

Seizing Life, episode 113
The Crucial Role of Nurses in Epilepsy Care
Guest: Lucretia Long
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy. Today on Seizing Life, I'm happy to welcome Lucretia Long to the podcast. Lucretia is an advanced practice registered nurse and a certified nurse practitioner at the Ohio State University Wexner Medical Center. She's been working with epilepsy patients for over 30 years, and is here today to inform us on the training and responsibilities of an advanced practice provider, and to offer her perspective on the current state of epilepsy care. Lucretia, thank you so much for joining us today. I'm going to check my notes because I want to make sure I get this right. You are an APRN and ACNP. So, for those in our audience who may not know what that alphabet soup of letters means, can you explain it to us?

Lucretia Long: Absolutely. So, I'm an advanced practice registered nurse and certified nurse practitioner. And really what that means is I'm a registered nurse with advanced experience and education. We are trained to not only diagnose and treat patients with acute and chronic conditions, but also to manage patients and families suffering from acute and chronic conditions.

Kelly Cervantes: Thank you for that explanation. And now, your focus is in adult epilepsy care. How did you end up in that specialty? Do you have a personal connection to epilepsy?

Lucretia Long: So interesting. I have one of my colleagues, Dr. Moore, many, many years ago. I've been at Ohio State for a super long time, actually about 30 years. I tell people while it was me and Jesus who started the Epilepsy Monitoring Unit, that's how long I've been there. But I originally worked as a neurology and neurosurgical staff nurse. And at the time my now colleague, Dr. Moore, was interested in hiring a nurse for the epilepsy clinic. And so, he approached me and asked me if I would be interested. And originally, I thought, you just need to give them Ativan. Why do you need a nurse to do this?

And then certainly after I explored the field of epilepsy, became very interested and basically fell in love with the opportunity to care for patients and families with epilepsy. So, that's how my initial experience occurred. But I do have somewhat of a personal story. My husband's, my mother-in-law had breast cancer that metastasized to her brain and she actually had a seizure. It wasn't epilepsy, it was a seizure provoked by her brain tumor. So, I do have somewhat of a personal story in terms of epilepsy.

Kelly Cervantes: I'm sorry to hear that. But we are so grateful that you did become interested in epilepsy and that the doctor did pull you into the clinic. You mentioned that your focus is with adults. I wonder what kind of adults do you typically see in the clinic? Is it a wide variety in how they developed epilepsy, either acquired or genetic? How many have developmental disabilities and that sort of thing?

Lucretia Long: Very good question. So, I have a really diverse patient population. We often time in the tertiary care center will get patients with epilepsy who have been diagnosed for quite some time. So, I don't see a lot of new diagnosis with epilepsy. Many of the patients that I see have been seen by either a primary care doctor or a general neurologist, and then they refer them to our center. I would say about 30% of patients that I see have what we call a static encephalopathy. So, they are developmentally delayed, but about 70%, they look like you and I, of course. And so, we have many patients who are doing really, really well. And then I have a host of patients who are what we call a little more difficult to treat or intractable, where they're not necessarily responding to pharmaceutical intervention. And so, we may need to entertain some non-pharmacologic management, neuromodulation, and other epilepsy surgeries and some of those other treatment modalities.

Kelly Cervantes: It's interesting. It's a similar percentage, I guess, which is what you would expect to hear, is the rule of thumb or what is out there in the literature, is two thirds are able to have their seizures treated with a first medication and a third are intractable. So, it's interesting that that is actually what you see in your clinic as well. I wonder what are your daily responsibilities with your patients?

Lucretia Long: So, my role is in the outpatient epilepsy center. And again, my priorities are taking care of patients with epilepsy. So, I'll see a patient in the clinic independently. Advanced practice providers are able to manage patients without a physician necessarily being on site. So, I have pretty much my own practice, although I collaborate with some epileptologists. And so, we basically talk to patients about their clinical presentation. I'm very passionate about patient education. So, not only do I implement treatment modalities, but I also am a huge advocate for self-management. And so, I do a lot of counseling. We implement seizure action plans, we talk about SUDEP risk reduction. SUDEP is sudden unexpected death in patients with epilepsy and it happens in about one in 1,000 adults with epilepsy. But we see a three times incidence of SUDEP in people who have three seizures within a 12-month time period. And so, I'm really very, very passionate about patient and family efficacy, and really giving patients the resources that they need to manage this diagnosis.

Kelly Cervantes: I want to go back. You have your own practice, you see your own patients. You said you do collaborate with neurologists. I wonder what that interaction and collaboration looks like. And also to that end, what is the difference between a patient seeing you versus a patient seeing a neurologist?

Lucretia Long: Yeah. So, what we do in clinic is just about the same. Advanced practice providers, we don't read EEGs and we can sort of read MRIs, but we certainly like to collaborate with, in this case, with our epileptologists, also with our radiologists and our neurosurgery colleagues as we're pursuing epilepsy surgery. And so, what we do in the clinic is basically pretty much the same. The difference again is that we don't read the EEGs, we don't interpret that. And so, we work as a collaborative team in those efforts. Many advanced practice providers across the country do see newly diagnosed patients with epilepsy.

And our center is set up for the physician, epileptologist to see new patients and then we see those patients in follow up. But certainly, we are very qualified to do neuromodulation to refer patients for receptive surgery. And so, we work as a collaborative team, but we do practice at the top of our license, which is again, diagnosing, managing treatment, treating and collaborating with our epileptologist.

Kelly Cervantes: That's incredible information to know, especially as patients are out there looking for care to know what kind of providers are available to them. You mentioned that one of your passions is patient education. And I wonder, do seizure action plans fall into that category? Do you help patients with seizure action plans? Because I think a lot of times people think of them mostly for pediatrics, something that the school needs to have or camp or afterschool care clubs, whatever, but I think we can agree that they're really important for adults to have as well. And is that something that you work with your patients on?

Lucretia Long: Absolutely. It's a wonderful point. I'm actually on a advisory board and we focus on exactly what we're talking about, the importance of disseminating what we know in terms of research into practice. And so, certainly, seizure action plans have been used for a long time, predominantly in the pediatric space. I'm actually working on my doctorate of nursing practice at Duke University, and my project is directly correlated with the utilization or increased utilization of seizure action plans in an adult epilepsy clinic. And so, I have been grateful to collaborate with some epilepsy experts across the country where we created what I think is a really amazing one-page seizure action plan. It's nice because it's color coordinated. And so, not only is it nice for patients, in our practice, we actually hand them out to patients when they're registering so that they can document what their triggers are.

And then that patient will speak with the provider, myself or another epileptologist, and they'll talk about what the triggers are. We'll go over how to look at seizure emergencies and how to identify those emergencies, how to intervene with rescue medicine. And then we'll talk about when to call emergency services. And it's really important as we look at reducing the risk of status epilepticus or those prolonged seizures, and also looking at risk reduction for SUDEP. So, all of these things come into play. And as advanced practice providers, I think we have an amazing opportunity to implement seizure action plans and counseling interventions as it relates to some of these challenges as we see with morbidity and mortality in this group, special population and patients with epilepsy.

Kelly Cervantes: Can I just say that you are amazing and your patients are so lucky to have you. Because I think that this is to me, and I think to a lot of people who have been in and out of this epilepsy world for years, understand how important this is, but it is so overwhelming as a patient or a caregiver to tackle these issues, to know when emergency services need to be called, to know and decipher what those triggers are. And having someone who can hold your hand and help you fill out a piece of paper is everything. And that can truly save lives and money, and

ambulance rides, and just general safety. It's really remarkable and I wish that more providers out there provided this sort of counseling.

Brandon: Hi, this is Brandon from Cure Epilepsy. Have you or a loved one been recently diagnosed with epilepsy? Are you looking for more information about epilepsy and available treatment options? Go to cureepilepsy.org/for-patients, to get resources and information about epilepsy. Now back to Seizing Life.

Lucretia Long: I think we have to do a better job as healthcare professionals and really prioritize allowing patients to receive the resource. It's our job to do that, to receive the resources that they need so that they can live amazing lives and to improve the quality of life so that they can go out and do what they enjoy doing. And so, I love the idea of patients also being advocates. And so, one of my roles was really to allow that patient to go into that provider and say, "I want you to help me with this action plan so that we are empowering patients and families." That's our job. I mean, that's why they come to see us. So, I feel that we owe it to them to give them what they need on a day-to-day basis. So, I appreciate that comment.

But my goal is not only to do this at Ohio State, that's a start. And I, again, am on a couple of boards where I'm really passionate about how can we disseminate this information across the board. And so, not just in Ohio, but across the board, as we look at adults with epilepsy. Adults deserve an action plan, as you mentioned, just as our pediatric population does. And it really becomes a challenge. As a healthcare professional, I can appreciate the time restrictions that we have. And so, again, our job with this seizure action plan was, okay, how can we make this efficient? So, we're including the information that's relevant for patients, but also understanding and appreciating the time constraints that providers have.

And I think we've been really, really successful. We actually published this action plan in, I believe it was in epilepsy and behavior. And so, we're able to not just disseminate it within our clinical practice, but publish it so that we can educate providers on the fact that we now have something that's time efficient, that can be super relevant for patients and families. In my mind, every patient deserves a seizure action plan. I don't care if they're seizure free or they have intractable epilepsy, I think the plan is different for each individual. But every single patient with a history of seizures deserves a seizure action plan.

Kelly Cervantes: Could not agree more. And I want to dive into something that you just brought up, which is the time that providers have with their patients. And this is something that we hear over and over again from patients and caregivers, is that they just don't have enough time with the provider and the wait times to get in to see someone can be months. And that's critical time when someone is actively seizing. Why do you think that is? What is the issue with the constraints there and is there anything that we can do about it?

Lucretia Long:

Yeah. So, I think there is really quite a bit that we can do about it. And really, the time depends on that provider's practice. So, for example, a lot of the neurology advanced practice providers and physicians who are maybe in private practice, they're going to have a little more time constraints than maybe we do at a tertiary care center. I've talked to a couple of, many actually, advanced practice providers across the country, and some of them have 15 minutes or 20 minutes to see a patient. And in my mind, that's not enough time to provide patients and families with what they need. And so, in those cases, our goal is to try to give them resources that they need, like the ASAP acute seizure action plan, so that they can use their time efficiently. But also, so in my center, we are grateful that we have the advanced practice provider. And I'm the lead outpatient advanced practice provider, and I've advocated for us to have a 40-minute time slot for all of our return patients.

And that gives us enough time to give them the counseling information that they need. And we really like to identify not only what we think is important, the seizure action plan, obviously compliance and suit up risk reduction. But also to entertain, okay, for you as a client, what is important to you and what goals can we establish together so we can move forward in a collaborative approach to get you where you want to be in terms of your epilepsy outcomes? So, I think that it really depends on the location you're in. And I'm just grateful in our department that our department chair is on board with the importance of advanced practice providers and what we bring to the table in terms of counseling and giving us the time and resources that we need to move forward.

The other important point that you brought up is access. And we know across the board that there is a decrease in the amount of physicians who are either interested in neurology or applying for that subspecialty. And it may even be across the board, even in primary care. I'm just more familiar with the epilepsy and neurology space. And advanced practice providers really serve an amazing role in terms of an opportunity to bridge that gap with access. So, on a national level, myself and other people across the country are looking at epilepsy, advanced practice provider, really neurology, advanced practice provider fellowships, and how can we engage our schools of nursing into a collaboration so that those nurses who are coming out are interested and not intimidated by neurology. So, we do a lot of precepting, we do a lot of onboarding. I collaborate with our college of nursing and we have students come over to see what we're doing so that we can increase that interest. And I think that will in a long run allow us to improve patient access.

Kelly Cervantes:

That is amazing to hear that there are already programs in place and people like you leading them that are helping to bring more people into the field, because it is really frustrating. And I know it's hard for the practitioners too, because they're putting in all of these hours and still the wait lists are long. And so, I can only imagine how draining that is. Back to these topics that so desperately need to be talked about within those clinic appointments. I can't even imagine how you get through any of it in 15 to 20 minutes, but hopefully you get closer to 40 minutes, because there are these topics that needed to be discussed like SUDEP,

which I know is something that you are also passionate about educating patients on.

Lucretia Long:

Absolutely. And so, interestingly, I don't know how many years ago, but I was at the American Epilepsy Society many years ago, and there was a lady at the table of the SUDEP table, and I went over to chat with her and she had mentioned to me that her sister had died of SUDEP. And she was very angry, not angry, she was upset that the provider didn't tell her and her sister about SUDEP. And so, I asked her, "Well, what do you think would've been different had they counseled and educated you and your sister on SUDEP?" And she said, "We would've been more compliant with her medication regimen. We would've minimized those triggers for risk recurrence. We would've made sure that she had nocturnal supervision." And she just sort of laid it out to me and I thought, wow. And so, it really sparked my interest in conducting a study where we surveyed patients and families and caregivers, care partners who were diagnosed with epilepsy, and I gave them information on SUDEP and basically asked them how they felt about SUDEP disclosure.

And they were close to 100 patients and caregivers, and 100% of those patients said that it was their right to know about SUDEP and that it was our job to educate them about SUDEP. And so, that was really empowering to me. And so, I've been on a sort of cheerleading rampage for trying to make sure that providers are educating patients and families with epilepsy. 30% of people that we surveyed said that that information made them a little more fearful, but 100% of that 30% still said it was their right to know. And then they also indicated that they would be based on hearing about that information, they would be more motivated to reduce those factors that can trigger seizures and also be more compliant. And there was a percent of those patients who were now interested in entertaining these non-pharmacologic treatment options so that we can try to embrace the idea of zero seizures, which is always a goal.

Sometimes we get there, oftentimes we get there, sometimes we don't, but that's always a goal. And so, I think that it's not the patient who doesn't want to hear about SUDEP, it's the provider who has challenges with how to present the information on SUDEP. I always tell people, it's not really what you say, it's how you say it. And so, I was grateful recently to be a part of a consortium where we developed a toolkit, not just for patients to talk to their providers about these tough conversations, but also to provide healthcare professionals with some resources so that they can learn how to talk about SUDEP. Even in that patient that is seizure free, they still deserve to know about SUDEP. And I typically will approach it and say, keep up the good work with your medication compliance. That reduces your risk of breakthrough seizures, life-threatening seizures and SUDEP.

So, no matter what that patient's presentation is, knowledge is power. And I always tell people that my job is to give you information so that we can reduce your risk. So, learning about SUDEP shouldn't be fearful. It actually empowers you. So, we can work as a team to reduce and minimize those risks. And we

certainly know from the guidelines that there are things we can do to reduce the risks of SUDEP. And so, it's really about educating healthcare professionals and patients and really giving them the resources that they need so that we can work as a team to reach outcomes for patients and families with epilepsy.

Kelly Cervantes: Yes, yes, and yes. It's not what you say, it's how you say it. And there is not one piece of that survey you conducted that surprises me in the slightest. People want to know, they have the right to know. And along the same lines of these more challenging conversations over and over, and over again, when I talk to people, mental health and mental illness continue to come up, these high comorbidity rates with people with epilepsy who have anxiety and depression. And whether it is because the anxiety and depression is caused by the situation that their epilepsy puts them in, or if it is a biological link in the brain, regardless, these comorbidities exist. Is that something that you treat in your office that you look out for and offer guidance on?

Lucretia Long: Yeah, that is so equally important. So, we actually have tools that we use to diagnose anxiety and depression. We use the generalized anxiety disorder tool, and we also use the NDDIE, which is the neurological disorder, depression inventory, and epilepsy. I had to make sure I get those [inaudible 00:22:47]. But we screen every patient, so that's a part of their registration paperwork. And based on the outcomes of those inventories, we can then either implement a treatment modality or refer them. And we do have resources, very grateful that we have resources at Ohio State where we can refer them to our neuropsychologists, or we have advanced practice providers who specialize in psychiatry. And so, typically in my practice, I will initiate maybe an initial therapy for depression and for anxiety.

But if that patient doesn't respond to that initial treatment, then I'm going to refer them over to a colleague so that we can collaborate to make sure their needs are being met in terms of counseling interventions and medication modification, because we want to make sure that they're on appropriate treatments that won't necessarily lower their threshold or cause some other interactions. And so, it's a nice process. But absolutely, you're right, talking to patients about suicide risk reduction and making sure that we're assessing those things are super important.

Kelly Cervantes: So important. And I'm so encouraged to hear that that's something that your office proactively is looking for and treating. It's so important to eliminate that disconnect between the mental health and literal brain health. You have over 30 years of practice in the epilepsy field, which is incredible. I wonder what changes have you seen in epilepsy in terms of care and treatments, the role of providers and general epilepsy awareness and knowledge?

Lucretia Long: Yeah, absolutely. I always tell people that this is a super exciting time to be in the epilepsy space. When I first started, and I tell people I started when I was three, if you're calculating my age, no, but when I first started, we were so limited in terms of treatment options. There were maybe five or six anti-seizure

medicines, and now we have over 30. And so, we have these novel medications with different mechanisms of actions, and we're certainly seeing improvements in terms of efficacy and tolerance. And so, super exciting from a medication perspective. But also we have these amazing treatment options now. We now have three neuromodulation devices. We have laser ablation and all these wonderful surgical procedures, diet modification. It's so exciting to be in the epilepsy space.

We have so much more that we can offer patients. And as you think about how important hope is for this patient population, we really, I think have made some amazing progress as we look at improving outcomes in patients and families with epilepsy. So, this has been so exciting for me to see the beginning of where we were years ago and now to see all of these opportunities. It's been great.

Kelly Cervantes: So, then as a follow-up to that, on the reverse, where do you see additional help, services and progress being needed?

Lucretia Long: Yeah. So, I think I love the idea, and we were sort of touching on this idea of customized care or how can we do a better job at predicting what treatment option will work best for what patient. And so, I think the idea of genetics and how we can incorporate and better understand the different... Epilepsy is a very diverse group as you know. And so, I think it will be super exciting if we can continue to move forward in conducting research where we can customize and precision care for patients and families with epilepsy. I think that's something that we are looking at, but we have a lot of work to do as it relates to customizing care for patients and families.

Kelly Cervantes: It sounds like we need more research.

Lucretia Long: Absolutely. I think not only do we need more research, but we need to be able to appraise that research and then to disseminate it into clinical practice sooner rather than later. There are some experts who suggest that once we've confirmed a treatment modality, that sometimes that information, even though it's published, is not disseminated until many, many years down the road. And so, I think we not only need research, but we need to evaluate what's working and then disseminate. And so, I think it is a process that we're moving forward on, but certainly we have some work to do in that area.

Kelly Cervantes: Lucretia, you are a wealth of knowledge. You have been an absolute delight to speak with. And we are just so grateful that you are able to carve out some time to talk to us today.

Lucretia Long: Thank you so much. I'm just grateful to be here. I'm delighted to have this conversation, so thank you so much.

Kelly Cervantes: Thank you, Lucretia, for sharing your vast experience and knowledgeable perspective on epilepsy care with us today. As Lucretia noted, the past 30 years

have seen an explosion in epilepsy medications, technology, and knowledge. Cure Epilepsy has been at the forefront of research that has fueled many of these advances in epilepsy treatment, but there is still much to do to achieve our goal of a world without epilepsy. If you would like to help us reach this goal, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

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