

Seizing Life, episode 99
Working to Overcome Disparities in Epilepsy Care in the Hispanic Community
Guest: Dr. Refugio Sepulveda
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
	00:17	Today I welcome Dr. Refugio Sepulveda to the podcast. Dr. Sepulveda is an Assistant Research Professor at the Mel and Enid Zuckerman College of Public Health at the University of Arizona. He is also a Co-principal investigator for the MINDSET Program, an epilepsy self-management tool that is currently being studied within the Hispanic community. Dr. Sepulveda is here today to discuss the particular challenges faced by the Hispanic community in accessing quality epilepsy care, and to explain how the MINDSET Program seeks to address those challenges. Dr. Sepulveda, thank you so much for joining us today. To get the ball rolling, I would love to know what spurred your interest in epilepsy and in public health.
Dr. Refugio Sepulveda:	01:06	Well, Kelly, thank you very much for having me today. It's an honor to be here with you and share my experiences with public health and epilepsy, in particular. As a minority Hispanic myself, I've experienced many of the political, social, and health disparities that many in my community and other racial minority groups face in our country. My interest in public health started at a young age when I had the misfortune of experience some of those big disparities faced by members of my community, specifically close family members. At the time when I was a teenager, my parents lacked health insurance and as such, they did not have access to quality care. At that time, my mom was diagnosed with a brain tumor. I was so young and naive, I didn't really have an understanding of what was going on, and the inability to help was really frustrating.
	02:21	I understood that she didn't have health insurance, that she couldn't be treated with her particular diagnosis, and I felt the need to step in and seek a career of profession where I could help fellow members of my community address some of these structural issues in our healthcare system with regards to access to care. Specifically with epilepsy, one of my cousins started college at a young age with me during our undergraduate years. Soon after we finished, my cousin started his career in the public sector, and out of nowhere in his mid twenties, he had his first seizure. He was driving early in the morning to work, we received a phone call that he had been in an accident. Later we learned that he had a seizure. The doctors couldn't really give us a precise answer as to what was going on.

	03:30	They said he had experienced a seizure. It could have been a one time thing. Test appeared to come back normal, and they couldn't really give us diagnosis of epilepsy at that point. Some of the questions that I had specifically was, well, what's the plan of action, of treatment here? They said, well, considering that it's the first time seizure, we really can't tell you or give you a particular treatment plan with regards to medication, but rather recommendations on certain precautions to take and what to do in the event that he were to suffer another seizure.
Kelly Cervantes:	04:17	Now, I know that you were young when your mother was diagnosed with the brain tumor, but did you see similarities in the care that your mother received, whether hearing about it later and then being in that room with your cousin?
Dr. Refugio Sepulveda:	04:35	Well, with my cousin again, he had just started working. Thankfully, unlike my mother, he had health insurance through his employer, but he did not necessarily have the knowledge or the understanding of what epilepsy meant or what questions or who to seek help from. So when he was diagnosed with a seizure, I eventually helped and we were able to get an appointment at a larger neurology center in our local community. He was seen by a neurologist, not necessarily an epilepsy specialist, but a general neurologist. When we went into the consultation, we really didn't have an opportunity to ask many questions. The physician at the time was overwhelmed with patients, but we went in with the series of questions and the doctor literally was telling us, okay, this is the medication that you will be on. This is what you will need to do, and so forth.
Kelly Cervantes:	05:50	I think that that is such a common occurrence that many families and patients can relate to, and I think it is why some of these mothers, myself included, get term coined with this term mama bear, because we walk in there and you really have to shake some heads sometimes in order to get answers, in order to get time, in order to get that attention, and I think if coming from, either another culture or not as clear of an understanding of how the medical system operates, that that can be an incredibly challenging position to be in. I wonder from your point of view, what other challenges does the Hispanic community face when trying to get epilepsy treated?
Dr. Refugio Sepulveda:	06:49	Yes, so epilepsy care among Hispanics in particular, some of the recent research findings have continued to document a lot of racial and economic disparities in the diagnosis, the treatment, and the overall care of epilepsy and its associated conditions within Latinos and Hispanics. With regards to treatment itself,

Hispanics and non-English speaking patients are significantly less likely to receive specialized and preventative epilepsy care compared to non-Hispanic, whites. We're also less likely to undergo surgical treatments at rates significantly lower than white patients. We're more likely to be treated in emergency rooms with seizures, and we're less likely to receive or comply with anti-epilepsy drugs treatment plans. And I continue to say we, as I'm fairly close to my community, but Hispanics myself, we appear to have limited knowledge about epilepsy in general and it's treatment.

07:58 There's a lot of barriers, again, to quality care. There's a lot of lack of social support and a lot of members of my community, depending on the culture and the generation, there's also many in my community that tend to seek alternative treatment for epilepsy. Again, all of these factors are likely a consequence of understanding and knowledge about community and within our community about epilepsy in general, language barriers, ultimately all of which could endanger low self-efficacy and self-management skills and knowledge to better treat and address these seizure disorders and epilepsy care.

Kelly Cervantes: 08:50 The language barrier alone, I felt when my daughter was diagnosed that I had to, I'm a native English speaker, and I still felt like I had to learn this entirely new medical terminology just to be able to communicate with her doctors. I can't even fathom how difficult that can be when English isn't your first language, and that's just communicating with the doctors. That's not communicating with the insurance system, that's not communicating at the pharmacy. There's just so many layers to managing epilepsy care. It's not just the communication in the clinic. It expands so far beyond that, and I love that you have dedicated your work to this.

Brandon: 09:43 Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide, currently live with epilepsy. For more than 20 years, CURE epilepsy has funded cutting edge patient-focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.

Kelly Cervantes: 10:06 I think many of us, probably not enough of us, are aware that these disparities exist, but it is incredible and encouraging to know that there are people like yourself who are out there trying to do something about it. Can you tell me about the Managing Epilepsy Well Network?

Dr. Refugio Sepulveda: 10:29	Yeah, so the Managing Epilepsy Well Network is a multi-site initiative that was established in 2007 with the support from the Centers for Disease and Prevention. The main Network aims to improve the health and the wellbeing of people with epilepsy by advancing self-management research, evaluation and program dissemination. I've had the opportunity to serve as a colleague, a researcher at the University of Arizona in partnership with the University of Texas, working with the large comprehensive team of researchers, both clinicians, public health practitioners, and the actual patients themselves, trying to look at larger picture of some of the issues that these patients may be experiencing from social determinants of health and all the cultural and social barriers with the ultimate goal of improving the quality of life of people with epilepsy.
Kelly Cervantes: 11:37	And how can that specifically benefit the Hispanic community or generally speaking, the non-white affluent community?
Dr. Refugio Sepulveda: 11:49	Yes, so there's a lot of implications for the health disparities that we are familiar with. People with epilepsy frequently report diminished socialization, a negative self-image, feelings of stigma, reduced earnings potential diminished hope and ambition, a lot of comorbidities that have long-term impacts on the overall quality of life. Together as a MEW Network, our primary activities are to collaborate and do research together, but also to involve community stakeholders in the implementation of these studies. We use participatory methods in the development and the implementation of our self-management tools, specifically related to Hispanics. We've had the opportunity to bring in fellow patients that have been diagnosed with epilepsy to assist us with the design and the development of some of our self-management tools that we currently have tested within the MEW Network, including MINDSET.
Kelly Cervantes: 13:00	Yeah. Let's go right into that. So there is this other program that you are a part of called MINDSET. What is it?
Dr. Refugio Sepulveda: 13:10	So a little program snapshot about MINDSET. MINDSET refers to a Management Information and Decision Support Epilepsy Tool. It is a bilingual self-management decision tool that is to be used during clinic visits to assist people with epilepsy and healthcare providers in assessing the patient's epilepsy self-management behaviors in three different domains. Seizure management, medication management, and lifestyle management.

Kelly Cervantes:	13:40	Dr. Sepulveda, can you give us a clear and layman's terms, step by step guide through what the MINDSET Program does. What someone can expect who is utilizing it?
Dr. Refugio Sepulveda:	13:56	Yes, Kelly. So as we're getting ready to start the efficacy trial on this new version of MINDSET, I'll give you a little step by step summary of what the program currently will entail. So anyone with internet access, again, will have access to the Program. The participant, the patient would be assigned a unique username ID for security purposes and a password, a PIN number that they could later change, again for their own security. The next screen of the Program will ask a patient a language preference choice as to how they wanted to complete the Program. Again, the question would be asked in English, Please select a language of your choice. Por favor elija su lenguaje de preferencia, in Spanish. The patient would later move on to an introduction of the Program entitled My Epilepsy. The first part of the Program, My Epilepsy would ask a series of questions related to the patient's seizure history and frequency and behaviors. So it would ask simple questions like, how many seizures have you had within the last 30 days?
	15:19	Has your frequency increased? Have you been having more seizures than usual? With regards to medication management, the Program would ask, what medications are you currently taking? Are you having any side effects of these medications? With the ultimate purpose of making any red flags for the physicians later on to be aware of. As you probably know, a lot of patients may be taking a particular medication and they never discuss any of the side effects with the providers because, either they may be intimidated, naive, not really not know, or they have never really thought about any of these possible side effects. So in the Program, we provide a list of potential side effects for each of the medications that we list. So with medication management, we ask the patients, okay, which medications are you on? Depending on the drug that they choose, with the feedback from the physician, the Program is programmed to list a long list of common side effects from the individual medications.
	16:40	So the patients would, again, they would select their medication, any side effects that they're currently having from their medication, and then a series of other medication management related questions. For example, have you missed any doses within the last 60 days or within your last visit? Are you getting your refills on time? Are you forgetting to take your medication? Are you taking your medication as prescribed? As you are probably aware, there's many patients that may not be

strict with regards to their medication plan for a number of reasons. Either they don't have the resources to get the medication. They may be experiencing a lot of side effects from the medication, so they may only be taking a portion. Again, a number of medication management questions. Then the Program asks a series of lifestyle management questions, all of which could potentially trigger seizures. For example, some of the questions would ask patients, are you getting enough sleep? Do you drink any alcohol? Do you exercise?

18:02 Or other lifestyle management questions that may potentially put a patient at risk if they were to suffer a seizure. Are you driving after having a seizure? Are you swimming alone and are you staying up late at night, drinking alcohol? And so forth. Later on in the Program, as part of the epilepsy self-management questionnaire, we are also evaluating the patient's current mood and depression. Again, using validated mood and depression scales where we're trying to get a better understanding as to where patients are with regards to their mood within the last month or since their last visit. We're asking patients very straightforward questions. Within the last 30 days, have you had any suicidal thoughts? Have you been feeling down or depressed within the last two weeks? Within the last two weeks, do you feel that you would be better off dead than alive? Again, just straightforward, simple questions for patients to understand, again, with the ultimate purpose of bringing these items as a red flag for the physicians to discuss with the patients.

Kelly Cervantes: 19:32 So the questionnaire is then sent to the doctor prior to the exam for the doctor to review, and then they can discuss in the clinic session. I have to say, I think that this is something that could be utilized across the spectrum, because I imagine that people are probably far more honest when they're filling out a sheet of paper versus when they are speaking face to face with a doctor and something might come up. Something might prompt, regardless of whether English is not their first language or they're from a lower income community. I also imagine that this opens up a lot of that limited time in that clinic session to discuss other concerns. When you're getting a lot of the generic questions out of the way on this form, then you can get in and talk about some of the deeper concerns, the meteor questions that a lot of times you don't have time to when you're in such a strictly limited timed session appointment.

Dr. Refugio Sepulveda: 20:40 Yes, Kelly, and that's exactly the purpose of having this questionnaire embedded in the Program, especially among racial and ethnic minorities. Again, like myself, sometimes we

tend to be a little bit more conservative with our thoughts and our feelings when it comes to issues like mood and depression. Many times, as you may probably be aware, and speaking for myself as well, we may not be as open and honest about our mood and any depression that we may be experiencing. With regards to epilepsy specifically, again, you've probably heard many times about that stigma associated with epilepsy, which is a bigger issue with racial and ethnic minorities, which may keep a lot of members from my community within Hispanics, to be a little bit more reserved.

21:40 Speaking specifically about mood and depression, again, this is something that, it's really hard for us to talk about, and like you said, if we have it on paper, it may be the only way that a physician would actually be able to learn of some of these issues that a patient may be experiencing otherwise, like you said, a lot of the physicians, a lot of the specialists are crunched in time. They have so many patients that if the patient won't bring up the issue, it's really hard for the physician to be made aware of what the patient may be currently experiencing with regards to their overall mood and their depression.

Kelly Cervantes: 22:24 So all of this information is gathered through the questionnaire and it is given to the clinician to help them, but how is that information then used to help the patient in the long-run?

Dr. Refugio Sepulveda: 22:39 Any red flags that would then be identified in the questionnaire, the patient would get a list, a summary of all of their red flags, and we're asking them to select from a particular red flag, a goal that they think would be achievable to complete during their next visit. Once the patient would select a goal in each of the three domains, seizure management, medication management, and lifestyle, we would then provide a list of suggested strategies to help them achieve some of these goals. Later on, right before completing the program, the patient would get a summary of their responses in what we call an action plan. The physicians themselves would then have access to the patient responses and review their responses before meeting with the patients during a clinic visit.

Kelly Cervantes: 23:34 I think it's incredible just how proactive the Program is. There's so many systems out there that sometimes I feel like it's just so much about data collection, but this is actually truly utilizing that data to improve the life of the patient. Yes, you are in this research phase now, but it will become this tool that can be used by patients and clinicians to truly better the lives of these communities. I wonder what other tools are out there that

patients should be asking about from their providers, their nurse practitioners, their clinicians?

Dr. Refugio Sepulveda: 24:19

Yes, so the new version of this Program also embeds algorithms to provide recommendations for other self-management programs that are available out there. I believe that you are a little bit familiar with HOBSCOTCH. HOBSCOTCH is a home based self-management and cognitive training that is designed to address some of the memory and attention barriers issues, experienced by some of the patients with epilepsy. So the Program is designed to help people with epilepsy learn how to better manage their memory and some of those behavioral challenges to help them regain control and improve their quality of life with regards to memory issues. Another program that we've partnered with and we also recommend to patients is a project called UPLIFT, which is Using Practice and Learning to Increase Favorable Thoughts. This is a phone based program designed to reduce depression in adults and a cognitive behavioral therapy to treat depression specifically.

25:33

Lastly, another program that we've also partnered with, to provide as a recommended resource for patients is called PACES. PACES refers to Program for Active Consumer Engagement in Epilepsy Self-management, and it's a program available in person or by phone, and it's also developed to improve self-management and health related outcomes in people with epilepsy. So it ultimately aims to increase medical, psychosocial and community adjustment issues with people with epilepsy. So again, as part of the MEW Network, we've had the fortune of working together in all of these self-management intervention tools to help each other out and bring as many resources to help improve the knowledge of epilepsy, self-management to our community stakeholders.

Kelly Cervantes: 26:36

That is incredible, and I am so grateful for the work that you're doing for the epilepsy community, for the Hispanic community, for our low income epilepsy patients and families and their caregivers. This is so desperately needed and it is encouraging to hear that the work is out there and only a couple years away from being accessible to the public. So Dr. Sepulveda, thank you so very much for joining us today. It has been a pleasure to speak with you.

Dr. Refugio Sepulveda: 27:10

Thank you very much again for having me. It's an honor.

Kelly Cervantes: 27:15

Thank you, Dr. Sepulveda, for sharing your personal experiences and insights about epilepsy care within the Hispanic community and for explaining how the MINDSET Program seeks to improve

epilepsy, self-management and care within the community. For over 20 years, CURE Epilepsy has been dedicated to funding research, to find new treatments and cures for epilepsy. If you would like to help us in our mission to end epilepsy, please visit cureepilepsy.org/donate. Through research, there is hope. Thank you.

Legal Disclaimer: 27:56

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