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LEWY BODY DEMENTIA: THE CAREGIVER EXPERIENCE OF CLINICAL CARE

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Abstract

BACKGROUND—Lewy body dementia (LBD) is the second most common cause of dementia, however, little is known about how the clinical diagnosis of LBD is obtained in the community or the caregiver experience while seeking the diagnosis.

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METHODS—The Lewy Body Dementia Association (www.LBDA.org) conducted a web-based survey of 962 caregivers over a 6-month period.

RESULTS—The mean age of respondents was 55.9y; 88% were female and 64% had daily contact with patients. The mean age of LBD patients was 75.4y; 62% were male and 46% lived with a caregiver. The most common presentation of symptoms as reported by LBD caregivers was cognitive (48%), motor (39%) or both (13%). The first diagnoses given to the patients were Parkinson disease or other movement disorder (39%), Alzheimer disease or other cognitive disorder (36%), or mental illness (24%). Fifty percent of patients saw >3 doctors for more than 10 visits over the course of 1 year before an LBD diagnosis was established. Neurologists diagnosed most cases (62%), while primary care-providers diagnosed only 6% of cases. No differences were found between the presentation of disease and the number of physicians, number of office visits, length of time to establish diagnosis, or type of doctor who finally made an LBD diagnosis. Caregivers viewed physicians as knowledgeable about disease manifestations and treatment options, but not about disease course/prognosis and available community resources and referrals.

CONCLUSIONS—These data highlight a need for increasing physician awareness and knowledge of LBD, which will facilitate accurate diagnosis and treatment. 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 experiences; diagnosis

INTRODUCTION

The Lewy body dementias (LBD) are the second most common cause of dementia after Alzheimer disease (AD) affecting approximately 1.5 million Americans [1]. LBD includes dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) – both syndromes share many clinical and cognitive features [2]. It may be clinically impossible to determine retrospectively, the precise onset of motor or cognitive symptoms sufficient to make an initial diagnosis of Parkinsonism alone, dementia alone or a combined Parkinsonism-dementia syndrome. In addition, there is no clinical or cognitive symptom that absolutely distinguishes DLB and PDD as both may display psychiatric symptoms, autonomic symptoms, rapid eye movement (REM) sleep behavior disorder, fluctuations in cognition, sensitivity to neuroleptics and abnormalities in attention, executive function, visuospatial abilities, memory and behavior [2]. 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 [1,2]. Consensus criteria have been published for both DLB [3] and PDD [4]. While these criteria have good specificity, they are limited by poor sensitivity [5,6]. Questions remain as to how well LBD is diagnosed and managed in communities without a large academic specialty clinic. In addition, little is known about the caregiver-patient experience of receiving a diagnosis and obtaining referrals to community services.

Because LBD shares clinical features with more widely recognized diseases such as the pure dementia phenotype of AD and the pure motor phenotype of PD, and psychotic and behavioral features similar to those seen in psychiatric disease, LBD is more likely to be under-recognized and initially mis-diagnosed [7,8]. Whether this is due to difficulty applying consensus criteria to patients not in research studies or to a lack of clinical familiarity with LBD among community physicians is unknown. Regardless, LBD caregivers face a number of challenges. Many patients with LBD have prominent difficulties with motor function, which lead to significant disability [9]. A large proportion of patients

have recurrent behavioral disturbances including: visual hallucinations, cognitive fluctuations and sleep disorders. These problems impact the LBD caregivers' subjective burden [10] and the patient's quality of life [11], and may present different challenges compared with caregivers of patients with AD or PD.

The Lewy Body Dementia Association (www.LBDA.org) conducted a web-based survey of 962 self-reported LBD caregivers over a 6-month period to address issues of challenges, burdens and frustrations facing LBD caregivers in obtaining a diagnoses and care for the patient. This goal of the survey was to ascertain the experiences of LBD caregivers and collect data to improve diagnosis and management of LBD.

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 perceptions of the difficulty obtaining a diagnosis for the patient and their experience with their healthcare providers. The survey was posted for six months on the LBDA website (www.LBDA.org) and a copy may be found at <http://www.lbda.org/go/LBDcaregiversurvey>. An announcement in the LBDA newsletter and an e-mail reminder 1 week prior to closing the survey was sent to all people who subscribe to the Lewy Body Digest, LBDA's free e-newsletter. The survey took 15 minutes to complete and 83% of 962 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. Most respondents self-identified themselves as LBD caregivers (n=962), the remainder identified themselves as LBD patients. Only caregiver respondents were included in the analyses. A check of IP addresses assured that respondents had only completed one survey.

RESULTS

Sample Characteristics

The mean age of caregiver respondents was $55.9 \pm 12y$; 88% were female, 41% were spouses, 74% had a college education and 64% identified themselves as the primary caregiver who had daily contact with the patient. Seventy nine percent of respondents were current caregivers. Caregivers of patients who had died were asked to respond based on the patients' condition at the time of their death. The mean age of the LBD patients was $75.4 \pm 8.4y$, 62% were males and 68% were married. In cases of LBD patients who were married but whose spouse was not the primary caregiver, this role was largely filled by a daughter. Forty six percent of patients lived with the respondent while 33% resided in long-term care facilities. Respondents who were primary caregivers were older ($p < .001$) and less educated ($p < .001$). The most common presentation of disease as reported by LBD caregivers was cognitive (48%) or motor (39%). The remainder (13%) presented with both cognitive and motor symptoms. There was no difference in any caregiver or patient characteristics based on type of symptom presentation. The most frequent symptoms first noted by caregivers and reported to the physician are shown in Table 1.

Caregiver Experience with Obtaining a LBD Diagnosis

LBD caregivers reported the time between the presentation of the patient's first symptom and completion of the survey was $6.6 \pm 4y$. Respondents reported that they frequently saw multiple physicians over multiple visits in order to establish an LBD diagnosis, this experience is shown in Table 2. Patients saw 3.3 ± 1.5 physicians regarding a variety of symptoms before an LBD diagnosis was made; 68% reported that more than 3 doctors were consulted, 15% saw more than 5 different physicians. The survey also asked how long it had taken to establish the diagnosis of LBD. The mean number of office visits needed to arrive at a diagnosis was 3.7 ± 1.9 ; 33% required more than 6 office visits. Nineteen percent of patients were diagnosed within the first month and 51% were diagnosed within the first year. However, it took more than 2 years from the start of symptoms for 31% to receive an LBD diagnosis. No differences in time to diagnosis or number of office visits were found between primary and secondary caregivers. Considering the group that initially presented with both cognitive and motor symptoms (N=150) likely had LBD from the onset, analyses of caregiver responses revealed equally long delays in diagnoses with 3.4 ± 1.5 doctors visited, 3.8 ± 1.9 office visits over a median period of 12–18 months to receive an LBD diagnosis. We compared the caregiver experiences based on type of symptom presentation (motor, cognitive or both). No differences were found between the presentation of disease and the number of physicians, number of office visits, length of time to establish diagnosis, or type of doctor who finally made an LBD diagnosis. No differences were detected between current and former caregivers. Secondary caregivers, who were more likely to be daughters, reported their family members were less likely to get an alternative diagnosis ($p < .001$) than reported by the primary caregivers.

Caregivers were asked to report the first diagnosis given to the patient. The initial diagnosis was a disorder other than LBD in 78% of cases. The most common first diagnoses were PD or some other form of parkinsonism (39%) or AD (26%). Less commonly other dementing illnesses were given as the first diagnosis: frontotemporal dementia (4%), vascular dementia (5%), mild cognitive impairment (6%) or some unspecified dementia (12%). Primary psychiatric diagnoses were first diagnosed in 24% cases: major depression (19%), bipolar disorder (3%), or schizophrenia (2%). Because we polled caregivers about the diagnostic experience and the obvious difficulty in retrospectively assigning correct diagnoses, we compared the type of symptom first noted by the caregiver with the first diagnosis given by the physician. The results are shown in Table 3. Caregivers reported that no diagnosis was given in 22% of cases when the patients' symptoms were first presented to a physician. An LBD diagnosis was established by a neurologist in 62% of the cases, followed by psychiatrists (9%), geriatricians (8%) and psychologists (8%). Primary care physicians made 6% of the LBD diagnoses, including family physicians (5%) and internal medicine doctors (1%). If a specialist (neurologist, psychiatrist, geriatrician) was the first physician seen, then LBD was more likely to be diagnosed based on the presentation of symptoms ($F=5.2, p < .001$).

Experiences after the Diagnosis

After the diagnosis was established, only 47% of patients continued to see the diagnosing physician. Once an LBD diagnosis was made, patients were referred back to internists and family medicine physicians in 58% of cases. Half of the LBD patients were seeing 2 or more clinicians for LBD-related problems (e.g. behavior, sleep disturbances, autonomic insufficiency); 58% caregivers reported they had difficulties coordinating care among the different clinicians. Differences were found between types of caregivers, with primary caregivers having less difficulty coordinating care than secondary caregivers ($p < .001$).

Caregiver Perceptions of Physician Knowledge

Overall, 70% of caregivers had found it difficult to find a physician who knew the criteria for diagnosing LBD and 77% of caregivers reported that it was difficult to find a physician who knew about treating LBD. Former caregivers reported greater difficulties than current caregivers ($p < .001$). The LBD caregivers were asked to evaluate the diagnosing physicians' knowledge of LBD symptoms, management, and ancillary services (Table 4). Caregivers thought both diagnosing and treating physicians were generally knowledgeable about individual disease symptoms and current treatment options. At the time of diagnosis, specialists (neurologists, psychiatrists, geriatricians) were rated as more knowledgeable about LBD diagnosis, symptoms, treatment options and answering questions than primary providers (all p -values $< .01$). Regardless of specialty, caregivers reported that the ability of the physicians to discuss prognosis and course of disease, provide additional sources of information for patient and caregiver education or refer to community services was inadequate. No differences were found between type of symptom presentation and caregiver perception of physician knowledge.

DISCUSSION

Caregivers of patients with LBD are often frustrated by their experiences with physicians. Obtaining a LBD diagnosis often required multiple visits to multiple physicians, causing significant delay in initiation of therapy. Over 40% of caregivers reported that it took more than 18 months to arrive at an LBD diagnosis from the time of the first visit to a physician, regardless of the initial symptom presentation. Although LBD was eventually diagnosed, caregivers reported that alternative diagnoses were given first in 78% of cases (39% PD or related disorder, 36% AD or other cognitive disorder, 32% mental illness). This does not necessarily imply misdiagnosis, as the symptoms of LBD can evolve over time. For example, if a patient started out with parkinsonism and only later developed cognitive or behavioral symptoms, LBD would not be considered by the first physician. Similarly, if a patient started out with cognitive symptoms, AD could have been a reasonable diagnosis until other core features became apparent. The purpose of this study was to gain an understanding of the experience of the patient and the caregiver with their physicians. However, if one considers the group that most likely presented with the LBD phenotype at onset, diagnostic experiences do not differ from the entire sample. Once diagnosed, most patients were managed by primary care-providers. While caregivers thought both diagnosing and treating physicians were knowledgeable about individual disease symptoms and current treatment options, most respondents reported their physicians lacked knowledge regarding not only the course and prognosis of the disease but also any available community resources or allied health referrals.

The importance of early diagnosis and treatment is supported by data suggesting LBD patients may have better responses to cholinesterase inhibitors than AD patients [12,13]. Early diagnosis provides opportunities to minimize exposure to medications that may aggravate symptoms or lead to potentially fatal conditions such as severe neuroleptic sensitivity reactions [14]. It also allows one to look for other commonly occurring and treatable disorders such as REM behavior disorder. Although prognosis varies among individuals, LBD is often a more rapidly progressive disease than AD [15,16]. Early diagnosis permits caregivers and families an opportunity for more timely therapeutic intervention, time to plan for expected decline in cognition, function and behavior, and avail themselves of community resources for information and support.

Several possible explanations exist as to why LBD caregivers perceived a delay in establishing a diagnosis. First, there may be a limited awareness of the signs and symptoms of LBD among doctors, particularly primary care physicians [7,17]. Second, the current

consensus diagnostic criteria are somewhat lacking in sensitivity, thus limiting their usefulness in general practice [5]. Third, mild symptoms that suggest LBD may not be observed by a clinician during a brief office visit or may not be reported by the patient or caregiver. This may be particularly true in patients with dramatic cognitive fluctuations who may be seen by the physician during a 'good time'. Fourth, early in the disease, it can be difficult to diagnose LBD with any certainty, even for well-trained specialists, so that some patients will receive a general diagnosis of dementia, until they present with more specific signs or symptoms. Lastly, there are currently no laboratory tests or validated biomarkers to confirm the clinical diagnosis of LBD.

Our findings are generally consistent with other reports of diagnostic patterns of other forms of dementia in the community. While primary care providers are generally knowledgeable about diagnosing and treating dementia, less clinical experience regarding epidemiology and differential diagnoses may make them less likely to recognize diseases such as LBD. A study of 127 general practitioners suggested that knowledge of local diagnostic and support services is less than general knowledge of dementia [17]. Additionally, one third of general practitioners expressed limited confidence in their diagnostic skills, while two-thirds lacked confidence managing the behavioral problems and other complications of dementia [17]. Physicians may also be more comfortable with diagnosing dementia than with managing ongoing issues, and with immediate medical and psychiatric problems rather long-term psychosocial issues [18]. General practitioners perceived lack of time and lack of social services support as the major obstacles to good quality care more often than they identified their own unfamiliarity with current management or with local resources [17]. A recent meta-analysis has explored possible reasons for diagnostic error in primary care [19]. This report suggests that less common disorders (i.e. LBD) are less likely to be recognized in primary care settings, leading to an increased number of more common diagnoses (i.e. AD). Specialists may be more likely to make uncommon diagnoses, which may reflect their research interests [19]. Often common medical conditions (malignancies, myocardial infarction, meningitis, and anemia) that occur frequently in the elderly are investigated first. Common difficulties in establishing diagnoses included atypical or non-specific presentations, conditions with very low prevalence, the presence of co-morbid illnesses and perceptual features [19], which are all characteristic of LBD. The difficulties described in community settings inform ways to improve the diagnosis of dementia in primary care by focusing on the need for timely diagnosis, developing guidelines that are applicable to a busy primary care setting, and identification of appropriate referral pathways and diagnostic strategies [20].

Our study is not without limitations. Respondents were self-reported caregivers of LBD patients. No independent observations or medical records were available to review symptom history or verify diagnoses. No objective information about the severity of patients' symptoms in relation to the time the patient was brought to medical attention was available. From the spectrum of clinical, cognitive and behavioral symptoms reported for the patients, the clinical picture at the time of survey completion suggest most patients were in the moderate to severe stages of LBD; however the stage of disease at time of diagnosis was not captured. The survey did not discriminate DLB from PDD diagnoses; evaluation of symptom onset (motor, cognitive or both) did not reveal differences in caregiver experiences based on initial symptom presentation. The reports of delay in diagnosis were based on solely on recall of the caregivers. There is no way to confirm whether physicians did not recognize LBD or if they considered LBD as a diagnosis but did not inform the caregivers as has been reported in other studies [8]. Caregivers were asked the specialty of the physician (e.g. neurologist, psychiatrist) but were not asked to specify if they were aware of any subspecialty interest (e.g. movement disorders, cognitive disorders). It should be noted that the purpose of this study was to assess caregiver perceptions of physician understanding of

LDB rather than evaluate physician knowledge. Lastly, caregivers who completed the Internet-based survey may not be representative of caregivers in general. Families who subscribe to newsletters by disease focused organizations such as LBDA may be better informed about the disease and may differ in other characteristics that we were unable to assess.

With these caveats in mind, these data highlight the need to increase physicians' knowledge of LBD, which should lead to accurate diagnoses and appropriate treatment [21,22]. Physicians caring for older adults may need a greater awareness of the prevalence and clinical presentations of LBD in order to make a timely diagnosis. They may also benefit from increased awareness of regional and national support services and diagnostic tools that can assist in arriving at a timely and correct diagnosis of LBD and other dementias. Community resources such as the Lewy Body Dementia Association may help to serve this end, while also providing practical information and support for caregivers. These findings highlight caregiver perception of unmet needs from physicians for LBD patients and their families/caregivers.

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Table 1

LBD Symptoms Most Frequently Reported by Caregivers to Physicians

| Symptom | N | % |
|---|-----|------|
| <i>Cognitive</i> | | |
| Memory Problems | 631 | 66.9 |
| Difficulties managing finances | 347 | 36.8 |
| Poor judgment | 294 | 31.2 |
| Difficulties managing medications | 294 | 31.2 |
| Difficulties doing other daily tasks | 265 | 28.1 |
| <i>Motor/Physical</i> | | |
| Shuffling or other walking problems | 446 | 47.3 |
| Difficulties driving | 393 | 41.7 |
| Hand tremors | 362 | 38.4 |
| Problems with vision | 269 | 28.5 |
| Slowness of movement | 261 | 27.7 |
| Falling | 258 | 27.4 |
| Speaking difficulties | 250 | 26.5 |
| <i>Behavioral</i> | | |
| Lapses in attention or alertness/Staring spells | 411 | 43.6 |
| Hallucinations | 402 | 42.6 |
| Depression | 351 | 37.2 |
| Personality change | 293 | 31.1 |
| Paranoid beliefs or accusations | 259 | 27.5 |
| Mood swings | 213 | 22.6 |
| Apathy | 179 | 19.0 |
| <i>Sleep Disturbance</i> | | |
| Excessive daytime sleepiness | 355 | 37.6 |
| Thrashing during sleep | 299 | 31.7 |
| Nightmares | 262 | 27.8 |

Table 2

LBD Caregivers Experience with Obtaining LBD Diagnosis

| Number of Physicians Consulted | N | % |
|--|----------|----------|
| 1 | 64 | 7.6 |
| 2 | 214 | 25.3 |
| 3 | 240 | 28.4 |
| 4 | 157 | 18.6 |
| 5 | 47 | 5.6 |
| More than 5 | 124 | 14.7 |
| Time from 1st Visit to Diagnosis | N | % |
| First visit | 77 | 9.3 |
| Within one week | 13 | 1.6 |
| Within one month | 69 | 8.3 |
| Within three months | 69 | 8.3 |
| Within six months | 97 | 11.7 |
| Within twelve months | 94 | 11.3 |
| Between twelve and eighteen months | 78 | 9.4 |
| Between eighteen months and two years | 74 | 8.9 |
| Between two and three years | 101 | 12.2 |
| More than three years | 159 | 19.1 |
| Total Office visits before diagnosis | N | % |
| 1 | 162 | 19.9 |
| 2 | 146 | 17.9 |
| 3 | 99 | 12.1 |
| 4 | 85 | 10.4 |
| 5 | 54 | 6.6 |
| 6 or more | 270 | 33.1 |
| Specialty of Diagnosing Physician | N | % |
| Family Medicine | 42 | 5.0 |
| Geriatrician | 69 | 8.3 |
| Internal Medicine | 9 | 1.1 |
| Neurologist | 518 | 62.0 |
| Neuropsychologist | 67 | 8.0 |
| Psychiatrist | 77 | 9.2 |
| Other medical specialty | 30 | 3.6 |
| Unsure of specialty | 23 | 2.8 |

Table 3

First Diagnosis Given to LBD Patients Based on Initial Symptom Presentation

| First Diagnoses | Type of Symptom Presentation (%) | | |
|------------------------|----------------------------------|-----------|------|
| | Motor | Cognitive | Both |
| No diagnosis given | 19.1 | 23.5 | 21.8 |
| AD | 9.2 | 19.2 | 8.8 |
| FTD | 0.7 | 5.4 | 1.2 |
| MCI | 1.4 | 1.6 | 1.2 |
| VaD | 3.2 | 3.8 | 5.3 |
| Unspecified "dementia" | 3.2 | 4.0 | 6.5 |
| PD | 38.5 | 8.0 | 18.2 |
| AD + PD | 4.6 | 7.3 | 9.4 |
| PD + MCI | 3.2 | 2.6 | 2.4 |
| AD + Depression | 1.4 | 5.9 | 2.4 |
| PD + Depression | 6.4 | 4.7 | 6.5 |
| Depression | 4.6 | 7.5 | 7.6 |
| Bipolar disorder | 0.4 | 2.1 | 0.6 |
| Schizophrenia | 0.4 | 1.2 | 0.6 |
| Other | 3.9 | 3.1 | 7.6 |

Key: AD = Alzheimer disease, FTD = Frontotemporal dementia, MCI = mild cognitive impairment, VaD = Vascular dementia, PD = Parkinson disease

Table 4

LBD Caregivers Perceptions of Physician Knowledge of LBD

| Variable (%) | Diagnosing Physician | | | Current Physician | | |
|---|----------------------|----------|-----------|-------------------|----------|-----------|
| | Inadequate | Adequate | Excellent | Inadequate | Adequate | Excellent |
| Knowledge about LBD | 10.6 | 35.3 | 54.0 | 25.8 | 48.9 | 25.3 |
| Explaining diagnosis | 19.9 | 42.1 | 38.0 | 33.3 | 45.8 | 20.8 |
| Explaining symptoms | 23.3 | 42.6 | 34.1 | 37.9 | 42.6 | 19.5 |
| Presenting treatment options | 26.8 | 42.3 | 30.8 | 38.7 | 42.3 | 19.0 |
| Explaining medications to treat parkinsonian symptoms | 23.6 | 45.2 | 31.2 | 35.0 | 44.5 | 20.4 |
| Explaining medications to treat behavioral symptoms | 26.3 | 42.8 | 30.9 | 38.3 | 41.4 | 20.3 |
| Answering questions | 20.8 | 38.5 | 40.7 | 27.0 | 45.9 | 27.0 |
| Telling what to expect in the future | 42.2 | 34.2 | 23.6 | 46.1 | 37.7 | 16.2 |
| Telling where to find more information on LBD | 56.1 | 27.0 | 16.9 | 64.3 | 22.7 | 13.0 |
| Telling where to find community services | 62.0 | 25.5 | 12.5 | 60.0 | 27.4 | 12.6 |
| Being sensitive | 25.5 | 37.9 | 36.5 | 25.7 | 44.7 | 29.6 |