

IMPACT OF LBD ON THE FAMILY CAREGIVER

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The combination of cognitive, motor and behavioral symptoms imposes significant challenges and stressors on caregivers. Education of and support for the primary caregiver is essential, and building a care team, when possible, can lessen the burden on any one individual.

Caregiver burden

Early symptoms that are characteristic of Lewy body dementias (LBD) are associated with higher levels of caregiver burden, above and beyond impact of stress associated with early dementia in general. Key factors in LBD caregiver burden include behavioral problems (e.g., psychosis, apathy and agitation), an impaired ability to perform activities of daily living (due to both cognitive impairment and parkinsonism), the caregiver's sense of isolation, and challenges with the diagnostic and treatment experience.

Research suggests that people with LBD may be more functionally impaired than individuals with Alzheimer's disease (AD) with the same level of global cognitive impairment. Loss of independence in ability to perform instrumental activities of daily living typically occurs early in LBD, including the inability to manage one's own medications and finances. Driving may also need to be curtailed early due to changes associated with LBD, i.e. variable levels of attention and alertness, visual hallucinations, slowed of reaction time, and decreased spatial awareness.

LBD caregivers need to increasingly supervise and monitor LBD patients as particular symptoms manifest themselves or worsen, including executive impairment (i.e., difficulty planning and completing tasks), fluctuations in alertness, incontinence, intrusive hallucinations, and falls.

Diagnostic Delays

LBD caregivers often encounter significant barriers in obtaining an accurate diagnosis for their loved ones. Most see multiple physicians over more than a year before their relative is diagnosed with LBD, and more than three-quarters of persons with LBD are given a different diagnosis initially.

Community-based services

The range and intensity of care required for LBD patient means that greater attention to and allocation of resources to assist LBD families are needed. One study compared resource use, cost of care, and determinants of cost of care in patients with dementia with Lewy bodies (DLB) and AD. DLB patients utilized more than twice the amount of resources compared with AD patients. Specifically, DLB patients used greater resources in accommodations (long term residential care), and required more outpatient care, informal care (measured by caregivers' lost production and lost leisure time), community services and pharmacological therapy.¹¹

Among neuropsychiatric features, apathy (i.e., loss of motivation to participate in routine activities) was found to be higher in DLB patients than AD patients. In addition, the cost of care for DLB patients with apathy was almost three times as high compared with AD patients with apathy. Thus, apathy is an important behavioral feature in LBD.

Low Public Awareness

The lack of LBD awareness in the general public increases the subjective burden of LBD on families, which echoes the experience of dementia caregivers in the days before extensive public education had been provided regarding AD.

Performance Worry

Also problematic for LBD caregivers are concerns about their own capabilities as caregivers, which is amplified due to fewer informational resources on LBD caregiving compared with those available for AD, LBD caregivers' sense of social isolation, and the challenges in finding supportive medical professionals or community services. Thus, LBD caregivers may be more concerned than other dementia caregivers about the quality of care they are providing.

Monitoring for depression and burnout

Family caregivers often experience sleep deprivation, have poor eating habits, and fail to exercise enough. When it comes to their own medical care, their caregiving responsibilities may prevent them from convalescing when ill, and they often postpone or neglect to make medical appointments for themselves.

The caregiver should also be considered a patient in some respects, as the stress of being in an intense, long-term caregiver role can lead to depression, poor health and burnout, which can increase the likelihood of institutionalization of the LBD patient. Healthcare providers should urge caregivers to prioritize their own health as highly as they do that of their loved one with LBD.

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