

***Seizing Life*[®], episode 84**
Learning to Manage Cognitive Challenges for People with Epilepsy
Guest: Elaine Kiriakopoulos
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Kelly Cervantes: 00:18 Today, on Seizing Life, I'm happy to welcome. Dr. Elaine Kiriakopolous, who is an Assistant Professor of Neurology at the Geisel School of Medicine at Dartmouth, and the Director of the HOBSCOTCH Institute for Cognitive Health and Wellbeing at the Dartmouth Hitchcock Epilepsy Center. Dr. Kiriakopolous is here to tell us about the HOBSCOTCH Program, which aims to improve quality life for those with epilepsy who live with cognitive challenges. Elaine, thank you so much for joining us today. I cannot wait to start talking about this incredible program, HOBSCOTCH. To begin with, why don't you tell us what HOBSCOTCH stands for and then give us a very general overview of the program?

Elaine Kiriakopoulos: 01:02 Sure. Well, thanks for having me, Kelly, I'm really excited to share this program with your community. So HOBSCOTCH is an evidence-based epilepsy self-management program. And HOBSCOTCH stands for home-based, self-management, and cognitive training changes lives. So you can see why we've condensed it to the acronym, HOBSCOTCH.

Kelly Cervantes: 01:29 It's a mouthful.

Elaine Kiriakopoulos: 01:30 Right.

Kelly Cervantes: 01:32 So what is the goals of the program?

Elaine Kiriakopoulos: 01:36 Right. So this is a program that targets adults with epilepsy at this point, although we're expanding our portfolio of who we think we can help with this program. But it targets adults with epilepsy who have memory and cognitive issues. So people who have subjective complaints of difficulty with their memory and thinking who have epilepsy are eligible to participate in this program.

Kelly Cervantes: 02:06 I mean, that's a pretty significant comorbidity, memory loss of epilepsy. I hear from so many adults that talk about that memory loss being so concerning. Can you tell us about the origins of the HOBSCOTCH Program?

Elaine Kiriakopoulos: 02:27 Sure. So HOBSCOTCH was the brainchild of my colleague, Dr. Barbara Jobst, and her fellow, along with a multidisciplinary team at Dartmouth. They all worked together to create

HOBSCOTCH back in 2013. And it was really born of the fact that patients who were being seen in clinic who had epilepsy and were having cognitive challenges at home really needed more support. And so for anyone that knows Dr. Jobst, she really takes excellent care of her patients and she provides comprehensive care. And so this came out of recognizing this need that she wanted to be able to do more for her patients. And so that's how HOBSCOTCH was first developed.

Kelly Cervantes: 03:19 And what are the overarching goals? What did you hope in the beginning? And we'll get to the actual results in a little bit. But in the beginning, what were you hoping to see from the patients enrolled in this program?

Elaine Kiriakopoulos: 03:39 Right from the very beginning, the goal was very patient-centric and the program was patient-centric. And it was really about allowing people to live happier lives, a higher quality of life, and to feel more productive. To not be so ministered, burdened with cognitive challenges that may leave them feeling frustrated from day-to-day, be it at school, or at home, or at work to really try to lift some of that burden for people.

Kelly Cervantes: 04:10 Now, for the people who are enrolled in the program, is there a set schedule, certain time constraints? What's expected of the epilepsy patients?

Elaine Kiriakopoulos: 04:24 Right. So the way our program works is when a person registers online, or if their physician refers them, or their nurse refers them, they meet with our program coordinator who does about a 30-minute phone call with them so that we could match them with a coach that we think will be most helpful to them. And so once that call happens, they get matched with a cognitive coach who's been trained at the HOBSCOTCH Institute and certified to deliver the program. And they will meet with their coach once a week for eight weeks, about an hour each time. And they'll receive one-on-one support as they make their way through the program. So it's an eight-week commitment. And we do have some flexibility built in, because life happens. Seizures happen. Sometimes, there may need to be a little pause before we restart. But in general, the commitment is eight weeks for completing the program.

Kelly Cervantes: 05:25 Okay. So let's dive a little deeper and get a little more specific. What is covered in each of these eight sessions?

Elaine Kiriakopoulos: 05:34 Sure. So there are some core components to the program. In the first session, we cover education, which is really, really important. And this session tends to be a little longer, runs

about 90 minutes. And so the cognitive coach will spend time with the patient going over epilepsy and memory, and just the basics of how the two are interrelated. How someone's cognitive function might be affected by seizures, or treatment for seizures, or other comorbidities.

Elaine Kiriakopoulos: 06:09 In that first session, we also do some self-awareness training. And that allows people to really think about internal factors and external factors that may be impacting them. So sometimes, things like anxiety or fatigue can contribute to those cognitive challenges over and above the seizures and the treatments for seizures. So it's important to help people look at those sorts of changeable factors for progress to happen through the program.

Elaine Kiriakopoulos: 06:44 And so that's the first session. And then from there on in, problem solving therapy is really a core component of the program. It's at the crux or the heart of the program. And what problem solving therapy is, it's a form of cognitive behavioral therapy. And it lets people systematically work through the different challenges they have, set goals, and work with their coach to find creative solutions to then take home and apply over the course of the week. And then come back and discuss what worked, what didn't, how things could be improved on.

Elaine Kiriakopoulos: 07:20 There are two other components. One is memory strategies that we use in the program, and we call these compensatory strategies, and they're behavioral strategies. And they're really practical skills, tried and true skills that psychologists and neuropsychologists use in their practice all the time. And we share these with the participants each week so that they can test them out and see if it's something that works for them.

Elaine Kiriakopoulos: 07:48 And then the final component is mindfulness. And mindfulness, in this program, consists of progressive muscle relaxation exercises, and also debrief exercises. And that's to help alleviate stress and anxiety for people, which could be contributing to some of the difficulties they're having cognitively. And so that's a really important part of the program, and it's one that participants tell us they love.

Kelly Cervantes: 08:15 I am so impressed. This is such an intricate and well thought out program. So to recap, we have the epilepsy education piece, the self-awareness training, problem solving therapy, compensatory memory strategies, and the mindfulness. I mean, this is a lot. And I can see how it would be beneficial. My question here is, is this something that people you remotely? Regardless of, if they

are not located near your clinic, can they still participate in this program?

- Elaine Kiriakopoulos: 08:50 Absolutely. And originally, the first and the last session in this program was done in person, and in between sessions were done over the telephone. We had already started to pivot to telehealth accessibility with online accessibility. And of course, COVID really catalyzed us to get that moving for people. And so the entire program can be done online and over the telephone with the majority. So seven of the eight sessions can be done on telephone.
- Kelly Cervantes: 09:22 That's brilliant. That's really amazing.
- Brandon: 09:28 Hi, this is Brandon from CURE Epilepsy. Did that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now, back to Seizing Life.
- Kelly Cervantes: 09:48 I understand that there have been controlled trials done. Can you speak to the efficacy of the program now that you've been utilizing it for several years now? What are the firm reportable results?
- Elaine Kiriakopoulos: 10:04 Sure. So the program began with a feasibility study back in 2013-14, followed by efficacy and effectiveness trials. And what the first randomized control trial nicely demonstrated was, for people who passed through the program, there was both an improvement in quality of life, as well as objective cognition. And so that was trial one and it was done at Dartmouth. And then the next randomized control trial, HOBSCOTCH 2, involved four epilepsy centers in New England. So Maine Vermont, and Massachusetts, and as well as New Hampshire. And what this really set out to do was to see ,if this program were taken into a different environment, could fidelity to the program delivery be maintained by coaching is and would we see the same effects? And the effects that we saw with the improvement in quality of life were even more robust in the second trial than the first. And there was also an improvement in cognition.
- Kelly Cervantes: 11:10 Wow. I love numbers. I love seeing the reports. But you talk about it being patient-centric. What do the patients who are enrolled in the program say about it?
- Elaine Kiriakopoulos: 11:23 Well, this is what keeps us going, Kelly. And this is what makes us really want to reach out and make this accessible to people

everywhere, not just to some people with epilepsy, but to all people with epilepsy, including the most vulnerable populations, and people who are in rural areas or inner city areas, people who wouldn't necessarily have access to a program like this. And so what we're hearing from people is that it's life changing. I have a great anecdote from just last Friday. We had a young woman who was a graduate student out in California, who worked with her coach and expressed to her that one of her big goals was to write a paper, publish a paper.

Elaine Kiriakopoulos: 12:07 And she'd had such a hard time because of her cognitive limitations and her memory at being organized and staying focused, that that was something she really wanted to work on. And so they did that. And just last week, her paper was published. So the nice thing about this is we hear stories like that all the time. And the program serves a spectrum of people from people who might have difficulty living independently, or going to school, or working, all the way up to executives, nurses, lawyers, college professors, all sorts of people can find benefit from this program. And that's what we hear, that it offers a support and it offers a solution. So we know it works.

Kelly Cervantes: 12:53 Those are my favorite kind of stories. Now, a HOBSCOTCH Institute opened in 2020. Talk to us about the Institute and the difference between the Institute and the Program.

Elaine Kiriakopoulos: 13:08 Well, the Institute that Dr. Jobst and I founded in 2020 is really meant to advance the mission and to provide some leadership for tackling this difficult problem of cognition for people with neurologic disease, including epilepsy. And what we've created through the Institute is a place for patients and families, a place for providers and researchers, to link with us as partners, and to really start to develop this community to tackle this problem together. Because it is a big problem. One in two people with epilepsy have memory or cognitive complaints of one sort or another. And so we really felt like people could come together, work towards goals, try to further disseminate the program, and adapt the program for specific populations. But also allowing past participants of the program to have a way to connect. And so we're really excited about this.

Kelly Cervantes: 14:11 You talked earlier about the coaches. I'm sure that they are an integral part of the formalized Institute. Who are the coaches and how do you find them? How are they trained?

Elaine Kiriakopoulos: 14:25 So the coaches come to us as licensed providers. So a big group are licensed providers. And so neurologists, epileptologists, neuropsychologists, and psychologists, advanced practice

nurses, epilepsy nurses, social workers, counselors, and non-traditional providers like community health workers and people who are epilepsy educators out at nonprofit organizations are also eligible to train if they have the experience in delivering one-on-one counseling and a good background in epilepsy. And so coaches have come to us from across the country. We really boosted our training in 2020 with the development of the Institute. And I'm pleased to say in North America, we now have 175 coaches delivering the program.

Kelly Cervantes: 15:17

That's incredible.

Elaine Kiriakopoulos: 15:19

Yeah.

Kelly Cervantes: 15:20

You talked about the grad student who was helped so much by this program, and it immediately made me think of how I talked to so many parents who, these young adults with epilepsy, they really struggle in college, and it's so difficult for them. I can see how this program would help them, but also put their parents at ease. And it makes me think, I know you had mentioned that you're looking at developing the program for younger audiences, adolescents, teens. I know, clearly, a teen mind is still changing and forming. I'm sure that that complicates this program. What's the process there, and how are you hoping to make that available for younger audiences?

Elaine Kiriakopoulos: 16:06

Well, what you're saying is so true, Kelly. These points of transition in life, particularly for youth into young adulthood, and young adulthood into life, events are so key. And I think it's one of the things that makes epilepsy so tricky is that life is dynamic. The disease can be dynamic as far as, are treatments working? Is the disease progressing? What else is in the picture? And so certainly, for young adults, we're targeting our program to adolescents that we're developing between the ages of 13 and 18. And some of the key differences is we've adapted it so that it's culturally more engaging for youth, is one thing.

Elaine Kiriakopoulos: 16:50

We've developed a HOBSCOTCH app for youth that will hopefully entice them to stay engaged with the program. We are working in the parents being able to attend the education sessions and to have communication with the coach as well. And really placing those decisions in the hands of parent and the youth who are participating in the program was very, very important to us. And we've been really fortunate to work with colleagues from the Pediatric Epilepsy Group at the Mayo Clinic and Boston Children's Hospital, as well as our providers at Dartmouth and several community organizations to really think

through it might work for youth and adolescents participating in a program like this.

Kelly Cervantes: 17:40 Which is all incredible, because I know how desperately a program like this could change their lives, just building that confidence and allowing them to move forward at an earlier age with those abilities and that skillset in place. Another group that I can't help but think this could greatly benefit is those who have been diagnosed with post-traumatic epilepsy or a traumatic brain injury. And I understand that service members, which is a group that CURE Epilepsy has focused a lot of time and energy on, that that is going to be a new focus group for you. Can you tell us about that program that you're starting?

Elaine Kiriakopoulos: 18:24 Sure. And you're absolutely right. Post-traumatic epilepsy brings so much challenge. The cognitive issues from the traumatic brain injury, followed by a second set of potential challenges, cognitively, that could come from epilepsy and its treatments. And so we're working on... Well, we've adapted our program for post-traumatic epilepsy, both with input from the community with caregivers and VAs across the country, as well as epileptologists and neuropsychologists, to really target this group. And we'll be enrolling in another randomized control trial that's supported by the Department of Defense to present and HOBSCOTCH PTE, so HOBSCOTCH post-traumatic epilepsy to veterans, as well as civilians are eligible to participate in the trial.

Elaine Kiriakopoulos: 19:21 Coming up here in the next few weeks, we'll begin enrolling in that program. So we're excited about that. And the other component about this particular adaptation of HOBSCOTCH is we've involved caregivers for the first time. And so we're incorporating, in this randomized control trial, dyads of the patient, and then their loved one who is a care partner or caregiver for them, to participate in certain aspects of the program to see if we can also alleviate some burden for caregivers. Because we know that caring for someone with epilepsy who has had a traumatic brain injury, and maybe working through cognitive challenges can be a lot for caregivers, too.

Kelly Cervantes: 20:06 I love that you are looping the caregivers in, if nothing else, as an asset, but to also figure out, where are the issues? Where can additional help be provided? What can be alleviated as someone who is so close to the patient? I think that it's such an important piece to include. So a question that is at the top of my mind, and I have to imagine that a lot of listeners may be wondering as well, is about the cost of the program. Is this a

research-based program? Is this something that is covered by insurance? How is it paid for?

Elaine Kiriakopoulos: 20:51

There's no cost for people who participate through research. In fact, we offer stipends to our participants, because we know it takes time for them to participate in a trial and an extended period of time. Now, for general delivery of the program, there is also no cost. So it's delivered to participants from coaches at the HOBSCOTCH Institute for no cost at all. So there is no cost for the materials, for the one-on-one support that's provided through the cognitive coaches. We manage to make it happen by grant funding. And our department is very supportive. Organizations that serve people with epilepsy, if they've sent someone to be trained, there's no cost at those offices either.

Elaine Kiriakopoulos: 21:41

In the clinical centers where we've had coaches train, the neuropsychologists can work patients through their insurance to help have payment for the program. But people are always welcome to come centrally to us as well, and have the program delivered without having to go through an insurance process. Our goal is to make the program accessible. And we're really proud of the fact that, last year with COVID, seeing the increased need, just from the Institute, we were able to share about 3,000 hours of one-on-one coaching with people at no cost.

Kelly Cervantes: 22:21

Wow. I mean, I'm floored. There are very few services, therapies, I mean, basically anything having to do with epilepsy, even the greater medical world that is free of cost to the patient. I'm in shock right now. So how does someone learn more about the HOBSCOTCH Program? How do they enroll? And for anyone who's interested in being part of the HOBSCOTCH PTE study trial that you are about to start, how would they get involved in that?

Elaine Kiriakopoulos: 22:59

Sure. So there are a number of ways people can find us online. People who want to connect with the HOBSCOTCH Program and participate in the program, or even if they just want to learn more of about it, the central place for them to be able to access us easily is HOBSCOTCH.org, which is our website. So that's H-O-B-S-C-O-T-C-H.org. The program is part of the CDC's Managing Epilepsy Well Network. So there's also a second website, managingepilepsywell.org, that people could visit as well if they want to learn more about HOBSCOTCH or other evidence-based epilepsy self-management programs. I want to share that because we have such dedicated colleagues also working on other epilepsy evidence-based programs that are so helpful. So

if you want to learn about HOBSCOTCH or other programs, managingepilepsywell.org.

- Kelly Cervantes: 23:58 I am just so in awe of the work that you're doing, and so grateful that this is being done. It is beyond needed for so many patients and families across the country. So thank you so much for your work. Thank you for sharing it with us, and best of luck to you and all of the epilepsy patients that you're helping out there.
- Elaine Kiriakopoulos: 24:22 Thank you, Kelly. It's been a pleasure to be here. And this is a passion project, really, for everyone involved with this work. We're happy to help. It's our goal to get this program in the hands of people who need it.
- Kelly Cervantes: 24:37 Thank you, Dr. Kiriakopolous, for your thorough overview of the HOBSCOTCH Program, and for the work that you do to help those with epilepsy overcome cognitive challenges and improve their quality of life. As Elaine noted, individuals with epilepsy may be cognitively impacted by both seizures and by the side effects of the medications they take to treat those seizures. That is why CURE Epilepsy is dedicated to funding research to find a cure for epilepsy. We hope you will join us in advancing science to improve the lives of those with epilepsy by visiting CUREepilepsy.org/donate. Through research, there is hope. Thank you.
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