

Mental Health & Childhood Epilepsy **CURE Epilepsy Webinar**

Laura Lubbers:

Welcome everyone to today's webinar. I'm Laura Lubbers, and I'm the chief scientific officer of CURE Epilepsy, and I want to thank you for joining us today. May is mental health awareness month, an opportunity for the epilepsy community to raise awareness, and challenge stigma about mental health concerns specific to people with epilepsy. Today's webinar is entitled Mental Health, and Childhood Epilepsy. Mental health, and behavioral problems are just a few of the concerns that can affect children with epilepsy, and these can vary greatly from one child to the next. One third of people with epilepsy suffer from some form of psychiatric disorder. While some people with epilepsy experience few, if any, mental health issues, others may suffer debilitating problems of inattention, anxiety, or mood disorders. It's important for parents, and healthcare professionals alike to address these concerns early in the diagnosis as this can have a big impact on the quality of life for both the child, and their support system.

This webinar is the fourth installment of the 2023 CURE Epilepsy 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. CURE is so proud to celebrate our 25th anniversary this year. Since our founding in 1998, we've raised millions of dollars to fund epilepsy research that supports our mission, which is defined a cure for epilepsy by promoting, and funding patient-focused research. CURE Epilepsy provides grants that support novel research projects, and that advance the search for cures in more effective treatments. Today's webinar will illustrate the prevalence of mental health conditions in children, and youth with epilepsy compared to the general population, and peers with other chronic medical conditions. It will also discuss the risk factors associated with co-occurrence of epilepsy, and mental health conditions, as well as emphasize the importance in outline the process of monitoring, evaluation, and management of mental health concurrently with epilepsy.

Finally, attendees will learn about this treatment approach using evidence-based mental health interventions. This webinar is presented by Dr. Clemente Vega, a board certified clinical neuropsychologist, and a certified subspecialist in pediatric neuropsychology, and the epilepsy center at Boston Children's Hospital. His clinical, and academic efforts focus on pediatric epilepsy syndromes, neurosurgical outcomes, and cross control application of neuropsychological assessment. He's also an instructor of psychology in the Department of Psychiatry at Harvard Medical School. Dr. Vega also practices as a consultant in criminal, and civil forensic neuropsychology, the public schools, and the Boston Red Sox.

Before Dr. Vega begins. I'd like to encourage everyone to ask questions. We'll address the questions during the Q&A portion of the webinar, and please keep in mind that you can submit your questions any time during the presentation by typing them into the Q&A tab located in your WebEx panel, and click send. We'll

do our very best to get through as many questions as we can. We do want this webinar to be as interactive, and informative as possible. However, to respect everyone's privacy, we ask that you make your questions general, and not specific to a loved one's epilepsy. So, with that, I'll turn it over to Dr. Vega. Welcome.

Dr. Clemente Vega: Thank you very much. Thank you for that kind introduction. Thank you for inviting me for this webinar. Today, I'll be talking a little bit about mental health, and childhood epilepsy. Just trying to get through this slide. I think it should work. There we go. I have a list of learning objectives here, some that have been already mentioned. I will talk about the prevalence of mental health conditions in children, and youth with epilepsy. I will talk about some of the risk factors that have been found to predispose someone with epilepsy to have co-occurring mental health conditions. And I'm going to talk about monitoring, and evaluating, and managing these conditions using some evidence-based mental health interventions.

As was stated earlier, there's a high rate of mental health conditions in folks that have a diagnosis of epilepsy. Some studies have shown that this can be as high as five times what has been found in the general population. That can be very alarming when we look at those statistics, but at the same time, I think it's important to understand that there's a pretty wide range of findings in studies. So, some studies can report that maybe one out of six individuals with epilepsy will have a mental health condition associated with it, or co-occurring with it. Other studies have found that it could be as high as 75% of patients with epilepsy that also have a co-occurring mental health condition. When we try to explain how there could be such variability between studies, one of the important distinctions to make is with a population that is being studied when there is a general population sample, like a population survey that's completed in a country, or sometimes by state.

I know I work in the state of Massachusetts, and there's a youth survey that is conducted every year, and usually done through the public school systems of high schoolers, for example. When the data is extracted from general population surveys like that, and they can analyze patients that have medical conditions like epilepsy, and what subset of those patients present with mental health conditions. Those are generally some of the studies that find lower levels of prevalence rates. So, for example, the one out of every six individuals with epilepsy also having a mental health condition. When the sample is the clinical population, it's taken out of a hospital like for example, my hospital, Boston Children's Hospital, we understand that these are patients that have epilepsy likely have maybe more challenges beyond just that medical condition. That's why they're coming to a tertiary care hospital like Children's Hospital. And also that people may come from out of town, out of state, out of the country, for treatment in our particular epilepsy center.

Therefore, there might be a bias towards people that have longer time with epilepsy, longer duration, maybe have more complicated types of epilepsy, and

therefore may present with more mental health conditions. So, it's important to keep in mind where is this data being collected. Also, the estimate may vary between mental health conditions, so some may, I will talk about some of these in the next set of slides, but for example, we find anxiety more often, depression more often, ADHD more often. But other behavioral conditions like conduct disorders, or oppositional defiant that are also frequently found in children, those may not be as prevalent in children, and youth with epilepsy. And the last thing that's important to always keep in mind is the type of diagnostic tools that are being used to make these assumptions about the rates of mental health conditions. It's not always based on thorough psychiatric interviews, or psychiatric evaluations. Sometimes it's just based on reports from parents, self-report from the patients themselves, or just looking through old archival records in the medical system.

And that may also have a bias in whether somebody's diagnosed, or not diagnosed with these conditions. All those caveats, we still, I can speak from my experience as a practitioner, and working in the field over a decade, it's clear to us that there is a much higher rate of mental health conditions in children, and youth with epilepsy compared to the general population. Many studies show that anxiety, and depression tend to be the most common co-occurring mental health conditions in children, and youth with epilepsy. And those studies frequently also cite the complexity of the neurological condition of the epilepsy as increasing the risk of mental health diagnoses. So, someone with more seizure burden, someone with a seizure that's secondary to a lesion in the brain, or a symptomatic of a underlying genetic condition. Those types of epilepsy syndromes that may be considered more complicated, they tend to have higher rates of mental health condition. Another important aspect related to mental health, and epilepsy, in my opinion, that we need to focus on is the co-occurrence of suicidality in patients that have epilepsy, and depression, and anxiety.

This is an area of particular interest of mine, because of the high rates, and because of the challenges in treatment of suicide in the high rates over the last decade, or so, which I will show in the next few slides. [inaudible 00:09:59] In general, suicidality increases during adolescence, and young adulthood for anyone that has mental health conditions. In some studies have found that up to 7% of adolescents, and young adults have had at least one attempt by the age of 20. Approximately 20% of children, and youth with epilepsy may experience suicidal ideation, that's what it's found in some studies, but again, in other studies they actually can go as high as 85%. We recently completed a retrospective review of medical records of patients with children, and youth with epilepsy in our hospital, and we found suicidality in approximately 75% of patients that had depression, and epilepsy. So much higher than the previous estimated rates of 20%.

So, why is this alarming? Well, part of it is because suicide is the second leading cause of death for youth in the United States. And another aspect of it is that it has significantly increased in the ages 10 to 24 over the last 15 years, or so, that

increase has been greater than 50%. Some of the contributing factors that were highlighted in that work include increased incidents of depression, hopelessness, and low self-esteem, problems with relationship, academic difficulties, and increase in substance abuse. Here's a graph that essentially shows that trend sometime around 2013, and 2014. We really start seeing an increase in adolescence ages 15, or 19, and young adults ages 20 to 24, significantly higher rates of the suicidality, just suicide thoughts, and suicide attempts. A map here shows by region where these rates may have increased more compared to other regions. And for someone like me who practices in Massachusetts, and we have a lot of patients that come from the northeastern general, I highlight the increase in these states around here, and how high it's been in these last 10 to 20 years.

Other mental health conditions such as ADHD, and disruptive disorders are also found more commonly in children in youth with epilepsy compared to the general population. In ADHD for example, the rates are estimated between 20, and 30% of children, and youth with epilepsy also presenting with ADHD. The rates may actually be higher with specific epilepsy syndromes, for example, childhood absence epilepsy in some studies has been associated with ADHD, and about 50% between 40, and 50% of those patient samples. And also there's been studies that look at focal epilepsy in the frontal lobes, and they have found co-occurring ADHD in almost 75% of those clinical samples. And that would make sense given the localization of ADHD as a syndrome to the frontal lobes in general. So, if there's epilepsy that originates, focal epilepsy that originates in the same area, it would make sense from an anatomical perspective that the risk of a medical condition, like ADHD, would also increase. The prevalence of oppositional defiant disorder is also higher between 10, and 20%. And similarly, conduct disorder also is higher, that has been estimated anywhere between five, and 20%.

Now, I think many folks in this webinar are probably familiar with the high rates, and whether it's 10, or 20, or 30 may in one study, or another study, maybe it's important to know, but not as important as what are we going to do about this? Why is this happening, and what do we do? So, one of the first things that we have to talk about is the influence of medications that are used to treat epilepsy in these mental health conditions. So, some of these medications are known to cause behavioral side effects that may mimic mental health conditions like behavioral disorders, ADHD, depression, anxiety, and so on. Some of these meds may actually have a positive effect on mood, so may have a transient, or a therapeutic benefit when they're prescribed for seizures. And then there's also another set of medications that may be associated with fatigue, and cause cognitive side effects like slow processing speed, and difficulties with attention, that may also either present as a mental health condition like ADHD, or a learning disability.

But may also secondarily cause increase in anxiety, and depression if the person, the child, and youth with epilepsy is feeling fatigue all the time, having some difficulties cognitively, which therefore causes problems at school, and can then

create sort of a cascade of difficulties in the environment that lead to anxiety, and depression. So, all of these variables need to be taken into account when we are trying to address the difficulties with mental health that we find in the population. So, why is this happening? I don't think this is the setting to go into a deep dive into the biology of these mental health conditions, and epilepsy, but I think it's really important to always keep in mind that there's not a causal effect. Epilepsy does not cause mental health conditions. There is a bidirectional relationship. We know that some of the anatomical areas, and some of the chemistry of the brain that has been found to be affected by epilepsy is similarly affected in mental health conditions. So, there could be something that changes the chemistry of the brain, or the neuroanatomy of the brain early on that then increases the risk of epilepsy.

Similarly, there might be something about a particular type of epilepsy syndrome that changes the chemistry, or the neuroanatomy of the brain that then may predispose, or increase the risk of that person having a mental health condition. I mentioned earlier, high association of focal epilepsy that arises from the frontal lobes, and ADHD as an example of that. Another important factor is the interaction between the environment, and our mental health. There are significant risk factors associated with early life adversity such as poor nutrition, neglect, abuse that have been known to really increase the risk, and almost predispose people to have mental health conditions including ADHD, difficulties with self-regulation that we find in conduct disorder, anxiety, depression, PTSD, et cetera. Age is also a risk factor that I think it's important to always take into account. If the epilepsy is diagnosed early in life, again, as I mentioned, it could cause changes in brain development from that point moving forward, that then can predispose some of the mental health conditions that I've talked about. The other important age risk factor that we find is in adolescence, and young adulthood.

These are very stressful times for anyone because there are periods of transition, independence, forming identity, and changing social situations at home, and at school. And youth with epilepsy are dealing with a very stressful, these very stressful situations while also trying to manage a chronic medical condition, and having to take medicine, and also maybe have some limitations in their activities of daily living like driving, or being able to do other things. Simultaneously, they're also experiencing, and all of us during our lessons experience some changes in our physical characteristics, our hormones, and that can also increase the likelihood of someone experiencing anxiety, and depression, which can then lead to more complicated mental health conditions, and presentation of suicide. And this is also adolescents is specifically as also an early adulthood. They are both times of life where people may be at increased risk, risk of substance use, and misuse, which are known to also be risk factors for having co-occurring, or co-presenting mental health conditions.

So, again, all of these factors are important, but what are we going to do about it? So, it's important to have active screening in clinic visits, and for caregivers, and parents, and other folks around individuals, children, and youth with

epilepsy to be mindful of the mental health state of patients that have epilepsy. The International League Against Epilepsy recommends some type of screening at every visit in clinic, whether it's at a visit to a neurologist, or to the pediatrician, or primary care provider. More detailed evaluation of the conditions that are known to have higher prevalence, and also known to have some more serious consequences like suicidality. So, conditions like anxiety, and depression. They may need to be evaluated in more detail at the beginning of the epilepsy onset every year, and also when there are changes to anti-seizure medications. Importantly, not all children, and youth with epilepsy who end up reporting suicidality later have been previously diagnosed with a mental health condition.

So, suicidality should also be evaluated for, should be screened for periodically even in patients children, and youth with epilepsy that have not been diagnosed with anxiety, depression, ADHD, or some of these other conditions. In particular, I think it's important to try to get a sense of a person's coping strategies such as whether they're avoidant, and disengaged, and the social support in their environment because these are factors that are known to predict suicidal thoughts, and suicidal behaviors in adolescents. Other variables that are important to identify would be a family history of depression, substance abuse in the family in a diagnosis of ADHD in the family. And the reason why I mentioned this here is because sometimes it can be overwhelming to keep an eye on every person, every child, and youth with epilepsy to the same degree. It's really hard to keep a close eye on every single one of the patients, or individuals with epilepsy that comes through our offices, or it's in our environment.

But there are some folks who may be at a greater risk, and these risk factors like coping strategies, social support, and family history may help us separate the patients that may be at a greater risk, and may require more early intervention, or may require more preventive measures really early in the process because of these risks. Now, if it's identified, how do we manage these conditions? Well, unfortunately, there is limited research on the efficacy of treatment, especially in children, and youth with epilepsy. There's some more research in adult populations compared to pediatric populations, but still not enough research has been done evaluating the efficacy of therapeutic interventions for mental health. Unfortunately, some of the findings with adult populations have been contradictory. That being said, there are general recommendations from the International League Against Epilepsy, and the National Institute for Health, and Care Excellence that specifically recommend evidence-based mental health interventions that have been shown with populations that do not have epilepsy.

So, any gold standard if you will, for depression, even if it hasn't been very in detailed, studied with patients that have children, and youth that have epilepsy, that should be the way to treat depression even in someone who has epilepsy as a co-occurring condition. The same thing with anxiety, and ADHD, and other conditions. So, for example, pharmacotherapy using SSRIs is what is the evidence-based practice for depression in general? Cognitive behavioral therapy

is the other option for treatment. Now, I can tell you speaking personally as a provider who has been doing this, as I mentioned earlier for a while, recommending medicine for a co-occurring mental health condition as a first line of treatment can be challenging, or it is not always received the same way because families are already dealing with possibly multiple medications, and they're having to manage side effects of medications, having to give the medications.

It's not uncommon for parents to talk to me about how hard it is just to adhere to meds, because children refuse to take the meds, or it upsets their stomach, or some of these side effects are really challenging, so don't my approach towards recommending treatment with medication specifically for anxiety, depression, and ADHD is very different with families that have children that are already taking meds that are already experiencing side effects of meds, and are hesitant to add yet another pharmacological agent to an already complex regimen of medications that they have to take daily. So, it would be fair to say that trying behavioral treatment interventions, therapy psychotherapy as a first line of defense would be accepted by many folks that abide to evidence-based practice. So, let's try therapy for three months, six months, let's see what the result is of that, with close monitoring of progress in someone who is first exhibiting signs of depression, or anxiety, or first being diagnosed with ADHD at the age of six, or seven.

That approach may be a bit too conservative in folks who have more longstanding depression, or anxiety. Kids who have now experiencing much more significant difficulties academically because the degree of ADHD, the severity of ADHD is much greater, or if there are significant concerns of suicidality. So, therapy as the first line may not always be recommended, but it's a very practical approach in some populations, especially early on in the process. Now, I always like to mention that there are studies that question the efficacy of cognitive behavioral therapy, which is frequently used for depression, and anxiety. Question the efficacy in some subset of individuals that have epilepsy. Some of the difficulties with translating cognitive behavioral therapy in persons with epilepsy have to do with the process of cognitive behavioral therapy, trying to change the mindset, or negative thinking behaviors of individuals. That may not always translate very well when the underlying reasons for feeling the way that we're feeling, or a significant contributing factor is a medical condition that I have very little control over, and actually feels like it's controlling a lot of me on a regular basis.

So, based on this idea, folks have tried to look at other types of therapeutic approaches that maybe don't try to change mindsets but maybe move towards more acceptance, more trying to manage, and develop coping skills for the things that are a little less out of our day-to-day control. And one of those types of therapy is known as acceptance, and commitment therapy. It incorporates some of these very useful aspects of cognitive behavioral therapy, but doesn't use all of it, and has more of a hybrid approach to the therapeutic interventions. This has been studied in folks with epilepsy, and it is showing some promise. For

ADHD, similarly, there are pharmacotherapy options like stimulant medication commonly things like Ritalin, and Adderall are used for treatment of ADHD. There's some studies that also show efficacy with non-stimulant medications that can be at times better tolerated. [inaudible 00:28:23] There are also behavioral therapy options like cognitive behavior modification that can be used in an outpatient clinic, but also in collaboration with the school in children, and youth that have epilepsy.

This type of therapy is a model that tries to encourage the individual, the child, or the adolescent into becoming much more in control of their behavior, a lot more aware, and also teaches a lot of coping skills, and problem solving strategies. When children are really young, and also even at any age, having some type of parent based therapy included for ADHD may also be recommended. It's important to have a multidisciplinary approach for treatment, and also prevention in managing mental health conditions in children, and youth that have epilepsy. That multidisciplinary approach may include parents, and other adults that are involved in the day-to-day life. Primary care physicians, medical, and mental health specialists, and some school personnel. Not everyone in the school needs to be involved. It's probably not recommended everyone's aware of it, but usually schools will have a nurse, and a school psychologist, or counselors that can be part of this multidisciplinary team, especially when we are trying to closely monitor the response to treatment intervention, or someone's suicidality, or more significant mental health presentation.

And lastly, I'm a true believer in a holistic approach to therapy, not just medicine, not just therapy, but really trying to look at what else in our lifestyle can be adjusted to improve our mental health. I have a citation here of an article published about 10 years ago in the AP American Psychological Association Journal that really talks about therapeutic lifestyle changes, and the importance of the things like exercise, nutrition, relaxation techniques, and mindful meditation, outdoor activities, and adequate sleep in improving our mental health. Not just mental health, but there's plenty of literature that shows that these therapeutic lifestyle changes can also improve cognitive function, difficulties with attention, and concentration, our fatigue, our depression, anxiety, and so on.

So, it is important to again, have a holistic approach that includes not just medicine, if that's necessary, not just psychotherapy, if that's recommended, or really looking at what else we can do outside of the clinical setting in order to improve any kind of mental health symptomatology. And that will cover the first part of the webinar, which is my presentation. Thank you very much for everyone, and I think we can open the floor to questions. Thank you.

Laura Lubbers:

Yes, yes, thank you Dr. Vega. That was amazing. Such great information, and such a breath of it. So, thank you so much. I know that was a lot to cover in a short period of time, and we can dig into more of it during the Q&A. So, just a reminder to our audience, if you have questions, please submit them via the

Q&A tab on your WebEx panel, and click send, and then we'll start getting to them. And I know there's already one in the queue, so can you briefly explain what ODD, or oppositional defiant disorder is?

Dr. Clemente Vega: Yeah, so it's essentially the difficulty following rules, and just adhering to the structure in the environment. It's essentially a child, or adolescent who does not have problems respecting authority, does not follow rules, breaks the rules on purpose, and presents with this type of behavior for at least six months, or more. And they seem to essentially also engage in other types of less socially appropriate behaviors like lying, or deceiving others, stealing, and so on.

Laura Lubbers: Okay, and how common is this in this population would you say?

Dr. Clemente Vega: In children with an epilepsy? The studies will show that it can range the prevalence anywhere between five, and 20%. It often co-occurs with other inhibitory condition, other conditions that present with difficulties with inhibition like ADHD, and it can also be a transient side effect of medication. So, sometimes medications that cause aggression for example, or cause a lot of frustration, difficulties with frustration tolerance. The way that presents in the environment is a child who just doesn't follow rules, breaks the rules, doesn't want to do what they're being told to do, whether it's at home, or at school. So, generally, studies will be as high as 20%, some as low as 5%. I think most of the meta-analysis will put it on the lower end. It's not as common as depression, anxiety, and ADHD.

Laura Lubbers: Great. Well, that's fascinating. I wasn't aware of that, and I know we've got another question, but I'm curious about this. So, it's really important to talk about the side effects of medication with the physician, and as you mentioned, some have negative side effects, and some have more mood supporting side effects, right?

Dr. Clemente Vega: Yes, and it's very important for me to mention that I'm not trying to talk about the medicines in a negative light. I think it's important to keep in mind that the medicine's goal is to try to control the seizures as best as possible, and having more seizures is going to have a worse long-term effect on mood, anxiety, ADHD, and academic performance if they're experiencing some cognitive side effects related to the medicine. So, the side effects of the meds sometimes are present, but they are less to a degree compared to how those same symptoms may present when the seizures are happening more often. There is a tipping point where the severity of the side effects, and the benefits therapeutically of the medicine from a seizure control perspective may not make sense for that particular individual. So, trying other type of meds may be a better option.

This is often seen for example in a medicine like Keppra, which does great, in terms of controlling seizures in a ton of in to ton of patients that have both generalized, and focal seizures but can present with side effects of irritability, negative mood, and some aggressive behavior. So, maybe that is [inaudible 00:35:57] Some people only have that in the beginning, or the first few weeks of

the medicine. Some people actually get... They don't go away. So, that's something I like to mention. I also think it's important for all of us when we are starting medicine to get a general sense of behavioral presentation in the weeks, to a month leading up to the beginning of the med, and the first four to six weeks after starting the meds, and then the next couple of months after. Because it all kind of blends together the frequency, and severity of behavioral side effects of meds, or cognitive side effects of meds with the difficulties that were there before the med was introduced, because they're just part of the epilepsy.

They're having a lot of seizures, or the disruption in sleep, or some of the other changes that are associated with the medical condition that may be there with, or without that particular medicine. So, having a, I'm not necessarily promoting journaling on a daily basis, but maybe on a week to week sitting down, and trying to get a sense of the presence of some of these mental health symptoms such as anxiety, depression, irritability, difficulties with attention, and problems in school. So, we can track little bit before meds in the beginning of the meds, and after the person has reached the therapeutic level of the meds maybe four to six weeks afterwards.

Laura Lubbers: Okay. That's a great strategy for us to think about as a community. Thank you for that detailed explanation. Really helpful, and I'm glad that you gave some examples, because we are aware that certain drugs can... Certain medications while intended to be helpful can also have these consequences, and so really being thoughtful, and monitoring, and managing it throughout to make sure that the person has the best quality of life is so important. So, thank you for that. So, here's another question for you. Are there any genetic epilepsies more at risk for psychosis?

Dr. Clemente Vega: I'm not familiar with any particular genetic conditions increasing the risk for psychosis. I can say, generally speaking, in the psychology world, we understand that psychosis is found more in populations that have neurocognitive impairment for example, and also in populations that have a family history. So, perhaps not necessarily, maybe it's there, and I'm just not familiar with it in terms of genetic conditions increasing the risk of psychosis. But we do know that genetic conditions also increase the risk of neurocognitive impairment compared to epilepsies that have a different type of etiology. And it may just be the multiple factors that are associated with the genetic epilepsies that increase the risk of psychosis if it's something that the person asking the question has been finding, or is familiar with, or something that makes sense to them. But to date, I haven't come across any literature that has presented that as a risk factor.

Laura Lubbers: Okay. Okay. Thank you. Thank you. Certainly more research to be done on these. Here's another question related to a genetic epilepsy, and this one is SCN 1A epilepsy. This person has heard that stimulants are not as effective with this type of epilepsy. Would that be true? Do you know?

Dr. Clemente Vega: So, I don't know about SCN1A, and stimulants specifically, but I do know that stimulants tend to be less well tolerated in some populations with epilepsy. SCN1A is a condition that usually comes with a lot of other situations. They tend to have a lot of medicine, because the seizures are hard to control, and in my experience a lot of my patients that have neurological conditions, whether it's epilepsy, or something else, have a higher risk of having side effects of any medicine that they are taking. So, stimulants are known to have side effects, and the population may just be much more at risk of having side effects. The problem with stimulants sometimes it's not that they don't help the cognitive aspect of the person, it's not that they're not helping attention, it's that we can't reach the therapeutic dose without having significant side effects such as irritability, depression, and difficulty sleeping, and appetite.

I also have worked with folks that spend a lot of their research career with populations that have autism, which is known to occur more frequently in genetic epilepsies that have SCN1A mutations, and their practice tends to be used more non-stimulant medication before stimulant medications like Stratera for example, because it's much better tolerated, and they can reach therapeutic levels compared to what type of efficacy they can have with the stimulant meds. But I haven't come across specifically research with SCN1A, but it would make sense to me if somebody publishes that, why that would be a problem.

Laura Lubbers: Okay, great. Thank you. So, are there ways for parents to screen for mental health, and needs in younger children like toddler, pre preschool-aged children?

Dr. Clemente Vega: That's a challenge for anybody, even parents that don't have children with... Whose children do not have epilepsy. It's most of the studies that look at general populations age when depression, and anxiety begins to actually present, when certain states have looked at this for example, and they estimate that anxiety, and depression really begin to emerge more between the ages of eight, and nine years old. So, ADHD presents more often between the ages of five, and six, but we hesitate to diagnose, or to talk about someone who's presenting very sad as being depressed when they are young like a toddler, or even a preschool-aged kid, or kindergarten age kid. Similarly, we are very hesitant to start thinking about ADHD in a toddler, or someone who's even three, or four years old, because in my experience most toddlers have a lot of difficulties paying attention, and they have a lot of hyperactivity.

So, it's very challenging to differentiate what is a clinical mental health condition versus just kind of normal brain in that young age. That being said, I will always recommend the parents of any age, of kids with any age to just monitoring change in their behavior over a course of on a week to week basis. Any of our kids can be a little bit more irritable, a little bit more sad, or a little bit more anxious, or different in their behavior presentation from one day to another. Kids are very sensitive to changes in their schedule, in their sleep patterns, in their nutrition, and we may just be seeing a transient change in behavior as a result of some of these environmental variables. But if we start measuring on a week to week, a change that seems to be a little bit more there between one

week, or another week, and really notice a change that we can compare to what was going on the month before, or the month before that, that's how we can start really identifying the potential presence of anxiety, depression, or sadness in children that are younger like toddlers, and kindergarten.

The studies also say, also show us that anxiety, and depression may present very differently at that young age compared to how it presents in middle childhood, or even as we get into adolescents, and in adulthood, they tend to, for example, in anxiety tends to present more as mutism, or social isolation when they're really young. If they're in school, they stop playing, they stop talking, they stop interacting with others. Mood changes may present much more as irritability, and crying, but not necessarily verbalizing that they're feeling a particular way. And also changes in their kind of basic physiological activity like changes in sleep patterns, changes in appetite. Those may also be more signs to be on the lookout for with younger kids that are three, four when we are trying to make sure that the anxiety, or mood are not being affected by whatever is happening, whether it's a condition, or changes in their treatment.

Laura Lubbers: Okay, great. Great things to look out for. Fabulous. For absence seizures, would mental health issues lessen if the child were to grow out of these types of seizures?

Dr. Clemente Vega: Unfortunately, the answer to that depends on that particular person. So, there is evidence that the curing the seizure, or outgrowing the syndrome does not always predict the resolution of a mental health condition. And they've done these kinds of studies in Canada where they look at folks that have these pediatric conditions, and trying to predict based on seizure control, or seizure severity whether the mental health condition will be benefited, or they outgrow it. And what they found is that there's very little way, there's no way to actually predict it. Some people get better, and some people don't. And we are still trying to figure out what may be some variables that can differentiate that. Is it the family history, that maybe predisposes some folks to have depression, or ADHD regardless of the presence of absence epilepsy? Is it environmental factors, or something else?

So, I would say that there is a subset of children, and youth with epilepsy that experience these mental health conditions as a consequence of their epilepsy that the effects that it has on their academics, or their quality of life is impacting them to the extent that it is increasing their anxiety, and their feelings of sadness, and depression, and honestly as a human being that makes perfect sense to me. Oftentimes, I think my patients are so resilient, and so strong because they don't present with the degree of anxiety, and depression, and other symptoms that I think would be a total normal response to having to deal with a medical condition like this.

And folks that are having this sort of direct response to the changes that they experience as a result of the condition, we would expect a lot of improvement as they outgrow the condition like absence epilepsy, and whatever contribution

may be there with the meds to their mental health that won't be there anymore if they're [inaudible 00:47:32] not taking meds. But there might still be an underlying biological process that is really contributing to their mental health that will be present, whether the seizures are still there, or not as they transition into adolescents, and adulthood.

Laura Lubbers:

Okay. Some of that is just a diversity in these mental health issues in our population. Yeah. Okay. And this is actually something that's come up a bit in previous webinars, and I'm so glad that you spent some time talking about CBT, and ACT is also a really interesting new topic for us, but to cognitive behavioral therapy, are there any books that you would recommend for mental health, ADHD, epilepsy on how parents can do CBT? What we know it's that while this seems to be an available treatment for adults, in some areas it's really hard to actually get access to a psychologist for children. So, are there programs that you would recommend, or books to support people in areas of our country where there don't have easy access to specialists who know how to do CBT?

Dr. Clemente Vega:

Yeah, so for ADHD first, there are a few books that were written for parents that I always find very helpful, and I recommend often. Maybe not for ADHD primarily, but for the symptoms of ADHD, which are frequently just executive dysfunction problems, just getting their task organized, planning, and problem solving. And there's a book that is called Smart but Scattered, there's version for younger children. There's a version for adolescents, and there are a version for young adults. Again, the book is called Smart but Scattered, and it was written by neuropsychologists who do a lot of work in ADHD, and it's essentially a parent guide. There are books on mindfulness, and on behavioral therapy that may also be available. There's a lot of these, I don't think I recommend one over the other. I would say a few things. Hopefully, now, as we are transitioning to more telemedicine availability, then people can have more access to mental health services compared to where we were before telemedicine became so normal.

So, that may increase access a bit. The other thing is that the providers who don't specialize in kids may be okay under certain circumstances. It's really hard to find someone who is a specialist in mental health that matches all of the needs of one particular patient that I work with who knows epilepsy well, and also knows anxiety, and also knows anxiety in this particular [inaudible 00:50:38] adolescent female that's 15 as an example. So, I tend to create a bit of a decision trait, because of the treatment that I'm referring for is the mental health condition, an anxiety specialist with good training is able to translate their work into epilepsy if they don't have a lot of work with children, and youth that have epilepsy, and may be able to adjust what they do. Someone with experience with adolescent may be able to work with a high functioning 10, or 11 year old, for example.

When it's younger kids, CBT may not actually be as helpful. It may be more helpful to do parent type of therapy that may be more accessible in the community, or something that can be managed with a multidisciplinary team

like the school, and counselors along with the parents, and some of the physician providers. I can probably go back into my library, and look for some of these CBT specific books that may be very helpful, and answer that question more specifically, but I can't think of a specific book off the top of my mind for that one.

Laura Lubbers: Okay. Well, those are great recommendations, and if you could send on any other titles, we'd be happy to post them as a part of our webinar recording on our website, and I'd love the smart but scattered recommendations so we can definitely post that, and provide resources for people for sure. Thank you. We've talked a little bit about Keppra, and its impact on mood. One question we have here is about phenobarbital. Do you know if it changes aggression, or mental health has an impact?

Dr. Clemente Vega: Well, I know that phenobarbital has cognitive effects, and it's associated with slowing processing speed, difficulties concentrating, and can cause fatigue. These can certainly have an effect on mood. As I mentioned earlier, if we are fatigued at any point, or for any reason, we're going to have more difficulty modulating our feelings, and our emotions, and maybe more anxious if we have cognitive effects, and have difficulty keeping up with what is expected of us on a regular basis, that's going to make us more anxious, and it's going to impact our mood as well. I'm not familiar with a lot of studies looking at higher rates of depression, or irritability in patients that are prescribed phenobarbital.

We tend to see more of a cognitive effective profile in that particular medication as opposed to more of a mood, or anxiety profile in that medication. But I think it's important to always keep in mind that anybody can have any kind of side effects with these medicines, because our brains are so different that we know of some side effects that may present more often than not, but that doesn't negate the potential of other side effects, or any side effects being there with any medication.

Laura Lubbers: Okay, great. Great to know. Got a question about CBT, and would it be recommended when adolescents also have cognitive regression?

Dr. Clemente Vega: So, I guess that may depend on the degree of regression, but if the question is related to an adolescent that may have some pretty significant cognitive difficulties, or maybe not to the degree of an intellectual disability, but certainly having a lot of difficulty keeping up with the expectation academically, or otherwise in their day-to-day. So, they're certainly not functioning at the level of their age, and maybe a few years behind. CBT may be much more challenging, or ineffective in someone who they can't process the information at a cognitive level, and it's a lot more reflective, or maybe is more immature in their behavioral presentation. So, behavioral therapy that is less cognitive, but more based on reinforcements, rewards for behavior, and designing more of a behavioral treatment plan that is similar to what we would do for someone who's younger, like a eight year old, nine year old, 10 year old, that may be much more effective for treatments compared to cognitive behavioral therapy.

If it's an adolescent with cognitive aggression that is presenting with more of the anxiety depression, there are other treatment options that may be better, like DBT, dialectical behavioral therapy has been shown to be effective in adolescents for treatment of depression, and anxiety, and it's a lot more on the here, and now type of behavior management as opposed to changing our cognitive thinking, or our patterns of negative thinking over the course of six months. That may be very challenging. Someone to make the slow gains if they have cognitive progression, and they may just need more of a here, and now type of approach for management like DBT can present, or other forms of behavioral therapy.

Laura Lubbers:

Okay, great. Certainly much more to learn, and new approaches to consider. Thank you so much for sharing all of this information. I know we have some other questions, and we will try to address those online as a part of the Q&A portion that's a part of our webinar that will be archived. So, I want to thank you Dr. Vega for a great, great presentation, very informative. I'd also like to thank our audience for great questions. As always, if you have additional questions about the topic, or wish to learn about any of the CURE Epilepsy research programs, or webinars, please visit our website, or email us at Research@cureepilepsy.org. We will be returning this fall with additional webinars, so stay tuned for announcements later this summer. I wish everyone a happy, and safe summer, and I thank you again. Be well.