sacrifice Burden	1,448	.11	.74	.001	1,441	.19	.66	.001
Heartfelt Sadness & Longing	1,448	5.89	.02*	.01	1,440	.15	.70	.001
Worry & Felt Isolation	1,448	.72	.40	.003	1,441	2.68	.10	.006

Note: * indicate significant difference ($p < .05$); the covariates used were the caregiver's relationship to the patient, the patient's age, and the patient's sex

Analysis of Covariance examining differences between caregivers on self report measures by diagnosis at the earlier and the later stages of disease

	DLB vs. AD								DLB vs. PDD							
	Earlier Stages				Late Stage				Early Stages				Late Stage			
	df	*F*	*p*	ηp^2	*df*	*F*	*p*	ηp^2	*df*	*F*	*p*	ηp^2	*df*	*F*	*p*	ηp^2
Revised Memory and Behavioral Problems Checklist																
Total Behavioral Problems Frequency	1,305	2.28	.133	.008	1,147	2.11	.15	.02	1,294	2.53	.11	.009	1,156	.001	1.00	.001
Frequency of Disruptive Behavioral Problems	1,306	1.91	.17	.006	1,158	.03	.86	.001	1,295	.48	.49	.002	1,164	.06	.80	.001
Frequency of Depressive symptoms	1,305	7.36	.007*	.02	1,164	.25	.62	.002	1,294	.35	.55	.001	1,170	2.09	.15	.012
Memory Problems Frequency	1,306	.60	.44	.002	1,147	7.88	.006*	.052	1,295	5.58	.02*	.019	1,156	.62	.43	.004
Zarit Burden Inventory	1,288	.78	.38	.003	1,158	.45	.53	.003	1,278	.15	.70	.001	1,165	.001	.98	.001
Marwit Meuser Caregiver Grief Inventory																
Total Caregiver Grief	1,290	3.00	.08	.01	1,157	.08	.78	.001	1,279	1.77	.18	.006	1,161	.42	.52	.003
Personal Sacrifice Burden	1,290	.17	.68	.001	1,157	.02	.90	.001	1,279	.27	.60	.001	1,161	.12	.73	.001
Heartfelt Sadness & Longing	1,290	9.03	.003*	.03	1,157	.13	.72	.001	1,279	1.39	.24	.005	1,161	.13	.71	.001
Worry & Felt Isolation	1,290	1.23	.27	.004	1,157	.05	.82	.001	1,279	2.79	.10	.01	1,161	.80	.37	.005

Note: * indicate significant difference ($p < .05$); the covariates used were the caregiver's relationship to the patient, the patient's age, and the patient's sex

Table 3.

Appendix A.

Revised Memory and Behavior Checklist

Instructions: The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened Use the following scale for your reaction. Please read the description of the ratings carefully.

Has it occurred in the past week:

0 = No
1 = Yes

Reaction Ratings:

0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely

Please answer all the questions for both frequency and reaction.

(RC11)

Problem	Has it occurred? (in past week)		Reaction (how much it bothered you)
1. Asking the same question over and over	NO	YES	
2. Trouble remembering recent events (i.e. items in newspaper or TV)	NO	YES	
3. Trouble remembering significant past events	NO	YES	
4. Losing or misplacing things	NO	YES	
5. Forgetting what day it is	NO	YES	
6. Starting, but not finishing, things	NO	YES	
7. Difficulty concentrating on a task	NO	YES	
8. Destroying property	NO	YES	
9. Doing things that embarrass you	NO	YES	
10. Waking you or other family members up at night	NO	YES	
11. Talking loudly and rapidly	NO	YES	
12. Appears anxious or worried	NO	YES	
13. Engaging in behavior that is potentially dangerous to self or others	NO	YES	
14. Threats to hurt oneself	NO	YES	
15. Threats to hurt others	NO	YES	
16. Aggressive to others verbally	NO	YES	
17. Appears sad or depressed	NO	YES	
18. Expressing feelings of hopelessness or sadness about the future	NO	YES	
19. Crying and tearfulness	NO	YES	
20. Commenting about death of self or others	NO	YES	
21. Talking about feeling lonely	NO	YES	
22. Comments about feeling worthless or being a burden to others	NO	YES	
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	NO	YES	
24. Arguing, irritability, and/or complaining	NO	YES	

Revised Memory and Behavior Checklist

RMBPC Scoring

Frequency Scoring: Sum items on subscales and total

Reaction Scoring: Sum scores on itms that had a frequency rating of 1 or greater on subscales and total

Memory:	7 items (#1, 2, 3, 4, 5, 6, 7) Possible range: 0-28 Frequency: mean = 18.33, sd = 7.02, range 0-28 Reaction: mean = 11.12, sd = 6.34, range 0-28
Depression:	9 items (#12, 14, 17, 18, 19, 20, 21, 22, 23) Possible range: 0-36 Frequency: mean = 11.40, sd = 9.28, range 0-36 Reaction: mean = 18.73, sd = 8.47, range 0-36
Disruption:	8 items (#8, 9, 10, 11, 13, 15, 16, 24) Possible range: 0-32 Frequency: mean = 5.64, sd = 6.44, range 0-28 Reaction: mean = 14.85, sd = 8.34, range 0-32
Total:	24 items Possible range: 0-96 Frequency: mean = 33.59, sd = 16.56, range 1-87 Reaction: mean = 22.69, sd = 15.60, range 0-77

Appendix B.

MM Caregiver Grief Inventory - Short Form

Thomas M. Meuser, Ph.D., University of Missouri – St. Louis
Samuel J. Marwit, Ph.D., University of Missouri-St. Louis (Emeritus)

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed below.

ANSWER KEY 1 = **Strongly Disagree** // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // 5 = **Strongly Agree**							
1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I feel I am losing my freedom.	1	2	3	4	5	A
3	I have nobody to communicate with.	1	2	3	4	5	C
4	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5	B
5	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
6	Dementia is like a double loss…I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5	C
7	My friends simply don't understand what I'm going through.	1	2	3	4	5	C
8	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
9	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
10	I will be tied up with this for who knows how long.	1	2	3	4	5	A
11	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5	B
12	I feel very sad about what this disease has done.	1	2	3	4	5	B
13	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
14	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
15	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
16	Independence is what I've lost…I don't have the freedom to go and do what I want.	1	2	3	4	5	A
17	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
18	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.

Personal Sacrifice Burden *(A Items)* = _____
(6 Items, M = 20.2, SD = 5.3, Alpha = .83, n = 292)

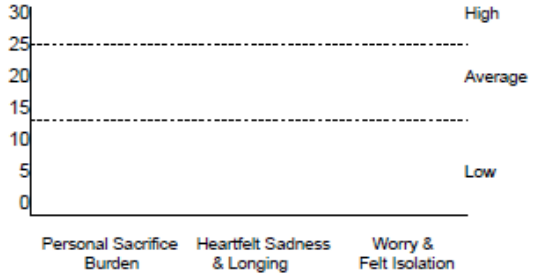
Heartfelt Sadness & Longing *(B Items)* = _____
(6 Items, M = 20.2, SD = 5.0, Alpha = .80, n = 292)

Worry & Felt Isolation *(C Items)* = _____
(6 Items, M = 16.6, SD = 5.2, Alpha = .80, n = 292)

Total Grief Level (Sum A + B + C) =_____
(18 Items, M = 57, SD = 12.9, Alpha = .90, n = 292)

Plot your scores using the grid to the right. Make an "**X**" nearest to your numeric score for each sub-scale heading. Connect the X's. This is your grief profile. Discuss this with your support group leader or counselor.

MM-CGI-SF Personal Grief Profile



What do these scores mean?
Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 292). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only— more research is needed on specific interpretation issues.

Appendix C.

Zarit Burden Inventory (12 questions)

The following statements represent feelings and attitudes of some relatives who are caregivers of patients with chronic illnesses. After each statement, please indicate how often you feel that way. Be as honest as you can, as each person's experience will be different. There are no right or wrong answers

Question	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
Do you feel that because of the time you spend with the patient that you don't have enough time for yourself?					
Do you feel stressed between caring for the patient and trying to meet other responsibilities for your family or work?					
Are you afraid what the future holds for the patient?					
Do you feel your health has suffered because of your involvement with the patient?					
Do you feel that your social life has suffered because you are caring for the patient?					
Do you feel uncertain about what to do about the patient?					
Do you feel angry when you are around the patient?					
Do you feel that the patient currently affects your relationship with other family members or friends in a negative way?					
Do you feel strained when you are around the patient?					
Do you feel you should be doing more for the patient?					
Do you feel you could do a better job in caring for your relative?					
Overall, how burdened do you feel in caring for the patient?					
Totals					
TOTAL BURDEN SCORE					