Seizing Life, episode 137

Older Adults and Epilepsy: the Causes, the Signs, and the Treatments
Guest: Dr. Rebecca O'Dwyer
(Transcript)

Kelly Cervantes:

Hi, I'm Kelly Cervantes and this is Seizing Life, a monthly podcast produced by Cure Epilepsy.

Today, Dr. Rebecca O'Dwyer joins us to talk about an often overlooked but significant subset of those living with epilepsy. Older adults. Dr. O'Dwyer is a neurologist and assistant professor at Rush University Medical Center in Chicago, and the director of the Comprehensive Epilepsy Clinic for the Elderly at Rush.

Dr. O'Dwyer, thank you so much for joining us today. I'm really looking forward to this conversation because it is something that I personally know very little about, so I am really excited for this. What we are about to talk about is epilepsy in older adults, which correct me if I'm wrong, happens to be the largest population of epilepsy patients. I think maybe to start, can we define what we consider an older adult and just go into some of the story behind that?

Dr. Rebecca O'Dwyer:

Absolutely, Kelly, and I just want to say thank you so much again for having me today. So, actually, in the US alone, one in four people newly diagnosed with epilepsy is age 65 and older. And so as the population ages, and we know from the last census data that by 2040 over 20% of the population is going to be aged 65 and over. So in the next 10, 20 years to come, this population is only going to grow.

We often think of epilepsy as a disease of youth, maybe disease of childhood, but when we look at the incidence rate, there is that peak around birth and in the teen years and early 20s. But then there's another peak in incidence, and it's actually higher starting from the age of about 55, and it actually tops out at about 75. And even neurologists themselves are not aware that this is actually a huge population in the epilepsy community.

Kelly Cervantes:

So why is it that older people are more likely to develop epilepsy?

Dr. Rebecca O'Dwyer:

So it presents quite differently and it's a little bit different to what we see in younger working aged adults or children. So the epilepsy in older adults tends to be a symptom of an underlying cause. So the number one cause of epilepsy in older individuals age 65 and older is actually stroke. So your risk of developing epilepsy after a stroke is three times higher than somebody the same age without a stroke.

And we actually know that in that people who are older who have their first seizure, in the first three to four weeks after that first seizure, they're twice as likely to develop a stroke. So when you have an older loved one who has their first seizure out of the blue without any warning, you need to get them to a hospital or at least to a neurologist who needs to really evaluate them for stroke.

So stroke is the number one cause. That's closely followed by traumatic brain injury. So as people get older, they develop balance problems. They're a little unsteady on their feet, they fall, they hit their heads, they're on a blood thinner for something else and they can have a brain bleed. And we all know that blood on the brain is very irritable and makes it easy for the brain to start seizing.

And then there is also tumors. So brain tumors, that's the third most common cause of seizures in older individuals. So again, that first seizure, an older person will definitely need an MRI of their brain to make sure that we're not missing an undiagnosed brain tumor.

And then the last big symptomatic cause for epilepsy in older people is dementias, all the neurodegenerative disorders. So when we look at the Alzheimer's dementia data, depending on what data you read, somewhere between 10 and 15% of people will develop seizures. If you look at people with Parkinson's disease, it can be up to 3%. Lewy body dementia is up to about 12% of people who will develop seizures. So again, this is a big problem that these seizures are happening.

Kelly Cervantes:

Yeah, I'm so familiar with all of these ideas of the various comorbidities with epilepsy, but I had not considered Parkinson's and stroke and dementia, and I suppose tumors, but it's interesting to hear about these other comorbidities which may even be more prevalent. I certainly didn't know if an older person has a seizure that they're more likely to have a stroke within three weeks. That's information that I think we all need to know. Certainly, anyone who is age 55 or older, but those of us who have aging parents so that these are signs that we can watch out for.

Conversely, I'm wondering, so we know that there are these comorbidities and we know that as we age our brains change, our memory starts to slip. You don't remember where the car keys are, you slip on names and addresses. So in general, what is the difference between a typical, or a healthy aging brain, versus a brain that might develop seizures?

Dr. Rebecca O'Dwyer:

That's a great question. So I think you hit it on the ball. What you described is the normal aging process. And we know as we age, our cognitive capacities do decline a little bit. I think when we need to worry about a loved one, be it a parent or a grandparent, is when these problems become periodic, or not periodic, but episodic. So if mom or dad have good days and then they have bad days where they just can't find their words, they don't really remember the day, that's when we need to start worrying about, well, maybe seizures are happening in the background.

I had a patient who, actually, he was this gregarious guy, he loved his granddaughter, his favorite granddaughter was getting married, and he went to the wedding and everybody thought he was a little off that day. He wasn't this talkative larger than life man and his daughter really got worried. So the mother of the bride got really worried when the next week when they were at the

dining room table talking about the wedding, he was like, "It happened? I don't remember being there." And he had no recollection of his favorite granddaughters wedding.

And his daughter got really worried and actually went to a dementia neurologist, a dementia specialist. And the dementia doc was like, this isn't dementia. And so he ended up in my clinic and we actually ended up diagnosing him with temporal lobe epilepsy. So when older people have these, like I said, these episodic maybe periods of confusion, or word finding difficulties, or just off days, we need to think about dementia, but we also need to keep in the back of our minds also that maybe these are actually epileptic seizures.

Kelly Cervantes:

How can you tell the difference? How is the difference determined? Because I know first thing I would think of is dementia or Alzheimer's or something along those lines. I am so ingrained in the epilepsy community and seizures would not be even the second or third thing that would come to my mind.

Dr. Rebecca O'Dwyer:

So this is the problem. We know that seizures in older adults tend to be much more subtle. They don't have those motor signs, these awful convulsions that we witness our loved ones having. And they can be very, very subtle. It really can be periods of confusion.

I had one patient who had been diagnosed with dementia, and she developed what her daughter thought was a tick where she would just tip her left shoulder like this. And then her daughter noticed, though, for the rest of the day, she was very tired and she was a little bit off. So this was the postictal period. And we were lucky enough, we brought her into the EEG lab and we caught one of these episodes where she just does this for like 5, 10 seconds. And we actually saw on the EEG a temporal lobe seizure. So sometimes you're not going to know. You really aren't going to know. And clinicians get it wrong all the time, as well.

I had another patient who was living in a nursing home and he got a new set of dentures, and his friends were giving him a hard time because he'd start playing with his dentures. But they would notice that if they were playing cards and he was playing with his dentures, that he would always lose the card game. And I guess apparently he was a card shark. And again, these were actually oral automatisms.

So it's really hard and it's hard for loved ones, and it is hard for clinicians, as well. And so, I always encourage my, it's really not my patients, it's more their families or their caregivers to really keep track of these stereotypical episodic events that are happening. And if they're associated with some sort of what we would call a postictal period, [inaudible 00:11:10] there's always a tiredness or confusion or something.

Kelly Cervantes:

So it becomes up to the patient themselves, or the caregiver, to really advocate and request a consult with an epileptologist and to really fight for that EEG.

Brandon:

Hi, this is Brandon from Cure Epilepsy. Do you have questions about seizures, medications, treatments, or other areas of epilepsy? Cure Epilepsy's new video series, Epilepsy Explained, provides answers to help you better understand the basics of epilepsy. Each month, a different expert offers short, easily understandable answers to questions from our community about a particular area of epilepsy. Doctors and researchers who are leaders in their field will cover questions about seizures, diagnosing epilepsy, medications, surgery, and many more topics. New episodes of Epilepsy Explained will be available on Cure Epilepsy's website and YouTube channel on a third Wednesday of every month. Now, back to Seizing Life.

Kelly Cervantes:

So then, ideally, I suppose once these very subtle seizures are occurring, they are caught. Ideally a medication is started, do you then see a return of perhaps what we thought was cognitive decline and then we're not seeing that anymore? So there's sort of a reversal there?

Dr. Rebecca O'Dwyer:

Absolutely. So I think that's the great thing about this. So I think we're so attuned, the baby boomers have hit Medicare, Medicaid age, and there's a lot of public, and even within the world of neurology, awareness about Alzheimer's dementia and all the dementias. And there's a lot of funding going into this research for dementias.

But the nice thing about patients with epilepsy is it's almost like a curable cause of dementia because we do see this. We know that when the aging brain, when you have a seizure, your cognition takes a hit. So I remember getting into this furious debate with a colleague, and everybody who listens to this podcast knows that the anti-seizure medications that we have have lots of bad side effects and can make you sleepy and patients feel doped up and older people are more prone to those side effects.

And so I remember my colleague and I, we were getting to this fierce debate, is it worth treating an older person because of the side effects, these possible side effects of these medications? And actually it is because you can reverse, at least to a certain point, the cognitive decline that is caused by continual or multiple seizures over and over again. And the good news is that often seizures in older adults can be effectively treated with much lower doses than what we see in working age adults, as well.

Kelly Cervantes:

That's incredible to hear. You're reading my mind. That was going to be my next question because it's true, but I suppose it's like any other neurological psychiatric medication. It's about finding the right one that not only treats the seizures but has the side effects that you can manage. But if it gives you back your memory, it's hard to argue that that wouldn't be worth it.

Dr. Rebecca O'Dwyer:

Absolutely. Because I think in the older age group, we're really trying to maximize the amount of time that an individual can live independently and interact with their family and have that quality time. And you can definitely give that back. And it's not really one seizure med fits all. And so certain medications,

like Zonisamide, for instance, in Japan, they actually use it as an anti-Parkinsonian medication. So when my patients who have Parkinson's disease, I'll often start them on Zonisamide and it actually helps their tremor, as well as controlling their seizures.

So there really is, there's a lot we can do for this population. The problem is that there's not a lot of clinical research being done on this, and we don't have any really good guidelines to help clinicians on how to treat seizures in older people or even diagnose it. It's almost a black box at the moment.

Kelly Cervantes:

That's bizarre. Especially since this is such a large part of the epilepsy population. I wonder are there certain types of epilepsy, or certain types of seizures that are more common in older adults?

Dr. Rebecca O'Dwyer:

So I think it really depends on the underlying cause. So when I think of seizures in older adults, if they're having lots of motor signs, convulsions, I often think it's either post-stroke epilepsy, or it's a brain tumor. And then when these more subtle seizures that we were talking about with maybe just oral automatisms, or episodic confusion, or word finding difficulties, then I often think about maybe it's a dementia or we do know about a quarter of those older patients with epilepsy, we just don't know why they've started to have epilepsy.

So I think if you see motor signs, there's going to be a lesion on that MRI, we're going to see something on the MRI. And then if you don't have those big motor seizures, then I think it's going to need a bigger workup.

Kelly Cervantes:

So are there mimics, are there things that might look like seizures but they're not seizures?

Dr. Rebecca O'Dwyer:

Yes. So this is what makes it clinically even more challenging. So sometimes older people will have irregular heart rates and that can cause them to faint, and then they'll have a little convulsion, a very short convulsion at the end. And so sometimes that is misdiagnosed as epilepsy when actually they have an underlying heart condition. So often when I see patients in my clinic, I also send them to a cardiologist, a heart specialist, just to make sure we're not misdiagnosing.

Other things to look out for, especially if patients are getting confused, is have there been changes in their meds. Like other medications or antibiotics, have they been added? Because these can all mimic what these seizures look like.

Kelly Cervantes:

Now, I have to imagine with all of these difficulty in getting a diagnosis, getting the right diagnosis, you were talking about one in four newly diagnosed are over the age of 55 or 65, how many more out there are undiagnosed?

Dr. Rebecca O'Dwyer: We don't know. We really don't know. And I think that's where I think our

healthcare system is maybe not ready for this. I like to think of sometimes

epilepsy in this population as a treatable cause of dementia. And you wonder how many people out there have been diagnosed with dementia when really it's actually a seizure disorder. It's not uncommon that some of the dementia docs that I work closely with will send me a patient and be like, "This is not dementia." And then we get the EEG and we figure out it's actually epilepsy.

Kelly Cervantes:

I would think that it would make sense that if someone is being diagnosed with dementia, that they should get an EEG when they see the neurologist who diagnoses them with dementia, that the EEG would be part of that diagnostic procedure just to rule that out. Because how amazing if there is a treatment that could help them. However, on the flip side of this, I have to mildly panic because we have a shortage of epileptologists and baby boomers are hitting these older ages, and are we prepared as a medical system to be able to handle this patient load?

Dr. Rebecca O'Dwyer:

So I don't think we are. I think there's definitely, there's growing awareness. So there is growing awareness in the epilepsy community. If you read the literature, there's a lot of review articles. I was a member for three years of ILAE and task force for epilepsy in the elderly. And then we went on to create our own consortium, and there is a commission now in the ILAE. So there is awareness.

The problem is that there isn't a lot of original research being done, and that's what we need. We have too many unanswered questions. You've talked about the EEG. The EEG is actually the least sensitive in this age group, which just only adds to the problem of getting to an accurate diagnosis, at least the scalp EEG.

So in LAM and their colleagues at Harvard, they actually took, I think it was 8 or 12 patients with Alzheimer's dementia, and they put them in the epilepsy monitoring unit. They hooked them up to scalp EEGs, but they also put in depth electrodes through the foramen ovale. And what they saw was behaviorally the patients weren't doing anything. And on the scalp EEG, they did show focal rhythmic activity, but it was the depth electrode that actually showed the seizure.

So there's all these sorts of studies that need to be done within the epilepsy community to say, "Okay, can we diagnose an older person with rhythmic focal slowing? Is that a seizure? Is that not a seizure?" So we're caught. There's just so much work that needs to be done, but there is growing awareness, which is a start.

Kelly Cervantes:

Absolutely. I wonder, we talk about growing awareness within the medical community and the need for this research. What about amongst caregivers, nursing home staff? Is this something that they are trained on or aware of? I have a funny feeling the answer is no.

Dr. Rebecca O'Dwyer: You're right, Kelly, I'm afraid. So myself and some colleagues at the University of Minnesota, and hopefully it's going to get published in the next couple of months, we actually sanctized a survey to nursing homes across America. And all the regions in America were well represented, and only 52% of nursing homes had a protocol for an acute seizure. So that's really scary. Only barely half of them had that.

> And there were a lot of questions. We asked, how would you treat the acute seizure? That was also shocking in terms of the choice of medications and Levetiracetam was the number one chosen, but it was quickly followed by Valproate. And actually in older people, Valproate can actually cause a tremor. And then it was followed by Phenytoin. So these are old medications with lots of side effects, lots of interactions with other medications.

Now, the one bright side of that survey was they were interested in education. So I think, again, there's another need, we as an epilepsy community maybe need to get out there and kind of educate our colleagues in nursing homes, in geriatricians offices, as well, as well as our general neurology colleagues.

Kelly Cervantes:

Absolutely. Now, what can people do to try and prevent seizures in older age? How do we keep our brains healthy?

Dr. Rebecca O'Dwyer:

So I think it's healthy diet. It's exercise, frequent exercise. I think for any age group, it's just like healthy living. And I know as people get older, it can be hard with arthritis. I'm actually a big fan of agua aerobics. I just did a class myself. And there's a lot of balance, there's a lot of strength, and it is easy on the joints. So I think I definitely recommend if it's hard to actually move, get yourself in the water, get moving.

And the other piece of advice that I give my older patients is read, read, read, read. So if you think about everything that you use in your brain to maybe follow the story of a novel, other than your motor cortex, you're creating images, your obviously verbal, you're putting the words, you're putting meaning, you're following a plot. So really keep reading. That's my number one advice. Read, exercise, and eat healthy.

Kelly Cervantes:

Done, done and done. We've talked at length about the need for more research, but what research is currently being done? Is there anything exciting that you can share with us?

Dr. Rebecca O'Dwyer:

So I think there's a lot of work in the world of Alzheimer's being done. Actually, now they're looking at the common mechanisms of action between epilepsy and Alzheimer's disease. So I think we're going to see a lot of progress there. And maybe this is shameless self-promotion, but from that ILAE task force, a group of us internationally created the International Consortium of Clinics for Elderly with Epilepsy, and we're 15 members across four continents. And so we're actually at the moment starting to work together to combine our clinical

resources and our clinical ideas and to start some of that original research to get it going.

And this is something I think that people also forget. When we think about new anti-seizure medications coming to market, often people aged 65 and older are excluded because they are more prone to side effects. And so drug companies don't want to include them because it's going to skew their side effect profile. Now, that's not true for all medications, but there is a trend. So yeah, we need more clinical trials aimed at older individuals.

Kelly Cervantes:

Well, very grateful for the work that you're doing, Dr. O'Dwyer. Clearly, there is so much work left to be done. Thank you so much for this incredibly enlightening conversation, and I wish you all the best on your future work.

Dr. Rebecca O'Dwyer:

Thank you so much, Kelly. Thank you for this opportunity. I know Cure is going to get the words out there for us or help us. Thank you.

Kelly Cervantes:

Thank you, Dr. O'Dwyer, for helping us understand the issues around older adults with epilepsy and for your efforts to bring awareness to this growing group of people living with epilepsy and the need for more research in this area.

Since 1998, Cure Epilepsy has raised more than \$99 million to fund epilepsy research and other initiatives that will lead the way to a cure for the 65 million people worldwide and the 3.4 million Americans living with epilepsy. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. Thank you.

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