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**CAREGIVER STRESS, BURDEN, AND ASSOCIATED DIFFICULTIES
AS A RESULT OF LEWY BODY DEMENTIA**

A Thesis in
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by
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ABSTRACT

People with Lewy Body Dementia (LBD) present a unique set of symptoms and challenges to family caregivers compared to other types of dementia. Prominent difficulties include motor impairment, ADL disability, and recurrent behavioral and emotional problems (BEP), and unique medical care and diagnostic difficulties. These problems are likely to impact caregivers' subjective burden. The present study used data from an internet survey conducted by the Lewy Body Dementia Association (LBDA). Respondents were 611 people who indicated they were currently involved in the care of their relative with LBD. Subjective burden was assessed with a 12-item short version of the Zarit Burden Interview (BI). A factor analysis revealed three dimensions: role strain, personal strain, and worry about performance. Multiple regressions were used to examine predictors of the three burden factors. We found that BEPs (summed and specific), ADL disability, isolation, and evaluation of the doctor were all significant predictors of specific factors. Formal service use had no significant associations with burden, but levels of use were low. These findings highlight the impact of BEPs, ADL assistance, awareness about LBD, and comprehensive medical care on subjective burden.

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Chapter 1. Literature Review

Lewy Body Dementia (LBD) is the second most prevalent type of dementia, accounting for between 10 and 20 percent of all dementias. It is often widely confused with and misdiagnosed as Alzheimer's disease (AD) (Tarawneh & Galvin, 2007; Gerpen, 2007). LBD, however, displays unique symptoms and presents many difficulties for patients and caregivers, apart from those presented by AD. Patients face the daily challenges that accompany their disease, and also have the added difficulty of receiving a correct diagnosis and proper medical care and treatment. Caregivers must assist with the additional primary stressors of the behavioral and emotional symptoms that accompany LBD and struggle through the confusion of receiving an inaccurate diagnosis for their relative. This paper reviews these issues, examines caregiver burden through a unique internet survey developed by the Lewy Body Dementia Association (LBDA), and discusses overall conclusions and strategies to address diagnostic issues and caregiver burden. As the prevalence of dementia is doubling every five years, research on LBD and caregiving issues will prove vital in the coming years as increasingly more individuals and their caregivers will face a dementia diagnosis (Gerpen, 2007).

In 1912, Dr. Frederic Lewy first described the Lewy body which he related as the main pathological feature for Parkinson's Disease and which has now come to be associated with LBD. LBD can be classified based on the predominant location of Lewy bodies in the brain: the brainstem, limbic, and neocortical areas (McKeith et al., 2004). A Lewy Body is a nerve cell with a core of the protein alpha-synuclein, which is believed to clump in the nerve cell so that it can't carry out its functions and will eventually perish (Gerpen, 2007). Research has been inconclusive, however, with respect to what function, if any, Lewy bodies have. For example, there is not a strong correlation between the number of Lewy bodies and the severity and

duration of LBD (McKeith et al., 2004). It is, however, clear that their presence is indicative of this form of dementia. Thus despite the controversy, Lewy bodies give their name and provide the pathological underpinning to this prevalent disorder.

LBD, like all dementias, is characterized by a progressive reduction in cognitive functioning including language, memory, judgment, confusion, and visuospatial and perceptual skills (Gerpen, 2007; Tarawneh & Galvin, 2007). Additionally, LBD is characterized by the presence of at least two of the following three core features: concurrent parkinsonian symptoms, varying attention and concentration, and repeated visual hallucinations (McKeith et al., 2004; Tarawneh & Galvin, 2007). The parkinsonian symptoms are integral in the LBD diagnosis but can easily confuse LBD with Parkinson's disease dementia. Individuals with LBD must show parkinsonian symptoms within one year of dementia onset to receive a diagnosis of LBD. It is possible that the two diseases are on the same spectrum, differing by onset of cognitive decline and parkinsonian symptoms (Stewart, 2007; Gerpen, 2007; Tarawneh & Galvin, 2007; Williams, Xiong, Morris, & Galvin, 2006). Parkinsonism also encompasses four types of symptoms, two of which are needed for diagnosis of this core feature. These symptom types include a rest tremor, bradykinesia (a reduction of automatic movements with expressions such as facial dulls, a drool, arm swing ambulating, etc.), rigidity, and postural instability (an impairment of the righting reflex which allows recovery after the center of gravity loses balance- this impairment often leads to falling) (Gerpen, 2007).

Other defining symptoms of LBD, all from consensus conference guidelines, include Rapid Eye Movement sleep behavior disorder, extrapyramidal signs (movement disorders), neuroleptic sensitivity with harmful resulting side effects, falls, syncope/fainting due to orthostatic hypotension, paranoid delusions, non-visual hallucinations, autonomic dysfunction,

depression, and loss of consciousness (Tarawneh & Galvin, 2007; McKeith et al., 2004; Gerpen, 2007). Many of these symptoms overlap with those suggesting an AD diagnosis, however, and thus it is important to note which features and characteristics of LBD are different.

LBD can be difficult to distinguish from AD due to the presence of overlapping symptoms. As many as two thirds of people with LBD may also have AD pathology; but in LBD the pathology more typically presents in the form of plaques and rarely tangles (Stewart, 2007). Characteristics that are more common hallmarks of LBD, and not of AD, are visual hallucinations, extrapyramidal symptoms and gait abnormalities, autonomic dysfunction, REM, and irritability and passive behavioral traits (Tarawneh & Galvin, 2007). As the disease progresses, people with LBD are more likely than AD patients to have impaired visuo-spatial skills, psychiatric symptoms, and functional impairment at diagnosis (Tarawneh & Galvin, 2007; McKeith et al., 2004). Psychiatric symptoms will tend to remain stable over time in LBD, whereas they tend to worsen over time in AD (Stewart, 2007; Tarawneh & Galvin, 2007). Furthermore, research has noted that LBD may progress faster than AD and have more variance with respect to an individual's good and bad days. Bad days for individuals with LBD often include pseudo-delirium which may last for weeks (Stewart, 2007). Researchers studying LBD have also noted a shorter time to institutional placement and mortality (Tarawneh & Galvin, 2007). The median age of demise for a person with LBD is 78 compared to 86 for Alzheimer's disease, even controlling for a gender effect (Williams, Xiong, Morris, & Galvin, 2006).

Other notable distinguishing features for LBD compared to AD include its higher prevalence in men and an extreme reaction to neuroleptics (Stewart, 2007; Tarawneh & Galvin, 2007; McKeith et al., 2004). Individuals with LBD will experience severe side effects resulting from neuroleptics, yet show more evidence for a positive response to cholinesterase inhibitors

than those diagnosed with AD (Gerpen, 2007; McKeith et al., 2004). Finally, LBD must be differentiated from Parkinson's Disease Dementia (PDD). As mentioned previously, LBD cases must present cognitive degeneration and parkinsonian features within one year of each other. In PDD, on the other hand, parkinsonian symptoms present first by at least a year (Tarawneh & Galvin, 2007; McKeith et al., 2004). Despite these differences, LBD and PDD are believed to be in the same spectrum of disorders.

While some distinguishing features of LBD exist, research is not as advanced for LBD as for AD, and this presents a problem in achieving accuracy in a LBD diagnosis (Tarawneh & Galvin, 2007). There is a degree of overlap in the symptoms of LBD and AD, and physicians admit the need for more detail regarding severity and frequency of symptoms. Thus confusion is common where there is currently insufficient differential information on LBD (McKeith et al., 2004). Problems that lead to difficulty in making a diagnosis include the unavailability to use neuropathology to corroborate a diagnosis, low sensitivity but high specificity of measures, and the prevalence of physicians untrained in geriatric pathology and/or families' concerns (Robillard, 2007). The Diagnostic and Statistical Manual (DSM), the most widely used mental health diagnostic guidance resource, offers information that is highly reliable for identifying Alzheimer's disease, but not for other types of dementia (Robillard). Thus, difficulty in diagnosis of LBD stems from a wide range of overlapping clinical features that make true recognition difficult. Consensus committees urge the identification of a biological marker and the increased publication of more clinical criteria so that LBD patients may be able to receive aid from cholinergic drugs and avoid the deployment of neuroleptics (McKeith et al.). Currently, there is no definitive way to separate AD and LBD diagnoses with a high degree of specificity, and this creates many difficulties for families and individuals with LBD who are looking for an

accurate diagnosis (Robillard). The present research will highlight how diagnostic difficulties are associated with caregiver burden.

Next, a careful review of the theory behind caregiver burden is important before looking at how LBD symptoms relate to negative caregiver outcomes. First, it is important to note that caregiving has become a very frequent activity in modern society as adults are living longer and are thus more at risk for succumbing to disease and disability associated with aging (Pearlin, Mullan, Semple, & Skaff, 1990). When older adults with disabilities are no longer able to take care of themselves and address their daily needs, family members typically must intervene to provide care. If available, spouses usually become the primary caregivers, followed closely in occurrence by an adult daughter. Sons, other relatives, or friends take the responsibility less often (Zarit & Eggebeen, 2002; Pruchno & Rosenbaum, 2003). Many empirical reports have emphasized negative outcomes associated with caregiving. For example, caregiving has been empirically associated with decreased well-being, depression, anger, anxiety, health and medical problems, guilt over not doing more, a sense of being trapped, and a loss of those providing care (Aneshensel et al., 1995; Zarit, 2008; Zarit & Eggebeen).

Initially, many researchers had assumed a simple, reductionist model of caregiving stressors having a direct impact on mental health outcomes. For instance, a caregiver's daily assistance with his or her relative's bathing procedure may be assumed to link directly with burden. However, it has been found that there is only a modest relationship directly between stressors and the burden outcome (Zarit, 2005). It is now known that stress is an unfolding, multidimensional process. One of the most important theories of caregiving, the stress process theory developed by Leonard Pearlin and his colleagues, models this process (Pearlin et al., 1990). The stress process theory describes the presence of chronic long term stressors as leading

to individual variability in caregiver burden and response. This is largely due to the subjective meaning caregivers place on the presence of stressors (Pearlin et al., 1990; Aneshensel et al., 1995; Zarit, 2005). This theory can also be conceptualized using the developmental terms equifinality and multipotentiality (Gottlieb, 1996). Equifinality refers to a single outcome being derived from multiple pathways. For example, many different stressors and experiences can lead to the same result of caregiver burden. Additionally, it is important to recognize the impact of multipotentiality, whereby one starting point may lead to many outcomes (Gottlieb). For example, one stressor such as an individual needing assistance to dress can lead to a pronounced burden for one caregiver and absolutely no trouble or difficulty for another. These terms help to exemplify the potential heterogeneity in caregiver stress profiles.

Pearlin et al.'s (1990) stress theory also models the different types of stressors that may be associated with varying caregiver burden. One main stressor confronting the caregiver that is often overlooked is the complete transformation of a core, intimate relationship. When relatives have a chronic impairment, caregiving may become the entirety of the relationship as all assistance and care only move from the caregiver to the relative. According to role theory, both the change in role and loss of emotional closeness lead to caregiver burden (Pruchno & Rosenbaum, 2003). This role reversal and loss of intimacy may be one of the most challenging transformations with which a caregiver struggles. The social exchange/equity theory states that caregivers experience stress due to the costs and inequities in the caregiving role (Pruchno & Rosenbaum). Burden outcomes may also be affected by background variables such as characteristics of the caregiver's relationship with the patient, history of caregiving, socioeconomic status, and family/social network support (Pearlin et al., 1990; Pruchno & Rosenbaum, 2003). Therefore in addition to Pearlin et al.'s theory, the role theory, social

exchange theory, loss of intimacy, and background variables could provide additional explanations for the stressful impact of a relationship change.

Clearly a wide variety of stressors exist, and thus it is helpful to categorize them. Pearlin et al. (1990) differentiate caregiving stressors as primary and secondary. Primary stressors are direct results of a relative's illness and only get worse over time. They can include a decline in cognition (memory loss, recognition problems, communication difficulties), problematic behavior that causes constant watch by a caregiver, resistance to caregivers, and a need for assistance in activities of daily living (ADL) and instrumental activities of daily living (IADL). Behavior and emotional problems, often occurring during the assistance with ADLs, are usually experienced as highly stressful events by caregivers (Zarit & Zarit, 2008). Results of these stressors are often overload, burnout, and relational deprivation (Pearlin et al.).

Primary stressors may produce secondary stressors through stress proliferation, whereby stress can continue into areas of a caregivers' life outside of the caregiving process. Secondary stressors include the two dimensions of role and intra-psycho strains. Role strains may pose family difficulties such as igniting old and new family grievances, varying beliefs regarding a relative's impairment, arguments over the quality of care a patient is receiving, and issues pertaining to the acknowledgment a caregiver is receiving from his or her family for administering the care. Occupation strains are also a possibility due to the conflicting pressures of providing care and meeting work commitments, though work may also have positive and protective effects. Economic strains such as a reduction or decrease in household income, having to spend more resources related to care and treatment, and a general lack of financial resources are also considered to be secondary stressors. Finally, the informal role strains of social life limitations may occur due to the necessity of having to consistently be with the individual with

dementia (Pearlin et al., 1990). The second type of secondary stressors, intra-psycho strains, include problems with self concept, self-esteem, mastery, role captivity (not wanting to be in the caregiver role), loss of self (loss of identity as relative's individuality also fades), and competence (adequacy of performance). However, such stress doesn't stem wholly from a stressor, but is due in large part to the way a caregiver's life is structured and how the caregiver perceives the stressors which they face (Pearlin et al.).

Stressors can also be characterized as objective and subjective (Pearlin et al., 1990; Zarit, 2008). Primary objective stressors are the direct result of a patient's illness. However, primary subjective stressors, the extent to which problems are experienced as stressful, are stronger predictors of caregiver burnout (Aneshensel et al., 1995). Primary and secondary stressors may both be additionally classified as subjective stressors (Zarit). These stressors may lead to mental health and physical health outcomes such as depression, anxiety, irascibility, and cognitive problems, injuries, and the inability to participate in normal activities. An additional outcome may be the relinquishment of caregiver activities by giving the responsibilities to someone else or institutional placement. These outcomes may be mediated by social support and coping resources, among other interventions which will be discussed at the end of this paper (Pearlin et al.).

Despite the active stress process often resulting in burden, it is important to recognize the stress containment process, through which protective factors can limit the adverse impact of stressors (Zarit & Eggebeen, 2002). Not all responses to stressors are negative. It is possible for caregivers to grow both personally and emotionally from confronting their circumstances, thus obtaining a beneficial result (Pearlin et al.). These processes further affect the heterogeneous

caregiver profiles, such that all caregivers experience stressors differently with varying subjective meanings and containment processes at work.

Caregivers of people with LBD are subject to the same primary and secondary stressors as are confronted by all dementia caregivers. They also, however, encounter some unique stressors that may impact their burden in an unparalleled way. One of the primary hallmarks of LBD is the existence of significant behavioral and emotional problems (BEP) such as hallucinations, delusions, sleep problems, and irritability and passive traits (Tarawneh & Galvin, 2007). BEPs are typically viewed as the most stressful symptoms with which to deal by caregivers and are correlated with mental health problems and emotional suffering (Zarit & Zarit, 2008; Gaugler, Davey, Pearlin, & Zarit, 2000). Researchers have found that BEPs are more prominent in predicting burden, than cognitive impairment and ADL needs (Gaugler et al.).

Building on Aneshensel et al.'s (1995) research findings of behavioral problems' longitudinal impact on caregiver's role overload and role captivity, Gaugler et al. (2000) found that behavior problems predicted change in overload over a 3 year period. An increase in ADL assistance was also predictive of role overload, but when entered in a regression analysis with behavior problems, only behavioral problems remained significant. Thus, the prevalence of BEPS in LBD may lead to increased role strain and sense of captivity in caregivers over an extended period of time. These results also lend some support to the well known wear and tear hypothesis that continual behavior problems lead to emotional distress (Gaugler et al.). Furthermore, Bedard, Pedlar, Martin, Malott, and Stones (2000) reviewed a number of studies on caregiver burden and found that BEPs were the best predictor of burden in over half of the studies. Looking specifically at LBD, the present research will also examine the impact of BEPs on caregiver burden.

Other unique symptoms of LBD encountered by caregivers include parkinsonian and motor symptoms. These symptoms may require advanced behavioral management strategies and are an additive burden on top of progressive cognitive decline. Similarly, extrapyramidal signs or movement disorders have been found to lead to early nursing home placement and are a predictor of mortality (Williams, Xiong, Morris, & Galvin, 2006). Thus, these notable LBD motor and movement disabilities clearly have a large impact on caregiver stress and the ability to perform care duties as they are predictive of institutional placement.

Another unique stressor that caregivers of people with LBD face, as discussed earlier, is the difficulty obtaining an accurate diagnosis as well as receiving the concerned care they deserve. Doctors may be ambivalent to families' problems and not believe anything unique is wrong. This is partly because they are often not trained on how to make a dementia diagnosis. This problem is confounded by the difficult differentiation between LBD and other dementias (Zarit & Zarit, 2008). An early and accurate diagnosis is important so family caregivers are able to talk with the patient about their preferences for care before the dementia progresses (Zarit & Zarit). This may be a complicated situation for LBD caregivers if a correct diagnosis cannot be achieved.

The current study focuses specifically on burden and stress of caregivers for relatives with LBD. In this study, caregiver burden is assessed using a shortened version of the most widely used caregiver burden scale, the Zarit Burden Interview (ZBI/BI). Originally a 29 item scale, the most popular BI consists of a revised 22 items, though many shorter versions such as the one in the present study have been developed. The ZBI was developed specifically for use among family caregivers of individuals with dementia living in the community, though its use has expanded beyond this original intent (Zarit & Zarit, 1990). Though some researchers have

cited shortened versions of the ZBI as having less reliability than the 22 item version (Bachner & O'Rourke, 2007), O'Rourke and Tuokko's (2003) analysis of the BI found that there was no loss in predictive validity for the shortened version of the BI when predicting CES-D depression scores. They believe this result would be consistent with predicting burden, as burden is believed to coincide with depressive symptoms. While other scales of caregiver burden exist (see Lawton, Kleban, Moss, Rovine, & Glicksman, 1989), the ZBI is most widely used. Lawton et al.'s scale is longer and borrows a number of items from the ZBI. It is also missing an important element of the quality of relationship between caregiver and care recipient, which is emphasized in the ZBI. There is, however, considerable overlap between the two scales.

Previous studies using the BI conducted factor analyses to assess unique dimensions of caregiver burden and to develop shortened versions of the BI. The dimensions of role strain and personal strain have consistently been found. For example, Bedard, Molloy, Squire, Dubois, Lever, and O'Donnell (2001), used principal component analysis with varimax rotation to build a shorter version of the BI based on high factor loading and item-total correlation. Two of their 12 items are different from the shortened version used in this study (feelings of loss of privacy and loss of control over life were used whereas our study includes the overall burden item and fear of what the future holds for the relative). Consistent with previous literature (ex. Whitlatch, Zarit, & von Eye, 1991), their short scale was composed of two dimensions: role strain and personal strain (These factors explained 50% of the variance). In contrast, Ankri, Andrieu, Beaufils, Grand, and Henrard (2005), used a principal component analysis (PCA) to assess the multidimensionality of the BI. Using the 22 item version, three factors with an eigenvalue greater than 1 were found: social consequences, psychological burden, and feelings of guilt. As previous factor analyses on the BI have typically looked at caregivers of patients with

Alzheimer's Disease or a generalized dementia diagnosis, this study was pursued to determine if a data set of entirely LBD caregivers would produce similar or unique dimensions.

Stressors were examined as predictors of the dimensions of subjective caregiver burden. The stressors (independent variables) included help needed with activities of daily living (ADL), behavioral and psychological symptoms (BPS), difficulty finding physicians to evaluate and treat the patient, overall ratings of satisfaction with medical care, amount of help received and feeling isolated. Based on the previous literature review, it was hypothesized that distinguishing characteristics of LBD, specifically, the patient's behavior and emotional problems and problems associated with medical care, would be associated with higher levels of subjective burden.

Chapter 2. Method

Procedure

The present study used data from an internet survey conducted by the Lewy Body Dementia Association (LBDA). The survey was posted on the LBDA website for four months between December, 2007 and April, 2008. The website invited family members who were caring for someone with LBD to complete a survey about their experiences. The survey was advertised with a LBDA homepage announcement and a click-through to an internal webpage with more information on the survey. An advertisement was also put in an article on the LBDA newsletter cover page that directed people to the homepage and email reminders were sent to newsletter subscribers. Participants voluntarily clicked on the survey advertisement tab. A brief section of informed consent was provided before participants began the survey that highlighted the purpose of the study, its anonymity, and where to call for further assistance. The consent was implied when responses were submitted and thus no signatures were required. There was no financial incentive provided for completing the survey. The survey was accessible to any website visitors. The software, Survey Monkey, was used to create the on-line interview and to tally responses. Reports with final survey results will be posted on the LBDA website and in the mailed newsletter for participants and other website visitors to access.

Participants

A total of 984 people responded to the survey. Eligible participants for the current study were individuals with LBD or caregivers of individuals with LBD who were at least 18 years of age and who responded to the internet survey posted by the LBDA. For the present study, I included only the 737 people who indicated that they were currently involved in the care for someone with LBD. Thus, I excluded those respondents who themselves had LBD and those

whose relative was no longer living. Due to list-wise reduction, the number for some of the analyses was 492. The socio-demographic characteristics of the sample are typical of LBD caregivers and individuals with LBD. The majority of caregivers (75.8%) had the main responsibility for care or shared it equally with someone else. Most relatives (63.6 percent) were seen daily by their caregiver. The relatives had been diagnosed with LBD on average 6 years previously, but with a range of one to 22 years. See Table 1 for more details on sample characteristics.

Measures

Drawing upon the stress process model (Pearlin, Mullan, Semple, & Skaff, 1990), and characteristics of LBD, the survey was designed to study early symptoms, difficulties in the process of obtaining a diagnosis, care for the individual with LBD, and stress placed on the family. After the informed consent section, eligibility questions included asking whether the caregivers themselves had LBD, and whether their relative was living or deceased. Next social demographic questions about both the caregivers and the relative for whom they were caring were asked. Questions were given regarding sex of the relative and caregiver, marital status, who the relative lived with, frequency of visits, housing type, education level, exact relation of the respondent to the person with LBD, and who had the main responsibility of care. Responses for all demographic questions were given by checking the item that best applied to the caregiver from multiple choice lists.

Caregivers were asked three questions regarding the difficulty they had in finding a physician and coordinating physicians. The three items were averaged for one score because one of the items was not asked of all caregivers. These items had an alpha of .79. Relatives were also given a list of items on which to evaluate the diagnostic physician on a four point scale of

inadequate to excellent and the items were summed to obtain an overall evaluation of the doctor. The 11 items showed high reliability ($\alpha = .94$). These items included explaining the diagnosis, presenting treatment options, answering questions, telling where to find more information, and being sensitive to what the family and patient were going through. Furthermore, caregivers provided their overall evaluation of the help they received. Questions included items such as their satisfaction with the quality of help from paid providers and whether the cost of paid help was a problem for their family. These items, however, were largely unrelated and service use was low in this sample.

The caregiving experience section incorporates questions from Lawton and Brody's (1969) Personal Activities of Daily Living (PADLs) and Instrumental Activities of Daily Living (IADLs) measures. Mobility questions drawn from studies of the oldest old (e.g. Zarit, Johansson, & Berg, 1993) were also incorporated in this section. PADLs include items such as dressing, bathing, using the toilet, etc.; IADLs include shopping housework, transportation; and finally mobility items which include walking, getting around indoors, and getting in and out of the bed or chairs. Caregivers were asked whether or not their relative needed assistance with each item of PADL, IADL, and mobility and items were summed for a total assistance score. The 18 items showed high reliability ($\alpha = .89$).

The survey also asked about the relative's current behavioral and emotional problems (BEPs). Items were drawn from existing measures (e.g. Weiner, Teri, & Williams, 1996) and from a panel of experts on LBD. Examples of the behavioral and emotional problems questioned included anxiety, hallucinations, nightmares, depression, irritability, etc. Caregivers were asked whether or not their relative had any of these BEPs and the items were summed for a total BEP score. The 19 items have a high reliability ($\alpha = .82$).

Next caregiver stress was examined and the section incorporated a 12 item short version of the Zarit Burden Interview (ZBI/BI) which was used as the dependent measure in this study (Zarit & Zarit, 1990). The BI questioned participants on how stressed, afraid, uncertain, angry, strained, etc. they felt in regards to their care on a 5 point scale of never to frequently. For example, a question would ask how frequently they felt their social life had suffered because of caring for their relative or if they felt angry around their relative. An additional question on how burdened the caregiver felt (on a five point scale of none to extremely) was asked and added to the BI for a summed burden score based on the 12 items. The combined 12 items have high reliability ($\alpha = .86$). Following the BI, an additional question was asked on how much caregivers felt isolated due to their communities lack of awareness about LBD (on a 3 point scale of not at all to very much).

Data Analysis

The first step in data analysis was to examine means, distributions, and outliers in the data. Next, as the Burden Interview (BI) had been used extensively with the AD but not the LBD caregiver population, a principal axis factor analysis with varimax rotation was done to check for unique dimensions of LBD caregiver burden. Finally, multiple linear regressions were run in blocks to see what specific elements of LBD and LBD caregiving may predict the dimensions of caregiver burden as assessed with the BI. In the first model, the first block included demographic variables (relative sex and age, informant sex, age and education level). The second block included potential stressors (amount of ADL assistance needed, summed behavioral and emotional problems, difficulty finding a diagnostic doctor, overall evaluation of the doctor, isolation due to others lack of awareness about LBD, and overall evaluation of help received). Next for descriptive reasons, a second regression model examined individual BEPs

that are common among patients with LBD. These stressors were used in place of the summed BEP score in the model to assess their strength as predictors of caregiver burden.

Chapter 3. Results

Initial summary statistics were reviewed, and participants showed moderate to high levels of burden. When asked how burdened they felt, 37 percent of caregivers responded moderately, 26 percent very, and 12 percent extremely burdened. When the 12 item ZBI was summed, a mean score of 37.6 was found ($SD= 8.8$). This average is somewhat higher than what has been found in other studies on the BI with ranges between 20.59 and 33.58 (Bachner & O'Rourke, 2007; Bedard et al., 2001; Ankri et al., 2005). On average, individuals with LBD needed fundamental assistance in many areas ($M = 13.2, SD = 3.8$) and presented a number of BEPs ($M = 10.5, SD = 4.0$). Caregivers had a difficult time finding a diagnostic physician for their relative. For example, 67.3 percent of individuals with LBD saw 3 or more physicians to obtain a diagnosis. Caregivers reported feeling very isolated due to a lack of awareness about LBD among their surrounding community with 85.9 percent of caregivers feeling somewhat to very isolated. Caregivers were somewhat satisfied with the overall help they received, though service use was low.

Next, principal component analysis (PCA) with varimax rotation was conducted on the shortened version of the BI. Similar to Ankri et al.'s (2005) findings, three factors had an eigenvalue greater than 1 and together accounted for 65.5 percent of the total variance. The factors included role strain (consisting of 5 items such as feeling that your health has suffered, caring has interfered with your social life, an overall feeling of burden, etc.), personal strain (consisting of 3 items such as anger around your relative, feeling strained, etc.), and worry about performance (consisting of 3 items such as feeling that you could be doing a better job, uncertain about what to do, etc.). Consistent with previous studies, role strain accounted for the largest portion of variance (41.2%), followed by personal strain (15.4%), and worry about performance

(8.9%). Though two factor solutions have often been found (Bedard et al., 2001), these results further support the viability of a three factor solution.

We then used multiple regressions to examine predictors of the three burden factors. Predictors included social-demographic characteristics of the patient and caregiver in the first block, and overall evaluation of help received, overall evaluation of the diagnostic doctor, mean difficulty finding a diagnostic doctor, ADL disability, BEPs, and feeling isolated in the second block. All models were significant at the $p < .001$ level [Factor 1: $R^2 = .239$, $F(11, 476) = 13.25$; Factor 2: $R^2 = .181$, $F(11, 476) = 9.36$; Factor 3: $R^2 = .183$, $F(11, 477) = 9.46$]. We found that BEPs and feeling isolated were significantly associated with all three factors ($p < .001$). Total amount of assistance needed was a significant predictor for personal strain ($\beta = -.148$, $p < .001$) and worry about performance ($\beta = -.125$, $p < .01$). Age and gender contributed in different ways to the three factors. For example, informant's age was a significant predictor of role strain ($\beta = .154$, $p < .001$), relative's sex was a significant predictor of personal strain ($\beta = .112$, $p < .05$). Relative's age ($\beta = .102$, $p < .05$), relative's sex ($\beta = .145$, $p < .01$), and informant's age ($\beta = -.173$, $p < .001$) were significant predictors of worry about performance. The amount of help received had no significant associations with burden, but levels of service use were low. Mean difficulty finding a doctor and overall evaluation of the doctor were not significant predictors, though difficulty and dissatisfaction had been reported frequently by caregivers. See Table 2 for complete details on the three regressions.

Next, we substituted specific BEPs (depression, irritability, hallucinations, delusions, falling, and other sleep disturbances) that are particularly prevalent among individuals with LBD for the summed BEP score in the model to descriptively see if there were any differences. All models were significant at the $p < .001$ level [Factor 1: $R^2 = .240$, $F(16, 437) = 8.32$; Factor 2: $R^2 =$

.228, $F(16, 436) = 7.75$; Factor 3: $R^2 = .197$, $F(16, 437) = 6.44$]. Each model, however, was slightly different. Delusions ($\beta = .118$, $p < .05$) and sleep disturbances ($\beta = .099$, $p < .05$) were significant predictors of role strain, irritability ($\beta = .179$, $p < .001$) and delusions ($\beta = .084$, $p < .01$) were significant predictors of personal strain, and depression ($\beta = .186$, $p < .001$) was a significant predictor of worry about performance. See Table 3 for more details on this model.

Chapter 4. Discussion

With a large sample of LBD caregivers, this study takes a unique look at prominent LBD stressors and their relationship with caregiver burden. The three dimensions of burden found in this study further validate the work done by Ankri et al., (2005). Though we name the factors differently, they are essentially the same dimensions found by Ankri and colleagues. Furthermore, the variance each dimension accounted for is similar to what was found by Ankri et al., lending support to a three factor model of caregiver burden. Several notable findings have come out of this study that can further future research and lend scientific grounding to caregiver's difficulties. Isolation due to few people knowing about LBD was a highly significant predictor of all three dimensions of burden in the first model and the second model with specific BEP stressors. Clearly, awareness about LBD is a major problem that is related to the burden caregivers have. The LBDA and researchers alike can make awareness a priority through publicity, conference presentations, etc. It was surprising that caregivers' mean difficulty of finding a diagnostic doctor for their relative was only a significant predictor of personal strain in the second specific stressors model. Many caregivers expressed having great difficulty with finding a doctor. However, if caregivers are surrounded by a community unaware of LBD and don't know where to look for medical care, they will likely have greater difficulty finding a doctor to give them a correct diagnosis. In addition to the significance of assistance needed with ADLs and BEPs (both significant predictors in this study), which are typical stressors for all types of dementia, a lack of knowledge and awareness surrounding LBD may present a unique stressor for LBD caregivers to confront when searching for medical care for their relative.

These findings further highlight the importance of BEP in subjective burden of LBD caregivers. As seen through the factor analysis on the BI, the summed score of BEPs was a

significant predictor of role strain, personal strain, and worry about performance. Thus, though BEPs may be found as a common problem in other dementias such as AD (Bedard et al., 2000), BEPs may be especially pivotal in disorders like LBD which have elevated rates of these problems. When BEPs specific to a LBD diagnosis were entered in a regression, delusions, sleep disturbances, depression, and irritability were found to be significant predictors of dimensions of burden, while surprisingly falls and hallucinations were not. Hallucinations and falls are often mentioned by caregivers as stressful, and future research should investigate this discrepancy. Some limitations in this study should be noted. First, we did not have an AD comparison group. A comparison group would have been helpful to directly analyze results between types of dementia. However, the results have been compared with previous burden research which has largely been done on the AD or general dementia population. In addition, there was low service use among participants. The overall evaluation of help received was not a significant predictor of burden, but a relationship may have been found amongst a population with greater experience in this area. Future research may investigate this discrepancy.

These unique problems and difficulties resulting from LBD are significant for several reasons. First, there is no cure for LBD and thus the progression of symptoms can not be reversed or stopped. Therefore family caregivers are caring for a relative who will have LBD for the remainder of his or her life. Caregiving, thus, demands a significant commitment in time, resources, and emotional capacity. These commitments and difficulties have also been empirically associated with decreased health and well-being in caregivers (Aneshensel et al., 1995; Zarit, 2008; Zarit & Eggebeen, 2002).

Interventions for caregivers and other forms of help and treatment are available and can help them manage their care successfully and decrease burden. We know that for each

recognized case of LBD, there are two to three cases not detected (McKeith, 2009). However, doctors should be able to give an accurate diagnosis to dementia patients and provide adequate care for families' concerns. Thus, while the dementia may not be reversed or stopped, caregivers and their families can and should receive proper care. Strategies can be undertaken to help decrease their problems and provide supportive services to contain stress (Barclay, Cherry, & Mittman, 2005).

The findings from this study are reflective of the Stress Process Model (Pearlin et al., 1990; Aneshensel et al., 1995) and lend suggestions for further research and intervention work. As noted in the Stress Process Model, caregiver burden is largely context driven and not a straight pathway from a specific stressor to burden. The burden a caregiver experiences is affected by stressors such as caregiving background/history, social support, coping mechanisms, and external stressors such as work or family conflict (Pearlin et al.). Thus, the burden experienced by an LBD caregiver may be different from that of an Alzheimer's caregiver's due to varying contexts, unique stressors, medical recognition and care, etc. In working with caregiver stress through interventions, it is important that a targeted and individualized approach be used as burden is not a "one-size-fits-all" difficulty. Caregivers should be treated only for present risk factors for the most beneficial result (Zarit & Femia, 2008).

Researchers estimate that the prevalence of dementia is doubling every five years and over the next 50 years, AD and LBD will likely reach 15 million cases (Gerpen, 2007). Currently, there are 800,000 people with LBD in the United States alone (McKeith, 2009). This presents an urgent situation for current dementia, caregiving, and intervention researchers as millions of families will be involved in future dementia care. Lewy Body dementia presents with progressive cognitive decline similar to other types of dementia, but has unique features such as

parkinsonian symptoms, visual hallucinations, and varying concentration and attention (Tarawneh & Galvin, 2007; McKeith et al., 2004). While some differential symptoms are known, there is considerable overlap in symptoms between LBD and AD leading to difficulty in receiving an accurate diagnosis from a physician. Furthermore, the primary symptoms of dementia along with the prominent behavioral and emotional problems of LBD are notable for their association with stress and burden in dementia caregivers. Caregiver burden is a multidimensional process that can be caused by many different stressors which lead to a variety of outcomes (Pearlin, Mullan, Semple, & Skaff, 1990). Due to the heterogeneity of risk profiles, a targeted and individualized adaptive intervention is advised to decrease caregiver burden.

More research does need to be pursued, however, on LBD and its distinguishing features from AD, PDD, and other dementias. While there is no existing cure for LBD and the neuropathology is still unclear, work should not cease in striving for these goals. A biological diagnostic marker and greater understanding of underlying pathology would both be major advances that could have a significant impact on individuals with LBD and caregivers alike. For now, however, researchers can only work to gain a better understanding of LBD and intervene in ways to make life more manageable for those with LBD and their caregivers.

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Appendix

Tables

Table 1.

Sample Characteristics

	Caregiver	Care Recipient
Gender (% female)	87	38
Age (mean, SD)	56.3, 11.8	75.1, 8.5
Marital Status (%)		
Married		68.6
Widowed		23.6
Divorced/separated		5.0
Single		2.8
Living arrangement (%)		
With caregiver		49.8
Long term care		28.2
With another relative		16.5
Live alone		5.5
Relationship to care recipient (%)		
Wife	35.8	
Husband	6.2	
Daughter/daughter in-law	44.4	

Son/son in-law	5.9
Other	6.3
Educational achievement (%)	
Grade school	0.6
High school	24.8
College	44.3
Post graduate school	30.4

Table 2.

Factor Loadings for the ZBI

Items	Role Strain	Personal Strain	Worry about Performance
Not enough time for yourself	.801	.229	.031
Interference with social life	.756	.227	.001
Stress between care and Personal responsibilities	.743	.220	.226
How burdened	.685	.324	.141
Health has suffered	.656	.239	.124
Feel strained	.245	.735	.230
Angry around relative	.277	.683	.132
Relative affects relationship with family and friends	.366	.563	.132
Feel you should do more	-.047	.106	.913
Could be doing a better job	.032	.128	.679
Uncertain about what to do	.274	.345	.426
Afraid of relative's future	.212	.089	.352

Table 3.

Regression of 3 Dimensions of Burden on Stressors

Variables	Role Strain			Personal Strain			Worry about Performance		
	B	SE _B	β	B	SE _B	β	B	SE _B	β
Relative age	.007	.026	.012	.011	.016	.032	.034*	.016	.102
Relative sex	.780	.455	.079	.683*	.291	.112	.850**	.281	.145
Informant sex	.879	.662	.058	.293	.423	.031	-.322	.409	-.035
Informant age	.062***	.018	.154	.013	.012	.050	-.042***	.011	-.173
Informant Educ.	.081	.260	.013	.090	.166	.023	.171	.160	.046
ADL assistance	-.025	.025	-.042	-.054***	.016	-.148	-.044**	.015	-.125
BEPs	.281***	.050	.241	.176***	.032	.244	.133***	.031	.190
Evaluation of Doctor	-.009	.022	-.018	-.009	.014	-.030	-.021	.014	-.069
Difficulty finding Doctor	.510	.336	.070	.407	.215	.090	.121	.208	.028
Isolation	2.354***	.306	.337	.942***	.195	.219	.689***	.189	.165
Evaluation of help received	.079	.054	.061	-.003	.034	-.004	-.006	.033	-.008

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 4.

Regression of 3 Dimensions of Burden on LBD Specific Stressors

Variables	Role Strain			Personal Strain			Worry about Performance		
	B	SE _B	β	B	SE _B	β	B	SE _B	β
Relative age	.009	.027	.015	.003	.017	.009	.024	.017	.171
Relative sex	.547	.483	.056	.518	.301	.086	.982***	.297	.168
Informant sex	.936	.701	.061	.300	.436	.031	-.248	.431	-.027
Informant age	.064***	.020	.155	.022	.012	.084	-.039***	.012	-.157
Informant Educ.	.173	.275	.028	.170	.171	.044	.145	.169	.039
ADL assistance	-.018	.026	-.030	-.053***	.016	-.144	-.034*	.016	-.096
Evaluation of Doctor	-.008	.023	-.015	-.015	.015	-.049	-.022	.014	-.073
Difficulty finding Doctor	.682	.353	.094	.571**	.219	.128	.144	.217	.033
Isolation	2.398***	.316	.345	.988***	.196	.231	.638***	.194	.154
Evaluation of Help received	.055	.057	.043	-.013	.035	-.016	-.012	.035	-.016
Depression	.382	.467	.038	.297	.291	.048	1.112***	.287	.186
Irritability	.444	.479	.045	1.095***	.299	.179	.066	.294	.011
Hallucinations	.112	.532	.011	-.469	.332	-.077	.051	.327	.009
Delusions	1.127*	.512	.118	.893**	.319	.151	.258	.315	.045
Falling	.824	.439	.086	.273	.274	.046	-.018	.270	-.003
Sleep Disturbance	.928*	.447	.099	.487	.278	.084	.412	.275	.073

* $p < .05$. ** $p < .01$. *** $p < .001$.