

***Post-Traumatic and Cognitive Training:  
Improving Quality of Life Through HOBSCOTCH***  
**CURE Epilepsy Webinar**  
**Transcript**

Dr. Laura Lubbers:

Welcome, everyone to today's webinar. I'm Laura Lubbers, and I'm the chief scientific officer of CURE Epilepsy. I want to thank you all for joining us today. As we get ready to honor those Americans who have served in the US military, we'd like to highlight research and resources for those diagnosed with post-traumatic epilepsy, or PTE.

Today's webinar will discuss this topic in greater detail, and is entitled Post-Traumatic Epilepsy and Cognitive Training: Improving Quality of Life Through HOBSCOTCH. [00:00:30] And it's intended for anyone diagnosed with PTE resulting from a traumatic brain injury, or a TBI, military-related or not.

People diagnosed with TBI are 29 times more likely to develop epilepsy compared to the general population. This fact is quite alarming when you consider there were 400,000 US military personnel diagnosed with TBI from 2010 through 2019, placing them at much greater risk for developing PTE. [00:01:00] This webinar is part of CURE Epilepsy's 2021 Leaders in Research webinar series, where we highlight some of the critical research that's being done on epilepsy.

Today's webinar, like all of our webinars is being recorded for later viewing on the CURE Epilepsy website. You can also download transcripts of all of our webinars for reading. For over 20 years, CURE Epilepsy has raised millions of dollars to fund epilepsy research that supports our mission, which is to find a cure for epilepsy by promoting and [00:01:30] funding patient-focused research. CURE Epilepsy provides grants that support novel research projects, and that advance the search for cures and more effective treatments. We are also proud to partner with the US Department of Defense on a \$10 million team-science project that focuses on post-traumatic epilepsy. This initiative brings together top minds to tackle this problem, and is looking to establish a foundation of knowledge regarding the types of injury that increase epilepsy risk, and understand how [00:02:00] the injury leads to epilepsy as a means of finding ways to prevent it.

Today's webinar will provide an overview of PTE and cognitive dysfunction, as well as some strategies to help improve quality of life for those with PTE and their families. This webinar will also provide details about a program called HOBSCOTCH, or the Home-Based Self-Management and Cognitive Training Changes Lives program. This behavioral program is designed to address memory and attention problems [00:02:30] in adults with epilepsy. As part of the webinar, we'll also discuss a clinical trial opportunity for veterans and civilians living with PTE.

This webinar is presented by Dr. Elaine Kiriakopoulos Kiriakopoulos, an assistant professor of neurology at the Geisel School of Medicine at Dartmouth College. She's also the director of the HOBSCOTCH Institute for Cognitive Health & Well-Being at the Dartmouth–Hitchcock Epilepsy Center. Her work is aimed at building multi-sector partnerships to reduce disparities in the care [00:03:00] of people with epilepsy, ensuring that the most vulnerable populations have access to quality epilepsy care and community resources.

Before Dr. Kiriakopoulos begins, I'd like to encourage everyone to ask questions. You may submit your questions anytime during the presentation by typing them into the Q&A tab located on your Zoom panel, and click Send. We'll do our best to get through as many questions as we can. We do want this webinar to be as interactive and informative as possible. However, [00:03:30] to respect everyone's privacy, we ask that you make your questions general, and not specific to you or your loved one's epilepsy. With that, I will turn it over to Dr. Kiriakopoulos.

Dr. Elaine Kiriakopoulos: It's great to be here. Thank you, Dr. Lubbers for the kind introduction and for the invitation to join the CURE community today to share learning and discussion on the topics of post-traumatic epilepsy and cognition, quality of life, and to share our epilepsy [00:04:00] self-management program, HOBSCOTCH.

There we go. Sorry about that. And so, I'd like to begin today by taking this opportunity to say thank you to all of our veterans and our active duty military [00:04:30] for their service to our country, and to thank their family and friends as well for the sacrifices that they make. I want to acknowledge our wonderful team at the HOBSCOTCH Institute who have contributed to the program and the research efforts that I'll share here today. It's really an honor to work with this group of committed and compassionate [00:05:00] researchers and clinicians.

I'd also like to acknowledge Dr. Barbara Jobst, and many of you may know her, but for those who don't, I'll share what a privilege it is to work alongside her. It was her quest to improve the lives of her patients that led to the creation of HOBSCOTCH back in 2014, along with her fellow, Dr. Tracie Caller, and a multidisciplinary team. [00:05:30] HOBSCOTCH was developed and first tested at the Dartmouth–Hitchcock Epilepsy Center.

Presented here are my disclosures for today's presentation. And as we set out together to discuss traumatic brain injury, seizures, and epilepsy, I wanted to ground us with this perspective, even though today's focus will be on post-traumatic epilepsy, [00:06:00] it's well-established that up to half the people with epilepsy have cognitive impairment that affects their health, their productivity, and their quality of life.

During our time together, the plan is to share a general overview of traumatic brain injury, epilepsy, and cognitive dysfunction, to discuss cognitive challenges in PTE and the impact that they can have on [00:06:30] quality of life for veterans and civilians. We'll also spend time introducing you to core components of the HOBSCOTCH program. And I want to share an upcoming clinical trial opportunity for both veterans and civilians living with PTE and cognitive challenges, as well as their caregivers.

Let's go ahead and begin with a little bit around traumatic brain injury, epilepsy, and cognitive dysfunction, and their intersection. [00:07:00] Now, Laura shared some numbers with you in her introduction today, but I'll go ahead and review again that it's estimated that in the United States, almost 3 million people suffer a traumatic brain injury each year. And although the mortality of TBI has decreased in recent years, there's not been a proportionate reduction in disability due to [00:07:30] traumatic brain injury. TBI is the most common cause of long-term disability and death among young adults, and is known to be a leading cause of long-term impairments in functional, physical, emotional, cognitive, and social domains. Studies have demonstrated, as Laura shared, that patients who suffer a TBI have a 29-fold increased risk of developing epilepsy compared to the general population, [00:08:00] and that the relative risk of developing epilepsy after TBI strongly correlates with the severity of brain injury that's incurred.

It's also well-understood that for a service member, veteran, or civilian who has suffered a TBI and subsequently develops PTE, the combined disability arising from the combination [00:08:30] of the two comorbid chronic conditions can severely impact their quality of life. Cognitive dysfunction, encompassing difficulties with memory, attention, and learning represents one key comorbid challenge for patients with PTE that really requires innovative solutions to enable patients to feel more in control of their day-to-day lives.

[00:09:00] I mentioned earlier that the risk of developing epilepsy correlates with brain injury severity, and research has also shown us, seizures which appear during the first week following a TBI also present a risk factor for subsequent development of epilepsy. The risk for developing post-traumatic epilepsy is highest within the first two years following a brain injury. [00:09:30] However, risk does remain elevated for decades in moderate and severe TBI cases.

Now, PTE is considered a heterogeneous or diverse condition, and that's specifically because of the spectrum of injuries that are inherent to TBI. Patients with PTE can experience both focal and/or generalized seizures, with seizures seen early in [00:10:00] the course of TBI often being generalized tonic clonic convulsive seizures.

PTE is one of the most common forms of acquired epilepsy, and it often manifests as refractory, so difficult to manage with medications or with surgical interventions. PTE has been shown to account for 5% of [00:10:30] patients seen at epilepsy centers, and is thought to comprise up to 20% of symptomatic epilepsy in the general population.

A tremendous challenge in PTE is that, currently, there are no known effective therapies to prevent PTE and no way for clinicians in hospital emergency rooms or in combat support hospitals [00:11:00] to predict with absolute certainty who will develop PTE. More recent studies have examined further, injury location and characteristics of the epilepsy, timing of seizures, the types of seizures, EEG characteristics and brain imaging injury correlates as potential predictors of PTE. But these studies have not been definitive, and large, prospective, [00:11:30] longitudinal studies are required to better define subtypes of PTE to assist in the development of timed and targeted treatments to lessen the likelihood of functional impact of PTE.

And I know this has seemed a little bit doomed and down, as far as the information that I'm presenting to you, but I want to say that there's hope, and there's hope to address [00:12:00] this challenge, including the work at CURE, which has in place a tremendous research program helping to move the needle on this front, having brought together multi-center, multi-investigator research teams dedicated to improving ways to study PTE in the laboratory setting, and looking at developing biomarkers and understanding risk factors to help to predict who will develop PTE following a TBI. And in this way, I just want to note [00:12:30] that CURE is truly laying the groundwork for the creation of novel therapies to prevent the development of PTE. We can be hopeful.

In looking at PTE, specifically in the military, the Defense and Veterans Brain Injury Center reported nearly 414,000 traumatic brain injuries among US service members worldwide between 2000 and [00:13:00] late 2019. The primary mechanism of trauma in recent Middle East wars was blast injury, and that was due to weapons, such as improvised explosive devices, grenades, mortars, and land mines. And in fact, TBI was designated as the signature injury for US soldiers who served in Iraq and Afghanistan. You'll recall, a few slides back I shared, that PTE [00:13:30] is thought to comprise about 20% of symptomatic epilepsy in the general population. In comparison, the development of PTE in the military population climbs to 50% for combat troops when considering both penetrating and non-penetrating brain trauma.

Let's talk a little bit about treatment in PTE. [00:14:00] It's an important consideration. And we know that PTE almost always requires treatment with antiseizure medications. And often, this treatment is required on a long-term basis. We also know that antiseizure medicines can have negative

side effects that might further influence a person's quality of life, their cognitive function, as well as neuropsychiatric symptoms.

[00:14:30] Coupled with PTE, traumatic brain injury rehabilitation is associated with worse functional outcomes and social reintegration at one-year post-trauma when compared to people with brain injury without epilepsy. And some of the reasoning for that may be some of the factors we just talked about, including the need for long-term medication therapy, which can have those cognitive and neuropsychiatric [00:15:00] comorbid effects.

I want to share with you briefly some recent work published from Dr. Jobst's cognitive lab that looked at the impact of monotherapy. So, treatment with one antiseizure medicine versus polytherapy. So, treatment with more than one antiseizure medicine and the impact it had on cognitive function. You'll recall, I shared earlier, that with PTE, often, seizures can be [00:15:30] refractory. And so the use of more than one medication is fairly common. What they found, looking retrospectively at data from 224 study participants who had participated in research conducted by the CDC-sponsored Managing Epilepsy Well Network collaborative, was that subjective cognitive impairment was significantly worse among individuals on polytherapy, so two or more [00:16:00] antiseizure medicines compared with those on monotherapy, and that the polytherapy was associated with worst, overall, subjective cognition in addition to impairments on verbal memory, working memory, and processing speed.

Let's talk about comorbidities in general when it comes to PTE. And PTE is commonly accompanied [00:16:30] by chronic neurologic, psychiatric, and cognitive sequelae. And when we think about neurologic sequelae, things like headaches and sleep, psychiatric sequelae, like anxiety and depression, and some of the cognitive symptoms that we've been walking through. It's a lot. And a broad spectrum of cognitive impairments can present in individuals with PTE, and it [00:17:00] can range from really major cognitive dysfunction, and mood dysfunction, and mental disability to subtle cognitive deficits, which are prevalent in more than half of individuals with PTE. Difficulty with memory, attention, planning, and executive function are very common. As a result, PTE presents challenges that can affect people's independence, their job opportunities, their educational pursuits, their [00:17:30] mental health, and their safety.

There are also pervasive and common challenges in the clinic. We know that cognition and mood form a basis of neural circuitry, which can be disrupted by trauma and influenced by seizures. In post-traumatic epilepsy, these possibilities often merge with individuals influenced by neurobehavioral and cognitive [00:18:00] changes linked to the location of a brain injury, as well as the superimposed complication of seizures, epilepsy, and its known cognitive and behavioral comorbidities. It can often be more difficult for

clinicians to isolate and characterize cognitive impairments after a traumatic brain injury when epilepsy is present.

We know that meeting the comprehensive [00:18:30] needs of patients with TBI who develop PTE, including addressing cognitive impairment, is not always possible in a clinical setting. And so many of us have recognized that there's a critical need for systems of epilepsy care to develop a more comprehensive approach to integrating epilepsy self-management that empowers patients to manage the cognitive challenges from day to day in their homes and diverse communities. And this is where programs [00:19:00] like HOBSCOTCH can offer support and skill-building for patients.

We also know the interplay between structural brain changes from TBI and pathophysiologic electrical abnormalities secondary to seizures, which we know can present early or late, have the potential to augment and complicate the cognitive and mood challenges that [00:19:30] an individual experiences. Added to this complex scenario are antiseizure medicines, often coupled with antidepressant or anxiolytic medications with a potential for additional cognitive side effects. Current literature aiming to dissect cognitive effects in PTE, separating the effects of TBI from the sequelae of seizures and treatment, supports the need for [00:20:00] further work to advance diagnostic and treatment possibilities.

Displayed in the images on the right is an example of structural brain changes following a traumatic brain injury, where the skull was fractured. And you can see the disruption of the bright white rim of the skull in the upper-right quadrant of each image, and that the broken bone has breached the covering of the brain and made its way to invading brain [00:20:30] tissue, causing injury and resulting in brain swelling and bleeding.

Each individual impacted by PTE presents a complex and unique set of medical and psychosocial issues for providers to manage in the clinic setting. And even when seizures are well-controlled, comorbid disease and psychosocial challenges often persist. The ability to manage [00:21:00] a chronic disease, to reach education and employment goals, to foster healthy relationships, and function confidently in society are all at risk when a person's cognitive function is impaired.

We know that the reintegration of civilians and veterans into society following a TBI and the development of PTE can present enormous challenges, both for the individual and the family of caregivers who support them. [00:21:30] And so cognitive dysfunction, encompassing difficulties with memory, attention, and learning represent one key comorbid challenge for patients with PTE that requires an innovative solution to enable patients to feel more in control of their day-to-day lives. And this is supported by studies, revealing that cognitive function is a significant predictor [00:22:00] of a person's self-evaluation of their quality of life in epilepsy.

And so when we... Sorry about that. When we think about quality of life, we can think about the definition for health-related quality of life. And it's defined as the value assigned to duration of life as modified by the impairments, [00:22:30] functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy. And that's a mouthful, but to put it in context, when we talk about quality of life, we're really looking at the whole person and all the circumstances that pose an influence on their day-to-day life.

And we know, epilepsy represents [00:23:00] a spectrum of disorders that not only affect health, but also quality of life. The Institute of Medicine released a report in 2012, advising a more integrated and coordinated national approach to care-centering on the whole patient. They suggested amplified attention be paid to patient education, the impact of comorbidities, and the quality of life. And they shared that there [00:23:30] was a real need to engage, not only people with epilepsy, but also their families to increase understanding of the burden of epilepsy and its comorbidities in order improve access to quality care and resources.

And so, I also want to touch on caregivers and PTE, because we know that caregivers play a crucial role in recovery of veterans and civilians who suffer a TBI and develop PTE. We also [00:24:00] know that there's a high level of caregiver burden that's associated with caring for someone with a brain injury, epilepsy, and on top of that, cognitive dysfunction. The challenge here is that caregiver directed interventions are currently absent. Again, there's a dire need to address challenges caregivers face caring for someone with PTE, because we know that it's critical to their quality of [00:24:30] life as well. And so, at this point, we're going to transition to HOBSCOTCH, and the potential solutions it can provide when it comes to PTE, cognition, and quality of life.

We'll start with a quick review of the concept [00:25:00] of self-management, which has been applied in programmatic ways across several chronic disease states, but you may be thinking, "What exactly is self-management?" And self-management is really defined as the ability to manage one's own health condition. And it's based in two main psychological theories, self-regulation theory, where a person is motivated by a desired goal, and social cognitive theory, which concentrates on a [00:25:30] cognitive, emotional, and behavioral aspects of behavioral change. And both of these apply to managing a chronic disease.

And in epilepsy, a key initiative was the establishment of the Managing Epilepsy Well Network in 2007. The MEW Network is a thematic research network of CDC's Prevention Research Centers program. [00:26:00] And it's an interdependent partnership that is comprised of community, academic, and public health institutions across the country who work together to develop, test, and disseminate evidence-based epilepsy self-management program. And there are multiple programs being delivered at clinical centers

and in the community that target different domains in epilepsy, including mood and cognition, community integration, and a reduction [00:26:30] of negative health events, just to name a few. Information on all the programs can be found online at the [managingepilepsywell.org](http://managingepilepsywell.org) website. The HOBSCOTCH program is one of these programs developed and tested in this network. And so you might be thinking, "How can these programs help, and in particular, because epilepsy is widespread and people are located in so many different settings [00:27:00] and have so many individual needs?"

What we want to share with you, that there is a growing evidence base for the benefits of epilepsy self-management programming. And a spectrum of benefits have been noted from 13 [00:27:30] randomized controlled trials, and they range from improvement measured by a reduction in seizure frequency, an improved quality of life, improved knowledge, a greater self-management ability and self-efficacy ability, as well as positive mood.

And when it comes to HOBSCOTCH, HOBSCOTCH was first [00:28:00] evaluated in a randomized control trial conducted at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, which is a level four epilepsy center. And the study was published in *Epilepsy and Behavior* in 2016. The study was done in 66 adult patients with epilepsy, with or without uncontrolled seizures, between the ages of 18 and 65. All subjects were screened for subjective memory complaints. And [00:28:30] so they didn't have to have a formal diagnosis of a cognitive issue. They were able to enter the study based on their reporting of difficulty with subjective memory.

Patients who met inclusion criteria were randomized via computer-generated random assignment. And the study found that those who received HOBSCOTCH showed a significant improvement in quality of life when compared to controls. And there was also a significant improvement [00:29:00] in objective cognitive performance, and that was found to be most notably in the domain of attention.

And so on this slide, the graph on the left displays the results I just shared from the first randomized controlled HOBSCOTCH trial. And the data is shown as a mean change from baseline, with the purple bars indicating the HOBSCOTCH intervention group, and the green bars representing the control group. And the primary outcome measured was [00:29:30] quality of life, with secondary outcomes of objective cognition measured with the Repeatable Battery for the Assessment of Neuropsychological Status, the RBANS, and depression measured by the PHQ-9.

And what we see is that there's a significant improvement in quality of life, as measured by the QOLIE 31, in objective cognition, particularly in attention. And while we did see some improvement in depression using the PHQ-9, the results [00:30:00] in this group did not reach statistical significance. And it may be that the number of participants in the study was too small to see a statistically significant effect on the front of depression.



On the right is a graph with a comparison of quality of life outcomes from HOBSCOTCH I, the bars in dark purple, and the interim results from the HOBSCOTCH II study, and those are the mint green bars. And this study has currently been submitted for review and [00:30:30] publication. We're waiting to hear back. But the primary goal of the second study was to replicate our primary outcome and show fidelity across four epilepsy centers in northern New England. And in total, 84 adults with epilepsy were enrolled at four epilepsy center sites in Maine, New Hampshire, Vermont, and Massachusetts.

And what this graph demonstrates for us is that across patients who received HOBSCOTCH at four different centers, the finding of [00:31:00] improvement in quality of life was replicable. Both HOBSCOTCH I and HOBSCOTCH II demonstrated a significant change as compared to control. And in fact, the results in the second study across the four centers were even more robust than in the first.

Currently, we're enrolling in a HOBSCOTCH III trial. And this at Dartmouth is an efficacy study for enhanced virtual delivery of the program, and testing [00:31:30] of a new HOBSCOTCH app, and national recruitment is underway for that. We're partnering with Emory University, who are doing a replication trial in a more diverse population outside of northern New England. And so they're recruiting patients from the Emory Epilepsy Center, and their Georgia community partners.

And so, let's talk a little bit about the program itself. HOBSCOTCH is an [00:32:00] evidence-based... It's been tested, as I've shared with you the results of those randomized control trials. It's an evidence-based self-management program for adults with epilepsy. It's designed to help treat cognitive symptoms, particularly addressing memory and attention to improve quality of life, to be delivered in a way that minimizes barriers of access to care. And it provides for each individual, eight weeks of one-to-one cognitive coaching via telehealth. [00:32:30] And I'm proud to share that through the duration of COVID, we've been able to provide, at no cost of participants, close to 3,000 hours of coaching from the HOBSCOTCH Institute to patients living with epilepsy and cognitive challenges across the country.

And so in case there are providers on the phone, there's a possibility to train as a HOBSCOTCH coach as well. And so, along with delivering [00:33:00] the program, we also ramped up our efforts to train new coaches at clinical centers and in community organizations so that more people would have access to HOBSCOTCH. And over the course of the past 18 months or so, during the time of COVID, we've had 130 coaches train with us, and they're centered all around the country at different epilepsy centers and in community locations. And it's great to know [00:33:30] that we're able to partner with them to deliver this program. And so some of those coaches are delivering it independently. Some came to become more informed

about the program and refer patients directly to us at our central hub. And others do a hybrid, where they're able to provide HOBSCOTCH for some of their patients, but they send us their overflow. Anyway we can work together to get this in the hands of the patients who need it, we're happy to do.

When it [00:34:00] comes to general delivery of HOBSCOTCH and eligibility, the program is eligible to anyone with epilepsy who has cognitive challenges, and those can be cognitive challenges related to medication, to seizures, possibly, to the duration of time they've had epilepsy, they've developed more cognitive challenges. It's non-specific. If someone is finding that they're having difficulty with their memory, and thinking, their [00:34:30] attention, any of those things, we're happy to have them join us for the program.

Currently, it's available to adults, age 18 and over. And people have to have online access for the first session of the program because we deliver our education via a PowerPoint in that first session. And then for the remaining sessions, the remaining seven sessions, we want to make sure people have reliable telephone access. But probably the most important thing [00:35:00] on this slide is that a person coming to the program is really committed to the eight-week program. They can't come because their doctor sent them, or their mother wants them to do it, or their husband wants them to do it, they have to be really interested in participating, because the program is a fair amount of work over these eight weeks working on building cognitive skills. And so, you see at the far-right of this slide, sort of the eight sessions laid out. And you'll see the first session, we need you to have online access, [00:35:30] and the final session can be done online or also on the telephone.

And so, as a participant, you'll receive materials to help you through the program, including a workbook, a day planner, MP3 files for mindfulness, a toolbox of strategies, and also most recently, our HOBSCOTCH app. And for those who might be on the line, who are coaches, you'll receive a treatment manual, additional forms [00:36:00] to help you with screening and recording how a participant does. The education module will come to you, as well as help with promotional materials.

I want to just focus a little bit on this newest component of our program, which is the HOBSCOTCH app. And it's an app, and you download it at the App Store, like you would any other app. And through this app, which was intentionally very simply designed, we're gathering [00:36:30] information about people's seizure frequency, their adherence to taking medicines, their use of memory strategies while they're in the program, their well-being. All of those things are very important, you feel, to evaluate to see how we're doing with the HOBSCOTCH program.

And so once someone downloads the app and registers, they'll have a daily reminder sent whenever they want, and it will help them to answer these four simple questions. [00:37:00] And the app is both iPhone and Android compatible. And so it looks like this. On the far-left, essentially, this is what would appear on their screen. After they get their buzz and log in, it asks them these simple questions. And it was intentionally designed this way because we didn't want for it to take too much time for people, because it's hard to do many things during the day. We wanted people to be able to get to it and do it in a fairly short amount of time. There are also opportunities to [00:37:30] have a calendar available to you to see when you're journaling and logging, and you can share that with your clinician. And you can see on the far-right, an example of someone putting in a journal entry, where you simply just type on your phone and it gets stored to the day in which you entered it.

All right. The core program components for HOBSCOTCH, there are five. The first is epilepsy education, and it teaches the basics of memory and how seizures and variables related to epilepsy [00:38:00] might impact a person's memory and cognition.

Next is self-awareness training, and this teaches people to be aware of the multiple factors that are surrounding them that could potentially impact their memory and attention. And so this would be internal and external factors, things like, "Is there a lot of noise around me? Is there a lot of distraction?" And internal factors, like, "Am I tired? Am I hungry? Could those potentially be contributors?"

The core of the program revolves [00:38:30] around problem-solving therapy, which is a cognitive behavioral therapy. And it can provide skills for people to systematically work through cognitive-related difficulties and real-life problems. And we'll share a little bit more about that in just a little bit.

The fourth is compensatory memory strategies, and these are tried and true practical skills that psychologists use all the time that can help people to feel in control of cognitive challenges.

[00:39:00] And the final thing on this list is mindfulness. And during the HOBSCOTCH program, people learn to do progressive muscle relaxation and deep breathing exercises to help them deal with stress in their days. And oftentimes, they'll schedule this, other times, people get really good at it and they're able to use it as needed.

And so with the epilepsy education, we share with people a little bit about the anatomy of memory and how seizures might be related [00:39:30] to the symptoms that they're having cognitively. We teach people about what's necessary for memory to function and how disruption at any point in the process can impact someone's memory.

During the self-awareness training, this is where we're asking people to think about their present-day problems, and really take a hard look at internal and external factors that are influencing them. And these are some of the [00:40:00] worksheets that are part of the program. And by completing these worksheets, what we can look for are high-risk situation for people. Where are they at risk of having cognitive difficulty or a cognitive challenging arising? Is there some pattern? Is it that they have more difficulty with their ability to remember or think through things when they're anxious? If that's the case, let's work on finding a solution to help them deal with their anxiety to [00:40:30] see if, potentially, that could be helpful to them.

We also help people to organize their challenges in three sections. So, organizational skills; thinking about things like making sure you're getting to appointments on time, disease management skills; making sure you're taking your medicine, you're getting enough sleep, those sorts of issues, and then social skills; things like remembering names or conversations.

Here's a little [00:41:00] bit more of an outline of how problem-solving therapy works, and you can see the seven steps laid out here. And the systematic way in which this is approached in HOBSCOTCH is intentional and meant to help decrease the frustration and increased stress that cognitive problems can have. It helps people define solutions that allow them to feel more in control. They're defining their problems, setting their goals, and brainstorming solutions. [00:41:30] And it lets people think about cognitive challenges as something that they can solve in this really systematic way from week to week.

And how we record those, and how a participant records those is... A coach and participant, you can see their materials match. The coach fills out the problem-solving worksheet at the same time as the participant does while they're working together on the phone. They work through solutions. [00:42:00] They decide on one solution they're going to implement for a week, and then they set aside a plan to achieve those solutions and action plan. They get back together the following week to review how things went.

Next on the list are the compensatory strategies, and you can see the list of them here. And compensatory strategies are really behavioral strategies that are designed to help people overcome problems with memory and thinking. And one of these strategies [00:42:30] on the list is memory routines. And we'll briefly just look at this one and share an example. And memory routines really reflect doing things the same way to prevent things or steps from being forgotten. And memory routines can be incorporated into a person's already daily routines.

And I like to think of them similar to the hard work that athletes, high-level athletes have to do, where you have to be practiced and patient, and then more practiced [00:43:00] until you get good at memory routines. And so

here's an example from a participant in the program, Margaret, who was 43, was diagnosed with epilepsy as a teen. And her seizures were well-controlled, but she has noted cognitive challenges impacting her from day to day for many years. She was currently working as a hospice nurse and her job was to go into long-term care facilities and do intake assessments. The problem she shared with her coach, [00:43:30] that she was feeling frustrated and embarrassed by having to spend time searching for her personal items after completing her evaluations. Because her job required her to go to multiple facilities in a day, this was an issue that was arising for her with each of the institutions that she visited.

And so while it seems fairly simple and not such a big deal to us, you could imagine that if this were occurring from day to day, over and over again, how this would feel really burdensome. [00:44:00] And so the solution that she came up with, working through problem-solving therapy, was finding one common work area that existed in all the facilities she went to, and leaving her personal items there irrespective of the building that she was working in. And she described implementing this as life-changing. She had been suffering for some time with these feelings of frustration and embarrassment.

The fifth component is mindfulness, and this is progressive [00:44:30] muscle relaxation and deep breathing exercises that we ask people to schedule and have a backup in place, and also to use as needed in their day. And it can be an adjunct to other mindfulness activities. And so, if we think about how epilepsy self-management can help, we've been able to jump the hurdles of geography and distance with telehealth. You don't need to live near an epilepsy center to have this. [00:45:00] We've also been able to jump the hurdle of adaptability, and that's because HOBSCOTCH is based on the participant. It's based on the person who's come to the program to work through things with a cognitive coach from week to week. The goals are your goals, and the solutions are your solutions. Your coach is there to help guide you and to teach you different cognitive skills that you can use along the way.

And I just wanted to share [00:45:30] that we have been able to receive referrals from across the country over the past year, and a little bit. And so this map is from the CDC, showing where people with epilepsy are located across the country, the prevalence. And what you can see is that we've been able to serve people across the nation with HOBSCOTCH from the HOBSCOTCH Institute.

And so, now, I just want to share with you a little bit about [00:46:00] the study, which we'll be enrolling early in 2022, where we're going to be adapting HOBSCOTCH and enrolling veterans, active service members, and civilians to come and participate in HOBSCOTCH's PTE. And we're thankful for the funding received from the Department of Defense to go ahead and

create a program specific to PTE to help both veterans [00:46:30] and civilians.

And so what we'll be doing with this study is adapting the HOBSCOTCH telehealth program for delivery to patients with PTE and cognitive challenges. We'll be evaluating its efficacy, and we'll be incorporating family caregivers into select components of the intervention to evaluate the effects of the intervention on the caregiver. And so how we are adapting our program is by inviting feedback from patients [00:47:00] living with PTE, as well as their caregivers. And that's an early step in the process, which we have passed through, and we have gotten so much valuable feedback from the community through our community engagement studios to help inform the adaptation.

So, people who have PTE, and their caregivers telling us, "Gee, when I was first diagnosed, I wish someone would've told me this." Or, "Now that we're two years into this, this [00:47:30] is what's missing. It feels like we're on our own, that we go to our doctor's appointments, but between them, there's not much to help us, or caregivers sharing some sort of respite or activity that I could do for myself in an easy way would be so valued."

We're learning so much from that feedback that we'll incorporate into our adaptation, and then we'll collect subject matter expert feedback from a multidisciplinary group to come up with the final product, which [00:48:00] we'll start to deliver in the new year. And the way this will work is we'll have our arm of patients with post-traumatic epilepsy in the study, and we'll have our arm of caregivers in the study. For the first session, they'll come together to be presented with new knowledge through an education module, the adaptation we just talked about, and to review the program materials. Once that's done, they'll again return together to meet with their coach [00:48:30] to walk through the education module and review instructions for mindfulness exercises. After that, they'll split.

The person living with PTE will walk through from sessions two to seven, those core components of the program we just described for you, the self-awareness training. They'll learn how to keep a schedule, a seizure diary, to use the app. They'll walk through problem-solving therapy exercises, [00:49:00] week to week, and implement both memory strategies and mindfulness. Their caregiver will do independent study. And so they'll be implementing mindfulness during the weeks two to seven, and also doing app-journaling for how things are going. They'll come back together for session eight to do a maintenance strategy session. And so the coach and the person living with PTE will review their problem-solving therapy progress [00:49:30] and their progress in the program from the past eight weeks, and then a maintenance plan will come together to help them keep up the new cognitive skills. And that's co-produced with the patient and the coach.

And then finally, the patient and caregiver will jointly review strategies to extend the benefits of the program with their coach, what value the caregiver felt from the program, from their loved one, having access to the strategies and solutions available in HOBSCOTCH, [00:50:00] and what was gained for them with regard to their independent study on mindfulness.

And so, who can participate in this study? Veterans, military service members, and civilian with PTE and their caregivers. This is an adult study. We prefer that people don't have any recent changes in their medications for at least a month prior to study enrollment, because we'll be assessing cognitive function. And we want to make sure, as I mentioned [00:50:30] earlier, with our routine delivery, that internet access is available for the pre-session and session one of the HOBSCOTCH PTE program, and that a telephone access is reliable for sessions two to eight. And I do want to share that patients with PTE can enroll without being accompanied by a caregiver. It's not necessary to bring a caregiver to the study.

And so the study outcomes and measures, you can see listed here. And I'll just emphasize the primary outcome measures, which [00:51:00] are quality of life and cognition for the patient and caregivers. For caregivers, it will be caregiver burden. And so after presenting that study to you, and you're possibly thinking about yourself or a loved one with PTE, and whether or not you might want to participate in a research study, we invite you to come join us. If you're not interested in the study, but are interested in the program, we also [00:51:30] want to hear from you. If you head to [hobscotch.org](http://hobscotch.org), you can fill out the application there. It's really short. You just send us your contact information. One of our study coordinators or our program coordinators will reach out to you to tell you more about the program, to let you ask as many questions as you have, and to see if the timing is right, and if your situation is right to participate in the program with one of our coaches.

[00:52:00] And so, I've shared a lot of information with you and some data from prior HOBSCOTCH trials, but the things that resonate with us at the HOBSCOTCH Institute is the feedback we hear from participants in the program. And you can see here, just some of the feedback. And if you head to our website, there's a blog there as well, where patients and also coaches and clinicians who refer patients to HOBSCOTCH [00:52:30] share their thoughts about the program and what value it is. But this is what keeps us going, this feedback that people are feeling helped by the program.

I want to mention that we work with multiple partners here in the US, but also the Canadian Epilepsy Alliance. If there are people in Canada logged onto today's call, several of your nonprofit community Epilepsy Alliance offices in Canada have sent [00:53:00] people to be trained as HOBSCOTCH coaches. And if you're having trouble locating them, just head to our website, email us, and we'll be able to share information with you.

I want to thank CURE Epilepsy for inviting us to share our HOBSCOTCH program, and the work we're heading towards, adapting HOBSCOTCH for patients with post-traumatic epilepsy and cognitive challenges. We look forward to beginning to enroll people early in [00:53:30] the new year in that study. I also want to thank the CDC epilepsy leadership, Rosemarie Kobau, and Maggie Moore, our MEW Network colleagues, once again, the incredible HOBSCOTCH Institute team, who makes all this happen, and our colleagues at the Dartmouth-Hitchcock Epilepsy Center.

And with that, I'll turn things back to you, Laura.

Dr. Laura Lubbers: Great. Thank you so much, Elaine. We really appreciate all that information. It's a very exciting program, and I'm glad you shared the breadth [00:54:00] of it. We have time for just one question at this point. I wanted to ask... A question that had come in earlier was, is this applicable for teenagers? Could teenagers eventually participate in something like this?

Dr. Elaine Kiriakopoulos: That's a great question, Laura, and I'm excited to share that we're currently working on an adaptation for HOBSCOTCH youth, which will target adolescents between the ages of 14 and 18. [00:54:30] And we're hoping to pilot that early in the new year as well. And so more information will come forth on that, but we feel like the program has a lot to offer adolescents as they transition to becoming adults, and helping with organizational skills, and disease management skills, as well as social skills. We're really excited about that program. And coming along with that program is a HOBSCOTCH app, specifically for youth, targeted to youth. [00:55:00] We think that'll be exciting for them as well, too.

Dr. Laura Lubbers: Great. Maybe we can sneak in one other question, which relates to one of the study sites you mentioned. Do Georgia-based HOBSCOTCH participants need to be under the care of an Emory neurologist?

Dr. Elaine Kiriakopoulos: No, not at all. You can contact us, and we'll make sure we can connect you to the team in Georgia at Emory. You can have your care with anyone [00:55:30] in Georgia. We're happy to have you join.

Dr. Laura Lubbers: That's great. It seems like such a broad and welcoming program that can bring so much value to people, giving strategies. We're always hearing about the cognitive challenges of epilepsy, and knowing that there are strategies out there to manage it, I think will be a benefit to so many people. Thank you for sharing that.

I do [inaudible 00:55:52], so we'll have to wrap this up. And I want to thank you for sharing, again, all of this information for our audience. I'd also like to thank our audience [00:56:00] for attending. Now, there's just this webinar, but throughout the year of webinars that we have had, if you have additional questions about this topic or wish to learn about any of CURE



Epilepsy's research programs or webinars, please feel free to visit our website, or email us at [research@cureepilepsy.org](mailto:research@cureepilepsy.org).

And this actually concludes our 2021 webinar series. We create these webinars for you, our community, and therefore, we rely on your feedback and suggestions for future [00:56:30] webinar topics. We encourage you to take the survey that's going to pop up immediately following this presentation, and we look forward to receiving your ideas on potential webinar topics for the coming year. With that, I want to thank you all. Again, I wish you a great end of the year, and be well. Thank you.