



Get to know Lewy body dementia

The third most common cause of dementia, this disease isn't well understood by many healthcare professionals. We give you the information you need.

By Amanda Perkins, MSN, RN

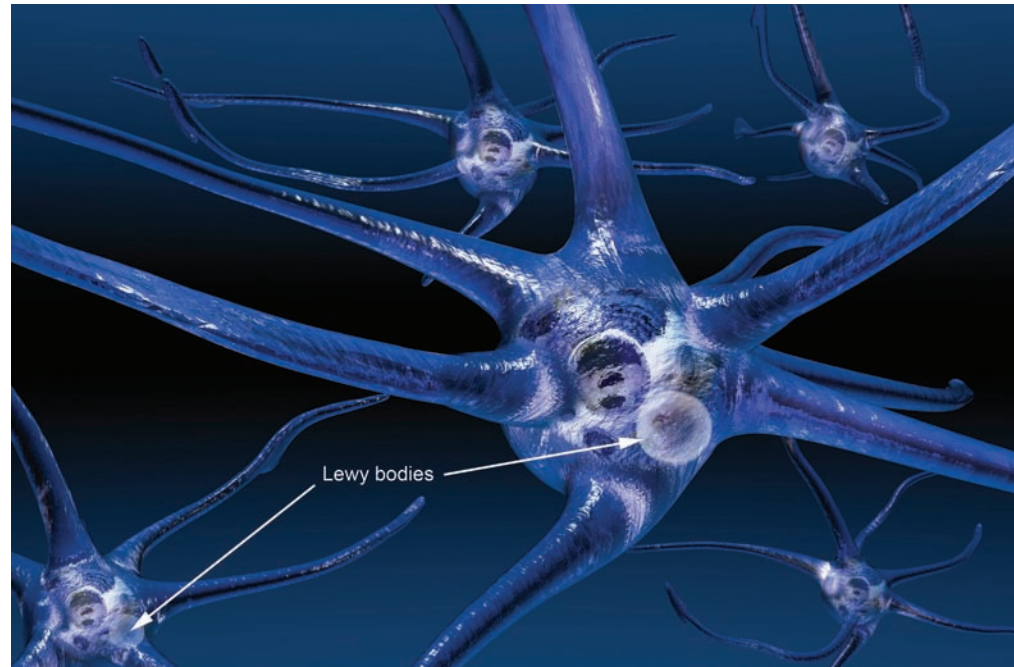
Lewy body dementia (LBD), also known as dementia with Lewy bodies, is a progressive disease that affects many parts of the brain, resulting in impaired thinking and reasoning, and the inability to function independently. More than 1 million Americans—men slightly more than women—are affected by LBD, according to the National Institutes of Health. LBD accounts for 10% to 25% of all cases of dementia, making it the third most common cause of dementia, according to the Alzheimer's Association.

This article provides information about LBD, including pathophysiology, signs and symptoms, diagnosis, treatment, and your role in patient care.

LBD explained

Found throughout the normal brain, the protein alpha-synuclein plays a role in the development of LBD; however, much of its function is unknown at this time. What we do know is that, in the healthy brain, alpha-synuclein protein is part of nerve cell functioning, especially at the synapses—the areas where brain cells communicate.

Picturing Lewy bodies



CAROL WERNER / DIOMEDIA

The changes seen in the brain of a patient with LBD are due to abnormal microscopic deposits, Lewy bodies, made up mainly of the alpha-synuclein protein. The Lewy bodies clump together in neurons, causing them to lose functionality and eventually die (see *Picturing Lewy bodies*). Neurons that are lost may include those which produce the neurotransmitters acetylcholine and dopamine. Acetylcholine plays a role in memory and learning, whereas dopamine takes part in behavior, cognition, movements, motivation, sleep, and mood.

Lewy bodies can be found in the following areas:

- cerebral cortex—information processing, perception, thought, and language
- limbic cortex—emotions and behaviors
- hippocampus—formation of new memories
- midbrain, including the substantia nigra—movement
- brainstem—sleep regulation and maintaining alertness.

Lewy bodies also affect brain regions that are involved with the olfactory pathways.

Lewy bodies are found in individuals with LBD, Alzheimer disease, and Parkinson disease. It's believed that the changes seen in the patient with LBD are related to how the brain processes the alpha-synuclein protein. It's also believed that Lewy bodies affect the chemicals found within the brain, altering important chemical processes. In addition to Lewy bodies, the patient who has LBD may also have plaques and tangles, which are typically associated with Alzheimer disease.

What does it look like?

LBD is typically seen in individuals age 50 and older, making age the biggest risk factor for the development of this disease. Rarely, it's seen in individuals who are younger than age 50. LBD is associated with both cognitive and motor symptoms; of the two categories, cognitive changes commonly lead to disability. The signs and symptoms associated with LBD tend to start slowly and progress over time, with death most commonly occurring within 5 to 7 years after

diagnosis. Although this is the typical course, it's important to be aware that death may occur as early as 2 years or as late as 20 years after diagnosis.

The following are signs and symptoms associated with LBD:

- changes in thinking
- changes in reasoning
- confusion and alertness that vary significantly from day to day and, sometimes, hour to hour
- Parkinson symptoms (see *Movement symptoms*)
- visual hallucinations
- delusions, often paranoid delusions
- difficulty interpreting visual information
- acting out dreams, known as rapid eye movement sleep behavior disorder (RBD)
- malfunctions with the autonomic nervous system (see *Autonomic nervous system problems*)
- memory loss.

Early in the disease process, patients may report that before diagnosis they had difficulty multitasking, following conversations, and following directions while driving. Visual hallucinations may be present in up to 80% of LBD cases; auditory hallucinations are less common. Visual hallucinations may be realistic and detailed, making it difficult to manage the patient. Note that visual hallucinations tend to occur in the evening when there's

Movement symptoms

- Muscle rigidity or stiffness
- Shuffling gait
- Slow movement
- Frozen stance
- Tremor or shaking (most prominent at rest)
- Balance problems
- Falls
- Small handwriting
- Mask-like appearance (reduced facial expressions)
- Difficulty swallowing
- Weak voice

Autonomic nervous system problems

- Changes in body temperature
- Problems with BP (typically decreased)
- Dizziness
- Fainting
- Frequent falls
- Sensitivity to heat and cold
- Sexual dysfunction
- Urinary incontinence
- Constipation
- Poor sense of smell

low light, therefore, adequate lighting is necessary for these patients.

With RBD, the paralysis that usually occurs during the rapid eye movement cycle is impaired. Patients can injure themselves and/or others when they enact their dreams. Patients with RBD may yell, flail, punch, and/or fall out of bed while they're sleeping. Additionally, it isn't uncommon for RBD to present years before other symptoms of LBD. Patients may also present with excessive daytime sleepiness, insomnia, and/or restless legs syndrome.

If a patient has delusions, they typically appear later in the disease process. The delusions are often paranoid delusions, in which the patient focuses on infidelity, house intruders, and theft. This can be very stressful for both the patient and family members/caregivers. Later in the disease process, the patient may also develop Capgras syndrome, a delusion in which patients believe that their spouse or other individuals close to them has been replaced by an imposter. If this occurs, it may become increasingly difficult to provide care for the patient in the home setting.

LBD and Parkinson disease dementia make up the LBD continuum. For more information, see *LBD and Parkinson disease*.

Diagnosis

Currently, there's no test that can diagnose LBD; however, early diagnosis is essential

so that a variety of complications can be prevented. Diagnosis is a clinical diagnosis, meaning that a healthcare provider, commonly a neurologist, will use his or her best judgment to make the call. Diagnosis can be difficult because there's often no family history of the disease and no genes linked with LBD have been identified.

In making a clinical diagnosis, the healthcare provider will typically complete a medical history, physical exam, and neuropsychologic testing, and order a variety of lab and radiologic tests, some of which may include brain imaging, such as computed tomography scans and magnetic resonance imaging. Brain imaging may be used to rule out other possible causes of the patient's symptoms or assess for structural changes in the brain such as atrophy. Initially, the atrophy seen with LBD is minimal; as the disease progresses, it may become more severe. Research is ongoing and there's hope that brain imaging will be able to provide more insight into the disease in the future. If a patient is having problems with sleep, the healthcare provider may order a sleep study.

As with Alzheimer disease, the only way to make a definitive diagnosis is through an autopsy after death. Be aware that in the early stages, LBD may be confused with Alzheimer disease. Generally speaking, it can be difficult to distinguish between the two.

LBD and Parkinson disease

It's believed that LBD and Parkinson disease may be linked due to an overlapping of signs and symptoms. In fact, it's been hypothesized that LBD and Parkinson disease are different phenotypic expressions of the same disease process. Recall that a phenotype is a description of physical characteristics. With LBD, the patient typically has neurologic symptoms, followed by movement symptoms such as a hunched posture, rigid muscles, and shuffling gait. These movement symptoms are also typically observed in patients with Parkinson disease. In Parkinson disease dementia, the patient typically has movement symptoms, followed by neurologic symptoms. Basically, one key difference between the two is the order in which symptoms present themselves. But at the time of autopsy, it may be difficult to differentiate between LBD and Parkinson disease dementia.

Research on diagnosing LBD is ongoing. It's hoped that positron emission tomography scans and single-photon emission computed tomography will be able to detect differences between Alzheimer disease and LBD. It's believed that, in the future, these scans will be able to detect dopamine deficiencies in the brain. Additionally, the use of lumbar punctures to measure proteins in cerebral spinal fluid is being investigated as a potential diagnostic tool.

Treatments

Treatments won't stop, or even slow, the damage that occurs with LBD. Due to the fact that this disease is progressive, there's no cure; treatment efforts are aimed at symptoms management. With this in mind, it's essential that both the patient and family members/caregivers are educated regarding the course of the disease.

For patients with sleep problems, it may be recommended that they avoid alcohol, caffeine, or chocolate late in the day. Although LBD and Parkinson disease have overlapping symptoms, patients with LBD often have a poor response to Parkinson disease medications.

Patients with LBD should be treated by a multidisciplinary team, including a neurologist, physical therapist, speech therapist, occupational therapist, nurse, and mental health counselor. Medications that may be utilized for treatment are cholinesterase inhibitors, levodopa, antipsychotic/neuroleptic drugs, antidepressants, clonazepam, and melatonin.

Cholinesterase inhibitors

These medications are commonly used in the treatment of LBD and are the current standard of care for cognitive and psychiatric symptoms. Cholinesterase inhibitors have been shown to improve cognitive impairments, psychotic symptoms, and agitation, and are typically well tolerated by the patient with LBD. The three medications that are commonly used are



did you know?

Lewy bodies were discovered by Frederic H. Lewy, MD, in 1912. Dr. Lewy, a neurologist, was conducting research in Dr. Alois Alzheimer's lab on the brains of people with Parkinson disease at the time of the discovery. Although Lewy bodies were first identified in 1912, it wasn't until the 1970s that they were associated with dementia. In 1996, LBD was first recognized as a disease after consensus was reached regarding clinical characteristics.

donepezil, rivastigmine, and galantamine. Of the three, rivastigmine is the only one approved for the treatment of LBD; however, the other two are still used and have been shown to be as effective as rivastigmine.

Levodopa

Levodopa may be prescribed to treat movement symptoms, but caution should be used when initiating this drug because it can aggravate hallucinations and confusion. When this medication is ordered, it's important to ensure that dosing is kept at the lowest effective level because this has been shown to improve movement symptoms with the least amount of adverse reactions. It's advised that levodopa only be initiated when movement symptoms are bothersome to the patient.

Antipsychotic/neuroleptic drugs

Although these medications are used in the treatment of LBD, they should be used cautiously. These drugs may be prescribed for behavioral problems; however, they're associated with serious adverse reactions in up to 50% of the patients with LBD who use them. Adverse reactions include sudden changes in consciousness, sedation, difficulty swallowing, acute confusion, delusions, hallucinations, and worsening movement problems. These drugs have also been associated with neuroleptic malignant syndrome—a potentially fatal condition characterized by a high fever, muscle rigidity, and muscle breakdown, which can lead to kidney failure. The increased risk of neuroleptic malignant syndrome makes it necessary for healthcare providers to avoid traditional antipsychotics, such as haloperidol, fluphenazine, and thioridazine for patients with LBD.

Antidepressants

Depression is common in patients with LBD, so antidepressants may be ordered. The most commonly used antidepressants

are selective serotonin reuptake inhibitors (citalopram and sertraline) because they're associated with the least amount of adverse reactions for the patient with LBD.

Clonazepam and melatonin

Clonazepam is typically prescribed to treat RBD. Melatonin is an over-the-counter (OTC) sleep aid that may be used independently or in conjunction with clonazepam. In general, benzodiazepines such as clonazepam should be avoided because they increase the risk of sedation, falls, cognitive changes, and paradoxical agitation. The prescribing healthcare provider will weigh the risks versus the benefits of initiating this medication.

Due to the fact that medications pose a high risk of adverse reactions in the patient with LBD, it's important to provide ongoing education to both the patient and family members/caregivers. For example, it may be important to educate both the patient and family members/caregivers that if hallucinations are present, but not frightening to the patient, treatment with medications may not be the best choice. However, if hallucinations pose a safety risk or if the patient is having delusions that are leading to socially unacceptable behavior, treatment may be necessary.

Patient care

It's important to discuss prognosis, symptoms, treatment goals, safety issues, disease progression, and end-of-life decisions early in the disease process. Due to the fact that behavioral and mood problems are common, it may be beneficial to maintain a consistent routine and environment. On the other hand, if behavior and mood problems are increased, it may be beneficial to assess if a change in the patient's routine and environment is needed. Stimulation, stress, lighting, daily routines, and relationships can contribute to behavioral and mood problems. It must



on the web

Alzheimer's Association:

www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp

Lewy Body Dementia Association:

www.lbda.org

National Institute of Neurological Disorders and Stroke:

<https://www.ninds.nih.gov/Disorders/All-Disorders/Dementia-Lewy-Bodies-Information-Page>

National Institute on Aging:

www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/introduction

also be determined if a medical condition, such as a urinary tract infection, is causing the change. Any underlying medical condition should be treated.

When caring for patients with LBD, simple tasks, consistent routines, regular exercise, sleep, and rest are important. Be

aware that these patients are sensitive to a variety of medications, especially antipsychotics. For this reason, teach patients and family members/caregivers about the potential dangers of antipsychotic medications. These patients may end up in a healthcare setting, commonly an ED, for behavioral and mood problems, and receive antipsychotic medications. When patients and caregivers are educated about the dangers of these medications, they become better equipped to be advocates. When caring for these patients, review prescribed medications, as well as OTC medications, and determine if any of these may be causing adverse symptoms.

Additionally, safety in the home should be assessed. Ensure that lighting is appropriate and there are no throw rugs in the home to reduce fall risk. Appropriate lighting is also important because it helps prevent visual hallucinations, which can also be lessened by avoiding patterns on curtains, walls, or furniture, ensuring furniture is placed in a way so that shadows are minimized, and reducing background noise.

The following nursing interventions may be helpful:

- maintain an uncluttered environment
- offer reassurance as needed
- reorient as needed
- provide stimulation by encouraging activities that the patient finds enjoyable

- assess for fall risk
- communicate effectively
- when in a healthcare setting, create a home-like environment
- ensure adequate hydration and nutrition.

The diagnosis of LBD can be scary and/or frustrating for the patient and his or her family. Frustrations are often increased because these patients will typically see multiple physicians over a drawn-out period of time before the diagnosis of LBD is made. It's also very common for individuals to initially be misdiagnosed. Make sure that the patient is receiving support.

When surveyed, patients and families reported that the following were lacking and would've been helpful after the initial diagnosis of LBD: what to expect in the future, where to find more information, and what community services are available.

When discharging a patient with LBD from a healthcare facility, ensure that family members are educated about what will happen as the disease progresses and where to find reliable information. It's also important to determine if the patient and his or her family would like information about and assistance with attaining community services.

Supporting the family

In addition to patient support, family support is also important. Individuals caring for patients with LBD report feeling burdened, especially when it comes to their personal lives, health, and emotional well-being. They also report feeling misunderstood and isolated. Caregivers may suffer from disrupted sleep, depression, and decreased health. Another common problem is financial burden. When the patient with LBD becomes symptomatic, he or she will be unable to work and, as a result, income may be lost. If a family member has to provide care for the patient, it may be another source of lost income.

Another stressor for family members is the patient's unpredictability. These patients will have behavioral and mood problems, often requiring visits to the ED during a crisis. Caregivers often report the following behaviors: talking aggressively, shouting, hitting, hallucinations, and delusions. Be aware of the potential for caregiver stress and burnout, and provide appropriate support, resources, and education.

Helping hand

Ensuring that you're appropriately educated about LBD allows you to provide the best possible care to both patients and family members/caregivers. They want to know what to expect, how and where to find more information, and what community resources are available. These patients and families need a strong support person—make sure you can help. ■

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