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Addressing Health Literacy in Clinical Practice

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- It's my pleasure to welcome back Dr. Alejandra Ullauri. Today she'll be presenting for us "Addressing Health Literacy In Your Clinical Practice." She comes to us from Chicago, and if you'd like to learn more about Dr. Ullauri, you can read on her bio on the course registration page. At this time, I'll hand the mic over to you.

- Thank you so much, Christy, and welcome everybody. Thank you for joining us today. We're gonna be talking about what we can do to address health literacy in clinical practice. So a little bit about me, I'm a clinician like you. I'm an audiologist in private practice based in Chicago. I'm also the founder and instructor and course instructor of Audiology en Espanol. I'm super excited to be here with all of you today. As Christy said, we'll take some questions at the end of the presentation, so please put them in the chat as we go, and we'll make sure that we get to them at the end. Here are my disclosures. Okay, so for today's presentation, we have some learning outcomes.

After this webinar, participants should be able to define health literacy for individuals and organizations, participants should be able to list low health literacy red flags, and participants should be able to identify tools that we have to improve health literacy for our patients in clinical practice. So to accomplish that, we are going to talk a little bit about definitions, we're gonna review briefly the class standards, we're gonna talk about red flags, but most of our presentation is gonna concentrate on tips that we can use, hopefully tomorrow, in clinical practice. So the main goal of today's presentation is to raise awareness about the role that we all play in addressing health literacy. So this is, health literacy, is not a problem that is pertinent only to the patient or to the family.

This is something that we all play a role in that we need to address in order to eliminate health disparities. So let's talk a little bit, let's go over some background. The Agency for Healthcare Research and Quality defines health literacy in two ways. Number one, personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health related-decisions and

actions for themselves and others. So this ability involves having reading skills, writing skills, numeracy, and of course in today's date, they all, it also involves having electronic, technology knowledge. When it comes to organizational health literacy, it refers to the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

So the key word in this definition is enable, and this is the role that we all play when it comes to our role in the healthcare system. So either as clinicians providing healthcare services, or leaders of clinical, of healthcare organizations, we play a role in enabling individuals, meaning our patients, to find, understand, and use information. So the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare, the last revision was published in 2013. They include 15 standards, they provide us with a legal framework. They were put together by the Office of Minority Health with the idea that we need to advance health equality, we need to improve quality of healthcare, and we need to eliminate disparities.

So yes, we all want to improve healthcare outcomes, but the main goal is to eliminate healthcare disparities. So as you can see, the Principle Standard, these are 15 standards, but the Principle Standard says, "Provide effective, equitable, understandable, and respectful quality of care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs." So you can see that health literacy is at the center of the class standards. So why is it at the center of the class standards? Because health literacy has an implication in healthcare. So it has an impact on health services utilization, it has an impact on personal healthcare access, and also on healthcare outcomes. So let's talk about a few examples.

So health services utilization, we know that low parental health literacy is associated with no health insurance for children. We also know that limited health, limited or low health literacy is associated with an increased use in emergency care. Also with that, with increased hospitalizations. When it comes to personal healthcare, individuals who experienced limited health literacy have difficulties understanding labels, medication instructions, how to use different aids or healthcare aids such as hearing aids, in our case, cochlear implants, or any other kind of hearing technology. They might also have trouble understanding appointment slips, and people that experience limited health literacy also use preventive care less, preventive services less. Preventive services will include something such as screenings. We also know that when it comes to healthcare outcomes, individuals with limited health literacy experienced overall lower healthcare status, especially among older adults, and they have higher rates of depression and higher rates of mortality.

So what do we know about individual or personal health literacy? So far, we know based on the National Assessment of Adult Literacy, this survey was published in 2003, and it looks at four different tiers, individuals that meet below basic literacy, individuals that meet basic, intermediate, and proficient health literacy. And the survey revealed that 53% of adults have intermediate health literacy, 22% basic health literacy, and 14% of adults had below basic literacy. So this means that 36% of Americans have limited health literacy. That means approximately one in three. We also know that the populations at risk of limited health literacy are adults who are older, adults who have limited education, come from lower socioeconomic backgrounds, have chronic conditions, and are non-native English speakers.

Some of the red flags that we need to keep an eye in clinic, these are patients or families that ask no questions, make excuses for not reading information provided, so they might say something like, "I forgot my glasses," cannot explain their diagnosis. So they cannot explain what their condition is, what they should be doing about that

condition. They come across as quiet or passive, but they can also become angry and demanding. And usually you'll see incomplete registration forms. So what do we know about organizational health literacy? And here's where things get a little bit more complex, because remember, this pertains to us, how we enable individuals who are our patients, to find, understand, and use healthcare information.

So for the purpose of highlighting where we are right now, we're gonna concentrate on four studies that have, three of them were published last year, and I just wanna highlight these, because these studies concentrate on major sources of information. So we're gonna review some brochures on newborn hearing screening, we're gonna review a study that looked at the EHDI website, so the EHDI system, and then the individual websites for different states. We're gonna talk about a study that looked into the readability and quality of online information related to cochlear implants, and then we're gonna talk about a study that looked into consumer materials provided in the ASHA website. So this is gonna give us an idea of what we're doing as organizations, and I wanna highlight that the studies that we're gonna review show information about major organizations.

So these are not studies that looked into, you know, my small private practice website. We're talking about the EHDI system. So let's go over each individual study. So the first study was published last year by a group in Vanderbilt, and they looked at newborn hearing screening brochures. So the brochures that were used at a state level to share information with with pregnant peoples, I'm sorry, they used this, they looked at the brochures that we were using at a state level in newborn hearing screening programs, and they assessed these brochures to see what was the readability score, the design of the brochures, the images, and also, what was the vocabulary that these brochures were using, and how the families that were receiving this information were processing or understanding this information.

So when, they used multiple formulas to assess the readability of the text in these brochures. They also looked at the design, so they paid attention to the font, to the color contrast, line spacing, quality of the printing materials, and so on. When it came to images and pictures, they went beyond, I mean, everything we talk about, pictures, we think like, oh yes, I know we have to use pictures that, you know, represent the communities we serve. We also have to use pictures that are relevant to the topic. And I know that this might sound redundant, and this might sound like, of course, but many of you know that sometimes we see a brochure that talks about, let's say, neonatal hearing screening, and the picture is a child with hearing aids.

That picture is not relevant to the information we're sharing. That picture might convey the wrong information. It might convey the message that anybody, that a child does that does not pass the hearing screening needs hearing aids. So very important that we pay attention to how relevant the images and pictures we use are to the topic we are discussing. And then they paid attention to the vocabulary, especially to the word "refer." So, for many years, we put a lot of effort into moving away from using "fail." So we no longer say the child failed screening, because there is a negative connotation. But, and then we moved on to using "refer." And "refer" is fine to use among ourselves as professionals in this field, but refer is not a word that families understand exactly what we mean by saying, "The child referred the hearing screening."

So this group, these researchers took a look at how families were understanding that. So what they found was that most brochures were deficient in at least one element. 30% of brochures used the word "refer" to convey that the baby did not pass the neonatal hearing screening, and less than half of participants understood its meaning. In conclusion, 88% of brochures available at a state level about newborn hearing screenings need to be modified to increase readability, and we need to pay attention to how we're using the word "refer" in these screenings. So you can see here, these are brochures that are used at a state level in order to convey information to families about

neonatal hearing screenings, and we know that 88% of them need to be improved, need to be modified to increase readability.

In this next study, the researchers took a look at 51 websites from the EHDI system. So the EHDI system is the national system that looks at early hearing detection and intervention. So each state has a website. So they took a look at the websites, and they concentrated on four subjects, information about hearing loss, information about technology, communication options, and resources for family. They wanted to make sure that the EHDI websites were relaying the information that it's in federal legislation and laws about early hearing detection and intervention, and they were relaying this information to families in a comprehensive, in a complete and comprehensive manner. So they found, so when they looked at hearing loss, they rated a website to be comprehensive if they included information related to types of hearing loss, unilateral versus bilateral levels of hearing loss, possible causes of progressive hearing loss, and what to expect at the hearing test appointment.

They rated websites to be comprehensive in hearing technology if they provided information about hearing aids, cochlear implant, and other assistive devices such as FM systems. they rated websites to be comprehensive in communication options if they provided information about the four main communication options used in the United States, so that would be American Sign Language, listening and spoken language, cued speech, and total communication. And finally, they rated resources as comprehensive in websites that provided information about state and federal resources or websites, so links to the State Department of Health and Education, or the CDC, the NIH, and also to nonprofits such as Hands & Voices, AG Bell, and so on. So they found that 26% of these websites were rated as comprehensive, 26%. 35 were rated as somehow, somewhat helpful, and 39% were rated as inadequate.

I found it shocking when I was going through the study that only 10 websites were rated as comprehensive when it came to providing information on hearing technology. So out of 51 websites, 10 provided comprehensive information regarding hearing technology. This is the EHDI system. So in our next study, we're gonna talk about a recent, recently published review of readability and quality of English and Spanish online health information about cochlear implants. So the researchers, what they did is they took a look at over 200 websites that, so initially, they found about 200 websites, and then after they took websites that were repeated and so on, they ended up analyzing 80 non-industry sponsored, so that would be non-manufacturer sponsored websites, 43 in English, 37 in Spanish, and 11 industry sponsored websites, four in English and seven in Spanish.

They use different formulas to assess readability. So depending on the formula that you use, you'll get a score based on the number of words, based on the number of paragraphs, words per sentence, and so on. And based on that score, you can use that score then to correlate it with a grade reading level. And we know that in healthcare, the recommendation is that information should be written at a fifth to sixth grade reading level. So the researchers chose a formula to work out the reading score, and then they also chose a questionnaire, in this case, the DISCERN questionnaire, and the idea of this questionnaire is to assess the quality of the information that is provided in those websites.

They found that both English and Spanish websites had reading scores that were more consistent with 10th and 12th grade reading level. So they were way above the recommendation of fifth to sixth grade reading level. They also found that there were significant concerns with the quality of the information based on the DISCERN questionnaire. And the DISCERN questionnaire basically goes on to say, to look at where the information comes from, is the website giving links and sources of that information? Is the website talking about risk factors? Is the website talking about

benefits? And so on. So it goes on for, over a list of different questions to assess the quality. And they found significant concerns with the quality of information that was shared.

Our last study, this study was published in 2014, and what the researchers did was they went to the ASHA website, they clicked on Information For The Public, and they saw 225 documents that were in this section that were meant for consumer information. They put these 225 documents into a software to calculate the reading grading levels, the reading grade levels, and they found that 85% of documents were above the fifth to sixth grade reading level recommended. So as you can see, in the last four studies that we've discussed, we're talking about major organizations, we're talking about the EHDI system, we're talking about ASHA, we're talking about state level brochures used in hospitals for universal neonatal hearing screening. So we see that we need to do more.

We need to make sure that the information we share with patients is something that is easy to find, is easy to understand, and it's something that they can use, meaning that they, that it's information they can benefit from in order to make healthcare decisions for themselves or for others. So so far we see that as organizations, whether it's in our role as clinicians or in our role as leaders of organizations, whether it's a small private practice or it's a big hospital department or a big academic center, we play a significant role in helping improve health literacy for our patients because we know the impact health literacy has on healthcare outcomes, healthcare disparities, and in the quality of services patients receive.

So, you might be thinking, okay, so how do I know if my patients have health literacy concerns, or health, if they experience limited health literacy? So there is a database in, when you download the PDF for today's presentation, you're gonna have active links, so you can click on these links, and here you're gonna find different measures. I'm

gonna discuss two with you today, but I also want you to know that, and there is a very good article that was published in 2015 about health literacy in primary care practice, and the authors talk about the use of screening tools, I mean, to screen for health literacy, in clinical practice. And they mention that it's not something that we use often in clinical practice, it's mostly used at a research level.

And the main reason for that is because you have to make sure that if you are gonna use a tool like this to screen for health literacy, it has to be used in a sensitive manner, because we don't want a tool like this to bring up feelings of shame or feelings of mistrust. So I wanna talk to you about two tools that are available, especially one that was recently adapted for hearing care use, I mean for hearing care services. But I wanna make sure that you keep in mind that these tools have to be used in a sensitive manner. So having said that, let's see, so the original Brief Health Literacy Screening was published in 2012. It has four questions.

"How often do you have someone help you read hospital materials?" "How often do you have problems learning about your medical condition because of difficulties understanding written information?" "How often do you have a problem understanding what is told to you about your medical condition?" "How confident are you filling out medical forms by yourself?" And then, each question you could answer, you have five different answers, depending on the answer, you get one point, two points, three points. So you can see that the maximum score is 20 points. So if you have, if you score between four and 12, you have limited health literacy, between 13 and 16, marginal health literacy, between 17 and 20, adequate health literacy.

So this tool was adopted and published in 2020 for use in hearing care, and it went down to three questions, "How confident are you filling out medical forms by yourself?" "How often do you have someone help you read hospital materials?" "How often do you have problems learning about a medical condition because of difficulty

understanding written information?" So you can see that the maximum score would be 15 points, and anybody that scores nine or lower, that reflects overall inadequate health literacy. So this tool has also been validated in Spanish as well, so I just wanna make you aware, I really like this one because it's three quick questions that you can use, but again, keep in mind that it has to be used in a sensitive manner, and you don't wanna bring up feelings of shame or something like with our patients. So let's talk a little bit about what can we do.

Number one, we're gonna talk about tips for us as clinicians in clinical practice, and then we're gonna talk a little bit about what we can do as organizations or as members of organizations. So number one, I wanna remind everybody here that we have to assume that our patients are at risk of not understanding. Always assume that. Why, because regardless of our educational background, we are all at risk of experiencing limited health literacy at a given point, because health literacy could be impacted by our emotional state, it could be impacted by acute pain or vision or hearing. So many of us that have worked with the pediatric population, you've often, you've heard from parents that they say, "The moment I heard that my child had a hearing loss, I don't remember anything after that."

So everybody, regardless of education, is at risk of experiencing limited health literacy at a given point. So always assume that your patient is at risk. The other thing, so because of this assumption and because of what we know that our emotional states might change and so on, always, always, always, practice universal health literacy precautions. So we're gonna talk about those precautions today. So when we share information, written information with our patients, I encourage you to visit plainlanguage.gov, and they have some recommendations as to what you need to pay attention when you write, or when you create written materials for patients. So this means the letters that you send to patients with results, the letters that you send to

patients reminding them of an appointment, or maybe you're reminding patients of the expiration of their hearing aid warranty.

Whatever letter you have to send to patients, I will encourage you to finish this presentation, print them out, and then put them through this lens, and let's see how many edits you might be able to do in order to improve the readability and the, in order to not only to improve the readability of the materials, but also, how easy is for patients to act on those materials. So plain language recommends that you use "you" to speak to the reader, you use "must" to express a requirement. So instead of saying, "Oh, we should follow up in six months," you say, "We must follow up, you must follow up in six months." Always use active voice, simple present tense, use short sections and short sentences.

Bullet points are even better. Use concrete, familiar words. This is a great example of the study we just talked about, about using the word "refer." Patients don't know, families don't know what you mean by that. We know, but they don't. So using "did not pass" is a better option than using "refer." If you are creating new forms, check boxes, it's much easier than if you give them a line to fill out the information. So for example, you are gonna say, "Have you had the following one in, have you had any of the following viral infections, measles, chickenpox, blah, blah, blah." It's easier if you list them and you give them a checkbox for them to check what they've had than if you said, "What viral infections, what kind of viral infections have you had," and then provide them with the space for them to write down.

So check boxes are a lot easier. When it comes to, so, before we move on, so I was saying, if you print out your letters, if you print out maybe the homepage of your website, put it through that lens, put it through that filter, and let's see, and you'll find, you'll be surprised as to how many edits you can make to improve the quality and the use of that information. When it comes to sharing electronic information, this adds a

layer of complexity, because not only the individual has to have reading skills, they also have to have access to electronic, to a computer with internet, they need to be able to navigate the computer, navigate the internet, and they need to be able to comprehend certain terminology that is specific to electronic sources.

So just know that sharing electronic information adds a level of complexity. So, after the studies that we have reviewed today, I think it's fair to say that before you share a link with the patient, visit that website yourself, gauge the quality and level of the content in that website that you are gonna share, and pick specific relevant pages within that website to share with your patient. If I share with my patient, if you go to the CDC website and type hearing loss, you get lots of amazing information. Very difficult for somebody that knows nothing about hearing loss to navigate. So it's a lot easier if you navigate the website and pick specific links that are relevant to your patient's journey, in, to your patient's hearing journey.

So if you are dealing with a family that is going through hearing screening, share a page that talks about hearing screening. No need to talk about cochlear implants or hearing aids, because we're not there yet. They can concentrate on what is a hearing screening, why we screen, what are the benefits, what to expect at the hearing screening appointment and so on. So just make sure that you assess the links you're gonna share, and share specific links with your patients. When sharing information verbally, obviously I think we are very familiar with this, use plain language, avoid medical jargon, and break down the information into small concrete steps. Concentrate on three key points per visit. I love this one.

I use it all the time with my patients during the hearing aid fitting appointment. If I see a patient is overwhelmed with the technology, with the size of the hearing aid, and everything that involves being there at that moment, getting hearing devices, all I say to them is, "Don't worry. I'm gonna see you a couple of times and we're gonna revisit all

this information. But today, before you leave, I wanna make sure that you have, that you are comfortable with three things, putting in your hearing aids, putting your hearing aids in your ears, and taking them out. Number two, you're comfortable turning your hearing aids on and off, and number three, you know how to change or charge the battery.

Everything else we're gonna review at the follow up appointment and so on." Based on their questions, and I can gauge whether they're ready for more information. Maybe we are gonna turn the, we're gonna connect the hearing aids to the telephone, or to introduce the app. But these are the three main things I want to concentrate. And after these, we can decide if there is room for more. But also, what I was gonna say is, if you identified the main appointments that you have in your practice, and then identify the three main, the three key points per appointment, make sure that those, your patients are very familiar, and they're comfortable with that information. And then of course, before they leave, you repeat those key points that you want them to remember.

When we share information in a conversation manner, so, you know, verbally, in person when we are with our patients, this time offers us a unique opportunity to check for understanding. So don't miss out on that opportunity. Because when we share information, when we give somebody a brochure or we send them a link, we say, "Oh, you can learn more about this in this website," we have no idea how, what they understood from the information we shared with them. But when we share information verbally, person to person, in a conversation format, we have that unique opportunity to check for understanding. So always, always, always use the teach-back method. So the teach-back method is a measure of your ability as a clinician to explain to your patient their condition and your recommendations.

It is not a measure of your patient's knowledge. It's a measure of your abilities as a clinician to explain. And basically you're asking them to explain to you using their own

words what their condition is about, or what you expect them to do about the recommendations. This is, there is a lot of research, this is an evidence-based approach to make sure you're checking for understanding. The next resource I wanted to talk to you about was the Ask Me 3 Questions. And the reason why I wanted us to talk about this is because the teach-back method allow us to check for understanding, but the Ask Me 3 Questions allow us to build knowledge. So I want us to keep in mind that our patients have a chronic condition.

They are gonna have a hearing loss for the rest of their lives. If we are talking about families, parents with children with hearing loss, we want them to build their knowledge about hearing loss, about hearing technology, about communication, because we want them to become their child's best advocate. If we are talking about adult patients with, dealing with chronic disorders such as diabetes, hearing loss, we know that their hearing can only deteriorate. We know that they need to understand their condition, they need to be able to engage with us, because we want them to report any changes in hearing, any problems with technology, and we are dealing with a condition that can only get worse. So what we are doing for them now might not continue to work five years down the line, and we might need to think about something else.

So the Ask Me 3 Questions is a tool to encourage learning, to help our patients build their knowledge about hearing and about hearing technology, and about communication and so on. It was, this tool was created by the Institute for Healthcare Improvement in Massachusetts. You can click on this link and you'll sign up and then you can download brochures and also posters in multiple languages. So basically it encourages patients and families to ask questions, to come to an appointment with questions. So this is not something that is beneficial to them in hearing healthcare, this is beneficial to them across healthcare. So the first question is, "What is my main problem?" Second question, "What do I need to do about it?" And third question, "Why is it important for me to do this?"

As you can see between question two and three, there is also a cause and effect. So introducing a tool like this, it's not only that we're checking that is the patient understanding what I'm saying, but we are helping them learn and get more information at their own pace about their condition. We wanna make sure they are engaged and they are active participants in their child's healthcare or active participants in their own healthcare. So remember, we can help our patients build that knowledge if we improve spoken communication, if we improve those opportunities for conversation with them, if we improve the quality of the written information that we share with them, if we encourage self-management and empowerment, and also if we help them connect with other support services.

So let's talk a little bit about tips for organizations. So remember, the key when it comes to organizations is that we need to, organizations must enable individuals to find, understand, and use health information. So the keyword is enable. So number one, take some time to familiarize yourself with the 10 attributes of organizations that practice good health literacy. These organizations integrate health literacy in everything they do, in every planning, in every strategy, in every services. Health literacy is embedded in everything they do. They train their staff, they include the communities they serve in the planning and development of materials. They, because they include the communities they serve, they are always working to meet the needs of those communities.

They always, always, always check for understanding. So they practice the teach-back method all the time. They make sure that the information is easily accessible. They design, they pay attention to how they design patient education materials. They always consider high risk situations. For example, a high risk situation would be medication use, but it could also be transition. So transition, when you are transitioning from one service to another. A good example would be a child transitioning out of early

intervention. So these are high risk situations because if the parents are not on board and the family is not knowledgeable about what are the next options, there could be a discontinuity of care after early intervention ends. So high risk situations could also include transition times.

And of course reimbursement. Reimbursement is a big issue because navigating the insurance landscape is pretty complex for patients, and we all know that many people, for instance, don't know about, they don't know about the fact that insurance cover cochlear implants. They always think that, or they tend to think that, "Oh, you know, I can't afford hearing aids, nevermind the cochlear implant." So they know, they don't know that difference in coverage and so on. So reimbursement is a big issue that organizations that practice good health literacy precautions, they take into account that. So the CDC put out a template for you to develop your own health literacy plan. The template is very detailed, from, you know, choosing the people you're gonna work with, your allies within the organization, identifying the people you need to convince that this is a good idea.

You also have a, this is, I guess the most relevant page for our discussion, is an honest assessment. You need to assess where you are at in terms of the quality of your materials, the quality of your letters, the quality of your social media posts, the quality of your website, and so on. So you have a good understanding of where you're at and what needs to be, you know, what's a priority in your health literacy plan and so on. Just remember, every time that you share information, remember that healthcare information must be accurate, must be accessible, and must be actionable. So patients need to be able to learn from this information, and then act on this information.

So as organizations, we can review signage, for instance, to make sure that we are improving access. An idea would be to develop a patient roadmap. So think about something, a roadmap for patients is pretty much a way that you can share with your

patients how they can navigate your system, whether that's the hospital department, whether that's a practice that has multiple sites, whatever that is. So that roadmap will tell your patients how to navigate that individual system. So it could be, I'm just gonna give you the example of the pediatric cochlear implant program. So you have in the multidisciplinary team working with these patients, you have ENT, you have audiology, you have speech and language pathology.

ENTs usually work alongside with nurse practitioners and physician assistants to provide care and so on. And so in your roadmap, you can tell patients what's the main number to call. Maybe you have a number for Spanish speaking patients, a number for English speaking patients. Then you can say, "This is your cochlear implant audiology. This is the best way to contact that audiologist. You will contact that audiologist if you have hearing difficulties. But if your child has ear pain, fever, then you need to contact the nurse practitioner, and this is the best way to contact the nurse practitioner," and so on. So you can give, in a sheet of paper, it doesn't have to be anything complex, you can give patients exactly how to access your services, how to navigate your system.

We talked about this before, review your website, your forms, your brochures, and so on, and train your staff about health literacy and how to include these health literacy precautions into clinical practice. I wanna highlight patient navigators as one tool that we need to explore more. And let me discuss quickly this study, and then we can talk a little bit more about patient navigators. This is, as far as I know, maybe the largest study of racial and insurance inequalities in access to pediatric cochlear implantation. So the researchers took a look at over 1500 children implanted in a period of 13 years. They found that black Hispanics and, no, black, Hispanics, and kids on Medicaid were significantly less likely to be implanted by age two.

Hispanic kids, even on private insurance, were still less likely. So we can see that our patients are facing multiple barriers. And the study looks at what's going on. The study doesn't look, didn't look in this case, at the possible causes. So you and I can sit here and discuss possible hypotheses as to why the services are delayed for these patient population groups. Is it that patients didn't have coverage soon enough? Is it that parents and families had trouble keeping up with appointments? Is it that families didn't understand that there is a, time is of essence in pediatric hearing loss and access to intervention? What is it? We can hypothesize all the possible reasons, but we need to change these, because time is at the essence of what we're trying to accomplish by giving these children access to technology, we're trying to help them develop language at the same rate as their typically hearing peers.

So patient navigators have been used mostly in cancer treatment. Well, that's kind of the area that developed this idea of patient navigators. They've made a significant impact on increasing screening rates and also follow-up care for cancer survivors. It's been such a great model that now it's been transferred to HIV care. And patient navigators, what they do, they help guide a patient through the healthcare system. This includes help going through the screening process, diagnosis, treatment, follow-up care of a given medical condition. I cannot think of a better place for a patient navigator to work in as a pediatric cochlear implant program. We're talking about a chronic condition. Our patients have a chronic condition that they will live with for the rest of their lives.

The patient navigator helps also patients communicate with their healthcare provider so they can get information in a more timely manner and act on that information. Patient navigators may also help patients set up appointments and get financial, legal, and social support. So what we see is that patient navigators help patients work around those barriers. Patient navigators help patients and families to overcome those barriers so they can access healthcare. Given this study, I think it's about time that we

think outside the box. We need to do more. These numbers are not gonna improve just by us making changes to our websites. We need to do more. I was really happy to hear a little bit people talking about this at one of the ACIA meetings a year or two ago.

So this is something that more of us have to put some time into it and think outside the box, how are we going to change these numbers? Somebody is gonna say, what about costs? I don't know about you guys, but when I worked in a hospital setting, I knew that sometimes we had a 30% no-show rate. So when it comes to cost, the cost of no-show rates because patients experience so many barriers, it can, you know, you can find some balance there, if we include or consider patient navigators for our programs. So with that, I wanna give you some additional resources that you can spend more time in reviewing and additional resources that I think you might find helpful when you are developing your health literacy plan.

It's a lot of information. You don't need to remember everything we've discussed today, but there is one thing that I'd love for you to take with you after this webinar. Remember that low health literacy doesn't have to stay low. We can help our patients to build their knowledge about their condition and about the options they have to access care. So it is up to us to meet these, to meet the need of our patients, and we have a responsibility to enable patients to find, understand, and use healthcare information that we provide them with. So with that, I wanna say thank you very much to everybody that is here, and maybe we can take some questions.

- [Christy] Thank you you so much, Dr. Ullauri. We do have a couple questions in the queue. The first one, this is from early on in your presentation, are there more current statistics on health literacy, and do you think it has changed since 2003 with greater access with the internet?

- Thank you, that's a great question. And no, that's the main source that is still being used, so that's still on the CDC website, is the main national survey that is the latest national survey that it's available, oh, that, yeah, so thank you. It's a great question, and I don't know about, with greater access to internet, I'm not so sure that improves health literacy, because health literacy refers to those skills that will allow you to read, to, it includes reading skills, writing skills, it includes numeracy, communication and so on. So I think it goes beyond accessing information as such. But to answer your questions, those are the latest stats that we have at a national level like that, thank you.

- [Christy] Thank you. We have another one here from Kiersha. "I live in rural Maine, and many of my patients need assistance."

- Yes, a lot of patients, I mean, we can do more. We certainly can, I mean, I think this is a good time, because we have this data, we can make decisions on this data. Before we were thinking, oh, it's a problem, but now we know that, we know exactly which websites we need to improve. We know exactly how to edit our letters. We know exactly, so I think with this data, we have more actionable, we have more information that we can act on.

- [Christy] Thank you so much Dr. Ullauri. It doesn't look like there are any other questions in the queue, but for those of you who might think of questions later on or would like to reach out to Dr. Ullauri regarding the resources you mentioned, you can reach her there via her website, or she also provided her contact email. And at this time, I just wanna thank you Dr. Ullauri, for coming back on again and sharing your wealth of knowledge and your expertise. I didn't know if you had any closing comments, but I'll hand the mic back over to you to close up the classroom.

- Thank you so much, Christie, thank you. I really enjoy talking about this topic, and I wanna thank everybody that joined us today for your interest and for wanting to do

more to improve the quality of services we provide, and to ultimately end healthcare disparities, so thank you everybody for joining us today.