An Overview of Hearing Healthcare Disparities

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- Hello, everybody, and thank you for taking the time to join us today. My name is Cody Curry. I'm the advanced bionics clinical specialist for the Ohio Valley region, and it is my absolute pleasure to introduce Dr. Matthew Bush. Dr. Bush is the vice chair for research and a professor in the Department of Otolaryngology Head and Neck Surgery at the University of Kentucky in Lexington, Kentucky. He holds the University of Kentucky College of Medicine Endowed Chair in Rural Health Policy. He earned his medical degree from Marshall University School of Medicine in Huntington, West Virginia. Dr. Bush completed otolaryngology residency at the University of Kentucky. He also completed a post-doctoral research fellowship and his otology, neurotology, and cranial based surgery fellowship at the Ohio State University.

Dr. Bush received a PhD in clinical and translational science in 2017 and in MBA in 2020, both from the University of Kentucky. His research is focused on hearing healthcare disparities. He serves as the PI of several NIH funded, community-based trials to promote hearing healthcare across access and utilization among underserved populations. Dr. Bush, thank you for joining us today.

- Thanks, Cody. It's a pleasure to be with you and all of our esteemed guests and I'm hopeful that this hour will be helpful. Hopefully, it will generate conversations, generate some interest in health disparities. They've been with us for a long time and will likely be with us for a long time in the future, but really it's up to all of us to learn about it, to understand some of the complexities and the challenges and the ways to describe health disparities and, you know, play a role actively in trying to address health disparities, especially as it relates to hearing healthcare. These are my disclosures. The research that I'll discuss from our lab has been supported by the NIH, specifically the NIDCD through several different grant mechanisms.

The learner outcomes for this presentation are to one, after this course, hopefully participants will be able to define the inequities in hearing health and healthcare, and

then also participants will be able to explain how to conduct equitable research in consideration of hearing healthcare disparities. And then also participants would be able to list the five social determinants of health. So I wanna start with taking you to the state of my birth. I'm from West Virginia. I was born in Charleston, West Virginia. And shown here in this picture is the New River, the New River Gorge, and the New River Gorge bridge. And we're gonna talk a little bit about today, about bridging new gaps. It's interesting that this river called the New River is not actually that new.

It's actually one of the world's oldest rivers. And there's been some evidence that this, you know, formed through the passage of time. You know, this deep gorge in the portion of Southeast West Virginia. But this, you know, huge gap between two different ridges in West Virginia represented an engineering challenge and the creation and the development and the completion of this new River Gorge bridge was really quite a feat of engineering and, you know, creativity. This is still one of the longest bridges in the world that is of steel construction, bridging this huge gap. And this is a site of sort of a West Virginia cultural interest area and a tourist trap. Frequently during October, the middle of October, there is a bridge day in which thrill seekers from all over the world will come to this area.

This is Fayetteville, West Virginia area, and they will attach parachutes and hurl themselves off of this new River Gorge bridge, hopefully to make it safely into the gorge below and to some of the safety teams below. But it's certainly an area that you won't find me jumping off any bridges, but it is an area of tourism and all around this region, it's a really beautiful area of hiking and rafting and fishing and all kinds of outdoor sports and activities. Growing up in West Virginia was known as being wild and wonderful, but the challenges I saw, even growing up as a child there, I could see immense health disparities and challenges in access to care. And so as we consider, you know, a big gap in, you know, the West Virginia area and this New River Gorge, it brings to mind some of these gaps that are in healthcare and health disparities.

So I'll ask you, you know, what are the disparities relevant to hearing healthcare? If we think about hearing health and the complexities and the technical advances and how far we've come in hearing healthcare, what disparities still exist? Well, to use the same picture, we could consider two different sides of the gorge as a gap here perhaps between novel research developments, innovations, even indications in devices such as cochlear implants and some of the advances that have been made there. And the gap between these advances and actual clinical practice, that is a disparity. And there's a disconnect between trying to connect the two. We also might see significant gaps between evidence-based care and the delivery of care, and actually the populations who need that care.

And how do we transition, you know, from what we know is effective and useful and meaningful, improving outcomes and quality of life and deliver it to those that are in need of care. To go a little bit further, even beyond just the delivery of evidence-based care, I think it's really important, in the spirit of understanding health disparities and to promote equity, to expand upon it and describe as a great need for full access to and utilization of evidence-based care. And that's different than just delivering care or having some access to care. We want full access and appropriate utilization of that care and being able to bridge that gap between that type of access to care and the populations that need the care.

So how do we define health and healthcare disparities? There's lots of different ways to define this. Here's one definition that comes from the Henry J Kaiser Family Foundation. "Health and healthcare disparities refer to differences in health and healthcare between population groups. Disparities can occur across many different dimensions, including race, ethnicity, socioeconomic status, age, location, gender, disability status, and sexual orientation." Healthy People 2020 describes a disparity as "Health difference that's closely linked with social or economic disadvantage". And

again, these disparities of differences in health could occur across many different dimensions and often are linked to social factors as well as economic factors. I'm gonna describe for you the tale of two four-year-olds. These are two representative patients from my practice that I've seen and that have certainly influenced my desire and direction in hearing healthcare disparities to pursue work in this field.

Our first patient is a four-year-old female who presented for a yearly follow-up visit. This child and her family live in a suburban area, less than 30 minute drive to their primary care provider, as well as all of their hearing healthcare and rehabilitation team members. This is a child who was born full term, no complications, who failed her newborn hearing screen in the birthing hospital. Three weeks after birth, she received a sleep deprived ABR at our academic center, which revealed a diagnosis of bilateral profound sensoral hearing loss. She had a confirmatory second ABR two weeks later. She subsequently was, at one month of age, fitted with hearing aids and she established a relationship with a speech language pathologist who she has still continued care with to this day.

At six months of age, she did have a sedated ABR, again, confirming sensoral hearing loss, along with an MRI that was performed at the same time while she was under sedation. This is a child who then underwent cochlear implantation bilaterally at 12 months of age. This was a few years ago prior to the change of the indications of cochlear implantation, but she received her bilateral cochlear implants on her first birthday. She has been able to continue weekly speech language pathology appointments and maintain her rehabilitation care and speech therapy, even during COVID, with some telehealth support. This child has made excellent progress, is really a star performer, and is actually enrolling in K-5 next year in a small private school.

And, you know, with full expectations and plans to be mainstreamed in school with oral and spoken language. Let me describe a second four-year-old. This four-year-old is a

four-year-old male from a very rural community who was referred to our center for a quote unquote hearing evaluation. This is a child who doesn't have, who lives in a very rural county, and there are no providers of any type, no healthcare providers, not even an emergency clinic or, you know, a urgent care treatment center. There's no hospital. So they really live in a healthcare desert within their county. So there's a significant drive for them to seek any type of hearing healthcare, any type of healthcare, let alone hearing healthcare.

This child was born full term, no complications, and he failed his newborn hearing screen at the birthing hospital in both ears. At three months of age, there was a scheduled sleep deprived ABR at an outlying hearing healthcare center, but the family had to drive two hours from their home and the child did not sleep during the test. They slept the majority of the way in the car and the test could not be completed and was rescheduled. A series of different scheduling challenges and cancellations occurred over an extended period of time. From three months, even up until four years, there was a confusion and questions between a primary care provider and even a local otolaryngologist. And ultimately, the child really never received any definitive diagnostic care, let alone any hearing healthcare treatment.

At four years of age, the child presented to our institution, underwent a sedated ABR which revealed bilateral severe sensoral hearing loss. So it's a patient like this that, you know, we might wonder, I mean, how does this occur in, you know, in the United States where modern medicine should have some safety nets and prevent this from happening? But in reality, this occurs in many different communities, and it doesn't necessarily have to be those from a rural community. It could be a child from a marginalized or vulnerable population that are overlooked because of cultural differences or language barriers. And so there are two very different stories and you know, it leaves us with thinking, you know, how and why does this happen?

A child like this, you know, seeing this child in my practice affects me as a father, as a physician, as a human being. And to see, you know, the way that healthcare has failed this family is really a challenge. So I'm gonna give you a little bit of backdrop about, you know, where I practice and sort of setting the stage and give you a little bit more detail about maybe how a child from a rural community like that could face a disparity. Rural populations have often been facing significant poor health as well as health disparities. This picture here to the right is a picture of the Appalachian region of the United States. This represents about eight to 10% of the US population that reside within this region that, you know, extends from New York all the way down to Mississippi.

This particular photo, or this particular figure, shows you the level of socioeconomic depression within the region with those counties that are more red having greater distress levels of socioeconomic depression. And you can see that where I practice here in the state of Kentucky is in Lexington, Kentucky, shown about where that gold star is. And unfortunately, the region that's in the eastern third of the state of Kentucky represents some of the nation's most socioeconomically depressed counties. And we see pervasive and persistent health disparities. And unfortunately, many of the Appalachian Kentucky counties have known something referred to as persistent poverty. That's where 40% of the county population are below the poverty line for 40 consecutive years. And that's really an oppressive and discouraging title to bear.

This region, as well as many rural regions, have been known for high poverty rates, lower levels of education, and low life expectancy. These regions also face pervasively high burdens of other chronic diseases such as heart disease, diabetes, and cancer. So what causes health and healthcare disparities? That's a complicated question I realize and not something we'll be able to fully wrap our brains around, but at least we can understand some different ways of thinking and characterizing some disparities and some of these causes we can think of in this, that this particular slide can help us

to understand. Complex and interrelated set of individual, provider, health system, societal, environmental factors contribute to disparities in health and healthcare. And we refer to these domains and these different areas as the social determinants of health.

These are the five different social determinants of health that influence all different forms of healthcare outcomes and health outcomes in individuals. Certainly we know they're biologic reasons and genetic reasons for hearing loss and different types of exposures and things like this that are medically related. But all of these factors are outside of the biological factors and have a great impact on not only the access to with the utilization of hearing healthcare. So access, educational access and quality is one of the domains listed at the top of the screen. Just going around the circle, social and community context, economic stability, neighborhood and build environment, and healthcare access and quality. And all these things relate together and they all influence health and healthcare.

There's different ways to think about those five different social determinants of health. This is a pretty helpful article that I refer to because it's trying to put a little bit more of, even though the social determinants of health is very valid in health and healthcare, it has sort of had a home in the public health domain and may not have had as much practical use and practical discussion in healthcare, especially in some of the specialties such as hearing healthcare, whether that would be audiology or speech language pathology or otolaryngology. This is a figure from this article from Torain in 2016 from the "Journal of American College of Surgeons", which is describing ways to think about surgical disparities.

And we don't necessarily have to only think about surgery as connected to these different domains, but we could think about hearing healthcare in this sense as well as it represents care outside of the primary care domain. So there are patient factors that

are influencing outcomes, they're provider factors, system and access issues, clinical care and quality, and post-op care and rehabilitation. And it would seem to make sense that all of these things would relate to hearing healthcare if you think about the complexity and the transdisciplinary nature of hearing healthcare. So if we go back to our picture of the New River and think about some of these, you know, persistent old disparities, you know, trying to gap full access and utilization of evidence-based care to the populations that need care.

The things that are negatively influencing or are having a significant impact on these disparities and causing this disparity are patient factors, provider factors, system and access issues, clinical care and quality, and post-op care and rehabilitation or in general, since rehabilitative services that are required for ongoing care in hearing loss patients. So why do we care about health and healthcare disparities? Because it's a hot topic, it's of social interest, it's trending on Twitter. Hopefully there's a much more, you know, basic reason that we care about this. First of all, it affects the groups facing disparities. As a human being, we need to have a sense of connection and care for our fellow human beings who are suffering and disease is left untreated, undiagnosed, undealt with.

And so from a human level, we really need to embrace this importance of health disparities. We also realize that health disparities limit overall improvements in quality of care and health for the broader population. So it's harder for us to move healthcare forward if we're still stuck with trying to provide some of the most basic needs for members of our society. But it also is important to consider the unnecessary costs that are due to unaddressed disparities. In a broad sense, health disparities are an expensive problem. 93 billion annually are spent in excess medical care costs per year as estimated by the Henry J Kaiser Family Foundation. 42 billion lost in productivity each year. And then economic losses due to premature death and significant impact of disparities on the health of individuals.

So now let's be more specific and talk about health disparities as it's more germane to our field, hearing healthcare disparities. So I'm going to give you kind of an overview of kind of an updated literature search on some, a wide range of different disparities. This is not an exhaustive list. There's a number of studies and a lot of work that's being put out there currently that describing different disparities among different populations. But I wanna give you a sense of how we might see disparities in some different populations and even connect some of those factors that connect in with those social determinants of health that could relate to hearing healthcare disparities. So first of all, if you think about incidence of pediatric hearing loss, we can see from this paper from 2018 from Lantos and others that non-white race has a significant, is a significant factor in the incidence of hearing loss with a 2.45 higher odds of hearing loss in those infants.

We also see that children from urban low income neighborhood also have a higher prevalence of hearing loss as well based on this large database research. We've done some research in our lab among vulnerable populations. We're really concerned considering the opioid epidemic that has occurred throughout the Appalachian region. We're grappling with some of the challenges of neonatal abstinence syndrome. Those are infants that are exposed in utero to different substances that are abused or used by the mother. And this can result in a variety of different health problems, but also is a part of, often, a socioeconomic challenge and lots of cultural challenges in management and care for a child who's parent is using or abusing illicit substances.

But this represents a vulnerable population. And looking at a nationwide database of infant hearing screening, the diagnostic care, this study documents that black children were more likely to fail in infant newborn hearing screens, similarly, were Native American infants. Those on Medicaid insurance had a higher odds ratio of actually being diagnosed with hearing loss. And then those children with neonatal abstinence syndrome had a lower likelihood of having a documented screening test in the

newborn nursery or in the hospital, perhaps due to some of the complexity of care around their condition. But also those infants have a higher likelihood of hearing loss. And so that represents a very, you know, alarming situation where they're less likely to get this screening test that may lead to diagnosis, but yet have a higher likelihood of hearing loss.

So that's concerning. Also from our research, we have really tried to investigate and describe different disparities as it relates to infant hearing loss, and the location of where children are that have a higher incidence of hearing loss. In this particular study that was published in "Ear and Hearing" in 2015, we looked at a geospatial scan analysis that enabled us to try to find regions, that based on our EHDI database data, where were children more likely to have a higher incidence of hearing loss. And we didn't find that the Appalachian region, the eastern part of the state had a higher incidence. We actually found that a similarly very rural region of the western-most part of the state, known as the Jackson Purchase area, has a significantly higher incidence with 3.08 times the risk of hearing loss in this region.

And the instance being about seven out of a thousand live births, which is alarmingly high. The factors behind this, we don't know. We don't know if there's some kind of environmental factors or any other things that might relate to perhaps maternal health. We're not quite sure, but nevertheless, we're seeing that, you know, rural populations may indeed have a higher incidence depending on the region that's being studied. Now let's talk a little bit about disparities in pediatric hearing healthcare utilization and actually, the timing of care. EHDI programs really matter. Early hearing detection intervention is really important. Infant screening and newborn diagnostic care and follow up rehabilitative care is really impactful and we're very fortunate in the United States to have a pretty well established program with, you know, data collection and reporting that helps us to track our outcomes.

This is a study from the "Journal of Early Hearing Detection Intervention" from 2017 that describes the haves and the have nots. Those countries that have EHDI services, you know, it's really an unbelievable disparity and a disconnect that there's 38% of the world's population that have no EHDI services within their country. And if you look at the timing of diagnosis for those infants that are born in a country that have EHDI, that's about 4.6 months versus those that do not have an EHDI system, that's 34 months. You see this huge, you know, cliff of disparity in differences in health and healthcare and it's oppressive to see that essentially the whole continent of Africa is without formalized, organized EHDI systems. Other research that was just recently published actually looked at factors or barriers to receiving hearing healthcare in the United States among different children.

And they found that children of non-white race and those that lack insurance or have public insurance like Medicaid were more likely to go without receiving hearing healthcare. And you can see that, you know, from this particular paper, this is a table that represents some of the different factors or the barriers such as a child not being eligible for services or difficulty with appointment, difficulty with transportation, the cost related to service. All these things are factors that, again, hail to and connect with those social determinants of health that are influencing health and healthcare outcomes in children in our clinics. This is some research from our lab that was published in the "Journal of Pediatrics" that described rural inequities in EHDI utilization.

And this is really an important issue because as I described in the tale of the two four-year-olds from earlier in the presentation, you know, even though I've seen it as a clinician, it's important to describe it and define it as a researcher. And that's where I think we have kind of a need and a clarion call for our professional communities to be not only embrace that disparities in health inequity is an important topic for us to take seriously, but for us to play a role in trying to define and describe where are the

disparities. This particular study showed that there is poor follow-up after newborn hearing screening and that rural infants are less likely to show up after a failed newborn hearing screen compared with their urban counterparts.

And then this leads to a delayed diagnosis. As we looked at children that were diagnosed in our center, we found that rural infants were diagnosed with congenital hearing loss about seven months after birth compared with urban infants that were at about five months. That's beyond, you know, the EHDI recommendation of no later than three months of age. But nevertheless, those that are in a rural population have a significantly delayed timing for the diagnosis. The factors behind this, this is similar to the study that was published in 2022, as we looked at our population, what factors are influencing these delays and these challenges? Here's some research that involves some mixed methodology from evaluation discussion of these factors from a clinician standpoint and primary care as well as a parental perspectives.

And we found that many parents lack, you know, educational levels and have the financial support to be able to travel to a specialist, you know, one or two hour drive away from their home. Distance plays a major role in access to care in rural America. Also, poor communication is really a problem in that, you know, 14% of rural parents whose infant had failed a newborn hearing screen were never told of the screening results based on some of this research we've conducted. And that's really a travesty that, you know, we think that we're communicating information and outcomes and data about the the child or about the patient, but it may not actually be hitting home, it may not be registering and they may not realize what is the implications of, you know, a failed newborn hearing screen.

There's also disparities as it relates to diagnostic services and treatment services for infants with hearing loss. And you're seeing a wide cadre of different types of services that are a part of general standardized type evaluation among children that have

hearing loss that may include genetic testing, EKG, speech language pathology relationship, and care, as well as even use of a hearing aid. And you're seeing racial and ethnic and even socioeconomic differences based on this study from 2020. Black race less likely to have genetic testing. Higher socioeconomic status more likely to receive that testing. Those of Asian population less likely to get an EKG or speech language pathology connection. Similarly, Hispanic patients less likely to work with a speech language pathologist.

And then black and Hispanic children less likely to receive a hearing aid based on this research. Race and ethnicity also matters and influences cochlear implantation. This is a study that was published by a friend and colleague, Cedric Pritchett, and is a database review of children that were implanted in the state of Florida over a 12 year period. And this represents over 1500 children. And what they found, looking at timing of implantation, they found that no black child was implanted younger than 12 months of age while there were white Caucasian children who had been implanted, other children that were non, that were not of black race. And so this is just, you know, compelling that this racism is basically right here before our very eyes that we see this racial difference without clear rhyme or reason.

Furthermore, in this study they looked at even just at a age of cochlear implantation by two, when they compared children to white children, they found that black children were less likely to receive their implant by two, Hispanic children less likely. Those on Medicaid less likely to receive a cochlear implant by age two compared to private insurance. And then even the white Medicaid or white self-paid children were more likely to receive a cochlear implant by two than black children, even if they had private insurance. So, you know, insurance is not a factor in this. There's a racial difference and there's racism at play in this particular data. Looking at rural population from our lab, we have studied how rural inequities influence cochlear implantation.

And this is a study that very much validated what I was seeing as a clinician and seeing two different four-year-olds, you know, one who was implanted early in life and has made excellent progress. And at their four-year-old birthday, they come in for a follow-up visit and they're doing well. Whereas the rural child has yet to receive the adequate diagnostic care or even treatment. This particular study documents that there's a difference in implantation that rural children with hearing loss take two times longer, in essence, to receive their hearing aids and two times longer to receive a cochlear implant than urban children. Some of the other aspects that further complicate rehabilitation care and access to care services are demonstrated in this paper where those children with cochlear implants that live in rural communities find that they have a longer distance to their audiologist or their speech language pathologist.

They also have a lower likelihood of early access to speech therapy. They also have a higher likelihood of device problems. And in this population, parental education really matters and lower education is linked to poor speech outcomes in cochlear implant recipients. Okay, let's shift gears a little bit and talk about adult hearing healthcare disparities as it relates to utilization and timing of care. And this is an area that's, you know, we're learning more and more about, and there's more attention to this topic and more research that's coming out. But this is some research that's from our lab in which we're looking at the impact of geography, rural versus urban residents and how that influenced timing of hearing aid usage and hearing aid amplification.

And what you're finding is that the social determinants of health are kind of coming out in these topics in that there is poor access in some of these rural communities and sometimes some economic instability for some rural populations that may influence their ability to purchase hearing aids. But if you compare urban versus rural adults with similar types of hearing loss, there's a significantly longer time period or a 26 year journey for rural adults to be fitted with hearing aids. And we know the audiology

shortage that's throughout the world, but certainly within the rural areas of our country play a role in this. There's a big waiting period that unfortunately occurs for many adults to receive cochlear implants.

From some research conducted by Tom Balkany, adults face, on average, 10 years of severe to profound hearing loss before cochlear implantation. And there's lots of reasons why that may occur, but we don't really understand them. We're not really able to fix that problem very easily. And unfortunately, most cochlear implant candidates have sentence testing scores of 10 to 15%, and Pure Tone Average of 90 decibels on initial cochlear implant evaluation. That tells us that adult cochlear implant candidates are presenting much later than they should or they could to actually receive a cochlear implant. Unfortunately, we lack really organized hearing healthcare within our healthcare systems and there's a lack of hearing testing or screening that's occurring on the primary care level. And so hearing is an aftermath or is a sort of recognized thing of aging and it's not really addressed seriously in a lot of primary care settings.

This is a figure that comes from Ashley Nassiri's paper that describes the journey for someone and as an adult to receive hearing healthcare. And, you know, I refer to this as the long and winding road and it really just causes you to wonder, you know, would we seek hearing healthcare if we had this long journey that begins in sort of self-identifying that I have a problem all the way through diagnosis, hearing aid amplification, cochlear implant candidacy testing, cochlear implant surgery, and then ultimately programming and finding sort of a new level of hearing and functioning with a cochlear implant. I mean, that is a long journey and I think that there's two major bottleneck areas that really deserve our attention.

One is going from self-identification to actually getting a diagnostic test by an audiologist. That's sort of that entry in the hearing healthcare. That's a big research focus that I have, especially considering our rural population. How do we get them not

only to identify that they have hearing loss, but to talk about it with a primary care provider, primary care being involved and trying to get them into an audiology practice and diagnostic care. But then there's also this bottleneck between all of this huge population that have hearing aids that are not being, are not receiving the best outcomes, perhaps, not receiving the best care and may indeed do better with cochlear implants. And how do we pursue cochlear implantation in that population?

That's complicated, obviously. So here's some research that comes from, you know, some pretty broad, diverse populations that include patients from Texas, Georgia, South Carolina among the three different papers. But this talking about how socio-demographics are influencing the access and timing of advanced hearing healthcare such as cochlear implantation. We find the lower likelihood of pursuing cochlear implants in non-white adults, older adults, and those that are single or widowed, perhaps lacking a social support system. We also find delayed implantation in non-white race adults. And in many states, Medicaid continues to be a barrier for cochlear implantation for delivery of services, a second side implant, or even repair or, you know, upgrades of technology that may become obsolete or non-functional.

Similar to our hearing aid paper in our rural population, we've published on how geography is influencing the access and utilization of cochlear implantation. Like we saw, a 26 year journey with the hearing aid population, if you compare urban and rural adults who get cochlear implants, it takes rural adults longer with similar type hearing loss than it does the urban adults. A 36 year journey between that self-identification of hearing loss until they actually get a cochlear implant and that's really a long time. So I've been involved in trying to, you know, wrap my brain around these social determinants of health for the last few years and trying to think how that applies to hearing healthcare. Here's a couple of recent publications that have come from my lab that, you know, tries to describe and define some of the social determinants of health

as it relates to hearing healthcare as in general, but also in cochlear implantation as well.

So I'll refer you to those and perhaps, again, it doesn't answer all the questions, but maybe just perhaps might be enlightening and might open your eyes to some of the complexities that are at play in hearing healthcare disparities. So the last few minutes that I have remaining in the presentation, I'd like to talk a little bit about how do we address these disparities. I don't want to leave you in the doom and the gloom and the frustration of all these disparities that are all around us, but we want to think about, you know, how can we address them? And again, just like trying to understand what causes them, this is a very complex exercise. It's also very difficult to think about all the things that may influence, you know, and alleviate some of these disparities.

But it helps to start clear, start simple, and start very focused. And I think first and foremost, that starts with setting an agenda to address disparities. I showed you the paper from Torain in 2016 that described kind of a surgical or specialty focused alteration or rewording of the social determinants of health. Emanating from that work has come an agenda, at least within the American College of Surgeons, to address disparities for surgical disparities. And again, this isn't just about surgery and cochlear implant surgery and disparities that need to be addressed by surgeons, but what I like about this is that the agenda that was set forth by the American College of Surgeons, I think is really applicable for hearing healthcare and for those of us that are sort of in a niche area of specialty care where patients don't necessarily come to us for annual checkups, you know, the general population.

They come to us if we've delivered care or if they want us to deliver care for specific reasons. So this agenda is really helpful as we think about how do we begin to conduct research or promote within our hearing healthcare programs an agenda that might keep equity on the forefront and how might we begin to break this down? First and foremost,

it starts with good communication. So there is a need for programs, research, and work to be done in the field to improve patient clinician communication, to learn to be culturally dextrous so that we can begin to communicate very well and communicate in a culturally appropriate way that does involve, and it's really critical to consider the diversity of our workforce and the diversity of the hearing healthcare field in that patients see providers that are culturally, ethnically, racially similar to themselves.

And so we need diversity within our workforce, but also understanding differences in communication styles and topics and methods across different populations. Secondly, we need to consider how community engagement and outreach through technology could help us address disparities. That might involve education, literacy, shared decision making. So there's work to be done in this field in engagement and outreach and how we do that's complicated. But you know, there's lots of ways to consider this. Development of a community advisory board has been a critical part of the research that we've done amongst rural communities in trying to get community buy-in, build trust, also have shared innovation in research that we're involved in. We also need to consider how we could develop research that's focused on improving care at centers that actually see a higher percentage of minority patients.

And so how do we support those centers that perhaps may be strained in their resources to meet the need of a population that's not socioeconomically privileged? We should also consider the long-term effect of interventions on functional outcomes and patient defined quality of life. This is an area that needs a lot of attention and research on the longer term impact of what we do for their functional outcomes and overall, their quality of life. We also need to improve patient centeredness by evaluating patient expectations. And there is a need for this in all fields, but specifically hearing healthcare really would benefit from a patient-centeredness approach and how we develop programs. I know you're thinking to yourself, that sounds exciting, that sounds, you know, encouraging.

How do we do that? I don't have the answers for how we address, you know, each of these agenda points, but I think these are things that we could rally behind and innovate together in how we would try to approach hearing healthcare disparities. These are some other areas that I think are really important for us to be able to address disparities specifically in hearing healthcare. Within our research programs, it is so critical to improve recruitment that reflects diversity, embraces equity, and we also need to report the socio-demographics of our population or samples that are involved in our research. These are two systematic reviews, one from the Hopkins Group with Carrie Neiman's leadership and then one from our lab.

Both of these systematic reviews talk about hearing related trials or cochlear implant related trials and some of the reporting of the participants in the 2021 publication. They found that recruitment was inequitable, that it didn't reflect gender. It reflected inequality in gender recruitment and there was racial and ethnic inequality in recruitment as well that did not reflect the population. In the systematic review that we've conducted here in our institution, we found that less than 10% of cochlear implant clinical trials and prospective research report key sociodemographic factors that we've already seen in this presentation, we know from the literature that have an impact on hearing healthcare outcomes. These factors just aren't reported in some of our most rigorous research and that's a problem in our field.

I think we also need to improve health information. Hearing healthcare is complex. The jargon that we use is complicated as well. And so we may not have the clarity, we may not have the readability in the information that we put out there for patients to digest and learn about our services, learn about the care that we can provide. This is a paper that was just recently published that evaluated the readability and the quality of both English and Spanish websites that were focused on cochlear implantation and looking at this large number of websites, we found, overall, that readability of that information

is very poor. The American Medical Association recommends that health information that's, you know, publicly available should not be beyond a sixth grade reading level, really should be probably about a fourth or fifth grade reading level.

In this study, we found that essentially every cochlear implant website averaged between 10th to 12th grade reading levels. So it's dramatically more difficult for the general population than we might realize to read the information we're putting out there. Whether that was an independent website or an industry-related website, this healthcare information is just not that readable. Also, the quality of it, overall, is not that great either based on the discerned criteria that describes a number of different metrics that are validated to support the quality of health information. Apart from the research recruitment, apart from the health information, we also need to just kind of think outside the box of how do we take our existing systems and improve them.

This is research that we're currently engaged in and the protocol we've recently published in BMJ Open that describes the CHIRP trial. This is an NIDCD funded trial that looks at improving pediatric infant hearing healthcare through a patient navigation intervention. So in this particular research, which is a pragmatic trial throughout the whole state of Kentucky in 10 different hearing healthcare, public health hearing healthcare centers, we're looking at the role of a navigator to improve the timing of diagnosis from a failed newborn hearing screen to the time that they present in the clinic for diagnostic testing. But we're also trying to simultaneously evaluate implementation factors. What are the barriers, the facilitators, the things that may influence the trial's success or the trial's failure?

And also to evaluate the cost effectiveness. How can we overall improve this system to make it more efficient and effective? We're also trying to think about new places to conduct hearing healthcare research and to provide hearing healthcare in general. It's not a surprise that we would like to be involved in providing hearing healthcare in the

primary care setting, but there's just not the funding and the mechanisms to support it. So this is a an NIDCD funded trial that we're also currently involved in, and which we've got two phases in this research where we're studying rural health clinics to explore some of the challenges, the experiences, the access, the options for adult hearing healthcare within these rural clinics that can provide care.

And then this will help us to evaluate and develop some of the priorities related to hearing healthcare. And then in the intervention phase, which is in the near future, we'll be begin in this part, is to similarly use a culturally appropriate patient navigation or patient guide program to support adults that are in rural health clinics to be able to get diagnostic care, specifically an audiogram, which is just a first step in hearing healthcare. So we'd like to use, you know, our research methods and flex our research muscles to try to explore new places and new ways to promote hearing healthcare. The last study I'll talk about is a current study that Susan Emmett, who's at the University of Arkansas, and I are leading.

And this particular study is also trying to think about, you know, if we're trying to reach a rural population, we can't necessarily get them to our clinic two hours away. What about the school system? You know, all of these children are enrolled in a local school in every county. Even most rural counties have a school within the county. And so how do we use technology such as telehealth, telemedicine improve screening program within rural school settings and promote children to then have further care and entry into hearing healthcare. And so this study adapts a telemedicine hearing screening program that Susan has led in rural Alaska for the rural region of Kentucky, as well as to be more representative of the lower 48 states.

and the rural communities will evaluate the effectiveness of this particular model to promote hearing healthcare and then simultaneously try to evaluate some of the implementation factors and outcomes. So this is probably the most important slide of

the presentation of just some practical ways apart from describing at the beginning of the, you know, what can we do about this section about setting an agenda. These are some practical ways that I actually am trying to conduct my research and promote equity in our clinic and on our programs here. First of all, we really embrace mixed methodology. That means understanding that quantitative data matters, but qualitative data is critical and it's equally essential because what people say is just as important, if not more important, than what data we collect about what they do or what their outcomes are.

And so we have to integrate the opinions, the experiences, the attitudes, the perceptions of those that are dealing head-on with disparities and understand from their perspective what they're dealing with. We wanna try to collect the social determinants of health. We wanna understand more where there are areas for opportunities and where there are barriers that prevent us from making progress for the sake of equity. And gathering data on social determinants is really gonna help us do that in hearing healthcare. We've gotta consider different populations and health systems. You gotta think outside the box and ask yourself where are the marginalized patients and how do I get access to them and how do I support their care delivery?

Community engagement is also a priority. Again, I talked about the community advisory board and how that could be vital. And then consider clinical trials, whether that be medical or behavioral interventions that involve robust diverse recruitment is really important for us to move the needle forward. These are a couple instruments that can be used for collection of social determinants of health data from the National Association of Community Health Centers, as well as the American Academy of Family Physicians. So again, I'll take us back to the New River again, talking about this, this old, entrenched problem of disparities, bridging that gap between full access and utilization of evidence-based hearing healthcare to the populations that need it. We

see, down at the bottom, all of these different barriers and these different factors that are influencing those and causing this gap.

If we apply and consider how we bring in that agenda for better communication, engaging communities, resourcing centers where minority care or marginalized patient care is provided, consider the long-term quality of life aspects and outcomes of our interventions and align our expectation and goals with patient expectations. These are some of the agenda items that could help us use research as well as new clinical programs to address some of these disparities in hearing healthcare. So in summary, I want to call you to action for equity. We want to be able to define inequities. These are evidence across socio-demographics and influenced by the social determinants of health. And we want to conduct equitable research using different data, different designs in our research that may inform how we actually move our programs forward into the community.

We also wanna incorporate novel models and methods of our programs to promote equity and efficient translation of research to broader practice as well as populations. So again, I hope this is not a daunting, discouraging, depressing topic to consider disparities. We've gotta be clear, we've gotta be, you know, frank and open about where these challenges are all around us and amongst a wide range of different populations, but realize that we're not hopeless and we're not helpless. We can actually take this seriously and work together in a multidisciplinary way to promote equity in hearing healthcare which will overall improve population health. So again, I'm thankful for the time that you've spent with me this afternoon or wherever you may be and whatever time it may be. And appreciate any input that you might have.

- Thank you again, Dr. Bush, for this presentation today. This is a very important topic and we appreciate all the insights that you've shared today. For those that are attending, please don't forget to complete the quiz after the session in order to receive

your continuing education credits. And then if you know of somebody who would be interested in viewing this presentation, please pass along the registration link as it will be available for on-demand viewing as well, which is also eligible for CEUs. And then finally, our next event will be in April and we look forward to seeing you then.

- Any of the attendees, do you have any questions? I'd welcome any. I'm happy to take some questions perhaps.

- [Helen] Yeah, let's see. Dr. Bush, we did have one question from an attendee back to slide 31. Could you just define for everybody what the OR stands for that's in the parentheses with the numbers by it, just for anyone who might not know?

- Sure, that OR is odds ratio.

- [Helen] Thank you.

- Yeah.

- [Helen] Okay, let's see. Next question is are you able to review the research design methods which support equity and also those that wouldn't support equity?

- Well, it's, the reality is there's lots of different research designs that as long as agenda, and if you have an agenda and you know you value equity, it will promote, you know, the ways that you may conduct that research. So you may say, "Well, what if I conduct a retrospective study? Is that equitable in nature?" And it may be, it may not be. It's an issue. Perhaps in the particular population or the sample that you analyzed through a retrospective way, there were some very strict criteria that caused you to exclude certain populations without meaning to or without realizing it. And that might

not reflect a diverse or generalizable population. I do think that prospective research is important.

I think prospective research that has very, very active and equitable recruitment methods is really where we would, you know, want to spend most of our time and really more of our resources trying to conduct research moving forward. When we are thinking with our scientist brain, we're often trying to focus on what do we need to do to ensure that our recruit participants, that they complete all of the outcomes, that the fidelity of the study is completed and conducted appropriately, especially if there are regulatory issues that are at play and the indications of a certain device, drug technology, it has to be tightly controlled. And so populations that may face challenges in following up with a study visit, for example, may be excluded from recruitment.

Or perhaps because we don't have the study documents and the consent form in Spanish, Hispanic patients would be excluded. And so it's important to really push and promote for equity and how can we, you know, make sure that all of our research is just not conducted among white, privately insured patients. So there's not a simple an answer to, you know, there is just one type of research that's inequitable, there's another that is equitable. It's about what you care about and trying to then integrate that into the DNA of the research that we're involved in. I hope that's helpful. I hope that helps to clarify a little bit.

- [Helen] Great, thank you. And one other question, what are RCTs?

- Great question. RCTs are randomized controlled trials. So a lot of our clinical trials are randomized. Perhaps one patient is, you know, randomized to intervention A, another patient randomized to intervention B or perhaps a control group. And so those sometimes can be challenging. Lots of our surgical trials, we don't necessarily randomize to one patient having a surgery, a real surgery and another patient having a

fake surgery. But perhaps they might be randomized to some other type of an intervention. But randomized control trials represent sort of the higher level of evidence as they're generally prospective in nature. And those are utilized to push and promote indications across, you know, the FDA and different regulatory bodies.

- [Helen] Great, thank you. And that looks like that's all of our questions for now and we're at the top of our hour as well. So thank you again for taking the time to join us and speak about this topic. It was a pleasure.

- Thank you, appreciate the opportunity. Everyone, hope you're well.