

Stress and Burden Among Caregivers of Patients with Lewy Body Dementia

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Purpose: Patients with Lewy body dementia (LBD) may present a unique set of symptoms and challenges to family caregivers compared with other types of dementia. Prominent difficulties include motor impairment, activities of daily living (ADLs) disability, recurrent behavioral and emotional problems (BEPs), and diagnostic difficulties. These problems are likely to affect caregivers' subjective burden. **Design and Methods:** The present study used data from an Internet survey conducted by the Lewy Body Dementia Association. Respondents were 611 people who indicated that 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. **Results:** A factor analysis revealed 3 dimensions of burden: role strain, personal strain, and worry about performance. Multiple regressions were used to examine predictors of these dimensions. BEPs, ADL disability, isolation, caregiver age, and patient gender were significant predictors of specific factors. Falls, formal service use, difficulty finding a physician, and evaluation of the physician had no significant associations with burden. **Implications:** These findings highlight burden experiences by caregivers of patients with LBD and the impact of BEPs, ADL assistance, and awareness about LBD on subjective burden.

Key Words: Lewy body dementia, Caregiving, Burden, Behavioral and emotional problems

Lewy body dementia (LBD) is the second most prevalent type of dementia in the United States, accounting for 10%–20% of cases (Gerpen, 2007; Tarawneh & Galvin, 2007). It is often confused with and misdiagnosed as Alzheimer's disease (AD; Gerpen; Tarawneh & Galvin). LBD, however, displays unique symptoms and presents many discrete difficulties for patients and caregivers, apart from those presented by AD, including recurrent visual hallucinations, spontaneous alterations in concentration and attention, parkinsonian symptoms, and rapid eye movement sleep behavior disorders (RBD; Gerpen; Tarawneh & Galvin). Caregivers must assist with the behavioral and emotional symptoms that accompany LBD, which are more pronounced than in AD, and with motor impairment, falls, and higher levels of disability than with other types of dementia (Ricci et al., 2009). These differences are most pronounced early in the disease process, and then as dementia worsens, there is more overlap between LBD and other dementias in behavioral and emotional symptoms (Devanand et al., 1997; Stavitsky et al., 2006). LBD caregivers also struggle through the challenge of obtaining an accurate diagnosis and adequate medical care for their relative (Galvin et al., in press). As the prevalence of all causes of dementia is doubling every 5 years, research on LBD and caregiving issues will prove vital for understanding the challenges that patients and caregivers will face (Gerpen). This

article examines dimensions of subjective burden of caregivers of patients with LBD using data from a unique Internet survey. We consider both those stressors that are commonly identified by caregivers of people with dementia as well as those more pronounced in LBD.

Defining Features and Symptoms of LBD

LBD, like all dementias, is characterized by a progressive reduction in cognitive functioning, including language, memory, judgment, attention, 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: spontaneous parkinsonian symptoms, varying attention and concentration termed cognitive fluctuations, and repeated visual hallucinations (McKeith et al., 2004; Tarawneh & Galvin). At least two parkinsonian symptoms should be present for this core feature: rest tremor (at a frequency of 3–5 Hz), bradykinesia (slowness initiating and performing repetitive motor tasks and a reduction of automatic movements, such as absent or diminished facial expression, excessive drooling, soft voice, and decreased blinking), rigidity (muscular stiffness often with a cogwheel character), and postural instability (impairment of the righting reflex that allows recovery after the center of gravity loses balance—this impairment often leads to falling; Gerpen). Cognitive fluctuations are spontaneous alterations in levels of concentration and attention, frequent staring spells, increased daytime somnolence, and disorganized or illogical train of thought (Ferman et al., 2004). Visual hallucinations are frequently well-formed images, such as small people or animals (Gerpen).

Distinguishing Features of LBD

LBD can be difficult to distinguish from AD due to the presence of overlapping symptoms and the temporal sequence of events. One reason for the overlap is that as many as two thirds of people with LBD also have AD pathology and the core features, while more common in LBD, also occur in AD (Stewart, 2007). LBD differs from AD in that clinical features such as visual hallucinations, extrapyramidal symptoms, gait abnormalities, autonomic dysfunction, RBD, passive personality traits frequently occur early in the disease course and once present tend to persist (Tarawneh & Galvin,

2007). In addition, LBD is more likely to have more prominent visuospatial and functional impairment than AD at the time of diagnosis (McKeith et al., 2004; Tarawneh & Galvin).

Despite these differences and consensus diagnostic criteria for LBD, diagnosis for many patients is often delayed (Galvin et al., in press). Physicians may have limited training on how to make a diagnosis of LBD or in managing the symptoms associated with it (Zarit & Zarit, 2008). Furthermore, the *Diagnostic and Statistical Manual (DSM-IV)*, the most widely used mental health diagnostic guidance resource, offers information that is highly reliable for identifying AD but not for other types of dementia (Robillard, 2007). Although many community services are available for caregivers, such as support groups, home health aides, or care managers, providers may have little knowledge or understanding of LBD (Lewy Body Dementia Association [LBDA], 2008). The difficulties that caregivers experience in obtaining an accurate diagnosis and understanding of their relative's condition may contribute to overall feelings of burden.

Subjective Burden

The current study focuses on subjective burden and stress of caregivers of LBD patients. Subjective burden refers to how caregivers appraise the emotional, physical, and social challenges they experience. Guided by stress models of caregiving (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit, 2008), we view subjective burden as the outcome of the interplay of stressors and resources that caregivers might use to manage those stressors. Subjective burden would be expected to increase as stressors such as behavior problems and activity of daily living (ADL) deficits increase. In turn, resources such as social support might be associated with lower subjective burden. Finally, characteristics of the caregiver and patient may affect how the caregiver perceives stressors and their impact on his or her life. Burden is a central concept in the stress process because how caregivers subjectively evaluate their circumstances will influence the decisions they make about providing care, seeking assistance, and whether they will continue in the caregiving role (Zarit, 1989, 2008).

One focus of previous research has been identifying specific dimensions of subjective burden. Using factor analyses of the Zarit Burden Interview (ZBI; Zarit, 2010), researchers have consistently

identified two dimensions: role strain and personal strain (Bédard et al., 2001). Three factors have also been reported. For example, Ankri, Andrieu, Beaufile, Grand, and Henrard (2005) found dimensions that they labeled social consequences, psychological burden, and feelings of guilt. The dimensions of social consequences and psychological burden conceptually represent the same constructs as role strain and personal strain and include similar items. As previous studies have examined caregiver burden in AD or undifferentiated dementia, this study specifically tests whether similar dimensions of subjective burden are found for caregivers of LBD and what predicts these dimensions.

Caregiving Stressors

Although stress process models describe a general relation of stressors to outcomes such as subjective burden, the types of stressors are likely to vary across different caregiving situations. Caregivers of people with LBD experience some stressors found in other caregiving situations but also face some unique challenges that are more common in LBD.

Behavioral and emotional problems (BEPs) are typically viewed by dementia caregivers as the most stressful symptoms with which to deal and are correlated with mental health problems and emotional suffering (Aneshensel et al., 1995; Gaugler, Davey, Pearlin, & Zarit, 2000; Zarit & Zarit, 2008). Researchers have found that BEPs are more prominent in predicting burden than cognitive impairment of the patient and ADL needs (Gaugler et al.). Aneshensel and colleagues confirmed associations between BEPs and caregivers' subjective appraisals of stress using both cross-sectional and longitudinal analyses. BEPs are upsetting because they are unpredictable, difficult to manage, and place great time demands on caregivers (Aneshensel et al., 1995; Zarit & Zarit, 2008). Similarly, Gaugler and colleagues found that behavior problems predicted a small increase in caregiver overload over a 3-year period. Thus, the prevalence of BEPs in LBD may lead to increased subjective strain or burden in caregivers over an extended period of time. These results lend support to the well-known "wear and tear" hypothesis that continual exposure to stressors leads to emotional distress (Gaugler et al.).

As noted, BEPs are more common early in the disease process of LBD than in AD. In addition, some problems (hallucinations, delusions, and irri-

tability) probably remain more frequent over time. Thus, we consider both BEPs that are common across different types of dementia as well as those problems that are more frequent in LBD.

Another hallmark of LBD, motor and movement disabilities, clearly has a large impact on caregivers and contribute to early nursing home placement (Williams, Xiong, Morris, & Galvin, 2006). These symptoms are difficult to manage in their own right and lead to other problems, such as falls and increased disability in ADLs (McKeith et al., 2006). Patients may also struggle or resist when the caregiver tries to help, adding to the stressfulness of the situation (Aneshensel et al., 1995). Resistance to help may be especially prominent in LBD patients (Gaugler et al., 2000).

Another potential stressor specific to LBD is that caregivers may feel isolated due to the lack of awareness about LBD not only by medical professionals but also in the surrounding community. AD has come to be viewed as synonymous with dementia, and so in anecdotal reports, LBD caregivers have said they find a lack of empathy or understanding from their friends and family and have difficulty locating other people dealing with similar issues (LBDA, 2008). No prior research, however, has examined this issue.

Hypotheses

In this study, predictors of subjective burden for caregivers of LBD patients are examined. We consider if disease- and caregiving-related issues in LBD, which are more distinguishing in earlier stages of the disease (Devanand et al., 1997; Stavitsky et al., 2006; e.g., LBD-specific BEPs, difficulty obtaining a diagnosis, perceived adequacy of ongoing medical care, isolation due to a lack of community awareness of LBD, and evaluation of help received), add to explanations of subjective burden over and above typical stressors found in other types of dementia (ADLs; general BEPs, such as memory problems, anxiety, aggression, apathy, etc.). As a first step, burden levels in LBD caregivers are examined. Next, we consider the structure of subjective burden and whether similar factors are obtained as with other types of dementias. Next, predictors of the dimensions of burden are considered. We hypothesize that distinguishing characteristics of LBD, specifically, the patient's BEPs, falls, ADLs, isolation due to others' lack of awareness about LBD, and problems associated with medical care, are associated with higher levels

of subjective burden over and above the effects of typical stressors found in other types of dementia.

Methods

Procedure

The present study uses data from a web-based survey conducted by the LBDA. The survey was posted on the LBDA website for 4 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 in the LBDA newsletter that directed people to the homepage, and e-mail reminders were sent to newsletter subscribers. Caregivers voluntarily clicked on the survey tab. Before caregivers began the survey, they were presented with text that highlighted the purpose of the study, their right and protection as study participants, and where to call for further assistance. 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.

Participants

A total of 984 people responded to the survey. Eligibility for the current study was limited to those respondents who indicated that they were currently involved in the care for someone with LBD. We did not include respondents in the present analysis who had previously been caregivers because of the concern that retrospective reports of experiences might be unreliable. After selecting for the eligible cases, a total of 611 current caregivers were used in the study. The socio-demographic characteristics of the sample are typical of LBD caregivers and patients with LBD (Table 1). Average age was 56 years for caregivers and 75 years for patients. Women comprised 87% of caregivers and 39% of patients. The majority of caregivers (75.8%) had the main responsibility for care or shared it equally with someone else. Most patients (63.6%) were seen daily by their caregiver. The patients had been diagnosed with LBD on average 6 years prior to completion of the survey (range 1–22 years).

Table 1. Sample Characteristics

	Caregiver care	Recipient
Gender (% female)	87	38
Age in years, 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	43.0	
Son/son-in-law	5.5	
Other	9.3	
Educational achievement (%)		
Grade school	0.6	
High school	24.8	
College	44.3	
Post graduate school	30.4	

Note: Total percentages may vary slightly from 100 due to rounding errors.

Measures

Socio-demographic.—The survey obtained information about demographic characteristics of the LBD patient and caregiver, level of disability, social isolation, and subjective burden. Respondents were asked social characteristics of themselves and their patient with LBD. Caregivers provided their gender, age, and education level. Caregivers also provided the patients' gender and age.

Behavioral and Emotional Problems.—Respondents completed a series of questions about the LBD patients' current BEPs. Seventeen items were drawn from existing measures (e.g., Braungart, Zarit, Femia, Hofer, & Stephens, 2006; Weiner, Teri, & Williams, 1996) and from a panel of experts on LBD. Eleven items were considered general to dementia (e.g., memory problems, judgment problems, hitting, shouting, and inappropriate sexual behaviors) and 6 were considered more specific to LBD (depression, irritability, hallucinations, delusions, sleep disturbances, nightmares, and unusual sleep movements). Caregivers were asked whether or not their relative had any of these BEPs within the last week. Internal alpha reliabilities

were .67 for the LBD-specific BEPs and .68 for general BEPs. The low alphas reflect that the items were dichotomous.

ADLs and Mobility.—The amount of assistance that LBD patients needed was assessed with Lawton and Brody's (1969) personal activities of daily living (PADLs) and instrumental activities of daily living (IADLs) measures and with a scale measuring mobility (Zarit, Johansson, & Berg, 1993). PADL items include dressing, bathing, using the toilet, etc.; IADLs include shopping, housework, transportation; and mobility items included 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. The items were summed for a total assistance score. The 18 items showed high reliability ($\alpha = .89$).

Isolation.—To measure isolation, caregivers responded to a single item on whether the caregiver felt isolated because few people knew about LBD. Responses were on a 3-point scale ranging from *not at all* to *very much*.

Difficulty Finding and Evaluation of a Physician.—Caregivers were asked three questions regarding the difficulty they had in finding a physician and coordinating medical care for the LBD patient. The three items were averaged for one score because the item on difficulty finding a physician to treat LBD was not asked of all caregivers as some caregivers had the same diagnostic and treating physician. These items had an alpha of .79. An 11-item scale was created for caregivers to evaluate the physician who made the diagnosis. For each item, caregivers rated the physicians' performance on a 4-point scale, which ranged from *inadequate* to *excellent*. 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.

Overall Evaluation of Help Received.—Caregivers provided their overall evaluation of the help they received. Five questions were asked regarding satisfaction with quality and amount of help received from paid providers. For each item, caregivers assessed their satisfaction on a 4-point scale

from *strongly disagree* to *strongly agree*. These items had an alpha of .76. 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.

Burden.—A 12-item short version of the ZBI was used as the dependent measure in this study (Zarit, 2010). The ZBI questions caregivers' experiences in terms of emotional, physical, and social strains or difficulties that result from their role as a caregiver. Items include topics such as feeling one's health has suffered, feeling that care affects relationship with family and friends, and how burdened one feels. Caregivers responded by indicating how often they experience each item, with responses scored on a 5-point scale ranging from *never* to *frequently*. Higher burden is indicated by a higher score. The combined 12 items have high reliability ($\alpha = .86$). Some researchers, however, have cited shortened versions of the ZBI as having less reliability than the 22-item version (Bachner & O'Rourke, 2007). For example, Bachner and O'Rourke found that studies using the 22-item scale had an average alpha level of .90 and studies using abridged versions had an average alpha of .81.

Data Analysis

SPSS version 17 was used for analyses. The first step in data analysis was to examine means, distributions, and outliers in the data. Next, a principal axis factor analysis with varimax rotation was done to determine the factor structure of the ZBI. Finally, a multiple linear regression was run to identify the relation of stressors and resources to dimensions of caregiver burden as assessed with the ZBI. As an initial step, we considered which covariates (patient's and caregiver's gender and age and caregiver's education) had a significant association with the dimensions of burden. To reduce the possibility of spurious results, we did not include covariates that did not have a significant zero-order association with the dimensions of subjective burden (Elashoff, 1969). The covariates that had significant associations, patient gender, and caregiver age were then entered in a block into the regression. A second block of potential stressors was then added, including the amount of ADL assistance, general and LBD-specific BEPs, falls, difficulty finding a diagnostic physician, overall evaluation of the physician, caregivers' feelings of isolation, and evaluation of help received.

Results

Caregiver Reports of Burden

Sample characteristics are presented in Table 1. Caregivers showed moderate to high levels of burden. When asked how burdened they felt, 9% of caregivers responded not at all, 18% slightly, 36% moderately, 26% very, and 12% extremely burdened. When the 12-item ZBI was summed, a mean total score of 25.6 (highest possible score was 48) was found ($SD = 8.8$). A mean item score was calculated so the shortened version could be compared with previous studies using 22 and 29 item versions of the ZBI. The mean item score was 2.133, which is higher than those reported in prior research on AD or undifferentiated dementia that ranged between 0.999 and 1.526 (Ankri et al., 2005; Bachner & O'Rourke, 2007; Bédard et al., 2001). Turning to ADLs and mobility, on average, patients with LBD needed fundamental assistance in many areas ($M = 13.2$ out of 18 total, $SD = 3.8$) and had numerous BEPs ($M = 9.7$ out of 17 total, $SD = 3.6$). This level of ADL and mobility disability is comparable to other community samples of people with dementia (Femia, Zarit, Stephens, & Greene, 2007; Zarit, Stephens, Townsend, & Greene, 1998). Caregivers reported they had a difficult time finding a diagnostic physician for their relative. For example, 67.3% of patients with LBD saw three or more physicians to obtain a diagnosis (Galvin et al., in press). The majority of caregivers reported feeling isolated due to a lack of awareness about LBD among their surrounding community with 85.9% of caregivers feeling somewhat to very isolated. Caregivers were somewhat satisfied with the overall help they received, though service use was low.

Exploratory Factor Analysis of LBD Caregiver Burden

Next, principal component analysis with varimax rotation was conducted on the shortened version of the ZBI. Similar to the findings of Ankri and colleagues (2005), three factors had an eigenvalue greater than 1 and together accounted for 55.2% of the total variance. The factors included role strain (consisting of five 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 three items, such as anger around your relative, feeling strained, etc.), and worry about performance (consisting of

Table 2. Factor Loadings for the Zarit Burden Interview

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

Note: Items' factor loadings are in bold.

four items, such as feeling that you could be doing a better job, uncertain about what to do, etc.).

One item, "afraid of the future for your relative," had a low loading on the final varimax solution. Examination of the item indicated a ceiling effect as most caregiver's strongly endorsed it. When this item was dropped, and a principal axis factor analysis was run again, the solution dropped to two factors: role strain and personal strain. However, as the third factor had practical significance, we decided to run maximum likelihood analyses forcing a three- and two-factor solution and comparing the chi-square goodness-of-fit test. Though both tests for the forced two- and three-factor solutions were significant ($p < .001$), which is not an optimal fit, the chi-square for the three-factor solution was more than 200 points lower ($\chi^2 = 155.9$, $df = 33$) than the chi-square for the two-factor solution ($\chi^2 = 384.6$, $df = 43$). This result shows that the three-factor solution has a better fit for the present model. Therefore, subsequent analyses use the three-factor solution and include the item "afraid about the future for your relative" on the worry about performance factor. See Table 2 for complete factor loadings.

Consistent with previous studies, role strain accounted for the largest portion of variance (25.5%), followed by personal strain (14.9%) and worry about performance (14.8%). Furthermore, worry about performance was associated with the greatest amount of stress, receiving a mean endorsement of 3.404 per item. Role strain received a mean endorsement of 3.326 per item, and personal strain received a mean endorsement of 2.468 per

Table 3. Regression of Three Dimensions of Burden on Stressors

Variables	Role strain		Personal strain		Worry about performance	
	SE _B	β	SE _B	β	SE _B	β
Patient gender	.411	.021	.273	.066	.264	.183***
Caregiver age	.017	.149***	.011	.028	.011	-.163***
BEPs: LBD	.142	.086	.094	.156**	.092	.072
BEPs: general	.115	.114*	.076	.087	.074	.136*
Falls	.428	.000	.283	-.032	.274	-.010
ADL assistance	.058	.168***	.038	.015	.037	-.061
Isolation	.303	.349***	.201	.218***	.195	.158***
Evaluation of physician	.022	-.026	.015	-.054	.014	-.064
Difficulty finding physician	.340	.053	.225	.090	.219	.034
Evaluation of help received	.053	.069	.035	.015	.034	-.019
R ²	.263		.151		.160	
R ² change	.258***		.148***		.086***	

Notes: ADL = activity of daily living; BEP = behavioral and emotional problem; LBD = Lewy body dementia.
* $p < .05$. ** $p < .01$. *** $p < .001$.

item. Paired t -tests were run, and the three means were significantly different from one another at a significance level of $p < .001$.

Relationship of Stressors and Resources to Dimensions of Caregiver Burden

Next, multiple regressions were run to examine predictors of the three burden factors. Predictors included socio-demographic characteristics of the patient and caregiver in the first block, and BEPs (general and LBD specific), falls, ADL disability, feeling isolated, overall evaluation of the diagnostic physician, mean difficulty finding a diagnostic physician, and overall evaluation of help received in the second block. All models were significant at the $p < .001$ level [role strain: $R^2 = .263$, $F(10, 457) = 15.92$; personal strain: $R^2 = .151$, $F(10, 457) = 7.96$; worry about performance: $R^2 = .160$, $F(10, 458) = 8.56$]. Age and gender contributed in different ways to the three factors. Caregiver's age ($\beta = .149$, $p < .001$) was a significant predictor of role strain and worry about performance ($\beta = -.163$, $p < .001$). Patient's gender ($\beta = .183$, $p < .001$) was a significant predictor of worry about performance. We found that feeling isolated was significantly associated with all three factors ($p < .001$). BEPs specific to LBD were significantly associated with personal strain ($\beta = .156$, $p < .01$). BEPs more common to all dementia types were a significant predictor of role strain ($\beta = .114$, $p < .05$) and worry about performance ($\beta = .136$, $p < .05$). Total amount of assistance needed was a significant predictor for role strain ($\beta = .168$, $p < .001$). The eval-

uation of help received, evaluation of the doctor, difficulty finding a doctor, and falls had no significant associations with burden. See Table 3 for complete details on the three regressions.

Discussion

With a large sample of LBD caregivers, this study takes a unique look at prominent LBD stressors and their relationship with caregiver burden. LBD caregivers reported high levels of burden, and burden was predicted in part by unique stressors faced by LBD caregivers. Although a direct comparison with caregivers of people with other types of dementia was not possible, the findings indicate higher scores for subjective burden than typically reported in caregivers of AD or mixed diagnostic groups (Ankri et al., 2005; Bachner & O'Rourke, 2007; Bédard et al., 2001). As burden is associated with decreased well-being, depression, anger, anxiety, and health and medical problems, it is important that LBD caregivers are able to receive adequate help and services they need (Aneshensel et al., 1995; Zarit, 2008; Zarit & Eggebeen, 2002).

The three dimensions of burden found in this study, role strain, personal strain, and worry about performance, and the variance accounted for each dimension are consistent with the work of Ankri and colleagues (2005) lending support to a three-factor model of caregiver burden. It is also important to note that we found worry about performance, a third factor not typically found in ZBI factor analyses, to be endorsed the most strongly by LBD caregivers. This finding may reflect the fact that

there is not as much information available about care of people with LBD compared with AD or other forms of dementia. In particular, caregivers may feel isolated and not be able to find supportive medical professionals or community services. Thus, they may be more concerned than other caregivers about how well they are doing. Spreading awareness about LBD may be the most essential first step in decreasing worry about performance, and perhaps also other dimensions of burden.

Several notable findings, in regard to predictors of burden, have come out of this study that can illuminate the difficulties that caregivers experience. First, the structure of burden was similar to studies using caregivers of AD or mixed dementia patients (Ankri et al., 2005). BEPs most frequently seen in LBD and distinct from other dementias, particularly until later stages of the disease (delusions, depression, sleep disturbances, irritability, and hallucinations), made a major contribution to personal strain, where general BEPs did not. However, BEPs that are common in all types of dementia significantly predicted role strain and worry about performance. Though BEPs in general play a similar role in other dementias such as AD (Bédard, Pedlar, Martin, Malott, & Stones, 2000), BEPs may be especially pivotal in LBD where patients are likely to have elevated rates of these problems (Galvin et al., in press). Falling, however, a significant mobility challenge faced by individuals with LBD was not a significant predictor of any burden dimension. Future research should investigate this discrepancy.

Assistance with ADLs was a significant predictor of role strain. As consistent with previous research (Gaugler et al., 2000; Pearlin et al., 1990; Zarit & Zarit, 2008), BEPs are often viewed as main source of burden, but ADLs also play an important role in the stress process. Patients with LBD have many unique ADL and mobility challenges (McKeith et al., 2006), and so assisting LBD patients may require considerable time and physical effort, leading to increased levels of burden.

Another factor that was found to be highly associated with subjective burden was isolation. We included this item specifically because there is little public recognition of LBD, and so caregivers may feel alone and isolated. In the past before extensive public education about AD, caregivers of people with that disorder often expressed that they felt alone and isolated in their situation (Zarit & Zarit, 1982). Increased public education about all the forms of dementia may be helpful in reducing

stigma and helping connect people more quickly to networks of other individuals coping with similar problems.

As with limited awareness among the general public, physicians are less familiar with diagnosis and treatment of LBD than with AD and other forms of dementia. Although our findings did not show that difficulty finding a physician to make the initial diagnosis or evaluation of the physician were associated with burden, dissatisfaction and difficulty were reported in the sample. It may be that these factors were initial contributors to burden but do not play a lasting role in the burden process as caregivers are now dealing with more immediate issues, such as BEPs and ADLs.

Prior work has often found that social support, particularly use of formal services, can help reduce burden among family caregivers (Aneshensel et al., 1995). We did not find a relation between caregivers' evaluation of the help they received and burden. This finding may largely be due to low rates of service use in the sample. Low service use is actually common in samples of caregivers, particularly when the sample is drawn from the general population, rather than from people seeking service (e.g., Aneshensel et al.). The very low rates may also indicate that LBD caregivers are less likely to connect to a network of services than caregivers with more typical dementia diagnoses. Getting adequate and timely assistance has long been noted as a problem for family caregivers (Beeber, Thorpe, & Clipp, 2008) and that is no different in the current sample.

In terms of socio-demographic variables, being an older caregiver was associated with more role strain and being a younger caregiver was associated with more worry about performance. Age of a caregiver, however, is confounded with kin relationship, with spouses who are providing care likely to be older than adult children. For example, research has found that older age was associated with less burden in Black caregivers due to the closeness of the spouse relationship (Lawton, Rajagopal, Brody, & Kleban, 1992). This could explain why caregiving affects older adults' role strain but not personal strain or worry about performance. Research has also found that adult child caregivers experience more distress because they may have not intended on taking on the care role (Biegel, Sales, & Schulz, 1991). Younger adults who may be working or have families of their own may then be more likely to worry about how well they are fulfilling this new role. In addition, caring

for a female patient was associated with more worry about performance for the caregivers. Though much research has focused on gender of the caregiver, with women frequently showing more psychiatric morbidity than male caregivers (Yee & Schulz, 2000), little previous work has taken into account potential implications of patient gender.

Taken together, the findings from this study provide support for the Stress Process Model of Caregiving (Aneshensel et al., 1995; Pearlin et al., 1990). As in other care situations, stressors and caregiver outcomes are best understood as multidimensional. Stressors are additive and may have a different impact depending on the outcome being considered. As noted in the Stress Process Model, caregiver burden is largely context driven and not a straight pathway from a specific stressor to burden. Thus, the sources of burden of an LBD caregiver may be different from that of AD caregivers due to varying context and characteristics of the two disorders.

Some limitations in this study should be noted. First, we did not have an AD or general dementia comparison group to make direct comparisons on whether sources of burden are similar or different across dementias. However, the results have been compared with previous research, which has largely examined samples of caregivers assisting someone with AD or where a nonspecific dementia diagnosis was used. Furthermore, we do not have any information about the number of hours per week that a caregiver provides care. This would have been helpful to know in predicting caregiver burden. Another limitation is that the sample consisted of people willing to take an Internet survey. As such, the sample may be somewhat better educated and younger than the population of LBD caregivers and probably also better informed to start with. Given that likely bias, it is all the more telling that respondents reported difficulty finding information and resources about LBD. One advantage of this sampling approach is that it would have been difficult to obtain a large and representative sample of LBD caregivers through usual recruitment approaches. The web approach opens up the possibility of identifying groups of caregivers of people with diagnoses less frequent than AD or with other special characteristics.

In conclusion, caregivers of LBD patients experience significant perceptions of burden that is heightened by BEPs, impaired ADLs, sense of isolation, and challenges with the diagnostic experi-

ence. Future interventions can now be designed to address each of these challenges, whether unique or common to the caregiving experience. At a more general level, public awareness campaigns that move beyond characterization of AD and dementia as synonymous and which address the other main types of dementing illnesses can help generate interest and understanding, and perhaps stimulate efforts to develop appropriate supportive services for patients and their family caregivers.

References

- Aneshensel, C., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. (1995). *Profiles in caregiving: The unexpected career*. New York: Academic Press.
- Ankri, J., Andrieu, S., Beaufils, B., Grand, A., & Henrard, J. C. (2005). Beyond the global score of the Zarit Burden Interview: Useful dimensions for clinicians. *International Journal of Geriatric Psychiatry, 20*, 254–260.
- Bachner, Y. G., & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit burden interview. *Aging and Mental Health, 11*, 678–685.
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist, 41*, 652–657.
- Bédard, M., Pedlar, D., Martin, N. J., Malott, O., & Stones, M. J. (2000). Burden in caregivers of cognitively impaired older adults living in the community: Methodological issues and determinants. *International Psychogeriatrics, 12*, 307–332.
- Beeber, A. S., Thorpe, J. M., & Clipp, E. C. (2008). Community-based service use by elders with dementia and their caregivers: A latent class analysis. *Nursing Research, 57*, 312–321.
- Biegel, D., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness*. Newbury Park, CA: Sage Publications.
- Braungart, E. R., Zarit, S. H., Femia, E. E., Hofer, S. M., & Stephens, M. A. P. (2006). Behavioral and psychological symptoms of dementia and caregivers' stress appraisals: Intra-individual stability and change over short-term observations. *Aging and Mental Health, 10*, 563–573.
- Devanand, D. P., Jacobs, D. M., Tang, M. X., Del Castillo-Castaneda, C., Sano, M., Marder, K., et al. (1997). The course of psychopathologic features in mild to moderate Alzheimer's disease. *Archives of General Psychiatry, 54*, 257–263.
- Elashoff, J. D. (1969). Analysis of covariance: A delicate instrument. *American Education Research Journal, 6*, 383.
- Femia, E. E., Zarit, S. H., Stephens, M. P., & Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *The Gerontologist, 47*, 775–788.
- Ferman, T. J., Smith, G. E., Boeve, B. F., Ivnik, R. J., Petersen, R. C., Knopman, D., et al. (2004). DLB fluctuations: Specific features that reliably differentiate DLB from AD and normal aging. *Neurology, 62*, 181–187.
- Galvin, J. E., Duda, J. E., Kaufer, D. I., Lippa, C. F., Taylor, A., & Zarit, S. H. (in press). Lewy body dementia: The caregiver experience of clinical care. *Parkinsonism and Related Disorders*.
- Gaugler, J. E., Davey, A., Pearlin, L. I., & Zarit, S. H. (2000). Modeling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging, 15*, 437–450.
- Gerpen, J. V. (Speaker). (2007). The many faces of Lewy body dementia (Video Recording). Coral Springs, FL: The Lewy Body Dementia Association.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179–186.
- Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology, 47*, 156–164.
- Lewy Body Dementia Association. (2008). *An introduction to Lewy Body dementia [Brochure]*. Atlanta, GA: Author.

- McKeith, I., Mintzer, J., Aarsland, D., Burn, D., Chiu, H., & Cohen-Mansfield, J. (2004). Dementia with Lewy bodies. *Lancet Neurology*, 3, 19–28.
- McKeith, I. G., Rowan, E., Askew, K., Naidu, A., Allan, L., Barnett, N., et al. (2006). More severe functional impairment in dementia with Lewy bodies than Alzheimer disease is related to extrapyramidal motor dysfunction. *American Journal of Geriatric Psychiatry*, 14, 582–588.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594.
- Ricci, M., Guidoni, S. V., Sepe-Monti, M., Bomboi, G., Antonini, G., & Blundo, C. (2009). Clinical findings, functional abilities and caregiver distress in the early stage of dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). *Archives of Gerontology and Geriatrics*, 49, 101–104.
- Robillard, A. (2007). Clinical diagnosis of dementia. *Alzheimer's and Dementia*, 3, 292–298.
- Stavitsky, K., Brickman, A. M., Scarmeas, N., Torgan, R. L., Tang, M. X., Albert, M., et al. (2006). The progression of cognition, psychiatric symptoms, and functional abilities in dementia with Lewy bodies and Alzheimer's disease. *Archives of Neurology*, 63, 1450–1456.
- Stewart, J. (Speaker). (2007). The many faces of Lewy body dementia (Video Recording). Coral Springs, FL: The Lewy Body Dementia Association.
- Tarawneh, R., & Galvin, J. E. (2007). Distinguishing Lewy body dementias from Alzheimer's disease. *Expert Review of Neurotherapeutics*, 7, 1499–1516.
- Weiner, M. F., Teri, L., & Williams, B. T. (1996). Psychological and behavioral management. In M. F. Weiner (Ed.), *The dementias: Diagnosis, management, and research* (2nd ed., pp. 139–173). Washington, DC: American Psychiatric Association.
- Williams, M. M., Xiong, C., Morris, J. C., & Galvin, J. E. (2006). Survival and mortality differences between dementia with Lewy bodies vs Alzheimer disease. *Neurology*, 67, 1935–1941.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40, 147–164.
- Zarit, S. H. (1989). Issues and directions in family intervention research. In E. Light, & B. Lebowitz (Eds.), *Alzheimer's disease, treatment, and family stress: Directions for research* (pp. 458–486). Washington, DC: U.S. Government Printing Office.
- Zarit, S. H. (2008). Diagnosis and management of caregiver burden in dementia. In C. Duyckaerts, & I. Litvan (Eds.), *Handbook of clinical neurology: Dementias* (Vol. 89, 3rd series, pp. 905–910). New York: Elsevier.
- Zarit, S. H. (2010). *The burden interview*. Retrieved July 6, 2010, from http://www.mapi-research.fr/t_03_serv_dist_ReviewZBI.htm
- Zarit, S. H., & Eggebeen, D. J. (2002). Parent-child relationships in adulthood and later years. In M. H. Bornstein (Ed.), *Handbook on parenting: Children and parents* (Vol. 1, 2nd ed., pp. 135–164). Mahwah, NJ: Lawrence Erlbaum Associates.
- Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Psychological Sciences and Social Sciences*, 53B, 267–277.
- Zarit, S. H., Johansson, B., & Berg, S. (1993). Functional impairment and co-disability in the oldest old. *Journal of Aging and Health*, 5, 291–305.
- Zarit, S. H., & Zarit, J. M. (1982). Families under stress: Interventions for caregivers of senile dementia patients. *Psychotherapy: Theory, Research and Practice*, 19, 461–471.
- Zarit, S. H., & Zarit, J. M. (2008). Flexibility and change: The fundamentals for families coping with dementia. In M. Downs, & B. Bowers (Eds.), *Excellence in dementia care* (pp. 85–102). New York: Open University Press.