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Author Manuscript

Alzheimer Dis Assoc Disord. Author manuscript; available in PMC 2011 April 1.

Published in final edited form as:

Alzheimer Dis Assoc Disord. 2010 ; 24(2): 177–181. doi:10.1097/WAD.0b013e3181c72b5d.

LEWY BODY DEMENTIA: CAREGIVER BURDEN AND UNMET NEEDS

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Abstract

Lewy body dementia (LBD) is a common cause of dementia but to date, little is known about caregiver burden. The Lewy Body Dementia Association (www.LBDA.org) conducted a web-based survey of 962 caregivers (mean age 56y; 88% women). The most common initial symptoms were cognitive (48%), motor (39%), or both (13%). Caregivers expressed concerns about fear of future (77%), feeling stressed (54%), loss of social life (52%) and uncertainty about what to do next (50%). Caregivers reported moderate to severe burden; 80% felt the people around them did not understand their burden and 54% reported feelings of isolation with spousal caregivers reporting more burden than non-spousal caregivers. Only 29% hired in-home assistance while less than 40% used respite or adult day care, geriatric case managers or attended a support group meeting. Lack of service utilization occurred despite two-thirds of caregivers reporting medical crises requiring emergency services, psychiatric care or law enforcement. Caregivers reported preferences for web-based information, directories of LBD expert providers, information on LBD research and location of local support groups. These findings highlight significant unmet needs for LBD caregivers and provide targets for intervention to reduce caregiver burden. Community resources such as the Lewy Body Dementia Association may serve this end, while also providing practical information and support for caregivers.

Keywords

Lewy body dementia; caregiver burden; stress

The Lewy Body Dementias (LBD) include both dementia with Lewy bodies (DLB) and Parkinson disease (PD) dementia. Clinically, it is often impossible to retrospectively determine the precise onset of motor symptoms sufficient to make a diagnosis of Parkinsonism or cognitive impairment sufficient to make a diagnosis of dementia. In addition, there is no clinical or cognitive symptom that absolutely distinguishes DLB and PDD as both may have

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psychiatric symptomatology, autonomic symptoms, REM-sleep behavior disorder, cognitive fluctuations, neuroleptic sensitivity reactions and abnormalities in attention, executive function, visuospatial abilities, memory and behavior.¹ Thus, LBD may be a more useful term to capture a common phenotype in the community and is used in the present report to encompass both DLB and PD dementia. LBD is the second most common cause of dementia after Alzheimer disease (AD) affecting approximately 1.5 million Americans.² Increasing knowledge has been gained in the basic disease mechanisms and consensus criteria have been published to help establish diagnoses.^{3,4} However many questions remain as to how the diagnosis of LBD impacts the patient and their caregiver.

Previous studies have examined caregiver stress and burden related to AD but to date there is little known about the challenges facing caregivers of patients with LBD. AD caregivers are prone to feelings of social isolation and depression, have a higher risk of medical illnesses and feelings of guilt due to the inability to manage the functional and behavioral decline of the AD patient.^{5,6} Studies of AD caregivers provide targets for intervention such as invoking social support networks as a protective and moderating factor, promotion of identification and utilization of supportive familial and peer relations and physician education regarding caregiver choices.^{7,8}

The clinical features that differ most between LBD and AD include greater difficulties with motor abilities, (which lead to greater functional disability), early and severe executive dysfunction, more prominent behavioral and emotional problems including visual hallucinations, cognitive fluctuations and sleep disorders in LBD. These problems are likely to impact caregivers' subjective burden and may present different challenges compared with AD. The Lewy Body Dementia Association (www.LBDA.org) conducted a web-based survey of self-reported LBD caregivers over a 6-month period to address issues of challenges, burdens and frustrations facing LBD caregivers. This goal of the survey was to ascertain the unmet needs of LBD caregivers and collect data to inform educational programming and enhance caregiver support.

METHODS

Survey Design

An internet-based survey was developed by the LBDA and placed on-line using Survey Monkey (www.SurveyMonkey.com, Portland, OR) to explore caregiver experiences, needs and burden. The survey can be viewed at <http://www.lbda.org/go/LBDcaregiversurvey> The Zarit Burden Interview⁹ was used to measure caregiver burden. The remaining survey questions were investigator generated using Likert scales to capture descriptive assessments of the LBD caregiver experience. The survey was posted on the LBDA website (www.LBDA.org) for six months; 971 responses were obtained. Fifty percent of the responses were completed by visitors to the LBDA website. The remainder was received in two large clusters. The first cluster was when the biannual LBDA newsletter was issued. This resulted in 150 responses within a few days of mailing. The second cluster was in response to a reminder e-mail to the newsletter subscribers that the survey would end in the next week. The survey took 15 minutes to complete and 83% of respondents completed the entire survey. All procedures met requirements of the Health Information Portability and Accessibility Act (HIPAA) and were approved by the Institutional Review Board at Pennsylvania State University.

Statistical analyses

Descriptive statistics were determined for the sample using SPSS v15.0 (SPSS Inc, Chicago, IL). Continuous variables were compared using Student t-test or analysis of variance, while

categorical measures were compared using Chi-square test. Pearson correlation coefficients were used to examine relationships between variables and corrected for multiple comparisons with Bonferroni correction.

RESULTS

Sample Characteristics

The mean age of caregiver respondents was $55.9 \pm 12y$. The respondents were mostly female (88%) and 62% had daily contact with the patients. Full characteristics of LBD caregivers and patients are provided in Table 1. Caregivers were asked to describe the first symptoms of LBD they noticed. The earliest disease manifestations reported by LBD caregivers were cognitive (48%), motor (39%) or both cognitive and motor concurrently (13%). Initial symptoms noted by family members included: Memory problems (67%), Shuffling or other gait abnormalities (47%), Lapses or fluctuations in attention or alertness (43%), Hallucinations (43%), Driving difficulties (42%), Tremor or other abnormal movements (38%), or Depression (37%).

Impact of Disease

Although no objective measure of disease severity was collected, the caregivers reported the time between the first symptom and completion of this survey was $6.6 \pm 4y$ (range 1–22y). Based on their answers, respondents were caring for people with LBD who had moderate to severe levels of disability. For complex and intellectually demanding activities, such as shopping and cooking, over ninety percent of persons with LBD were unable to perform the activity. Even for basic activities of daily living (ADLs) such as dressing and bathing, over 60 percent of respondents reported the patient could not perform those activities (Table 2). Instrumental ADLs such as preparing meals (94%), finances (97%), transportation (97%), managing appointments (97%), medications (97%) and housework (94%) were largely taken over by caregivers. The LBD patients also required significant assistance with basic ADLs such as dressing (82%), bathing (76%), toileting (65%), eating (46%) and drinking (41%).

LBD caregivers also indicated the LBD patients had high rates of cognitive and behavioral problems (Table 2). LBD patients had significant difficulties with memory (96%) and judgment (91%); hallucinations (71%) and delusions (63%); depression (70%), anxiety (76%) and apathy (69%). Disturbances in sleep (53%) and gait/balance (44%) were also frequently reported. Verbal (43%) and physical (19%) aggressive behaviors were less common.

Caregiver Burden

In order to assess the impact of cognitive, affective and behavioral symptoms and the increasing dependence of patients for their instrumental and basic ADLs, we assessed levels of caregiver burden using the 11-item short version of the Zarit Burden Interview.⁹ Respondents typically reported medium to high levels (mean score 37.6 ± 8.8 , range 11–55) of burden associated with caring for the patient (Table 3). Overall, 36% reported moderate burden and 38% reported feeling very to extremely burdened on 7 out of 11 items measuring burden. The most frequent burden items reported by LBD caregivers were fear of the future for their loved ones (77%), stress between caring for their relative and personal responsibilities (53%), that caregiving has significantly interfered with the caregivers' social life (52%), and uncertainty about what to do (50%). There was no difference in either total burden or in frequency of individual items by symptom presentation (motor, cognitive or both). There were differences in burden by caregiver type. Spousal caregivers reported greater total burden (mean 35.2 ± 7.7) compared with non-spousal caregivers (mean 33.6 ± 8.2 , $p=.008$). After correction for multiple comparisons, the total burden scores were associated with the presence of any cognitive, behavioral or affective symptom reported by the caregiver, with the strongest relationships

between total caregiver burden and patient disturbances in mood ($r=.328$, $p<.001$) and sleep ($r=.293$, $p<.001$).

Respondents were also asked to describe how caregiver burden impacted their personal lives, health and emotional well-being. In response to the question “Do you feel people in your life understand what you are going through in caring for your relative?” 25% reported that no one understood what they were going through. In response to the question “Do you feel isolated as a caregiver because few people know about LBD?” 40% reported that they felt very isolated for this reason.

Caregiver Response to Disease

Caregivers were asked “Have you had to deal with a crisis situation with the patient in the past year?” Sixty four percent of respondents indicated that a crisis situation had occurred. In response to this, the most frequent place where respondents sought help for their relative with LBD was a hospital emergency room (296 visits (73%) followed by the need to call emergency medical services or law enforcement. Fifty seven caregivers reported the need for inpatient psychiatric care (12%), while another 23 (5%) sought assistance from outpatient mental health services.

Interestingly, despite the severity of disease, the level of burden and the presence of crises in the majority of cases, most respondents indicated that they were not currently receiving paid help to assist with care, and most had not received paid help in the past (Table 4). Only 29% were utilizing paid care in the home and only 21% used an adult day services program. Twenty-three percent of respondents were attending a support group and only 12% received ongoing counseling. Thirty-eight percent of respondents reported they received no help at all and only 30% were satisfied with the help they were already receiving. Forty percent reported they needed additional help, but most (75%) rated that the cost of these services was a problem.

There were differences between spousal and non-spousal caregivers in support service utilization. Non-spousal caregivers were more likely to use meal services ($\chi^2=15.8$, $p=.03$) while spousal caregivers were more likely to attend support groups ($\chi^2=38.8$, $p<.001$), enlist case managers ($\chi^2=10.8$, $p=.03$), financial planners ($\chi^2=12.2$, $p=.02$) and legal services ($\chi^2=13.8$, $p=.008$) and utilize hospice services ($\chi^2=12.8$, $p=.01$). There were no differences in service usage based on initial symptom presentation.

Respondents were interested in gaining more information and education about LBD diagnosis, management and treatment. Thirty nine percent reported they were currently seeking more information on research and 30% were looking for educational opportunities. The types of services and assistance that LBD caregivers were seeking are listed in Table 5. Respondents were most interested in web based information about LBD (65%) and the formation of on-line or in-person support groups. Other unmet needs of caregivers were a desire for information on LBD clinical trials, a directory of physicians who were skilled in LBD diagnosis and treatment, and of nursing homes skilled in LBD care.

DISCUSSION

Caregivers of LBD patients differ in characteristics from reports of caregivers of patients with AD. Most LBD caregivers were women, equally divided between wives and daughters. The Alzheimer Association reports that caregivers of AD patients (family and paid caregivers) are 60% women and only 6% of family caregivers are spouses.¹⁰ LBD patients were mostly men, consistent with reports of gender differences between LBD and AD.¹¹ Faced with a wide variety of motor, cognitive and behavioral problems, LBD caregivers reported increasing dependence of the patients for both instrumental and basic ADLs. For complex activities such

as shopping and cooking, over 90% of LBD patients were unable to perform or needed substantial assistance. Even for basic ADLs such as dressing and bathing, over 60% of respondents reported the patient could not perform these activities.

The loss of independence appears to occur early in LBD. The duration of onset of symptoms to time of completion of survey was 6 years consistent with other reports that functional decline in LBD is more rapid than that seen in AD.¹¹ Driving may be curtailed in LBD due to visuospatial deficits, hallucinations or fluctuating cognitive abilities. LBD patients may be more functionally impaired in ADLs than patients with AD with similar scores on cognitive testing due to their extrapyramidal symptoms.¹² This more rapid decline in functional ability and increasing dependence may increase the use of resources and the cost of care in LBD compared with AD.¹³ LBD patients generally have more severe behavioral symptoms and more compromised functional abilities compared with AD.¹⁴

Respondents reported high levels of burden due to demands of providing care and supervising LBD patients. Caregivers reported the highest burden when describing impact of providing care on their personal lives, health and emotional well-being with spouses reporting higher burden than non-spouse caregivers. Although association does not necessarily equal causation, LBD caregivers burden correlated most strongly with mood (depression, anxiety, apathy) and sleep disturbances in the patient. Two out of 3 LBD caregivers had to deal with crises in the past year. This increasing burden also led to feelings of social isolation and lack of understanding and adequate support from family, friends or providers. This suggests that burden entails more than just time, effort and energy, and includes emotional and financial stressors. These findings are consistent with other smaller studies of LBD caregivers where distress was higher for LBD compared with AD caregivers and correlated best with psychotic features, apathy and anxiety.¹⁴ Increased caregiver burden may also correlate with reports of more impaired ratings of quality of life¹⁵ driven by behavioral symptoms (particularly apathy and delusions) and poorer instrumental ADLs.

A surprising finding was the lack of utilization of available resources. Most LBD caregivers were not receiving any form of paid help and 38% reported receiving no assistance from any outside services. This may be explained in part by the higher proportion of spouses who answered our survey compared to surveys of AD patients. Spouses differ from other caregivers in their reaction to being a caregiver and their use of outside services.¹⁶ Spouses report that in-home services do little to reduce the burden of spouses who are dementia caregivers.¹⁷ Rather, spouse caregivers express preferences for adult day care and respite programs that provide not only patient supervision but help reduce the spouse's sense of social isolation.¹⁷ This is in agreement with our finding that spousal respondents had a preference for day care/respite (60%) compared with in-home help (38%). It is clear that LBD caregivers are in need of greater sources of information and support. Perhaps in part due to the increased burden and functional and behavioral limitations of the patient, respondents expressed a preference for internet based education materials and support groups. They also indicated desire for a compendium of physicians and facilities equipped to diagnose, treat and manage LBD patients.

This study has several limitations. Respondents were self-reported caregivers of LBD patients; however no medical records were available to verify diagnoses. Although we were unable to discern differences in PD dementia vs. DLB diagnoses given to patients, evaluation of symptom onset (motor, cognitive or both) did not reveal differences in caregiver burden. The group of individuals using the LBDA website and choosing to participate in this survey was highly educated and therefore may not be representative of the entire population of LBD caregivers. No objective information about the relationship between patient disease severity and burden reported by the caregiver was available and it is possible that caregivers of patients in the milder stages of disease were less motivated to respond to the survey. Investigator generated questions

were used to gain qualitative information from the caregiver; however these questions have not been previously validated. Quantitative measurements of burden such as the number of hours in direct supervision or caregiver health outcomes were not collected. From the spectrum of clinical, cognitive and behavioral symptoms and the functional dependency reported for the patients, the clinical picture at the time the survey was completed is largely consistent with moderate to severe LBD. Additionally the extent of LBD caregiver burden and its association with neuropsychiatric symptoms is consistent with reports in caregivers of patients with AD,¹⁸ frontotemporal dementia¹⁸ and Parkinson's disease.¹⁹

LBD caregivers face a number of challenges: social, medical, functional and financial. LBD caregivers feel isolated and often have to respond to crises, but are not currently receiving adequate support from family, friends or healthcare providers. These features have the potential to lead to adverse outcomes for the caregiver "burnout"²⁰ including stress,²¹ depression^{18,22} and poor health.²³ Poorer caregiver outcomes directly lead to increases in patient institutionalization and declines in quality of life.²⁴ This may be particularly important in LBD where patients are at an increased risk of institutionalization and mortality.¹¹ These findings highlight significant unmet needs for LBD caregivers (and patients). We now have identified potential targets for intervention to increase social support,^{7,8} improve educational opportunities,²⁵ referral to community-based services,²⁵ dementia care plans²⁶ in order to reduce caregiver burden that may have direct effects on both patient and caregiver outcomes.^{7,8,27,28} For example, LBD caregivers may be encouraged to enroll their loved ones in day programs rather than get in home services. Community resources such as the Lewy Body Dementia Association may serve this end, while also providing practical information and support for caregivers.

Acknowledgments

The authors thank the LBD patients and their caregivers for their time in completing this survey. The study was supported by the Lewy Body Dementia Association (www.LBDA.org).

REFERENCES

1. Lippa CF, Duda JE, Grossman M, et al. DLB/PDD Working Group. DLB and PDD boundary issues: diagnosis, treatment, molecular pathology, and biomarkers. *Neurology* 2007;68:812–819. [PubMed: 17353469]
2. Lewy Body Dementia Association website (www.LBDA.org). [Accessed on August 28, 2009].
3. McKeith IG, Dickson DW, Lowe J, et al. Consortium on DLB. Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. *Neurology* 2005;65:1863–1872. [PubMed: 16237129]
4. Emre M, Aarsland D, Brown R, et al. Clinical diagnostic criteria for dementia associated with Parkinson's disease. *Mov Disord* 2007;22:1689–1707. [PubMed: 17542011]
5. Sanders S, Ott CH, Kelber ST, Noonan P. The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Stud* 2008;32:495–523. [PubMed: 18958942]
6. Gruffydd E, Randle J. Alzheimer's disease and the psychosocial burden for caregivers. *Community Pract* 2006;79:15–18. [PubMed: 16435497]
7. Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging* 2005;20:634–644. [PubMed: 16420138]
8. Mittelman MS, Roth SL, Clay OJ, Haley WE. Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention. *Am J Geriatr Psychiatry* 2007;15:780–789. [PubMed: 17804831]
9. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–655. [PubMed: 7203086]
10. Alzheimer Association website (www.alz.org). [Accessed on August 28, 2009].

11. Williams MM, Xiong C, Morris JC, Galvin JE. Survival and mortality differences between dementia with Lewy bodies vs. Alzheimer disease. *Neurology* 2006;67:1935–1941. [PubMed: 17159097]
12. McKeith IG, Rowan E, Askew K, et al. More severe functional impairment in dementia with Lewy bodies than Alzheimer disease is related to extrapyramidal motor dysfunction. *Am J Geriatr Psychiatry* 2006;14:582–588. [PubMed: 16816011]
13. Bostrom F, Jonsson L, Minthon L, Londos E. Patients with Lewy body dementia use more resources than those with Alzheimer disease. *J Geriatr Psych* 2007;22:713–719.
14. Ricci M, Guidoni SV, Sepe-Monti M, Bomboi G, Antonini G, Blundo C, Giubilei F. Clinical findings, functional abilities and caregiver distress in the early stage of dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). *Arch Gerontol Geriatr* 2009;49:e101–e104. [PubMed: 19084284]
15. Boström F, Jönsson L, Minthon L, Londos E. Patients with dementia with Lewy bodies have more impaired quality of life than patients with Alzheimer disease. *Alzheimer Dis Assoc Disord* 2007;21:150–154. [PubMed: 17545741]
16. Sussman T. The influence of service factors on spousal caregivers' perceptions of community services. *J Gerontol Soc Work* 2009;52:406–422. [PubMed: 19382027]
17. Sussman T, Regehr C. The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health Soc Work* 2009;34:29–39. [PubMed: 19281100]
18. Mioshi E, Bristow M, Cook R, Hodges JR. Factors underlying caregiver stress in frontotemporal dementia and Alzheimer's disease. *Dement Geriatr Cogn Disord* 2009;27:76–81. [PubMed: 19155621]
19. Stella F, Banzato CE, Quagliato EM, Viana MA, Christofolletti G. Psychopathological features in patients with Parkinson's disease and related caregivers' burden. *Int J Geriatr Psychiatry*. 2009 Mar 25; [Epub ahead of print].
20. Yilmaz A, Turan E, Gundogar D. Predictors of burnout in the family caregivers of Alzheimer's disease: evidence from Turkey. *Australas J Ageing* 2009;28:16–21. [PubMed: 19243371]
21. Molyneux GJ, McCarthy GM, McEniff S, Cryan M, Conroy RM. Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. *Int Psychogeriatr* 2008;20:1193–1202. [PubMed: 18588725]
22. Ferrara M, Langiano E, Di Brango T, De Vito E, Di Cioccio L, Bauco C. Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health Qual Life Outcomes* 2008;6:93. [PubMed: 18990207]
23. Di Mattei VW, Prunas A, Novella L, Marcone A, Cappa SF, Sarno L. The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. *Neurol Sci* 2008;29:383–389. [PubMed: 19083150]
24. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008;20:423–428. [PubMed: 18786017]
25. Dang S, Badiye A, Kelkar G. The dementia caregiver--a primary care approach. *South Med J* 2008;101:1246–1251. [PubMed: 19005434]
26. Fortinsky RH, Kulldorff M, Kleppinger A, Kenyon-Pesce L. Dementia care consultation for family caregivers: collaborative model linking an Alzheimer's association chapter with primary care physicians. *Aging Ment Health* 2009;13:162–170. [PubMed: 19347683]
27. Andrén S, Elmståhl S. The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *J Clin Nurs* 2008;17:790–799. [PubMed: 18279282]
28. Holley CK, Mast BT. The Impact of Anticipatory Grief on Caregiver Burden in Dementia Caregivers. *Gerontologist* 2009;49:388–396. [PubMed: 19386826]

Table 1

Sample Characteristics

Variable	Value
Age patient, y (SD)	75.4 (8.4)
Patient Gender, % Male	62.2
Patient Marital Status, % Married	68.2
Age respondent, y (SD)	55.9 (12)
Respondent Gender, % Female	87.9
Respondent Education, %	
Less than High School	0.6
High School	25.5
College or Higher	73.8
Respondent Relationship, %	
Spouse	40.6
Child	51.7
Other Relative	3.8
Friend	3.8
Former Caregiver, % Yes	21.0
Patient Living Situation, %	
With Respondent	46.3
With other relative	15.9
Alone	4.6
Long Term Care	33.3
Respondent Primary Caregiver, %	63.8
Frequency of Patient Contact, %	
Daily	62.3
At least weekly	28.5

Table 2

Functional, Behavioral and Affective Disturbances Experienced in Past Week.

ADL	% affected	Symptom	% affected
Managing medications	97.3	Memory Problems	95.9
Managing appointments	97.3	Problems with judgment	91.4
Managing financial matters	96.9	Difficulty speaking	81.6
Transportation	96.9	Anxiety	76.2
Getting around in an unfamiliar place	95.6	Hallucinations	70.5
Taking Medications	94.6	Depression	69.9
Housework	94.0	Apathy	68.5
Preparing meals	93.9	Irritability	68.0
Shopping	93.6	Delusions	62.7
Dressing	82.3	Unusual sleep movements	62.0
Bathing	76.4	Other sleep disturbance	54.5
Getting in/out of bed/chair	73.8	Difficulty staying asleep	52.8
Cutting food	73.3	Nightmares	51.0
Walking	68.8	Falling	44.2
Using the Toilet	64.6	Difficulty Falling asleep	43.4
Getting around indoors	62.5	Verbal aggression	43.0
Eating	46.1	Physical aggression	19.1
Drinking	41.2	Inappropriate sexual behavior	9.9

Table 3
 11-item Zarit Burden Inventory in LBD Caregivers (most frequent responses are in bold type)

Variable (% response)	Never	Rarely	Sometimes	Quite Frequently	Nearly always
Not enough time for oneself	6.4	11.9	36.7	30.1	14.9
Stress between caring for relative and personal responsibilities	4.2	10.7	31.9	26.9	26.3
Afraid of the future of relative	2.6	5.1	15.5	29.7	47.1
Feel your health has suffered	13.7	17.4	32.6	20.7	15.6
Caring has interfered with your social life	8.5	12.2	26.1	24.6	28.6
Uncertainty about what to do	8.6	14.3	27.1	25.7	24.4
Angry around your relative	27.0	31.0	29.8	9.5	2.7
Relative affects relationships with your family and friends	27.6	25.5	27.6	10.9	8.4
Feel strained	19.3	25.1	33.5	13.7	8.3
Feel that you should do more	8.3	18.0	34.1	21.1	18.6
Feel that you could be doing a better job	12.7	26.7	33.6	15.5	11.6

Table 4

Paid services utilized by LBD Caregivers

Service (%)	Have not used	Used in past	Use Currently	Likely to use in future	Unlikely to use in future
Home care assistant	28.4	15.8	29.2	21.1	5.6
Home health aide	44.5	15.0	12.4	17.5	10.6
Home RN visit	42.3	16.9	13.4	16.9	10.4
Day respite care	34.7	13.1	21.3	25.0	5.9
Adult day program	50.4	11.9	8.9	13.7	15.1
Overnight Respite provider	48.3	9.7	8.9	21.2	12.0
Housekeeper/ Housecleaner	40.4	11.1	24.2	11.0	13.2
Meal services	57.0	7.2	7.6	7.4	20.9
Transportation services	50.9	10.3	9.6	11.9	17.3
Counseling or psychotherapy	47.2	15.3	11.9	13.5	12.2
Support group	40.0	12.6	22.6	17.9	6.9
Case or care manager	41.4	11.9	16.2	21.4	9.0
Financial planning	42.4	11.0	18.4	14.5	13.7
Legal services	25.9	30.5	23.8	11.1	8.7
Hospice Care	39.8	2.5	10.0	40.9	6.9

Table 5

Most Requested Services by LBD Caregivers

Web-Based Information	76.4
Directory of LBD specialists	66.2
Directory of LTC facilities specializing in LBD	62.2
Information on New Medications	60.7
Local Support Groups	56.7
Publications and DVDs	55.5
On-Line Support Groups	54.1
Educational Conferences	35.2
Toll Free Helpline	33.4
Telephone Support Groups	19.3

Key: LBD = Lewy body dementia, LTC = long term care