Lewy Body Dementia

Course Description:
Lewy Body Dementia is an umbrella term for two separate diseases: Parkinson's Disease Dementia and Dementia with Lewy Bodies. This course allows the caregiver to recognize the differences and similarities of Lewy Body Dementia. It is important that home health direct care providers understand the unique features of this neurodegenerative disease as it is the second most common dementia. Yet it is the most frequently misdiagnosed and highly under-diagnosed. The symptoms can look like Parkinson's Disease or Alzheimer's, but several unique symptoms make it a separate disease spectrum.

Learning Objectives:

1. *Recognize differences and similarities between the types of Lewy Body Dementias(LBD), Dementia with Lewy Body and Parkinson's Disease Dementia.*
2. *Identify LBD's unique symptoms affecting a client's plan of care.*

This activity contains a post-test. You must complete the entire learning activity and test and score an 80% or higher to obtain a certificate of completion. Partial credit will not be given.

Contact Hours: 30 minutes, including a required quiz.

While most people associate dementia with Alzheimer's Disease, there are thought to be as many as 70-80 different types of dementia. All types of dementia have common characteristics, but they have different causes and, more importantly, different symptom manifestations and progression.

Dementia is the gradual loss of mental functioning that affects memory, mood, thinking, concentration, and judgment. These changes often affect a person's ability to perform everyday activities and care for oneself. Dementia usually happens slowly and has a progressive nature. Behavior changes can include apathy, depression, anger, anxiety, and irritability.

After Alzheimer's, it is thought that Lewy Body Dementia (LBD) is one of the most common types of dementia. However, a specific Lewy body dementia diagnosis can be difficult because it is not uncommon for people with dementia to have more than one type. Once the brain decompensates, it may make it more vulnerable to other conditions. It is more common to have LBD along with another type of dementia, generally Alzheimer's disease or vascular dementia. Over 70% of LBD patients have co-occurring Alzheimer's (LBDA.org). Because LBD so commonly exists with other dementia types, it is under-diagnosed.

Like with other dementias, there is no definitive diagnostic test for Lewy Body dementia. It is extremely difficult to always recognize because it so commonly occurs with other types of dementia. Lewy body dementia does have some distinctive features that are particular to this

form of dementia. Lewy body dementia is a broad term covering two disorders: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). A person with DLB develops dementia and some other broader LBD symptoms, including rigidity, changes in movement, or parkinsonism tremors. But, in PDD, a person will first present with changes in movement, rigidity, or tremors and then, often, years later will develop many of the dementia symptoms seen in DLB.

Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms. The earliest signs of dementia with Lewy bodies and Parkinson's disease dementia are different, but both are due to the same underlying biological changes in the brain. In Dementia with Lewy Body, the Lewy bodies attack the area of the brain that produces acetylcholine in the cortex initially, resulting in dementia-type symptoms first, and in Parkinson's dementia, the brain becomes damaged in the movement center of the brain first. Regardless of how the symptoms present, usually by the end-stage of Lewy Body dementia, a person will have profound dementia symptoms as well as movement issues.

Core Features of Lewy Body Dementia

It is important to know that there are some core features that appear in many of those with DLB. Each person's experiences and symptoms are unique, and they may not have each of these issues, but generally, for a diagnosis of probable DLB, they must exhibit at least two core features. The features that are considered core criteria for DLB are that fluctuations of both cognitive and non-cognitive symptoms, visual hallucinations, and movement abnormalities called parkinsonism symptoms.

As with other dementia types, the person must experience a progressive cognitive decline that interferes with their normal activities. In addition, people with dementia with Lewy bodies generally have more issues with executive functioning. So, things such as trouble maintaining attention, judgment, planning, and organization may be seen relatively early. A person with DLB may become disoriented to time or location. And in general, those with DLB may have more trouble retrieving information that has already been stored vs. an encoding problem with memory that occurs with Alzheimer's disease. Because memory isn't always affected, many family members think the person is faking it. However, because memories with early DLB may be stored but more difficult to retrieve, it may mean that cues may be more helpful in triggering a memory. If cues are helpful, it may be helpful to use pictures on cabinets or drawers or leave items out that trigger the person to do what they are supposed to do.

Another problem that may make it difficult for caregivers to understand is the fluctuating dementia symptoms that are thought to occur in as many as 15-80%. These fluctuations or changes in cognitive skills may come on suddenly and may last minutes, hours, or even days. Fluctuations can be interspersed with periods of near-normal functioning. Early in the disease process, there are just glimpses of altered functioning, but as the disease progresses, cognition is abnormal more often than not, with a few hints of near-normal functioning.

The fluctuations also seem to influence alertness. The person with dementia will be alert and then suddenly have acute episodes of confusion or staring off into space. These fluctuations can occur at any time of the day and maybe even multiple times a day. Still, because these fluctuations commonly happen in the evenings, the symptoms are commonly attributed to "sundowning" and are not recognized as a feature of DLB. These fluctuations may also be seen in their physical skills and activities of daily living. They may be able to walk one day and may need help walking the next. Or they may be able to be independent of dressing in the morning but unable to do so in the evening.

Visual hallucinations and visuospatial dysfunction may be the best predictor of DLB. In DLB, hallucinations may even appear prior to cognitive symptoms, which can be confusing and scary. Visual hallucinations are quite common, and studies demonstrate that they occur in 59-80%. These hallucinations are usually, but not always, visual and are not necessarily frightening to the person. The hallucinations in DLB tend to be recurrent and well-formed, and many times, they consist of children or animals. Some people know they are experiencing hallucinations, but many will not have this insight. In that case, it is best to work within their reality, and if the person is not bothered by the hallucinations, it is best not to try to correct them or tell them there is nothing there.

Another sign of Dementia with Lewy Body is sleep disorders. The sleep issues in DLB are also called REM Sleep Behavior disorders. During periods of REM or deep sleep, the person with DLB will act out or talk in their sleep; they may thrash around and injure their sleeping partner. These active dreams may appear decades before any signs of dementia. REM Sleep Behavior Disorder may be the earliest symptom of LBD in some patients and is now considered a significant risk factor for developing LBD. It was found that nearly two-thirds of patients diagnosed with REM Sleep Behavior Disorder developed degenerative brain diseases, including Lewy body dementia, Parkinson's disease, and multiple system atrophy, after an average of 11 years of receiving a diagnosis. Those with Lewy Body disorders also generally have problems with daytime sleepiness and, therefore may fall asleep very easily and nap often during the day.

Lewy bodies attack the Autonomic nervous system too. The autonomic nervous system is the part of the nervous system responsible for the control of bodily functions not consciously directed, such as breathing, heartbeat and blood pressure, temperature regulation, and bladder and digestive processes. We don't actively control these functions, but they are crucial. And this can cause issues that are unique to dementia with Lewy bodies and can also be troublesome and contribute to safety issues. Some of the issues that can be seen as a result are extreme fluctuations in blood pressure, particularly upon rising or changing positions. This occurs in about 50% of people with LBD. The person may suddenly drop to the ground, faint, or even lose consciousness. They may have even more problems with their blood pressure after a big meal.

The autonomic nervous system also controls the functioning of the gastrointestinal tract, which can result in sluggish digestion and chronic constipation. Constipation, which is a common issue with LBD, is not usually solved with changes to eating habits or laxatives and can be a

significant issue for the person. They may also have problems maintaining bladder functioning because the autonomic nervous system controls the bladder and all of the sphincters of the body. When these don't work right, urine may remain in the bladder, and this can cause frequent UTIs.

Additionally, some of the throat muscles are controlled by the autonomic nervous system, and as these muscles weaken, it will make swallowing more difficult, and this can happen much earlier than we typically see swallowing problems in many other dementia types.

Repeated falls are common for people with Lewy Body diseases, both DLB and Parkinson's disease dementia. Falling can be a very early symptom of dementia with Lewy bodies (DLB) and may occur with or without a trigger. It can be related to parkinsonism symptoms previously discussed, cognitive fluctuations, or to blood pressure control fluctuations that are common. But some people just suddenly seem to lose muscle tension, and they fall to the floor without warning. About half of all people with DLB will experience 'freezing' while they are moving. They stop suddenly for no apparent reason and can feel as though their feet are stuck to the floor or that they can't move easily, which can make them feel unsteady and put them at risk of falling. 'Freezing' can last for a few seconds or minutes.

Turning around can be a particular problem that can also lead to falls. People without a movement problem can normally turn around to face behind them (turning 180 degrees) in two or three steps. But people with parkinsonism may need to take four, five, or more steps and these steps tend to be small. When possible, aim for a gradual rather than sharp change of direction, as people with Lewy body disorders can have trouble shifting their weight.

It is thought that those with dementia with Lewy bodies may have more visuospatial issues than those with Alzheimer's disease. That is, they have more problems interpreting all the incoming visual stimuli, so things either take longer to interpret or are fuzzy, so their brain may misinterpret what they are actually seeing. These issues may account for the increase in delusions and misperceptions that are common in DLB. Many say that objects seem to move or change shape or color, or they have a harder time determining what something that moves quickly is. The visual issues commonly seen are difficulties with depth perception, object recognition, directional sense, and illusions. They also may have problems with contrast sensitivity, and they may perceive normal lighting as brighter than it actually is. They may have more issues with getting lost, even in familiar environments, or may not recognize their home or spouse. Again, this too can fluctuate, which can be perplexing to caregivers.

Delusions occur in 56% of DLB persons at first presentation and in just over 65% at some point in the disease. Compared with delusions in Alzheimer's disease that are based primarily on memory loss, delusions in DLB may be more fixed and complex. Part of the problem with delusions is that the person truly believes their behavior is rational. Delusions of spousal infidelity and theft are common. Other common delusions believe their home is not their "real home" and trying to find their home or believing their spouse or family members are not who they say they are. These delusions may start well before any other cognitive symptoms. These

can be very traumatizing to the family. These delusions will also fluctuate, so one moment they may be looking for their wife, who is standing in front of them, and the next moment they will ask their wife where she has been.

Although Sensitivity to particular drugs will vary with each person, it is a significant factor that must be considered in Dementia with Lewy bodies and can be a troublesome issue for many caregivers. Even in small or therapeutic doses, certain drugs can cause extreme sedation, increase rigidity, and confusion that can last for days or even weeks. The riskiest drugs include anti-anxiety drugs, anti-psychotics, cold and allergy drugs, older anti-depressants, and some Parkinson's drugs. Many DLB patients will manifest the motor symptoms of Parkinsonism, but unfortunately, the anti-Parkinson drugs often make the cognitive and behavioral problems worse and thereby force a choice between the lesser of two evils.

Who Gets Lewy Body Dementia?

Although researchers are unsure about what causes improper Lewy protein folds, they currently believe that in most cases, genetic and environmental factors interact to cause Lewy Body disorders. As with other dementias, age is the most common risk factor.

Genetics accounts for a small percentage of those diagnosed with LBD, but if a family member has been diagnosed, there is a greater chance that others in the family may have a greater than average risk of developing Lewy body disease. A family history of PD, history of stroke, and even APOE genetic variant found in many with Alzheimer's disease was also associated with increased risk.

As discussed previously, those with active dreams or certain sleep disorders are more likely to go on to develop a Lewy body disease. The active dreams may appear decades prior to any signs of dementia or Parkinson's disease.

Finally, although the loss of smell may not increase the risk of developing LBD, it is a common warning sign as many with these disorders do experience an early loss of smell, particularly in Parkinson's disease, as the brain damage that occurs is very near the olfactory nerve for our sense of smell.

Treatment

There are no approved medications for behavioral treatment in DLB. For movement issues in Lewy body disorders, medications are used to help with dopamine deficiency. Those with PD seem to get some benefits from these particular medications. However, in those with dementia with Lewy Bodies, these medications may have no effect and may even make hallucinations, delusions, or confusion worse.

It has been suggested that treatment with Cholinesterase inhibitors, common treatments for AD, may be more effective in dementia with Lewy bodies than Alzheimer's due to early loss of

acetylcholine that is associated with DLB. In a small minority of patients, motor features are worsened with cholinesterase inhibitors.

Resources:

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