

Seán Collins:

A video of this podcast, including captioning and ASL interpretation, is available on our website. Visit [www.HearMeNowPodcast.org](http://www.HearMeNowPodcast.org) and click on the link for Deaf Health Equity.

(theme music) This is the "Hear Me Now Podcast," which comes to you from the Providence Health System and its family of organizations. Hello, I'm Seán Collins. Thanks for being with us. On today's program, a discussion of the barriers that exist for deaf and hard of hearing people receiving the best healthcare possible. To begin, I'd like you to meet Christine Kostrubala, who's deaf and a cancer survivor. She recently described for us some of her experiences navigating the healthcare system. She's in conversation here with her friend Sarah, who's also her interpreter.

Christine Kostrubala:

When I told my family members about this opportunity to Hear Me Now, most people are like, wait a minute. They've never heard about a perspective of this person with cancer and going through the medical field. So I asked my good friend Sarah to be involved with this too, because we've known each other for several years. And so it would be a very easy conversation to have with each other.

Sarah Rasmussen:

And this is Sarah, and I'm going to be the voice of both Christine and myself because I'm also an interpreter in addition to a friend of Christine. And we've known each other for a long time and we've shared lots of good times and difficult times. And I look forward to just hearing about and talking to you about your perspective and experience of going through that medical field with your experience with cancer and recovery. And continued recovery. I hope.

Christine Kostrubala:

Christine, they hope too. Oh, my journey's not over yet, but it's getting there and I have noticed some things are getting much better now. So continues.

Sarah Rasmussen:

And Sarah is saying, I just know from other friends who have brought their deaf kids to the doctor or a clinic or the ER, and it's like I had one friend who brought in the ER for a broken arm and the first question from the doctor's mouth was, so how did your son become deaf? And my friend's like, it doesn't matter. Look at his arm. I'm not asking you to diagnose his deafness or deal with that. Move on. Let's focus on what the need is.

Christine Kostrubala:

And Christine is like, yes. At one time I went to the ER with an issue with my knee and I had a good friend that came with me. And there's this kind of unspoken rule in the deaf community that I would never tell my friend that your voice isn't very clear. It's not very good. That's considered rude and mean and judgmental. So I didn't say anything like that, but my friend was thinking that she was speaking clearly. Anyway, I kind of discouraged her if we're talking to the doctor, because the doctor came in, it's like, oh. And he saw and talked to the two of us, and then he labeled us and assumed we were mentally retarded. I was like, what? Wait a minute. That's got nothing to do with my knee issue. And it was because of my friend speaking her best, but she didn't realize she wasn't clear. And the doctor, just because of that one thing assumed we were both mentally retarded.

Sarah Rasmussen:

(gasps) And Sarah's asking, Christine, do you feel like if you went to the ER today, would it be a better experience?

Christine Kostrubala:

Christine's saying, oh yes. Now it's a much better experience. And so far, I mean, I've had some struggles. I've had to stand up for myself. I had to advocate. I've had some discussions with the staff. Sometimes I got angry, but I did get what I need and I've still got a way... The whole profession's got a long way to go.

Seán Collins:

That's Christine Kostrubala and her friend and interpreter Sarah Rasmussen. Christine's story is not unique, far from it. The research literature is filled with stories about deaf deaf-blind and hard of hearing people meeting barrier after barrier after barrier as they seek care in a healthcare system that seems to not quite understand their needs, nor the best way to meet those needs. And that's what we're focusing on today. I'm very happy to be able to introduce to you our two distinguished guests who approach the issues of access and equity from two related but distinct perspectives. Dr. Poorna Kushalnagar is the Chief Research Officer in the Office of research at Gallaudet University, where she's also the director of the Center for Deaf Health Equity.

Poorna Kushalnagar:

(signs) Thank you.

Seán Collins:

Also with us is Dr. James Huang, family physician, who's now the medical director of Student Health Services at Gallaudet. Welcome to you both. I'm so glad you're able to be with us on the podcast today and help to point towards some solutions.

James Huang:

Thank you for having us.

Seán Collins:

Just to provide a framework for the discussion, Dr. Kushalnagar, you're coming at these issues from a research perspective. And Dr. Huang, you approach them from the perspective of a clinician, a physician in practice. So may I start by just asking, what are healthcare providers still getting wrong?

Poorna Kushalnagar:

So the mistakes that healthcare providers are making, I'm going to share from the deaf patient perspective. So for example, they'll ask patients to lipread when in fact they can't. They make that assumption that patients are able to. Providers make assumptions that deaf patients don't have language, cannot speak, and they provide as a result, less patient-centered care. And they show less cultural humility in their practice. They in fact bring biases on the limited understanding that they may have about deaf, deaf-blind and the hard of hearing community. And this is based on probably the limited information that is out there in mainstream media about this population. Dr. Huang, would you like to add?

James Huang:

Yes, thank you. So yeah, I'd like to add more about the accessibility piece. A lot of healthcare providers don't understand fully the Americans with Disabilities Act, so the ADA. The ADA was passed in 1990, really protecting effective accessibility to effective communication. And so a lot of providers still think that deaf patients have to provide or bring their own interpreters. And this is in fact not the case. Clinics and hospitals are required to provide accessible communications. That means providing ASL interpreters or other interpreting services that help patients have effective communication with your healthcare provider.

Seán Collins:

Are those services available to clinicians online? Say through a telehealth connection with an interpreter?

James Huang:

So there is an option called video remote interpreting or VRI that is becoming more popular and more health systems are adapting to using those mechanisms of communication. It is actually very helpful in cases of emergent cases like an emergency room when sometimes or into the clinic, if someone's coming for a same day appointment without a scheduled appointment. So often we don't have, you to schedule an interpreter in advance, usually 72 hours or more in advance. And so when a patient comes unexpectedly who is deaf, it is VRI is very inconvenient and helps bridge that gap for patients to get... So it helps to get interpreters in person because unfortunately with the VRI, there are a lot of challenges still.

For example, there can be a lot of internet issues, connectivity issues, so often they'll be like freezes during the communication which can be very frustrating for both the provider and the patient. Also in certain situations, VRI is not ideal. For example, if someone is in labor, you don't necessarily want to be contorting yourself and trying to communicate with someone on a video screen while you are trying to deliver your baby. Or if you have a head injury in the emergency room, you might not be able to see the screen clearly. So there's, for many reasons, VRI is a good option, but not necessarily the best option.

Seán Collins:

Or if you're in distress.

James Huang:

Correct.

Poorna Kushalnagar:

Yes, that's correct. And it's also inappropriate for use in eye exams. So if you're testing somebody's vision in a dark room, you can't use VRI. And this happens quite often that providers will provide VRI in an exam room during vision exams, but they can't see them because they keep the room dark. And so it becomes a really uncomfortable situation. Oftentimes the VRI interpreters that are hired through the company are well trained. So that is a plus. So the issue isn't necessarily about the interpreter quality, but about the system. So the suppliers oftentimes don't train front desk staff, nurses, healthcare assistants and so on, on how to set up the video relay interpreter machine. And so when a deaf person comes into the office and they need to use VRI, those who work at the hospital aren't able to set it up for them because they're unfamiliar. And so simple training of staff would be able to resolve those types of barriers.

Seán Collins:

That's a great point. Well, let's turn to successes. Where are providers doing it right?

Poorna Kushalnagar:

Well, providers are doing it right when they ask the deaf, deaf-blind, hard of hearing patient directly, what type of accommodation that they need or they're using teach back in their practice. So for example, a doctor may be explaining particular information through an interpreter. The interpreter relays the information and then the doctor could ask the patient to rephrase what they understood from what they had said. And so this is the opportunity to catch any type of misinterpretation that may have gone on or misunderstanding depending on the context. And so for those who have grown up in families that did not have access to communication or full access to information in the household due to not sharing the same language, or may have grown up in a mainstream environment or didn't have access to the mainstream environment such as TV, radio, to be able to hear different types of information, their health literacy and knowledge may be very low.

And so the doctor may have the responsibility to add additional context and information to fill in those literacy gaps regarding healthcare. That way the patient knows the information that they need to know to take care of themselves as they leave the office.

And the last point I'd like to make about when providers are doing it right is when they ask patients what they prefer in terms of communication. So some, not all, will require the use of interpreters. Some prefer using live transcription, a live transcribe, which is an app on the Google phone. And I'm not endorsing this for Google necessarily, but it is like a speech to text translation that works pretty well. And so for those people who are fluent in English, this is a good way to work with your doctor and especially in situations where you're not able to get an interpreter. Some patients like to write in English back and forth with their interpreter or with their doctor rather. For some more complicated situations such as giving diagnoses and even for privacy issues, patients may not prefer to use an interpreter. Patients may prefer to use an interpreter. And so it's important that the provider ensure that the patient is using the type of communication method that they have selected during the appointment.

James Huang:

Yes. Some other things that the healthcare system's getting right is when hospitals have ASL interpreters on staff. So they're readily available for when deaf patients come to the emergency room or if they're hospitalized often within a deaf community, they like label that hospital or that healthcare system as deaf friendly. And so that will kind of spread throughout the community and they'll tend to favor that particular hospital or clinic.

Another way is how we can utilize our electronic medical record or EMR or EHL. We can really use that EMR to be proactive rather than reactive. And what I mean by that is we can set up global alerts in patients charts and label what communication preference they have and make sure that we do schedule an ASL or whatever interpreters they require ahead of time. And so that way we can be proactive and have that set up. Because often what happens is deaf patients have to ask for their own interpreters and really we want to be a system that accommodates and meets their needs of the patients without being proactive.

Seán Collins:

Earlier in the program, we featured Christine Kostrubala and her friend Sarah Rasmussen, I want to go back to them for a few minutes. During their conversation, they suggested some ways healthcare providers might make things better for their patients. Here are Christine and Sarah, again with some practical advice.

Sarah Rasmussen:

And this is Sarah. Sometimes it seems that when you have a deaf person it might take a little bit longer and part of it's just the language. And even if you have an interpreter, sometimes it does take a little bit more time. So try to be a little bit flexible with the schedule...

Christine Kostrubala:

(nodding yes)

Sarah Rasmussen:

...and Christina's is nodding strongly yes.

Christine Kostrubala:

And it also helps if you give any notes. You don't need to give me the notes like a coloring book. It's like, no, just give me some nice professional notes. That would be very helpful.

Sarah Rasmussen:

And Sarah's adding, oh, you mentioned earlier about sounds to make sounds visible, but also anything visual if you're trying to talk about something abstract, if you have a picture in your office or in a book or something.

Christine Kostrubala:

(signs yes)

Sarah Rasmussen:

And Christine is adding, yes.

Christine Kostrubala:

For example, if you want to explain a concept of cancer, draw a picture and label, put the names on that. Because if you just throw it out and the interpreter spells out these different words, remember we have to process the information. So it's going from English to ASL and then I'm trying to get a new word and I'm trying to learn this and it's very difficult and it takes a lot of time for me to process that. So it'd be great to have the note with information, any drawings, with any labels, anything that you can make it visual be so much helpful. So much better.

Seán Collins:

That's Christine Kostrubala in conversation with her friend and interpreter, Sarah Rasmussen. This is the "Hear Me Now Podcast" and we're talking today about the challenges that deaf, deaf-blind and hard of hearing people face when accessing healthcare. My guests are Dr. Poorna Kushalnagar, who directs the Center for Deaf Health Equity at Gallaudet University. And Dr. James Huang, a family physician and the medical director of Student Health Services at Gallaudet.

I'm curious if you see any regional differences across the country. I'm thinking about places like pockets of Louisiana or in Maine where there are larger than average numbers of deaf people living in the community. Do you find that providers and patients in those places have come to find strategies that work well for them?

Poorna Kushalnagar:

That's an excellent question, and I think that needs to be investigated further. I can only speak for the East Coast, Washington, DC area where we have a very large deaf community. One of the nice things is that we have Gallaudet University close to a very large healthcare system. And so we have people in the deaf community who attend that healthcare system. So it's become very accessible. So anybody that comes into this hospital doesn't even have to ask for an interpreter. It is ready. And if an interpreter is not there in person, they will bring a VRI machine. The staff know how to do that. Every.

Staff and medical provider on each floor does a warm welcome to somebody who is deaf. They're not nervous about the communication barriers, and so they see deaf people all the time. And so patients who go to those hospitals know that they'll get good quality service and that they'll be welcomed into that health system. I don't believe that other areas have the same experience, maybe due to the fact that they have smaller deaf populations. Now,

if there are preferred clinics where there are lots of deaf patients, then they may have that same type of familiarity and knowledge, but this type of information really does need to become widespread and part of the training for how to work with deaf, deaf-blind, and hard of hearing patients. Dr. Huang?

James Huang:

Yes, Poorna pointed out there are different areas that have the larger pockets of the larger deaf community just because of deaf institutions tend to be in one place in each state. And so there would be a larger deaf community within that. But then in the more rural areas, they'd probably be scattered and probably less support services for people who are deaf. And I think also to keep in mind when we talk about VRI, there's differences within ESL regional signs that can be different. And so if someone is in Louisiana and the VRI interpreter is stationed in Northeast, there might be some signs that the VR interpreter doesn't really understand and so have to ask for clarification. But also just to keep in mind that ASL is different, just spoken English to different like words. And so I think we have to keep that in mind as well as we talk about different parts of the US.

Seán Collins:

Right. It's a living language. Right?

Poorna Kushalnagar:

Yeah. I'd like to add that we did a study at the Center for Deaf Health Equity over the patient experience working with interpreters. We'd asked several questions like, did you understand the interpreter? The interpreter understand you? And then we did an assessment of their interaction with the interpreter, the skills that the interpreter used to be able to help provide a perception it in patient centered communication by the doctor. And so it was interesting because what we found was that those who didn't understand what the deaf patient was saying struggled most to relate to their healthcare provider. Those who understood the deaf person well, but were able to express themselves in an okay manner, were able to connect with the provider in an okay way. And so I find this impact to be quite true for many deaf patients in their experience.

And so there are subgroups within the deaf community. For example, the black deaf American, which are all over the United States, but particularly here in the East Coast, the sign language that they use is a particular dialect that is different than white deaf people may not be able to understand. And it's also because of the cultural difference, not just because of it being a regional dialect, but understanding the language use as it is embedded in culture. And so an interpreter who doesn't share the same culture may make assumptions in their interpretation that may relate wrong information to the doctor, and



the doctor has no way of knowing if that information that they've received is correct or not. And so they have to rely on what they're getting from the interpreter to trust that it is reflective of the deaf patient.

And so in very real ways, this can be harmful and have serious consequences for deaf patients, whether it be a misdiagnosis, getting incorrect medications. And when we think about our particular deaf members who have intersectional identities and marginalized identities, they may be less likely to return to see that doctor because there are now mistrust issues because of the interpretation process. And so these are areas that we need to recognize and our research has done that. We're working to address these issues.

Seán Collins:

It's such a good point that the consequences of misinterpreting what a doctor tells a patient or what a patient tells a doctor can be quite serious, can be grave.

Poorna Kushalnagar:

Yeah, indeed. And I would like to ask Dr. Huang, how do you address that issue? What can a doctor do to mitigate receiving misinformation when using an interpreter?

James Huang:

Yeah, so I think some ways that healthcare providers can make sure that their understanding of the patient understands is you mentioned earlier the teach back method. So in terms of the teaching back method is you try to educate a patient on a particular medication or a health condition, and then you ask the patient to explain in their own words what they understood and took away from that teaching. And so that really will help you understand if the patient understood or not, and then really try to explain further if you feel like the patient did not understand.

Also, I think a lot of times in communication, nonverbal communication makes up a large percent of in terms of how we communicate. So I think making sure that healthcare providers look at the patient when they're speaking, when the interpreter is speaking and not look at the interpreter as well.

Seán Collins:

I wonder about the level of health literacy. I know and then we're going to talk about this a little bit later on the bias that a lot of deaf people face in terms of being thought of as somehow developmentally challenged or somehow having a lower intelligence when they're in certain settings. So I know we're going to talk about that issue, but I am interested in the issue of literacy. Is there any reason to believe that the multiple hurdles that deaf people

have to face to get information may lower their medical literacy so that there may be a need for greater education at the bedside or in the clinical setting?

Poorna Kushalnagar:

We had done research on the deaf community and all over the United States, and what we had found is that education within the deaf community doesn't always translate to health literacy, which you may think is odd because in other areas, that is often the case, but not within the deaf community. Now, we do have college educated deaf people who have less understanding of and health information compared to a college educated person who is hearing, and that is because of what you had just mentioned, the barriers to access to information. Not all health information is widely available and easily understandable in a language for the deaf community.

So we are seeing growth in accessible information to the deaf community with the creation of ASL videos. Oftentimes those videos are didactic. They focus on vocabulary. There are not a lot of videos that explain procedures or explain specific medications. And so there's so much that we need to do to make that information accessible.

Health literacy for this community is perceived more as tied to what I would call information deprivation. And so I'd mentioned earlier that a large number of deaf people are born to families who have never had a deaf person in their family before, or their primary language is the spoken language, maybe English. And so majority of those families do not use sign language. And so it puts the deaf person at risk for missing a lot of incidental information, and it puts them at risk also for not learning a language.

And so as they grow older and go to school, they may not have access to interpreting services. They may not have access to peers who are literate in their language or have information to share with them about healthcare literacy. And so what we've found is that if there is a peer who is deaf, deaf-blind, or hard of hearing that is health literate, then that other... And they receive that information from their parents and they communicate well, that's what we have found. And so they're able to then share that information to other peers who are less healthcare literate. And so this is a very successful method of transmitting information across the community. And so at our center, we've created a health navigator program to train workforces of people who in the deaf hard of hearing and deaf blind communities to become patient advocates who are literate in healthcare information to reduce the disparities in health so we can increase healthcare literacy.

James Huang:

So I think the first thing to remember is that American Sign Language is a language within itself. And so for many deaf people, that's their primary language. And so as I was pointed out, if information is written, a lot of users using that person's second language. So that's

why I think it's important to continue to develop materials in ASL, which would be many people's first language.

And then I think the second thing is going back to the deprivation, there's also in terms of thinking about incidental learning. So meaning that often around dinner tables or at the gatherings, people just talk... The hearing family will talk about something, oh, like Uncle Bob had a heart attack, and we think it's because he's been smoking. So if they're saying that, but not translating it for the deaf person, that deaf person's not going to understand that their Uncle Bob had a heart attack, probably maybe doing this to smoking, and that smoking, it could lead to heart disease. And so I think that health literacy, as health literacy is often gained from our peers. And so I think that's why it's also important to train deaf community health workers to educate their peers on these different health topics.

Seán Collins:

We're talking about the challenges that deaf, deaf-blind, and hard of hearing people face when accessing healthcare. My guests are Dr. Poorna Kushalnagar, who directs the Center for Deaf Health Equity at Gallaudet University, and Dr. James Huang, family physician and medical director of student health services at Gallaudet in Washington, DC. Can we talk about best practices? We've mentioned some, but I want to make sure that if there's anything out there that we haven't mentioned that you have an opportunity to explain it.

James Huang:

Sure. I think one best practice would be to make sure that we're educating healthcare professionals on how to work not only with people who are deaf, hard of hearing, or deaf-blind, but also with people with disabilities. So really there's such a misunderstanding within the healthcare professionals that we should really be focusing on education, whether it be nursing school, physical therapy, medical students. We really need to make sure that we're educating this workforce and how to work with people with disabilities. I think another best practice would be to increase the amount of healthcare professionals with disabilities, not only so that they can educate their peers, but also really connect with patients, the people with disabilities, the growing population. So I think that would be another best practice.

Seán Collins:

Is there a medical association for deaf practitioners?

James Huang:

There is. It's called American Medical Professionals with Hearing Loss or AMPHL. And so it's a professional organization, interdisciplinary of folks with hearing loss of different degrees,

and the mission is to increase the amount of healthcare professionals with hearing loss in the different medical fields and offer support and mentorship to students.

Seán Collins:

I'm going to guess based on what we know about other issues related to health equity, that if available, I bet deaf patients prefer being seen by deaf practitioners.

James Huang:

Yes, absolutely.

Poorna Kushalnagar:

I actually wouldn't make that assumption. I think it would be very easy to make that assumption, but not necessarily. The deaf community is very small, and that's one thing to remember. So it's very possible that the patient could know the doctor and have the same social circle and may not be comfortable seeing that doctor as a result. We've seen situations where even though the deaf doctors are guilty of having a bias. And so if the person, let's say is white and is a deaf doctor and they see a female patient, they could be making assumptions about their depression level. They could be giving them medicine when in fact they don't want it. Right? And so we've seen stories where doctors, regardless of hearing status and can communicate very well, have biases about their patients. and so, as a result, they prefer to see another healthcare provider. But then we have, on the other hand, those who are thrilled to see a deaf doctor. So I wouldn't necessarily make the assumption that, that would be a preference.

I think each patient deserves the opportunity to make the decision of the type of practitioner that they prefer to see and who they're comfortable working with.

Seán Collins:

Yeah. Dr. Kushalnagar, do you have other best practices that you want to highlight?

Poorna Kushalnagar:

Yes. Going along with what Dr. Huang had mentioned, in healthcare professions, mental health professions, need to be aware about deaf, deaf-blind, and hard of hearing patients. We need to incorporate training in medical schools, a requirement in medical education about disabilities and about these populations, and also make it a part of continuing medical education. So maybe some type of a module or certificate related to deaf, deaf-blind, and hard of hearing patients. This hasn't been established yet. There are several working groups that are working towards creating something like this. Cultural humility is

also another best practice that could be applicable to all patients regardless of their identity or language that they use.

Seán Collins:

Let's talk about a family situation that I'm sure is not uncommon and that is that a hearing child might be asked to serve as an interpreter in an encounter between a deaf parent and a doctor. What do you have to say about that situation?

James Huang:

I can speak from personal experience. Both of my parents are deaf, so growing up, I often was asked to interpret for my parents and it's not a great position to be put in, as a child, especially because there might be sensitive topics that the doctor is talking to your parent about and you shouldn't really ask a child to interpret. In general, that's not a good practice at all, regardless of like ASL Spanish, whatever language we're talking about. So I think what would happen in that case is the healthcare provider should find alternate means of communicating with the parent and not ask the child to interpret.

Poorna Kushalnagar:

My husband and I are both deaf and we have two sons who are hearing, and my husband and I are educated, so we don't ask our children to interpret for us. If there is a situation where there is no interpreter, we find other ways of communicating, such as writing, using that app that I had mentioned, or schedule the appointment for another time. I never put my children in that situation for that exact reason that Dr. Huang had mentioned.

Seán Collins:

Have you noticed any effects, since the pandemic began, in healthcare related to people who use ASL? Has it changed anything? I'm wondering about telemedicine in particular.

Poorna Kushalnagar:

Yes. Our center had done a study on that exact topic. We had done a baseline and follow-up study with individuals during the pandemic who had used telemedicine and telehealth and had also gone to clinics in person, such as the emergency room. We asked about how use of masks had impacted their ability to communicate with healthcare providers, the use of interpreters, their experiences in using telehealth platforms and how impactful that was, if they were able to see a doctor or an interpreter on the screen? All of those questions. And what we had found in that study was, is that there were a lot of problems, particularly on the medical providers' side. A lot of medical providers were unfamiliar with how to integrate the use of interpreters on the screen, how to use Zoom, for example. They did not

know how to turn on the live captioning. They didn't know where the chat box was to be able to utilize it. And there are a lot of learning curves that doctors had to go through. The patients seemed to be more comfortable using these platforms over the doctors, based on what we've seen in our research. In terms of those who did in-person visits, masking was very difficult for deaf patients to understand interpreters and proprietors who were using masks. And so they quickly learned how to rely on the use of eyebrows and eyes and the expressions that come through that as a part of the interpretation. But now we're seeing that patients are asking interpreters to put their mask down, which leads to a very uncomfortable situation. But then, soon after, clear masks became more widely available and I believe lots of interpreters are using that, and so we see that helping reduce barriers.

Even with the use of clear masks, however, there are fog issues that can reduce visibility and their ability to understand the interpreter or the doctor.

Seán Collins:

May I interrupt just to ask you to clarify — the reason the masking is such an issue is that, although many hearing people may think ASL is a language that's conveyed entirely with the hands, in fact, much of the grammar exists on the face and having access to a clear view of a person's facial expression is crucial to understanding subtle nuance in the language.

Poorna Kushalnagar:

Precisely. That's exactly it. And there are mouth movements that are a part of the language of ASL that helps with enhanced comprehension. And so you could imagine at that time masking was such a huge barrier. There was lots of frustration in miscommunication, which is why many deaf patients preferred telemedicine because they'd be able to see the interpreter and the doctor clearly. Now, fast forward to 2022, things are much better than when the pandemic first started. I think the system is much more accommodating. Doctors are more willing to move their masks temporarily to allow patients to lipread them if necessary. And so I think there's much more awareness now than there has been before. Dr. Huang, you wanted to add something?

James Huang:

Yeah, so I think during the pandemic there were some unintended consequences of certain policies. So, for example, only allowing the patient to come in without anyone else. That prevented ASL interpreters coming in. It prevented the patient from bringing in a close

friend that might help them interpret or help with comprehension. It prevented kind of that accessibility. And I think many of the issues around masks have been mentioned.

I think there was also an opportunity for healthcare providers to learn more about how to contact patients in telemedicine. I think a lot of times there was confusion on how can I call this person if I'm using my voice and their deaf? And, without realizing that when you, as a hearing person, call a deaf person's video phone, it automatically connects to a video interpreter. This also goes to how we're reimbursed for telehealth visits. So there's reimbursement for video, which is seeing the patient, and then also audio. So for a while there's a consideration of removing that audio reimbursement, and so that would be detrimental to the deaf patient because often healthcare providers are calling the patients and connecting through a video interpreter, but they're not actually seeing the patient, right? So they're talking to the interpreter who's interpreting for the patient.

Really this is a point of advocacy and making sure that we continue to reimburse for both video and audio telehealth visits.

Seán Collins:

At the beginning of this podcast, we shared a moment from Christine and Sarah's conversation, which included the really shocking description of Christine's encounter with a provider during an emergency room visit, where the provider assumed that Christine was developmentally disabled, demonstrating just a complete lack of respect for the intelligence of a deaf patient. I'm wondering, how do you begin to combat that in a systematic way? How can that sort of attitude be changed?

Poorna Kushalnagar:

It is a big problem. Education is really important and it, again, needs to start in medical school. They need to rehearse early how to explain these types of situations and also modeling deaf, deaf-blind, and hard of hearing individuals in a positive light and see real stories about these people, that they're just like everyone, but they use a different language.

James Huang:

So I think we have to recognize this term called ableism. So ableism where it's similar to any other ism where you think that someone is inferior because of their disability. So, really, healthcare providers and people in general have to kind of look at their own implicit biases and really do some self-reflection. And that can be done either through different online modules, core education. So I think we have to name — we all have some sort of ableism and recognize that and then we can start to address the way how we treat people, if we acknowledge that.

Seán Collins:

Are you seeing traction in any of the medical schools? Are you getting into their curriculum?

James Huang:

So, yes. It's tricky. There's a lot of things to cover during your four years of medical education. So it might be lucky if we get an hour or two around ... And it's probably more generalized as like patients with disabilities rather than focusing on the deaf, hard of hearing, or deaf-blind communities. And so I think, as we continue to gain traction, we have to expand the curriculum more to include different people with disabilities and focusing on specific disabilities.

Poorna Kushalnagar:

Yes, I'd like to mention a partner that we have at Yale University who actually just recently moved to Harvard, I believe, who's very active in incorporating deaf studies in the medical curriculum for medical schools. That's happening this year as a part of their fellowship. And she's very committed to making this widespread throughout the United States, and so we should expect, within the next five years, we'll see more medical schools including deaf studies-related topics into their curriculum.

Seán Collins:

Well, Dr. Huang and Dr. Kushalnagar, I'm really grateful for you taking the time today. I think you've talked about things that will change the thinking of a lot of the providers who are listening to us today. And I'm grateful for you being so honest and so forthright and congratulate you on the research you're doing and the work you're doing.

Poorna Kushalnagar:

Thank you so very much, and it's been a pleasure to be here to share our work with you. Thank you for inviting us and having us here.

James Huang:

Yeah, thank you very much.

Seán Collins:

And may I also thank Neerja and Su. Thank you both for interpreting today. Your participation made our discussion pertinent in such a meaningful way, and I'm grateful.



The "Hear Me Now Podcast" is a production of the Providence Health System and its family of organizations.

Find us on the web at [www.HearMeNowPodcast.org](http://www.HearMeNowPodcast.org)

You'll find links to the work of the Center for Deaf Health Equity, which Dr. Kushalnagar directs. You'll also find a link to a longer version of the discussion we recorded with Christine and Sarah about Christine's experience navigating through the healthcare system.

Our program is produced by Scott Acord and Melody Fawcett.

We have research help from medical librarians Carrie Grinstead, Basia Delawska-Elliott, Sarah Viscuso, and Heather Martin. Our theme music was written by Roger Neill. The executive producer is Michael Drummond.

Join us in two weeks when we'll be exploring the plasticity of the brain and the role that meditation can play in changing how we think, how we react to the world around us, and how we feel. I hope you'll join us.

I'm Seán Collins. Thanks so much for being with us today. Be well.