CURE EPILEPSY™

Disparities In Epilepsy:
Overcoming Barriers to Improve Care and Treatment Outcomes
(Transcript)

Dr. Laura Lubbers: 00:00 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 celebrate Epilepsy Awareness Month. In response to the recent resurgence of the social justice movement, today's topic, Disparities in Epilepsy: Overcoming Barriers to Improve Care and Treatment Outcomes, will help viewers define the social factors or determinants that influence health and health disparities and how these translate to the epilepsy community. Will also help identify strategies that it can address disparities in epilepsy care. This webinar is the final segment of CURE Epilepsy's 2020 Leaders in Research Webinar Series, where we highlight some of the critical research that's being done on epilepsy.

Dr. Laura Lubbers: 00:49 Today's webinar is being sponsored by our friends at the BAND Foundation. CURE Epilepsy's mission is to find a cure for epilepsy by promoting and funding patient-focused research. Our health is shaped by a combination of many factors, such as the conditions in which we are born, work, and live, as well as broader forces and systems influencing the conditions of daily life. The differences in these factors across societies result in inequities or disparities in both health status and access to health resources, such as healthcare. Disparities in epilepsy have been identified based on factors such as socioeconomics, race and ethnicity, and address or location. Increasing awareness and knowledge of social factors that influence epilepsy healthcare is the first step to eliminating disparities and improving outcomes for all people with epilepsy.

Dr. Laura Lubbers: 01:46 Today's webinar is presented by Dr. Magdalena Szaflarski, a medical sociologist and health disparities researcher. Her research focuses on barriers to optimal health for vulnerable populations, including racial and ethnic groups, low income groups, and people living with chronic conditions. Dr. Szaflarski will be joined by her research collaborator and spouse, Dr. Jerzy Szaflarski for the Q&A portion of the webinar. He is an adult epileptologist and director of the University of Alabama at Birmingham Epilepsy Center and he can address questions related to clinical treatment and care. Before Dr. Szaflarski 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 at the bottom of your Zoom panel and then clicking send.

Dr. Laura Lubbers: 02:39 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, to respect everyone's privacy, we ask that you make your questions general and not specific to a loved one's epilepsy. I also want to mention that today's webinar as well as all previous and future webinars are recorded and are available on the CURE Epilepsy website. So with that, I'll turn it over to Dr. Szaflarski.

Dr. Magdalena Szaflarski: 03:10 Good afternoon, and thank you for this introduction. Thank you for inviting us to present in this webinar. We appreciate the organizers and all of you attending this session. Here are our disclosures. We have received funding from federal and state agencies, private foundations and industry partners. We have also received consulting and speaking fees from industrial partners and are members of several journal editorial boards. So the learning objectives for today's session are to define the social determinants of health and health disparities, to review the social determinants of health and disparities in epilepsy, and to identify strategies that address disparities in epilepsy.

Dr. Magdalena Szaflarski: 04:21 The social determinants of health are defined as the conditions in which people are born, grow, live, work, and age. The framework for understanding social factors in health was developed by the World Health Organization Commission on the Social Determinants of Health. By the 1980s, some of the groundbreaking research had appeared on how social position shapes the health of individuals, groups, and whole social classes. Specifically, research from all around the world has shown that health is shaped to a large degree by the distribution of money, power, and resources at all social levels. Since the distribution of power and resources is unequal, that is social inequality is a norm to varying degrees in all societies, health inequalities are also pervasive.

Dr. Magdalena Szaflarski: 05:24 Examples of the social determinants of health include socioeconomic status, including income level, educational opportunities, and occupation, as well as employment status and work safety. Other factors include gender and gender identity, race and ethnicity, especially racism and racial and/or ethnic segregation, food insecurity, and access to housing and utility services. Additional factors include early childhood experiences, social support and community inclusivity, crime and violence rates, availability of transportation and other neighborhoods related to conditions and physical environment. Showing in this slide is the comprehensive guiding framework on social factors in health, what they are and how they operate.

Dr. Magdalena Szaflarski: 06:27 Please think of it as a causal model in which the social economic and political contextual factors on the left from policy to culture and societal values provide a backdrop for the social structure of the society, with the different classes and groups with varying levels of social power and resources. These are called the structural determinants of health. These factors in turn shape health outcomes through the so-called intermediary factors, which include material conditions, behavioral and biological factors, and psychosocial resources. There are also feedback effects that are believed to exist. In particular, improvements in health and health equity, the box on the far right, are expected to improve the overall social context and structure and lead to further health and health equity advancements.

Dr. Magdalena Szaflarski: 07:31 As you can see, the associations between social factors and health are quite complex. Multiple pieces of evidence over time and from varying contexts provided and continue to provide a base for understanding the social determinants of health. As I noted, the WHO framework makes an explicit reference to health inequities. In the United States, health agencies, health systems, and much of the health research community tend to use the term health disparities. This term doesn't have a uniform definition but broadly means unequal distribution of disease and mortality across different groups based on socioeconomic status, gender, race, ethnicity, and other social possessions and identities. Eliminating disparities is a national objective for public health in the United States.

Dr. Magdalena Szaflarski: 08:36 Evidence about health disparities in the United States has been documented in prominent national reports, such as Unequal Treatment, which highlight disparities affecting racial/ethnic minorities and under-represented groups. With that overview of the WHO framework, let's turn to what we know about the social determinants of health in epilepsy. I will review some of the key social factors, especially social economic status and race, as well as mechanisms through which the social determinants of health operate to influence epilepsy care and outcomes. Please know that I'm just highlighting what's known and largely focusing on my own work. It is really just scratching the surface of the field, there's much more out there to what I'm presenting and also to what needs to be learned in the future as well.

Dr. Magdalena Szaflarski: 09:38 In terms of socioeconomic status, research has shown that socioeconomic deprivation likely increases the occurrence of epilepsy, that people living with epilepsy have lower education, household income, employment opportunities, and health status compared with people without epilepsy. However, research findings are not consistent across studies and most studies are limited in the ability to unpack the complexity of relationships among social factors in epilepsy. What we see in the literature is that associations between social factors and epilepsy care and outcomes vary across health measures, outcomes, and controls that are used in the studies, that is, we may see different associations when examining the prevalence of epilepsy versus medication non-adherence or when looking at access factors such as insurance or psychosocial resources such as health literacy.

Dr. Magdalena Szaflarski: 10:48 In national adult samples of people with epilepsy, current data show no race and nativity differences in visits to neurologist and use of anti-seizure medications, but African-Americans are shown to have higher rates of acute care, deaths, and less advanced treatments, for example epilepsy surgery. People with epilepsy of other minority backgrounds have also been indicated to experience barriers to care, epilepsy stigma, and potentially poor outcomes. However, evidence on race and ethnicity in epilepsy is still limited, especially, little is known about the role of so-called implicit racial bias in epilepsy care and its effect on outcomes. And little is known about how intersections of multiple marginalized or stigmatized statuses or identities, for example, intersections of minority background, poverty, and stigma affect care experiences and outcomes among people with epilepsy.

Dr. Magdalena Szaflarski: 12:03 Age is also a social determinant of health in epilepsy as people with epilepsy in different age groups have special epilepsy-related needs and vulnerabilities beyond biological factors, but derived from their social standing or social and biological intersection. Childhood and old age are particularly vulnerable stages in life. This advantages, for examples, experiences with prejudice and discrimination, can also accumulate over the life course. So age should be viewed as a social, not only biological factor in epilepsy. Some gender differences in the use of care and outcomes have been shown among adults but not among children with epilepsy. For example, women have been shown to have higher use of neurology care versus general practice services for epilepsy.

Dr. Magdalena Szaflarski: 13:06 Also, quality of life in epilepsy may vary based on gender. For example, women of childbearing age may have unique needs and vulnerabilities which may affect their quality of life with epilepsy. There is little information about people with epilepsy from different sexual and gender minority backgrounds and how they fair in healthcare and treatment outcomes. This area deserves more attention. Contextual conditions are coming to the forefront as we examine place-related quality of life and access to epilepsy care which is limited in some locations and affect epilepsy outcomes. Some studies show, for example, that people with epilepsy assess their neighborhoods as less safe than people without epilepsy. Also, in this study by our group shows that people with epilepsy residing in regions outside of the northeast are less likely to visit an neurologist or epilepsy provider.

Dr. Magdalena Szaflarski: 14:16 The association is strongest for people living in the south, which is becoming to known as the epilepsy belt, with relatively more cases and uncontrolled cases of epilepsy. There may also be urban-rural differences, but research in this area is inconclusive. There are multi-level contextual factors in epilepsy, both structural and cultural, that are not fully understood though the high economic and human burden of epilepsy is known and has been quantified. The overarching goal is to develop interventions at different social levels to help to reduce the toll of epilepsy. Health policy, health systems, and professional education must be addressed. Cultural interventions, such as increasing public awareness and stigma reduction, are also key. On this note, I would like to emphasize that stigma in particular is now considered one of the fundamental causes of health disparities alongside of social class and racism.

Dr. Magdalena Szaflarski: 15:44 There is significant complexity to social determinants of health in epilepsy, then evidence about mechanisms through which the social determinants of health operates to influence outcomes is limited. One place to start is to recognize that based on the social determinants of health framework, multiple mechanisms exist and follow this framework to build farther evidence to guide future interventions to reduce disparities in epilepsy. So this is a proposed social determinants of health epilepsy framework with specific items under the social context in the box on the left, including public policy such as epilepsy care and treatment regulation, funding for research, education, and care, onto discrimination laws, public education about epilepsy and epilepsy advocacy, as well as cultural factors, including social knowledge and beliefs about epilepsy and attitudes and behaviors toward people with epilepsy and their families, especially levels of stigma and discrimination.

Dr. Magdalena Szaflarski: 16:59 Then, embedded in the social cultural context of epilepsy, we have the social hierarchy or structure with individual social statuses or identities in the middle left. These are positions with varying degrees of social power and resources. Then there are material, behavioral, and psychosocial factors in the middle right, plus social capital, for example, epilepsy social networks in the circle spanning over the middle domains. Finally, epilepsy care is a big factor in the outcomes in epilepsy and shaping disparities. Epilepsy care is conceptualized here as formal access, insurance, having regular source of care, and patient-provider relationship and related factors. So a whole web of factors that are proposed here to shape the items on the right, including epilepsy epidemiology, patient outcomes, and disparities.

Dr. Magdalena Szaflarski: 18:11 With our colleagues, we continue researching disparities in epilepsy care. In the study shown on this slide, we showed that lack of insurance and region are key barriers to seeing a neurologist for epilepsy among adults while poverty is a key barrier to accessing anti-seizure medication. We have also examined socioeconomic factors in patients with treatment-resistant epilepsy treated with cannabidiol or CBD. Even though majority was white and socioeconomically advantaged, some patients struggled financially. 23% of patients reported having family incomes of less than 40,000 a year, 18% experienced money troubles, 13% food scarcity, and 8% could not always afford medications. We also showed the overall health status of those patients that was associated with higher age and lower income in combination.

Dr. Magdalena Szaflarski: 19:27 The graph shows the health ratings from poor or zero to excellent or four for patients in the lower and higher income categories. For a 10-year-old, gray bar, and a 40-year-old patient, the black bar. Even though all lower income patients, the left bars, had lower health ratings than the higher income patients, the right bars, the younger patients in both groups had advantage over the older patients. So based on existing evidence about disparities in epilepsy, the Institute of Medicine published recommendations for action to reduce disparities. These recommendations include surveillance of epilepsy, not only case-wise but in terms of service use and cost, access of and quality of care, risk factors, and patient-centered outcomes.

Dr. Magdalena Szaflarski: 20:32 Health policy in the public health system from national to local levels must be on board and do their part for which public health funding is essential for both data collection and public health interventions, such as access to services and treatments. Healthcare organizations and systems must do their best to evaluate, track, and improve quality and value of epilepsy care for all types of patients but especially for racial and ethnic minorities and socioeconomically disadvantaged groups. Epilepsy professional education needs to evolve as well to change culture, strengthen disciplinary expertise, and empower epilepsy organizations and centers of epilepsy care. Additional recommendations include improvements in quality of life and community resources for people with epilepsy as well as education of patients and families and public education.

Dr. Magdalena Szaflarski: 21:40 In addition to the Institute of Medicine guidelines, the national public health plan, Healthy People 2020, specified a national objective to increase the proportion of people with uncontrolled seizures who see a neurologist at least once a year. The progress on this objective has by now been reported. Over a decade, 10% improvement on this measure has been achieved leaving still over a third of those patients in a vacuum or not being able to access or receive appropriate care. One way that further progress can be made is by various epilepsy stakeholders working together, and I think it's happening more and more across the country. From our perspective, academic institutions especially have a multi-dimensional role to play in all these areas, including education, research, practice, and community and public engagement.

Dr. Magdalena Szaflarski: 22:49 So to recap the major points from this presentation, the social determinants of health are responsible for most variation in health status across populations and social groups and for production of disparities. The WHO framework guides us in efforts to understand what the social determinants of health are and how they impact health and healthcare and how to develop and prioritize interventions. This framework also applies to understanding epilepsy and epilepsy care disparities and it's necessary for us to be able to develop interventions at various social levels, and again, a lot of evidence has been already provided but a lot of work still needs to be done. And stakeholder in all these efforts include providers, patients and families, policy makers, public health officials, researchers, and community and advocacy organizations.

Dr. Magdalena Szaflarski: 23:56 We are unclear on how much work remains to be done there. We know there's been progress and there are stakeholders working together on these efforts, but it's never been quantified. So one area to investigate would be to see where there are areas for improvements in this particular area. Okay. Here are a few resources I recommend if you're further interested in this topic. Thank you very much for listening.

Dr. Laura Lubbers: 24:31 Great. Thank you, Dr. Szaflarski. We'll now begin the Q&A session and also invite Dr. Jerzy Szaflarski to join us if there are questions related to clinical care. Again, if you have questions, please type them into the Q&A tab located at the bottom of your Zoom panel and click send and we'll do our best to get through them. So I know we've got a number of questions that have already come and I actually have my own as well. I think this is an incredibly important topic that we really need to address to increase awareness and improve the outcomes for people with epilepsy. We know this, but how do we do this? So let's get to some of the questions. The first one is, has there been research that shows evidence on the most effective types of awareness campaigns? I think we all know that we need to increase awareness of epilepsy, but one of the best strategies for doing that?

Dr. Magdalena Szaflarski: 25:30 So first of all, I believe, based on my experience, that to develop any campaigns or any educational programs, it is necessary to have different groups represented. These types of interventions programs are most effective if they're put together by different stakeholders working together, right? Because we researchers have our own perspective about how to do this, but we need to listen to the patients and families, what they respond to, and what is important to them. The same thing include healthcare providers and just lay people without epilepsy as well and see where the gaps in knowledge are and awareness and develop programs that work best. For example, in this day and age, in this year in particular, maybe webinars are way to go for some groups and some communities.

Dr. Magdalena Szaflarski: 26:30 And we have health departments across the country doing different webinars for groups of stakeholders but also expanding some of these town hall meetings to whole communities and then people can communicate in that. But I think the essential part is to not only pull together evidence that would be presented to a community, but also have the stakeholders to weigh in on what is the most important information and how it is the best to present this information to others.

Dr. Laura Lubbers: 27:12 It's a terrific point about the need for multi-stakeholder voices to craft the right message.

Dr. Jerzy Szaflarski: 27:18 I wanted to add one thing from the clinical perspective, is important to recognize that most of the centers around the country, epilepsy centers, have patients symposia and patients are invited to come, clinicians meet with patients, present the most recent epilepsy data, but these symposia are also designed to listen to patients, to hear their concerns, hear what they need to learn from us so we can in many ways provide better education to our patients.

Dr. Laura Lubbers: 27:53 That's terrific to know. It would be great to find more information that we could share for our community on those symposium. There's another question. I was fascinated too by the comment around the epilepsy belt. The question is, can you help us better understand the reasons for regional differences in care and outcomes, for example, in the northeast versus the south?

Dr. Magdalena Szaflarski: 28:21

So from the research perspective, we know there's evidence that there is a growing number of cases of epilepsy, and specifically uncontrolled epilepsy in the south. So the term the epilepsy belt has been borrowed from the term the stroke belt in the south. So looking at the regions where there is a high prevalence of neurological disorders and looking at the reasons for it, and in the south, it is the whole area has been plagued by very high rates of health problems, including neurological disorders, but also we have higher rates of poverty and we have high numbers of minorities living in this area. This, and also access issues, can be compiled to contribute to both, I think, the occurrence of epilepsy, but also the trajectory for people with epilepsy to get into care and treatment. I'll let Jerzy elaborate a little bit farther because he, with his colleagues, also did different additional research on this so-called epilepsy belt.

Dr. Jerzy Szaflarski: 29:41

So I think the most important factor is that the risk factors for developing epilepsy are very similar to risk factors for developing stroke. So there will be overlap, but we are recognizing now... And I think first time I saw the term stroke belt... I'm sorry, epilepsy belt, was about seven or eight years ago in one of the papers from my colleagues. The risk factors are in many ways similar and access to care is limited, hence what we see is that the conditions in some ways get... maybe not the best word is neglected, but certainly don't receive as much attention as other conditions, like for example cancer. And access to care is another reason why there is increasing disparity in the care that patients with epilepsy receive.

Dr. Jerzy Szaflarski: 30:40

I actually made that comment a few days ago that the change to telehealth and telemedicine that I've been promoting in Birmingham for the last five or six years has actually made access to care better and we see that the participation of patients in their care is much, much better from what we saw about 30% of no-show rates to now about maybe 5% no-show rates. So we are actually providing more care now than we were providing before, which is one of the very few positive things of this pandemic. So that's certainly is something that we see. However, what we also looked at was the disparities in the care the elderly receive, so Medicare beneficiaries. The interesting part was that although the care that the Medicare beneficiaries receive is very similar across all racial groups, actually the

		existence of comorbidities drives that the cost of care, especially in patients of African-American descent. So that creates another disparity that we have observed here in Alabama at least.
Dr. Laura Lubbers:	32:02	Interesting. Thank you. Thank you for both answers. That's really insightful. Another question; what should be the role of government, health providers, and pharma industry in trying to equip liberate equal or similar access to health?
Dr. Magdalena Szaflarski:	32:25	Is there further to the question? I'm sorry.
Dr. Laura Lubbers:	32:27	Yes. What about providing health education? Which one do you believe is more important or more probable to reach the target population and have positive impacts to ameliorate these disparities?
Dr. Magdalena Szaflarski:	32:42	Let me start with maybe the partnership between government, health agencies, federal agencies, and pharmaceutical industry. This relationship is very important. So Jerzy and I come from Europe where there is much higher occurrence of negotiation between the government and pharmaceutical industries and basically the prices of drugs are lower than in the United States where the pharmaceuticals are more independent, I think, and they can dictate the prices of drugs. So somehow you look at the models around the world, it would be important at implementing developing models for the United States, where there's a closer relationship, where there is more regulation basically on pricing of drugs and I think that really helps. The United States has a long way to go, but we have seen these efforts, I think, at the federal level, the government trying to negotiate the prices of drugs in the United States.
Dr. Magdalena Szaflarski:	33:51	And it's possible, other countries have done it, so we just have to learn about those models and try to implement some here. But for that, we need public advocacy, right? We need to encourage our government to do this kind of activity and work on our behalf to reduce the prices of drugs. So that's one way to address this question. In terms of education, could you repeat that question, please?
Dr. Laura Lubbers:	34:28	Sure. What about improving education or health education? I suppose that feeds into the advocacy piece as well?
Dr. Magdalena Szaflarski:	34:44	There are two, I think, ways of looking at it. One is education of patients and families and then the second is educating the wider public about epilepsy. So on the first front, I think

healthcare providers as well as advocacy groups, organizations, provide a great platform for educating patients about new treatments and having this relationship between providers and researchers, epilepsy centers, and organizations like CURE and others, epilepsy foundation, and so on, to create the platform for dissemination of information. While the information for patients and families could be more specific in terms of treatments and also any axillary maybe services available to patients and families within a healthcare setting is important, then on the public level, we've seen educational campaigns through the media educating about what epilepsy is and maybe what to do in case somebody sees a person seizing with epilepsy and so on, right?

Dr. Magdalena Szaflarski: 35:55 Knowing more about epilepsy and its source, that it is... in some cultures, it's still considered... the source of epilepsy is not well known and so there are maybe these spiritual beliefs about epilepsy that exists in certain communities and there is a taboo in terms of talking about epilepsy and also isolating individuals with epilepsy from the larger community. So the more the public knows about what epilepsy is and how to respond and how to improve the treatment of people... treatment, I'm talking about the social relations with patients affected by it and families. So that kind of education is also very important and can be done both by the health agencies, public health agencies, but also private foundations and advocacy groups.

Dr. Laura Lubbers: 36:58 That's important. Right? Very good. So a question from another person. Who is an international organization? Is there a US agency or office that oversees and/or coordinates initiatives to address epilepsy healthcare disparities?

Dr. Jerzy Szaflarski: 37:21 I think that the most international organization that addresses these issues is International League Against Epilepsy and the American Epilepsy Society is part of the International League Against Epilepsy. International League Against Epilepsy provides not on the education at the provider level but also at the patient level. So it can be accessed through multiple resources, either through webinars or through lectures or through other resources that are available on the International League Against Epilepsy webpage.

Dr. Laura Lubbers: 37:58 It's a great suggestion. Yes. Need to highlight that work. But within the US government, there really isn't an agency that oversees this?

Dr. Jerzy Szaflarski: 38:15 Not that I'm aware of.

Dr. Laura Lubbers:	38:18	Okay.
Dr. Magdalena Szaflarski:	38:18	So the Centers for Disease Control and Prevention, the CDC, has a small division of mostly researchers but also public health workers that focus on epilepsy, and there are some research funding opportunities and intervention development opportunities through the CDC. They've done a nice job trying to garner some funding and also they are a source of very great data in epilepsy. We can find it on the web, at the cdc.org and look for epilepsy information and their statistical information. There's basic information about epilepsy, what it is as a disease, but then also statistical information about how many people are affected and some additional things about healthcare and treatment. So the CDC is a good source. Then at the local public health departments level, in some areas geographically, there is some focus on epilepsy as well, and there could be a small sources of local epilepsy data through health departments around the country.
Dr. Laura Lubbers:	39:38	Okay. Terrific. I know the CDC group is very interested in raising awareness and ensuring that it continues to be funded to do this important work.
Dr. Magdalena Szaflarski:	39:49	Right. I see a comment there from Sarah Franklin here at the Epilepsy Foundation, Alabama, that obviously the Epilepsy Foundation has done tremendous work as well to educate and to disseminate information.
Dr. Laura Lubbers:	40:04	Right. Absolutely right. Yes, the advocacy groups play important roles. So a question; in terms of disparities, many people with epilepsy also have intellectual and cognitive challenges, are there studies that have looked at the particular challenges and opportunities for this population?
Dr. Jerzy Szaflarski:	40:27	There are number of studies that look at the challenges, especially controlling the seizures but also creating a safe environment for patients with epilepsy who have intellectual disabilities, whether this is home environment, whether this is a group home environment, whether this is institutional environment. I'm not aware of any studies that look specifically for other opportunities outside of providing better care and better seizure control for these patients that I may be able to say more about that.
Dr. Magdalena Szaflarski:	41:08	I would say that evidence is limited, they're small studies, and it's sometimes hard to extrapolate to larger populations. However, I think where we need to pay most attention is we have this large population of patients with uncontrolled seizures

and there are many cases among those where there could be improvement if only the right treatment was applied. So one of the issues is that people don't always have the access to the best maybe advanced epilepsy care. If we can improve the care and improve the outcomes in terms of seizure control especially, then I think the people who have additional comorbidities or intellectual disabilities, mental health issues and so on, their additional problems could be better addressed as well.

Dr. Magdalena Szaflarski: 42:13 It's been suggested in the literature, but again, the studies are limited on multi-disciplinary groups, teams, at medical centers and healthcare settings working together, so that you can have epileptologists working together with a mental health specialist, with a psychologist, with a social worker, and that their referral system is easy through the healthcare setting to help these patients and families. I think there's much more work to be done to understand how these systems of multidisciplinary teams is working and where the gaps are and how to maybe expand that area to provide better overall holistic care to these patients.

Dr. Jerzy Szaflarski: 42:58 One important aspect that I wanted to add is the transition of care, so something that we see more and more emphasis on when pediatric patients are transitioned to adult epilepsy care. And that is really in every aspect of medicine, we see expansion of the transition of care programs because there are very unique needs that the pediatric patients have, and when they are transitioning to adult care, their needs may not necessarily be changing if they have multiple handicaps. And that is very important. It's very strongly supported in epilepsy care by the American Academy of Pediatrics in collaboration with the American Academy of Neurology and there are multiple centers around the country that are investigating the most adequate or the best pathways for transition of care. I think that's an important aspect of that discussion.

Dr. Laura Lubbers: 43:55 Most definitely.

Dr. Magdalena Szaflarski: 43:56 I would like to add one more thing. Sometimes we usually think about the patients, persons affected by a disease such as epilepsy, but I think more work need to be done to understand the situation and experiences of the family, especially the caregivers. We have recently done a nice study of caregivers of people with treatment resistant epilepsy and to understand how they are fairing, and they do not fare so well. Some things that they indicated they would like to see is more support for the caregivers to have places where maybe you can provide care even for an hour or two for a patient so that the caregiver can have an hour or two for themselves to basically recoup and try to relax and so on. So giving more attention to the caregivers as well, especially in those severe cases of epilepsy is important and improve their quality of life as well.

Dr. Laura Lubbers: 45:06 It's such an important point and I want to thank you for bringing that up because we do know that many people are cared for by caregivers and those caregivers become exhausted and that also impacts the care of the person with epilepsy. So these are really intertwined issues that need to be addressed. I want to thank you for that and it sounds like a great another topic for another webinar in the future. Still staying somewhat on this topic, how is patient satisfaction or rating of neurologists factored into the research? Patients without neurologists may have negative experiences with providers and some people give up. So how is that factored in as a social determinant?

Dr. Magdalena Szaflarski: 46:03 So, again, there's very little systematic research on this, but I think what's important is to think how much we have to go in terms of changing the culture among healthcare providers somewhat to address specifically social determinants of health, such as different social statuses that their patients may have to be more aware of their socioeconomic status and race and gender playing a role. And I think that education of medical trainees in this area is very important and I think medical schools are actually doing it more and more these days to produce neurologists and other medical doctors who are more compassionate and who understand the barriers that patients may have, also to understand their own biases they bring to the profession and to the care being from different social backgrounds.

Dr. Magdalena Szaflarski: 47:04 And the self-reflection is very important because that is something that could influence the relationship between the provider and the patient and the family and strengthen both not only each other's understanding, but then having better communication about treatments and also empowering the patients on this treatment journey. So there are some factors there to consider for sure. In terms of just neurologists, I'm not sure in terms of rating neurologists and how people feel about it. But what we know, for example in terms of race, generally in medicine, that patients prefer to have a provider that is from the same racial and ethnic background, right? They have a better understanding if the provider is similar to who they are. I mean, we are lacking a minority neurologists in this country.

Dr. Magdalena Szaflarski:	48:13	There are very few racial ethnic minorities that go into this specialty and so we need to focus on how to attract people from different racial ethnic groups into the profession because then we can serve the patients better through this.
Dr. Laura Lubbers:	48:31	Great point. Another question; is there information about disparities in participation in epilepsy support groups across the country? Is there some strengthening that can be done there?
Dr. Magdalena Szaflarski:	48:48	So I have seen many studies on social support groups, and in specific programs in specific healthcare settings, they seem to be working well. What I have not seen is research across different healthcare settings and how social support groups across different healthcare settings work. Also, you have social support groups outside of the healthcare system, right? So you may have them through advocacy groups and more and more so through social media and networking. You have social media outlets where groups of people with different types of health problems can get to get together and help each other. Right? So there are support groups forming online these days as well. But there is no systematic research, there are small studies here and there, so there's a lot to be done in terms of gathering evidence and to see where maybe improvements can be made and how.
Dr. Laura Lubbers:	49:55	Sure. Certainly for some, having a support group, a network, a Facebook group, can provide a lot of emotional support and ideas.
Dr. Magdalena Szaflarski:	50:04	Right. And we can have different groups, we can have families with patients, we can have those patients who can communicate well with others, could participate separately, and then you can have caregiver groups as well or maybe providers and patients together. So there are different types of models, I think. It could be thought through and some of them I'm sure are already implemented and used in different settings. But there's a little systematic evidence about that except to say that they are working well in specific settings.
Dr. Jerzy Szaflarski:	50:40	I think it's a very important comment about patients working with patients. I used to practice in Cincinnati now I practice in Birmingham, but I see... and patients ask the question many times, "Doctor, you are advocating for me to have epilepsy surgery. That's great, is there a patient I could talk to?" And in both centers, we had groups of patients we could refer to patients to. They wanted to be informed, they wanted to hear from other patients who had questions and explain their experiences with epilepsy surgery. And that's actually very

successful. Many patients who are very hesitant, after they talk to others and have better understanding from the patient's side, they are much more willing to undergo the evaluation and then eventually epilepsy surgery, there are candidates.

Dr. Jerzy Szaflarski: 51:38 So patient-to-patient discussions are very important. 20 years ago, there was no Facebook, so this was okay. "Here is the phone number of so-and-so, please call them if you're interested." Today, there are Facebook groups, there are multiple other venues where patients meet and discuss these things. We know about it because we hear from the patients or we hear from people who run these groups, whether this is Epilepsy Foundation, whether this is other group of people taking cannabis for the treatment of seizures who want to learn more. There are multiple groups like that where patients get information and they come to us then to verify it or say, "Well, you said this, but they said this. What are we supposed to do?" Then of course we are in the middle answering questions, but that's great because that also forces us to address the patient needs and their questions in more detail.

Dr. Laura Lubbers: 52:42 That's terrific. It's a great opportunity for all of us to learn. Another question, and you touched on this already somewhat, but in your opinion, why do African Americans have less advanced treatments?

Dr. Magdalena Szaflarski: 52:58 Multiple factors are at play. One is that trust between the provider and the patient seems to be an issue for racial and ethnic minorities. One explanation is, of the past treatment of minorities in medical research, we know that there have been abuses of patients in clinical trials, the syphilis Study, for example, the Tuskegee Experiment. So within African American community specifically, there is still some mistrust after all these years of the medical profession, of medical treatments and so on. So medical centers specifically have been doing a lot and building trust in the community, especially in large urban centers where there are large populations from racial ethnic minorities. Outreach efforts are underway in those big cities trying to educate minorities and give them opportunities to be more active in seeking healthcare and to even collaborate and partner with medical centers and community health interventions.

Dr. Magdalena Szaflarski: 54:21 So mistrust is a problem. The other thing is that some research shows that African Americans have lower levels of knowledge about medical treatments. And we don't know exactly why that is. It could be that they have less contact overall maybe in terms of the temporal dimension, not spending enough time with your

		physician to actually learn, to increase their health literacy through interactions with providers, and maybe it's the provider that are at fault a little bit not being forthcoming with information about advanced treatments thinking maybe that they're not maybe appropriate for these specific groups or something else. So there are definitely patient level and provider level factors that have been identified from mistrust to lack of information and other things that we need to work on from different angles within the healthcare setting on the provider side, but also engaging communities in their health more as well to increase trust.
Dr. Laura Lubbers:	55:37	Great points, and gives me some ideas for how do the different advocacy organizations reach out to help gain that trust and help provide the information and how one approaches learning for these types of situations. So we have time for just two more questions. The first one I want to offer is that epilepsy can be viewed as a spectrum disorder with a broad range of impact on patients depending on severity, ability to gain seizure control for example. How did the studies and figures on quality of life elucidate how disease severity impacts quality of life?
Dr. Magdalena Szaflarski:	56:21	I'll let Jerzy answer it. He spent most of his life studying quality of life in epilepsy.
Dr. Laura Lubbers:	56:25	Sure.
Dr. Jerzy Szaflarski:	56:29	Thank you for putting me on the spot. Yeah. So, this is actually a very important question. However, we know that there are multiple aspects of epilepsy care that affect quality of life, whether this is seizure control or lack of control, whether this is medication side effects or not having side effects, whether this is some other factors like mood, for example, that definitely affects quality of life as well. There's a lot of interplay between them. We know from epilepsy surgery studies that quality of life of patients who achieve seizure freedom after epilepsy surgery improves. No question about it. We also know that with improved seizure frequency, there is improvement in quality of life, and when patients go back to driving and when patients go back to full employment their quality of life improves.
Dr. Jerzy Szaflarski:	57:23	So as we are treating our patients, we're focusing not only on, "Here's the pill," or, "Here is the treatment that you should have," but how we affect their quality of life, their mood, their ability to live independently, their ability to go back to a full employment or to be employed. Those are very important aspects of epilepsy care and questions that we are asked and answer every day.

Dr. Magdalena Szaflarski: 57:56

Sometimes this balance has to be achieved between what kind of quality of life I can provide with this treatment or another treatment. So if there are severe side effects in the case of one treatment, then what do we recommend and also what patient prefers, right? So patient preferences are very important to consider in the treatment decisions about what they're willing to maybe give up or accept in order to improve their quality of life. And just to keep in mind, we always just say quality of life in general, health-related quality of life, but it is a complex construct, right? We are looking at different dimensions of life, of functioning, of mental health, social health, and so on, and when we're starting quality of life, we're actually looking at these different dimensions and how treatment effects the different dimensions of quality of life.

Dr. Laura Lubbers: 58:57

Wonderful. Thank you for the different responses. Now, we are actually at the top of the hour, so maybe we will leave it here. I know that there are some questions that were not addressed but we'll try to capture those and get answers. So I want to thank you both for such an engaging presentation and Q&A session. We so appreciate you sharing your expertise and your knowledge and your time with us today. I also want to thank the BAND Foundation for sponsoring today's webinar and our audience who was clearly very engaged. I know that there will be more who are watching and eager to hear the answers via the archive version of this webinar. So if you do have additional questions about the topic or wish to learn more about CURE Epilepsy researches, our programs, and future webinars, please visit our website at www.cureepilepsy.org. Please also stay tuned for the announcement for our first 2021 Leaders in Research webinar coming shortly. Thank you to all and please be safe.