



The Brain Briefing, Episode 2

Dr. Luedke: Quality of Life in Epilepsy, Feb. 7, 2023

Credits:

Host – Maria Perrone

Guest – Dr. Matthew Luedke

Audio Engineer – Stephany Perez-Sanchez

Maria Perrone (00:00):

Welcome to the Brain Briefing, brief conversations with neurology experts with information for everyday people. With us today is Dr. Matt Luedke, a neurologist who specializes in the care of seizures in hospital patients. And today we'll be talking about quality of life in epilepsy.

(00:21):

Quality of life is a phrase you often hear, but what does it mean specifically for people with epilepsy? What kinds of things are you referring to when you talk about quality of life for someone with this specific condition?

Dr. Matt Luedke (00:33):

So quality of life is the human experience, right? It's how we experience our day-to-day existence and how our health and our livelihood and our interactions and experiences make our experience either positive or negative. A way of looking at it is, if you have a great job and a great family life, but at the same time you have chronic pain that's going to be a drag on your quality of life, even though parts of your life are good parts of your life, have a drag on them. And in the setting of epilepsy, we're faced with a couple of challenges. First, seizures even for people who have a lot of seizures, really only occupy a few fractions of a percent of your lifetime. Their impact on your life is dramatically longer than the length of the seizures. After a seizure, we can't drive; after a seizure, we might have prolonged periods of anxiety or depression.

(01:36):

Having a seizure in your workplace might make you concerned that your colleagues aren't going to treat you the same way. There might be some embarrassment there. So these brief but powerful experiences have long-lasting effects and consequences that go well beyond the end of the seizure and your recovery. And we need to account for that. Those are things that are hard to measure and they're hard to quantify. Taken away from the seizures alone though, there are other things that go along with epilepsy, for example, medications. Some people will do great on one medication and some people on that same medication will be just miserable. And everyone's neurochemistry, everyone's brain is a little bit different, and you can't necessarily expect how things are going to go before you try a medicine. And so those medication side effects, whether it be sleepiness, irritability, fatigue – those all play into the quality of life.

(02:35):

We talked a little bit about driving, but this is the United States, driving is really critical to most of our day-to-day life. We don't have excellent public transportation with the exception of a few cities. And so, to get from here to there – whether that be from work or to a friend's house, or to a restaurant, to a

doctor – can have a remarkable impact on your quality of life when you can't do it on your own and in your own terms. And while there are some things that have helped with that, for example, ride-sharing, that still costs money. And that takes us to economics – your job, your financial well-being are critical to quality of life. Financial challenges often come in situations where people have frequent seizures or even one or two seizures depending on their impact, on their job. If your job is built around driving or getting to a workplace that's far away and you can't accommodate with things like telecommuting, it can be a real problem.

(03:37):

And so all of these different domains of your life can be affected by these brief events. To our credit, we really are concerned as seizure doctors about how many seizures you've had because that's a big feature in terms of quality of life. But we also need to focus on those experiences that go beyond the seizure frequency. I'm acutely aware of the fact that about half of people with epilepsy, little less, also have anxiety and depression, and that's independent of the disability caused by their seizures. So getting that assessed and treated as well is important too. So when you work with a provider, when you work with your neurologist or your primary care doctor, or (if you work with a mental health provider) your mental health provider, talking about those things that go just beyond your seizure experience into those downstream events that are affected by these brief moments, painful moments, but brief moments in time will help them understand better your experience. And I think that's important.

Maria Perrone (04:37):

So now that we have a more clear idea of what quality of life looks like for someone who is experiencing epilepsy, how can you take stock or think about your quality of life and how epilepsy might be impacting you?

Dr. Matt Luedke (04:54):

So to study quality of life in epilepsy, there are different surveys, there are different tools that you can use. And I don't think you need them as an individual, but it sort of helps to approach it from how those surveys look at you and they break things down into different domains, the impact of seizures on your life directly. Do you get injuries during your seizures? Do you have frequent seizures? After your seizures are you fatigued for hours or sometimes days on end? Do you get confused after seizures? Have you had a shoulder dislocation or a back injury during a seizure? Those things are important to understand, right? Because again, not to dismiss seizure frequency as an important thing to measure, but for some people each individual seizure is a catastrophic and disastrous event in and of itself, and we need to understand that.

(05:44):

But for some people, each individual seizure is less of a critical issue, some people may even be seizure-free. And so if that set of questions is less important, then you still need to look at other things because that can play a major role in your life. For example, let's say you're not having seizures, but you are on medicines, and the medicines make you feel miserable. Take an account for that. Are the medicines making you sleepy? Are the medications making you nauseous? Are you grumpy? I've had family members who on some medications have almost gotten a divorce, and when we've changed the medications their relationships have improved remarkably, just because the medications can sort of tint your experience in a very negative and irritating way, and you might not even be aware of it unless you ask the question.



(06:32):

So those medicine side effects, those are important, economics, work. Is your seizure disorder impacting how you get to work? Is it impacting your ability to stay at work when you get there? Is it causing a drain on your finances? One thing that's a problem for people who have frequent seizures but are still getting out and about and participating in the world is that well-meaning colleagues or bystanders might call the ambulance on them and they're stuck with hospital bills because they get dragged to the emergency room and they don't need to. Looking at those things, coming up with strategies to address that with your doctor or your employer can be very important to improving your financial quality of life. Working with a social worker to find opportunities and options if you are out of work because of your seizures and how to pursue community resources to get the care and the services you need is a critically important thing.

(07:28):

Mental health is an important problem. I say this to many people many times, if you look at the numbers, almost 50% of people with epilepsy have anxiety or depression and it's not something to be ashamed about. It's not something that we should feel bad about. It's part of the brain chemical process that leads to seizures that seems to be hand in hand with these symptoms of anxiety and depression. And recognizing that and reaching out for help, talking with your doctor can be an important step to improving that. In the end, when you start taking an inventory of your life from these domains, it can really help you see things that you may not have been aware of before and that tie into your seizure disorder.

(08:10):

And a final domain to consider, too, is particularly adults who develop epilepsy, often their seizures are related to other health problems. And so taking care of your general health, whether it's cardiovascular disease and strokes or heart disease or other medical conditions like diabetes and hypertension, working with your primary care doctor to treat those, and engaging in healthy behaviors and activities can overall improve your quality of life. And there's that old saying, "A rising tide raises all boats." Improved general health can improve your quality of life in epilepsy as well. So sometimes it can be hard to in one gulp break down all the things that go into your quality of life. So I recommend starting with the personal inventory, look at these different domains in your life that affect your quality of life, your family life, your social life, your work life, and economic life, the medical life that you have, your other illnesses or conditions, and your medication side effects, your exercise, and physical wellbeing. And if you break these down into these different components, it can allow you to get some insight that you can't if you just approach things more broadly.

Maria Perrone (09:29):

Thanks to Dr. Luedke for talking to us today. Thanks to our audio engineer Stephanie Perez-Sanchez. And thanks to you for listening to this episode of The Brain Briefing. You can find more info about the Duke Comprehensive Epilepsy Center at <https://neurology.duke.edu/DCEC>.