Lewy Body Dementia: What you should know about this frequently misdiagnosed and mistreated disease

On August 26, 2021, Banner Health Foundation presented an online presentation and discussion featuring clinical experts from Banner Alzheimer's Institute: Allan Anderson, MD, Director, BAI – Tucson, and Helle Brand, PA. The program was moderated by Heather Mulder, Associate Director of Outreach Research for BAI. Dr. Anderson and Helle Brand, PA answered the following questions after the session due to time constraints:

Questions:

Q: Is Lewy Body Disease genetic?
A: Lewy body dementia is not considered a genetic disease, but having a family member with it may increase a person's risk. Most cases are considered sporadic, without any genetic links. There are a smaller number of familiar cases of Dementia with Lewy Bodies.

Q: Could you please explain the symptoms of Lewy Body Dementia?
A: Dementia with Lewy bodies symptoms include visual hallucinations, fluctuations in concentration and alertness, memory and cognitive changes, REM sleep disorders, and movement symptoms of slowing, losing balance and coordination, tremors and stiffness. Sensitivity to medications and temperature, problems with blood pressure, fainting or near fainting, incontinence, sexual dysfunction and/or constipation are some of other symptoms that can also be seen.

Q: What is the prognosis for Lewy Body?
A: Dementia with Lewy Bodies as well as Parkinson's Disease Dementia are progressive, meaning all symptoms gradually worsen, causing loss of all function ultimately and ending in death.

Q: What is the life expectancy difference between Alzheimer's and Lewy Body Dementia?
A: We generally talk about life expectancies for dementias running from 7-10 years, with health complications, age of onset and complications from the dementia as variables. In general, the life expectancy in Lewy Body Dementias is shorter than Alzheimer's disease.

Q: Will there be a recording of this program?
A: Yes, please view the recording here: https://www.youtube.com/watch?v=VUOUWRwzJE0

Q: Does the isolation from SARS Co V-2 accelerate patients with Lewy Body neurologic deterioration?

A: As we discussed, losing normal routines outside the house, losing social contact, having less physical activity contributed to greater concerns for depression, anxiety, more general deconditioning (weakness, decreased endurance)

Q: What is the LBD arm movement mentioned in the presentation?
A: They can have tremors, or shaking in their hands, decreased dexterity, rigidity, and might later have abnormal movements in their arms that might be due to medication side effects

Q: Why did TK fall to the floor? I don't recall that is a typical LBD symptom, or is it?
A: These diseases often effect the autonomic nervous system. This can lead to changes in BP including drops in BP upon standing leading to falls.

Q: Does this dementia cripple the patient's body?
A: Yes, it makes their body very stiff, movements hard to control, loss of balance and coordination, and make walking very difficult as the disease progresses.

Q: How are high blood pressure and diabetes associated with dementia? (see next page)
A: What affects the heart also affects the brain, so any heart disease, hypertension, diabetes, high cholesterol, history of strokes are considered risk factors. They may specifically cause vascular dementia, which can also be mixed with other forms of dementia. These conditions are also all considered risk factors for Alzheimer's disease.

Q: Are violent episodes common with Lewy Body?
A: Violent episodes can occur in all dementias, but are not the norm or common.

Q: What percent of LBD patients and/or Parkinson's patients have a history of sleep disorders before their symptoms appear?
A: It is true that the sleep disorders may often appear before other symptoms, sometimes present for years prior to the occurrence of other symptoms. We do not know the specific percent of cases in which this occurs.

Q: Do I understand medication is to treat symptoms rather than to treat the disease itself?
A: For the most part, medications are targeting symptoms including Parkinsonian movements, cognitive deficits, hallucinations, depression, anxiety, REM behavioral sleep disorder, and others. The treatment to improve cognitive deficits, while considered symptomatic, often address other symptoms of the dementia. We look forward to the day when there might be a treatment that addresses the core of the disease.

Q: I am pastor who visit people in care facilities. Do I need to approach a Lewy Body Disease patient differently than I would an Alzheimer's patient?
A: The approaches are the same, respectfully, calmly and patiently. Make sure you have good eye contact and are in a quiet environment because it may be hard to hear them. They should, when possible, be optimally positioned in sitting so that they can best see you and engage. Validate feelings, offer reassurance, address their spiritual side as they are able.

Q: What is the typical age range for this disease?
A: Typical age range may be between 50-85, but those over 60 are at greater risk. With peak age range for development maybe between 70-79, according to one study. It affects men more than women.

Q: Is there a relation to assumed LBD and overuse of antihistamines?
A: Antihistamines generally are not recommended for anybody with dementia because of the potential for increased confusion. They block, as anticholinergic medications, the sending of signals in the body and the brain. One study published in JAMA suggested some risk for dementia from taking anticholinergic drugs such as diphenhydramine and other antihistamines, in higher amounts and often every day. It is a risk, not a given. It is important to know that these older sedating antihistamines are often ingredients of over the counter sleep aids. Experts in dementia care advise patients to avoid such medications.

Q: Could treatment for sleep apnea be a very early treatment?
A: Sleep apnea is not necessarily a condition that is commonly seen with LBD. It can occur and it is vital to address it and offer treatment like use of CPAP as untreated obstructive sleep apnea is a risk factor for dementia.

Q: Is the wellness center/gym open yet?
A: The wellness gym and physical therapy program will be open this fall and is located at Banner Alzheimer's Institute - Tucson, 2626 E River Road, Tucson 85718. The phone number is (520) 694-7021.

Q: Is there one test that can make the diagnosis?
A: The diagnosis is made from a clinical presentation, cognitive and neurological testing, and imaging, like CT, MRI and/or DaT scan. No single test is definitive.

Q: Is there a connection between Valley Fever and Lewy Body Dementia?
A: Valley Fever is a fungal infection that can affect the brain, causing meningitis, headaches or cognitive complaints, but not Lewy Body Dementia, which is caused by the presence of protein deposits called Lewy bodies inside the cells of the brain.

<u>Case Questions:</u>

Q: My mother recently passed at age 90 after being diagnosed with LBD when she was 80. Throughout, she exhibited bizarre behaviors and had constant hallucinations. I did not hear anything about that with TK. She also had a lot of anger when anyone tried to prevent her from displaying those behaviors (e.g., hiding things and thinking they were stolen, wearing inappropriate cosmetics, dressing poorly when she was always concerned with her appearance). Does that sound like LBD or do you think she may have been misdiagnosed and didn't really have that form of dementia?

A: The anger you are describing is not unique to DLB, rather a response to communication. Her behaviors were consistent with memory loss, not understanding the world the same way, not remembering how to dress, and when challenged, corrected or reasoned with, or told "No, you can't". People with dementia can become angry. Hallucinations are part of DLB, but can be unique to each person as to when they occur, and how much. They can trigger behaviors like agitation if they are frightening.

Q: I believe my 88-year old sister-in-law, who lives with us, may have LBD but has not been diagnosed. Where do we start to have her tested and get her help she may need?
A: Contact Banner Alzheimer's Institute in Tucson at (520) 694-7021, Phoenix (602) 839-6902, or Sun City (602) 832-6530, depending on where you live.

Q: I have REM sleep disorder that started about three years ago and has gotten more severe recently. They are recommending a sleep study after an at-home one with central sleep apnea. Would a brain scan be recommended or a good course of action?
A: Unless you have symptoms suggesting some neurodegenerative problem, or recommended by your physician for any other reason, there would be no reason to have a brain scan.

Q: My mom had a kind where her body was 100% crippled and she lived with it for about five years (before that her mind was failing). Was it LBD?
A: If she displayed the symptoms we talked about, it is possible that she had dementia with Lewy bodies. It is possible, too, that some people in later stage Alzheimer's disease lose the ability to walk and may become bed-ridden, so without knowing the full clinical picture, it would be hard to say whether she had a Lewy Body Dementia.

Q: I am a retired psych nurse (RN) formerly with the VA and The Air Force Reserves. I also have a BS in Natural Resources. So I tend to look for answers in a more open sphere than the narrow one of humans. In California, there is a Bristle Cone Pine tree named Methuselah, which they feel is 1,500 years old (example). To look at it (I have seen it closely enough to touch and examine closely). It appears to be mostly dead, but with a portion of live bark on one or two sides with dead heart wood in the middle. In some mountains in the Near East where there are mountains inhabitants have a tendency to live very long lives (I read about this in Scientific American possibly 30 years ago). These long-lived people were thin, very hard-working and vigorous. Could it be that because we may be eating too much? And that Alzheimer's or Lewy Body Disease is a result of too constantly high concentrations of nutrients? So that fasting may be a helpful therapy. I have seen this not just in humans, but other organisms (trees). Another factoid I have heard is that six of the world seven main religions have fasting as part of their ritual. Christians used to do it until Catholicism said it was okay to eat fish on Fridays. Because no one likes to fast if they can get away with it. I have read from more scientifically-based research that fasting does have merit. What do you think?
A: As you have studied, and more and more research points to, the merits of consistent exercise and healthy diet, more specifically, focusing on the Mediterranean/Mind Diet in controlling risk factors and benefiting general health and many disease states are significant.

We used to be nomads, we worked all day, we subsided on many of the foods from nature, but our diets and our lifestyles have changed, witness the obesity epidemic. Inherent to those days likely were times of fasting, if only because of hardship. There are animal studies that would support some form of intermittent fasting as protecting the brain. These were done in animals genetically engineered to have abnormal brain amyloid accumulations such as what we see in Alzheimer's in humans. To date there have been no human trials of any size that would support a benefit of intermittent fasting. Intermittent fasting may also be problematic for some individuals such as patients with diabetes.