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Dementia with Lewy Bodies • December 2, 2016

EDITOR'S PEN

Gary Barg, Editor-in-Chief

Caregiver Thought Leader Interview: Scott Losk, PhD

Principal Investigator
Summit Research Network

Gary Barg: Let's start at the beginning. What is dementia with Lewy bodies?

Dr. Scott Losk: Dementia with Lewy bodies happens to be the second most common cause of dementia affecting somewhere between a million and a million and a half people in the United States.

The symptoms are very different from Alzheimer's disease though. I know that people get them confused, but the symptoms are different, especially the symptoms that we see early on in the course of the disease. Symptoms include visual hallucinations or seeing things that are not there. A large percentage of afflicted individuals experience REM sleep behavior disorder, so sleep is disrupted by thrashing around and sometimes really bad dreams. It is an impairment in the actual cycle of sleep.

Some of the other symptoms include variability in the level of alertness or arousal that a person may have. Cognitive symptoms include visual-spatial dysfunction, maybe some memory dysfunction and then what we call executive functioning impairment is often seen. This is a difficulty with mental tracking and organization and planning and those kinds of things.

The pathology in Lewy Body Disease are alpha-synuclein bodies that affect the brain in different places than the plaques and tangles we see in Alzheimer's disease. Which is why we get the different symptom presentation.

Gary Barg: And it is harder than most dementias to diagnose from what I understand.

Dr. Scott Losk: If you are not aware of some of the early kinds of symptoms, you might miss it because you are looking for well, how bad the memory is or, how bad is one's ability to learn new information? And frankly, a lot of my Lewy body patients are still able to learn fairly well. On memory testing they might actually perform at something close to the normal range and that is obviously very different than what we see in Alzheimer's disease. So, if we see some of these symptoms I have described earlier, early in the course of the dementia, the evaluator (neurologist, geriatric psychiatrist, neuropsychologist, even primary care physician) needs to be thinking dementia with Lewy bodies (DLB). Then if we see any Parkinsonian symptoms in the individual, it is highly likely that DLB is going to be the more accurate diagnosis.

Gary Barg: We just had a conference in Tampa and a lot of the morning was taken up talking about Alzheimer's and at lunch a lady said, "Please talk about Lewy body. It's so much more difficult than just having a loved one live with Alzheimer's because I've had both."

Dr. Scott Losk: I've got a couple of situations where mom has dementia and the caregiver's sixty-five-year-old husband also has dementia. So both cases are unrelated. There is no heredity, there, but this person happens to be a caregiver for two people with Alzheimer's or dementia. A horrible situation, but certainly, I think for caregivers, it is important to help the physician understand that the symptoms in each person are not the same. Because frankly, the patient with dementia with Lewy bodies may walk into the primary care doctor's office and take that brief Mini Mental State Exam, or that MOCA, and perform nearly perfectly. Then the primary care doctor may say, "Oh, there is nothing wrong with you. You do fine on this brief memory test." Well, the problem is that particular cognitive test does not measure what we need to be measuring in early onset dementia with Lewy bodies. We need a robust assessment of executive function, of visual spatial function and then a robust history that tells us more about the sleep disturbance and the hallucinations and about Parkinson's type symptoms. So it can be difficult to diagnose, but in the hands of a skilled evaluator, this differential can be made relatively easily.

Gary Barg: And Lewy bodies came into the public eye two years ago when Robin Williams had experience with the disease. Tell me some of your thoughts about his story.

Dr. Scott Lusk: Yes, it is a horribly sad story. I'm convinced that one of the cognitive attributes that makes a person brilliantly funny is to be able to tell a story, or to tell a joke, and then at the very end, the path where your brain is going, is not where his brain goes, and it ends up being this disconnect that happens to be hilarious. And he had an incredible gift for being able to do that. He had what I would call extremely advanced frontal lobes. The frontal lobes are responsible for being able to reflect on one's own condition, being able to plan for the future and being able to empathize with other people. It is also that gut level intuition that comes from the frontal lobes. So he was acutely aware of his brain changing at the hands of dementia with Lewy bodies.

Gary Barg: You are involved with a clinical trial dealing with DLB, aren't you?

Dr. Scott Lusk: Yes, we're involved in the first and only ongoing clinical trial for dementia with Lewy bodies. We are looking at a new compound that enhances the cholinergic system in the brain. That's one of the systems in the brain that's responsible for not only new learning and memory, but also the management of mood and to some degree other aspects of behavior.

This compound is really meant to be an add-on to ongoing therapy. Typically, we use some of the same compounds for the treatment of DLB that we use in Alzheimer's disease, including Aricept (donepezil), Exelon (rivastigmine), Razadyne (galantamine) and Namenda (memantine). The compound we are studying, RVT-101, is really designed to further enhance cholinergic functioning and hopefully help with the management of symptoms in the afflicted individual.

Like any clinical trial, this is a double blind placebo controlled trial and participants are randomly assigned to one of three groups. There is a higher dose group, a lower dose group and a placebo group. A study must have a placebo group as a control group to compare against because if we do not use that control group, we cannot measure the difference between how people are doing on the active medication and how people do with no medication alone. And that measurement, that ability to measure that difference, is what either gets a medication through the FDA and gets their approval, or not. The medication of course has to be safe and well tolerated, but efficacy is that piece that allows us to say, hey, this medicine does a better job than taking no medication.

Gary Barg: How does a caregiver whose loved ones are living with DLB find out about the trial?

Dr. Scott Lusk: There are a couple different ways to find out about this

particular trial. There is a dedicated website, Lewybodystudy.com, or you can call 855-235-1529 to find out whether or not an individual may qualify for participation.

Gary Barg: Would you have any specific advice for DLB family caregivers?

Dr. Scott Losk: Yeah, I actually do. One, is if there is still a lack of clarity as to what your loved one's condition is, first and foremost spouses and caregivers, adult children, really need to be assertive about getting the necessary evaluations done, or referrals to specialists. In this particular case it is neurology, geriatric psychiatry or get them into the hands of a competent neuropsychologist who can do a detailed evaluation.

As a family caregiver, it is of critical importance to not allow your loved one's disease to completely and totally own you. I mean, it is going to have a huge impact, there is no way around that, but maintaining some of the interests, activities, socialization and involvement for the caregiver in their regular routine, is crucial. And hopefully being able to have one or two or three friends and loved ones that they can share some of their burdens with, and some of their experiences with, and so forth.

The other piece is just to continue to get better and better educated. The involvement in a clinical trial, in a study, will result in getting educated. Not only about the study, but about the condition under study. In this case, it's dementia with Lewy bodies and learning more about symptoms, prognosis and more about how to manage specific symptoms with medications and some behavioral interventions is also a very important piece for caregivers.

Scott Losk, PhD, obtained a doctorate at Fuller Graduate School of Psychology in 1989, and did a post-doctoral fellowship in medical psychology at Oregon Health Sciences University. He has been in private practice since 1990, with an emphasis on clinical psychology, neuropsychology, and geriatric psychology. Dr. Losk joined Summit Research Network, formerly Pacific Northwest Clinical Research Center in 1990. He has been an investigator in over 100 clinical trials evaluating treatments of disorders of the central nervous system, and the principal investigator in over 75 clinical trials evaluating treatments for Alzheimer's disease. Dr. Losk is currently conducting a clinical trial for dementia with Lewy bodies, which is the second most common cause of dementia after Alzheimer's disease.

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