# Clinician and Patient Perspectives on Unexplained Hearing Complaints, in partnership with the American Academy of Audiology

**Presenter: Aryn Kamerer, PhD**

At this time, it's my pleasure to introduce our presenter. Aryn Kamerer is an assistant professor in the Department of Speech and Hearing Sciences at Utah State University, where her research focuses on developing sensitive tests of sensory and neural pathologies, especially those that go under, diagnosed or undetected by audiometry. Such a great topic. I invite you to read more about Dr. Kamerer on our website and in the handout. And I want to thank the Academy for collaborating on this course with us.

Dr. Kamerer, over to you. Thanks, Carolyn. All right, so thank you all for being here today. So I'll be talking about a very common dilemma faced by clinicians since the dawn of audiology, and that is patients with unexplainable hearing difficulties or concerns. But before we begin, I'll start with a quick message from the Academy.

Welcome. I'm Tish Gaffney, the president of the American Academy of Audiology, and I'm here to share important information about the organization. The Academy is dedicated to achieving recognition of audiologists as the experts in hearing and balance care and the field of audiology as an independent clinical specialty that is integral to the healthcare team. Through our partnership with Audiology Online, we're excited to offer courses like this one to help you broaden your knowledge and skills. We also offer the latest resources in practice management and evidence based clinical practice so you can grow professionally and improve patient care.

We advocate for our members in Washington and across the country to ensure that the voices of audiologists are heard and we help connect audiologists to one another through our valuable networking opportunities like our annual convention. To learn more about the Academy, make sure to visit audiology.org thank you.

Okay, so these are my disclosures. All my research that I'll present today was funded by the NIH and Utah State. And these are the limitations and risks for today's course and these are the learning outcomes for today. So by the end you'll be able to describe the relationship between the basic

audiologic evaluation and self reported measures of hearing disabilities. I want you to identify themes in patient, clinician and student perspectives on the evaluation appointment and think about and critique practices and wording choices when interacting with this special patient population.

And I want to thank you, and I want to thank AAA for inviting me here today.

And I especially want to thank all the collaborators and students who have been a part of this work. I could not have done any of this alone, so I don't think many people are very familiar with me and my work. So I want to take a second to introduce myself and my background. So I got my undergraduate degree in speech and language pathology because I wanted to help people, just as I'm sure all of you got into this field to help people. But I realized by the time I graduated that this is not in fact how I wanted to help people.

So I realized that I really had no idea what I wanted to do other than something to do with research. So I taught overseas for a couple of years while I thought it out and decided to become an audiologist and maybe pursue a PhD. But after a year it became very clear that I, I really didn't enjoy the patient facing aspects of the job. So I moved to a purely PhD track. My graduate research was focused on animal models, the effects of noise exposure and neurotoxic agents on the cochlea.

I really enjoyed modeling, which I never thought in a million years that it would be something that I enjoyed. In fact, I didn't take any math classes in my undergraduate degree. But I did not particularly enjoy doing live animal surgery and I did not have the patience or the focus for histology. I sought a postdoc where I could do clinical research. I really felt that my career journey has been a process of elimination and I'm really glad that I did not continue doing the things that I did not enjoy because I ended up here at Utah State where I have a clinical research lab.

But I get to collaborate with animal researchers. And because of my journey, my program of research spans from pure quantitative modeling studies, which is a lot of what I do, to physiological and behavioral experimental studies, which I'll show a bit of that today, all the way to qualitative narrative interview studies which you'll also see today. And I love being able to work with human and animal data and I love collaborating with and being able to talk to mathematicians, basic scientists, clinicians, and especially students or audiologists in training.

So today we are going to talk a bit about but about unexplained hearing disabilities. But I'm going to start with some definitions. So we'll start with what are unexplained hearing concerns, what is a disability and how common is it?

So the WHO and the ADA have similar definitions of a disability which is an impairment that negatively impacts a life activity. And I'm going to use the word disability quite a lot today. So I want to differentiate it from an impairment which is the, you know, problem or dysfunction with the body or the mind, while a disability is that functional limitation that is caused by that impairment. And then I will also be using, we'll Talk about the hearing handicap inventory. So I want to differentiate a disability from a handicap, which is more of that disadvantage that the disability causes in people fulfilling their personal role in life compared to maybe a healthy peer.

And so the most common complaint of anyone walking into an audiology clinic is that difficulty understanding speech in the presence of background noise, which has impacted their activities, their life activities, enough that they are now seeking answers or treatment. When people seek healthcare for hearing concerns in the United States, they undergo an audiological evaluation that includes a professionally guided standard battery of diagnostic tests. And the American Speech Language Hearing association publishes a series of preferred practice patterns that describes their recommended basic audiologic evaluation, which was Last updated in 2006, so 20 years ago, that advocates for

performing a case history and external ear examination, otoscopy, emittance, air and bone audiometry, speech reception thresholds, and superthreshold word recognition on every adult patient of this basic audiologic evaluation. Many would argue that audiometry holds the greatest diagnostic weight. But when this battery fails to detect an impairment, our patient here is left, you know, with an unexplained hearing disability.

And these kinds of hearing concerns, despite normal audiometric thresholds, has gone by many, many names and has many presumed sites of lesion or causes. And I'm going to use the term, you know, unexplained hearing concerns because first I found it personally to be the least likely to make reviewers angry. And some of the other terms that it's gone by in the past have presumed sites of lesion attached to them. For example, a much older term, King Kopetsky syndrome, originally implied a purely psychogenic cause. And auditory processing disorder, which may describe a subset of this group, has historically assumed a central cause, which may not be the case for all these folks.

So I like unexplained hearing concerns because it doesn't presume a site of lesion or a cause. It really just acknowledges the limitations of the diagnostic tests that are, you know, clinically available to us today.

So it's difficult to determine the prevalence of an unexplained, you know, hearing disability because not all people with hearing concerns will seek hearing health care and because of variable definitions in what is considered, you know, a hearing disability versus a normal amount of difficulty. I mean, everyone here today experiences some amount of trouble understanding speech when there is a lot of noise in the background. But the Beaver Dam offspring study can provide some insight into the prevalence in, in the United States. So this is a population based study that includes included in depth audiometric testing and self report measures. So of the 2,800 participants from Beaver Dam, Wisconsin, a quarter had hearing within normal limits.

And of those people, 12% had significant hearing concerns. So overall, about 3% of the total sample from Beaver Dam, Wisconsin had unexplained serious hearing concerns, with the primary complaint overwhelmingly being difficulty understanding speech in the presence of background noise. So if this is generalizable, potentially 3% of the population in the US has an unexplained hearing disability. But from this study, we are still unsure what percentage. Seek help.

Surveys completed by us and folks up in Oregon found that about a half to a third of audiologists see at least one patient a month with unexplainable hearing concerns. So for those of you who are comfortable with zoom, if you want to use like your response button to show, to raise your hand if you think that your clinic sees at least one patient a month with unexplainable hearing concerns.

If I can see them.

Oh, okay. I see some thumbs up. Yay. Here we go. They're floating.

They're floating. Yeah. Okay. There's quite a few. There's quite a few.

Yeah. Okay, so let's try again. Let's see. Do you think you see at least two patients a month?

Okay, we see a few. Okay, laugh the laughing face.

Okay, what about three? Three patients a month? Okay, there's, there's still more.

What about four?

Okay, we've lost, we've lost people there. Okay, so people that we've survey, audiologists we surveyed, and these, these folks in Oregon found that up to a quarter of audiologists see at least four patients a

month with this problem. So it seems to be at least a very common patient profile in a adult clinic.

So unfortunately, when our battery of hearing tests can't explain, you know, hearing concerns, a provider is left with little guidance as to a diagnosis or treatment recommendations. And a big part of this problem, I'm going to argue, is due to the audiogram. So the audiogram is, you know, our golden, the golden child in our diagnostic battery. And it does a really nice job of detecting loss of hearing sensitivity in a frequency specific manner. And it's the basis on which we fit hearing aids.

It can also differentiate between pathologies of the conductive mechanisms of the ear, so the outer and middle ear and the sensory neural mechanisms, which is everything else. But it is not good at pinpointing the site of lesion or the location of pathology that causes a sensorineural hearing loss. And there is a lot of stuff in the cochlea and central auditory nervous system that Are important for hearing. So this is a cool AI image of the central auditory nervous system, and for some reason, it put it in a motel pool. But there are a number of pathologies and disorders that have been discovered since audiometry that will not affect hearing sensitivity and therefore will not show up remotely on an audiogram.

So you can have a tumor on your auditory nerve sometimes without it showing up on this test. There are kids with auditory neuropathy spectrum disorder who may not be able to understand speech, but can still have a normal audiogram. So it's a great tool for fitting hearing aids. I argue it's a bad test for actually figuring out what is wrong in the ear.

So where did the audiogram and this basic audiologic evaluation that is recommended by asha come from in the first place? So the basic audiologic evaluation as we know it today essentially came about between the first and second world wars. The hazardous noise levels that were experienced from the technological innovations in artillery and mechanical engineering in the first world war Resulted in unprecedented levels of hearing loss in the European soldiers who returned home. Some estimate that

soldiers regularly experienced sound pressure levels of 100.

So this amount of noise and the resulting noise induced hearing loss on this scale had never been seen before. And these boys were demanding compensation from the British government. So the British government decided that it needed a standardized way to quantify hearing.

So prior to the first world war, tuning forks were the primary test of hearing. But post war demands for compensation and treatment for hearing loss required professional methods of standardization and validation of hearing loss. The government actually called on the British post office, who created an artificial ear. So they recreated the impedance of the outer and middle ear. And they used this to actually test telephone signal fidelity.

So it's like, what would the telephone signal sound like after going through the outer and middle ear? And they got their normative data for these impedance measurements from 10 normal ears and two abnormal ears. And the British government then used people's ability to successfully hear over the telephone as their standardized way to distinguish Distinguish normal hearing from deaf hearing. So, unfortunately, doctors and the government still thought that many of these soldiers were faking their hearing loss or that it was some form of shell shock. And they actually called it hysterical hearing loss.

So they still wanted some way to measure how much hearing loss someone had as a means to catch all of these terrible, malingering soldiers trying to steal from the government or avoid further service.

Amplifox comes around in the 1940s with this small, compact audiometer that actually comes as a little kit. And it Measures sensitivity of hearing in decibels, which had become a popular unit for sound measurement at that time. And soon after, the audiogram was lauded as an objective measure by otologists so they could measure hearing instead of having to rely on the statements that were made by their patients. It was from this point in time forward that impedance and pure tone audiometry became

the foundation of the basic audiologic evaluation and it has endured ever since.

I think it is important to know that the audiometer was originally invented in London in 1879 by David Edward Hughes and it also used the telephone and it was commercially produced and researched. So using this audiometer was how we found good threshold finding techniques. So this is Hughes, as in like Hughes Westlake procedure. This is how we found out that right handed folks had slightly better hearing in their right ear and that atmospheric pressure affects hearing thresholds. But this audiometer did not catch on at the time.

Doctors thought that their tuning forks were good enough. And some of the reason why it didn't catch on is that several researchers who use this published talks and papers shortly after this invention reporting that while measuring hearing sensitivity is cool and all, it doesn't relate to speech perception and that you could have a problem with one aspect of hearing like speech, and not other aspects like hearing sensitivity. So 150 years ago, audiometry was not considered useful because it was not an ecologically valid test of hearing. So people weren't really interested in using it. And it wasn't until they needed a way to catch who they thought were malingerers did the government pressure doctors into implementing audiometry.

So just kind of wanted to let that sink in for a minute. So I've already not so subtly hinted at problems with the basic audiologic evaluation and my bias against it, but I will now show you some data from a study that we completed a little bit ago highlighting this as well.

So in this study we recruited folks both with and without complaints of hearing difficulty who have never been diagnosed with a hearing loss. And we wanted to show how well the basic audiologic evaluation that is recommended by ASHA explains variability in self reported hearing ability is in folks with normal and near normal hearing sensitivity. So it may surprise you or not that speech in noise testing is not in fact recommended by ASHA in the basic audiologic evaluation or even in the advanced evaluation. But

a good chunk of audiologists do implement speech and noise testing. So we wanted to see see if the variance explained by the evaluation improves when you add a speech in noise measure.

So we recruited 121 adults with normal or near normal as you can see audiometric thresholds. These folks also had symmetrical thresholds between ears, no airbone gap and type A timps.

And we also had them complete the speech spatial and qualities of hearing scale which asks about your ability to hear in different listening situations, especially speech and noise, as well as localizing and processing temporal and spectral aspects of sound. And a higher score means a better hearing ability. And we looked at the relationship between self reported hearing ability and 4 frequency pure tone average on this scale. We have actually just broken up the speech spatial and qualities of hearing, just those speech in noise related questions on the y axis and the 4 frequency pure tone average at 500, 1000, 2000 and 4000 Hertz on the X axis.

And we did not find any relationship. We also looked at self reported ability, speech and noise ability and NU6 word recognition score. And again we did not find any relationship. And everyone here, all except for two folks, scored above 90%. And those two are lined up right here at 85.

So really everyone here is scoring at ceiling on word recognition.

So when we use the basic audiologic evaluation to try and explain self reported ability in people with normal and near normal thresholds, it explains exactly zero percent. So what if you add a speech and noise task? So we added a very difficult speech and noise task. So this was a sentence recognition task in the presence of two talker babble. And these were presented at zero degree azimuth.

So both the target and the Babel were presented at 0 degrees. We had four speech, four speech and noise conditions. We had it in quiet, we had it at a four signal, plus four signal to noise ratio, plus two

and minus two. So that minus two signal to noise ratio is more difficult than the most difficult quicksand condition. And again, we did not see a relationship with this task either.

So no relationship between people's self reported speech in noise ability and their performance on a difficult speech in noise task.

So adding a speech in noise task did not improve the basic audiologic evaluation's ability to explain self reported hearing ability in these folks. So of course our question was, are these folks who are reporting hearing difficulty really even having a problem? Well, we also had them complete the hearing handicap inventory because while we did expect there to be a correlation between their hearing ability in their hearing handicap score, we know that these are different constructs and they tell us different information. So in this figure we've put now we've put hearing ability, that SSQ on the x axis and we put hearing handicapped score on the y axis. And with the HHI Hearing Handicap Inventory, a higher score means a more significant impact of hearing limitations on their social and emotional life.

And there are folks in this group who are considered to have a mild too significant hearing handicap according to the clinical categorizations of the HHI. And there seems to be this line of an SSQ score of a 7, where people who score above 7 never report a hearing handicap and people below 7 may or may not report a hearing handicap.

So something that did explain a lot of the variance in self reported hearing ability was this questionnaire that we had everyone fill out. It's called the Meaning of Life. I love the name of this. It was developed by two audiologists turned hearing scientists, that's Rich Tyler at Iowa and Ann Perrot at Augustana. It includes questions about friendship and outlook on life, various aspects of physical health, mental health and satisfaction.

And we looked particularly at people's satisfaction with their families finances. And we found that people who rate themselves poorly on their speech, on their speech in noise ability, scored lower on friendship and positive outlook in life.

They also scored lower on physical health.

Everybody scored lower on mental health. These data were collected in the year coming out of COVID but I don't know how much things have changed since. But people who rated themselves more poorly on speech and noise ability rated themselves significantly lower on mental health and significantly lower on satisfaction with finances. Which is interesting because the Beaver Dam Offspring study also found in their study that people who reported a hearing disability with normal thresholds reported not doing well financially compared to their peers with no hearing complaints as well.

So from this study we learned that people with, you know, normal audiometric thresholds can report significant hearing disability and all the way from mild to significant hearing handicap. We learned that the basic audiologic evaluation provides little guidance on people's perceived hearing ability when audiometric thresholds are within normal limits. And folks who report difficulty understanding speech in noise may also have poor well being in other aspects of their life.

So we've seen from an objective viewpoint that the basic audiologic evaluation may not be providing the patient with answers to their questions when they come into the clinic, or it may. And it may not be providing the clinician with guidance for diagnostic and treatment recommendations. But we don't know what the patients are experiencing during their evaluation appointment. So we decided that the best way to get at this perspective was through narrative interviews where we ask the patient to tell us their story. So narrative interviews, as opposed to a structured interview or a survey, gives the patient the freedom to express what's important to them rather than what we, as the researchers think is important.

So when patients express, get to tell their narrative, it helps them make sense of the world. It allows them to organize information and their experiences. It allows us and clinicians a firsthand view into the effects of, of living with their experiences. And from this, listening to these patients, this can give us and clinicians a really, really good idea of what we need to do to better their experiences and where to go next in terms of research. So most of the work from this study was completed by Mackenzie Meadows, who was an audiology student at the time, has since graduated, she's an audiologist now.

And we she interviewed 15 people across the US who had sought a professional hearing evaluation due to their hearing concerns, but received a diagnosis of normal hearing. And all of our interviews were done via zoom. And they started with this narrative prompt of tell me the story about when you went to get your hearing tested. And then they had some follow up questions of course, afterwards.

And then the interview transcripts were analyzed via thematic analysis. And this is an entirely inductive process of identifying common themes across patient responses. And we were looking for themes specifically related to their experiences seeking hearing health care.

And the three themes that we found were dismissive hearing health care providers, a misalignment of patient concerns and assessment protocols, and doctor shopping.

So the first theme to emerge, and by far the most salient was dismissive healthcare providers. So this theme specifically reflected portions of the narratives where providers were downplaying or disregarding patient concerns. So we heard stories of overtly dismissive behaviors, like Stacy here, who told us, you know, the first two providers I went to, I was quite upset, you know, especially the first lady, she just kind of went, I don't believe you. You know, flat out said it, rolled her eyes at me, thought I was just seeking attention. She told me.

So this mirrors findings in qualitative research on patients with other kinds of medically unexplained symptoms, where patients with these unexplained symptoms are often worried that providers view them as frauds or malingerers, or that their medically unexplained symptoms are psychological and therefore not a legitimate illness. And this has happened a lot in very recent past, especially with chronic illness and things like, you know, fibromyalgia.

But most of the folks that we interviewed described a much more subtle, insidious kind of dismissal. So providers saying, good news, you have hearing loss, as Jane told us. And then after it was all done, the provider just ripped off the paper and gave me the yellow sheet and said, oh, you have a clean bill of health. And I mean, it was really weird to me because I felt like I had some concerns. I felt like it was kind of dismissed.

So a study that was completed in 2008 by Price Wainwright in the UK, I also found a theme of dismissal in similar patient reports in seeking hearing health care. So very similar theme also in a different country, in a different health care system. So the second theme to emerge was a misalignment of patient concerns and the assessment protocols. And this was reflected in our participants stories when they visited the clinic with a specific concern, which was always really challenges hearing in noisy environments, and yet explicitly recalled that the clinician did not conduct assessments that targeted that concern. And again, I want to remind you that we did not ask what assessments were given, we just asked to tell their story.

So these were people who on their own brought this up. So Ava told us, you know, maybe the setting of being in a noise controlled room or booth with headsets with only one noise coming in is an ideal place for me to listen and hear things. But that's not where I am every day. I'm not in a silent padded room where nothing comes through except the noises I make. I'm not ever going to be in that spot.

A study that was done in Australia in 2020 by mealings and colleagues also heard similar reports from their patients. In our group, of all the appointments that were recounted by participants, only four appointments included descriptions of speech and noise testing, and only one provider referred a participant for auditory processing testing.

And the third and final theme was doctor shopping. And this is a term that describes behaviors where patients seek out more than one provider. But we also used it to describe stories where patients were referred around by their providers as well. So many of our participants recalled seeing more than one kind of hearing healthcare provider, including primary care physicians, audiologists, ENTs and neurotologists like Carl here, who said, I went back to my doctor because I was going between my doctor and the audiologist and that sort of thing. I did get an ENT referral.

So the ENT said that she couldn't like, there was nothing for her to like do because my audiograms were coming back normally. And then I came to another city and again same same thing. So the literature tells us that the largest contributor to whether or not a patient may partake in doctor shopping is provider behavior.

So we were honestly upset by the themes that emerged from these patient stories because it doesn't align with our idea of how we train our students to provide care for patients. So at this point, you know, we know that we only had one perspective, the patient's perspective. So we really wanted the audiologist's perspective. We also wanted to get students perspectives on this clinical dilemma that we are facing with this patient population.

In our next study we chose to do a case vignette method. A case vignette is where we provided the clinicians with a mock patient and we asked them open ended questions about their clinical decisions and how they would interact with this particular patient. Most of this work was done by two awesome second year audiology students. We had 49 practicing audiologists participate in this survey from 24

states, a variety of practice settings and a range of one to 42 years of practice. Then we also had 123 audiology students from 19 states and all four years of study complete the survey as well.

In the case vignette we provided a brief case history narrative and then we asked some open ended response questions just about that case vignette. After they answered those response questions, we then showed them the test results of a basic audiologic evaluation and then asked them some more open response questions. Yeah, so here is that full case vignette narrative. If you're a fast reader you could go through it. But I'll just give you some of these highlights.

So this is a case of a guy named Jim Smith where we tried to make it pretty clear that he is relatively young for this to be age related. He's 45. He only started noticing issues five years ago. The issues are isolated to speech in noise, not one on one conversations. He is clearly socially and emotionally impacted by his hearing limitations and there are no otologic or medical explanations for his problems.

And I also want to note that there nowhere in this study information in the title or in the consent form of the description did we mention that this study had anything to do with unexplained hearing difficulties or hidden hearing loss or anything like that.

We asked about how you would interact with this patient prior to testing just given this case vignette. Then we asked what tests would you run on this patient? It was promising to see that the majority of clinicians would include speech in noise testing. So studies that are that have looked at the relationship between reported speech and noise ability and performance on speech and noise tasks are finding mixed results. So I just showed you our study that did not find a relationship other store other studies have found or relationship and some of it likely has to do with the underlying constructs that are being tested by all the different speech in noise measures that are out there.

So some speech and noise measures are more taxing on the auditory system, and some are more taxing on working memory and attention. But it is well established that word recognition in quiet definitely is not related to reported speech and noise ability. So I will argue, and there's a lot of folks out there that are arguing this, like folks like Matt Fitzgerald. Matt Win would argue that if time is an issue in an evaluation appointment, you know, why not do words in noise or the quicksand instead of word recognition and quiet, especially for people with normal pure tone thresholds? Because people with normal thresholds will perform at ceiling on word recognition and quiet, and it won't provide more or different information than pure tone thresholds will.

And especially for these folks who complain of speech in noise problems, it might be able to tell us more information than word recognition and quiet will. And even if the quicksand shows absolutely nothing is wrong if they're scoring within normal limits, we've at the very least shown the patient that we are listening to their primary complaint, and we've actually tested for it. And then we can, you know, kind of remove that problem of that misalignment between that patient concern and that test protocol. We also thought it was very interesting that, you know, 40% of the clinicians surveyed would also include otoacoustic emissions, either as just their standard practice or because these clinicians just reading that case history suspected a hidden hearing loss problem.

So after we asked, you know, what test you would run, we then gave those test results for a basic audiologic evaluation. And in the basic audiologic evaluation, everything comes back within normal limits. Otoscopy is unremarkable. It's got type A temps, reflexes are in a nice range, Word recognition score is at ceiling, really? And pure tone audiometry is within normal limits.

So they're given these results, and then they are asked to describe how you would inform the patient of his test results and describe any next steps, including recommendations and referrals you would offer to this patient.

So when we analyzed the clinician and student responses for how they would inform the patient of his test results, we did that exact same thematic analysis as we did with those patient interview transcripts. And the three themes that we found were that the clinicians provided results in a clinician centered manner, that they provided results in a person centered manner, and that there was frustration with the basic audiologic evaluation. That third theme, frustration with the basic audiologic evaluation, was actually the clinicians being frustrated with us as the researchers for not providing results for speech and noise. But we purposefully only used the basic audiologic evaluation. So that first theme is characterized by really only focusing on the test results being good or normal and not relating them back to the primary concerns of the patient or, you know, validating that impact of those patient concerns.

It also often included a very detailed description of the test results for the patient. So on the top here we have a quote from a practicing audiologist who says, as you can see, all your thresholds are within the normal range of hearing. You also respond to words within normal range. Everything is excellent. All results point to normal hearing.

Then on the bottom here's a quote from a first year audiology student where they would let him know good news hearing test indicates normal hearing. And then at the bottom it says all those word tests, you got an A.

And then I want to contrast that with that second theme which is providing results in a person centered manner which is really characterized by telling the patient that the hearing test results or hearing tests performed were not able to get at the problem that he was having. And it often was characterized responses where the providers chose to avoid words like good to describe the patient's hearing. On the top here we have a quote from a practicing audiologist who said, I would let the patient know that while his hearing thresholds are considered within the normal range, it does not mean that the whole auditory

system is functioning normally. And then on the bottom we have a quote from a second year audiology student who said, based on our testing, you know, you don't have any results that are immediately concerning. However, these tests primarily look at anatomy and not how you're actually processing sound.

So when we looked at the responses for what would the next steps and recommendations be, we found three themes. Recommendations for follow up care, recommendations for treatment and providing patient education and follow up care had sub themes of referrals to other professionals like primary care physicians, ENTs and neurologists, referrals to other audiologists for APD testing and recommending the patient come back for regular hearing tests. So many of the patients that we interviewed in that previous study talked about being referred to medical doctors by their audiologists who couldn't help them. So we're speculating entirely. But in reading responses and interviews from patients in the previous study and the clinicians in this study.

But it seems to us that there really isn't much of a medical reason to refer to ENT neurology or especially a primary care physician and the medically unexplained chronic Symptoms literature tells us that this may actually cause more harm to patients than good. So this may cause a roller coaster of hope and disappointment for the patient. It costs the patient money and ultimately can result in the patient losing trust in you and trust in the healthcare system in general. And these patients that we interviewed absolutely picked up on the fact that their audiologists were trying to pass them off onto other professionals.

And only one of those patients that we interviewed was provided a referral for auditory processing disorder, though many of them noted that they'd heard of auditory processing disorder through their Internet sleuthing and thought that it could explain their difficulties. And then we found, and it's been confirmed by other studies, that people with, you know, unexplained hearing concerns have a poorer

quality of life. Now I can only speculate on the relationship here. You know, I don't know whether a poor quality of life may be contributing to hearing problems or whether the impact of hearing problems exacerbates other life difficulties or whether there is, you know, some underlying mechanism that is contributing to both. But we do know like, you know, we as audiologists can screen for, we can ask about, and we can refer to mental health specialists.

Another theme was recommending treatment such as training apps and amplification.

Other studies have found that when audiologists fit hearing aids, the audiologists believe that their patients keep them and have at least moderate, if not major benefit from them. This is specifically for this patient population.

In studies done by Christina Rupping, they have found that when they fit low gain hearing aids on people with self perceived poor auditory processing, they found a significant decrease in hearing handicapped score and better speech and noise scores like better speech and noise performance with the use of low gain hearing aids. They also found that though, that the difference between people with audiometric hearing loss, you know, and those with normal hearing sensitivity is that, you know, this population of folks may only be wearing their hearing aids as needed, you know, in those noisy situations. So that same study found that most of their participants were only wearing their hearing aids one to four hours a day. Even though they loved them, they really benefited from them. So counseling these patients with their hearing aids may look a lot different than counseling patients with hearing loss and their hearing aids.

Then the third theme was providing patient education, which really looked like focusing on effective communication strategies.

I'm going to wrap this up with just a couple ways that we can really help these patients right now in the clinic, even though we don't know what is going on that is causing their hearing concerns. So first is changing from that clinician centered mindset, where that focus is on figuring out what the impairment is and trying to fix it. To a person centered model, where we realize that the patient is here because there's a, some activity that they want to participate in and they believe that their hearing limitation is getting in the way of that. Because in a clinician centered mindset, when the test results come back normal, we have nothing to fix. But in a person centered mindset, we realize that there are lots of ways that we can assist patients in participating in the activities they want to participate in.

Whether that's just listening to their narrative and validating their concerns.

We can provide serious counseling on communication strategies. More so than just, you know, providing a brochure that's kind of like that, you know, packaged response and low gain hearing aids or remote mics or FM systems. So, so it's actually taken me personally many years to make this transition. Myself as a basic hearing scientist, I want to find what the problem is and I want to develop a pharmaceutical treatment to fix that problem. Yes.

So this has been my personal journey as well. And a key component, and the first step really is acknowledging that patients are the experts on their own experience. And we may know the science behind hearing loss and what works for the majority of patients, but we don't know the individual circumstances that creates a disability or a resulting handicap. But patients know this, and this is from a patient that we interviewed when we asked them what they would like others to know about their experience. So here is Joey that we interviewed.

He said, I guess if things can't exactly be defined or pinpointed, people are still experiencing things and kind of just being aware of that, being aware that we don't all fit the same thing. And if something's not visible or obvious or labeled, we are still going through experiences. So just kind of be mindful of that

and respond from that point of view.

So allowing that space for the patient to tell their story can be therapeutic in and of itself. So I spent some time describing that narrative interview process because it can actually be used therapeutically.

So earlier I said that allowing that narrative, patients can make sense of their own story. It can allow them to organize their thoughts and process their own experiences.

And that brings us to some counter examples of care providers that were engaged in strong person centered care and offered treatment and speech and noise testing. So while Stacy had a negative experience with her first two providers, she told us so the third provider, he's the first one who did more than a two minute hearing test for me and he said. He answered all of my questions. And he even said, I bet you have trouble with this and this and this. And he said, how about you try these hearing aids?

If they help, great. We'll move forward. If not, we'll look into other avenues. And so he gave me some hearing aids to try for a week or two, and they helped immensely.

So I do realize that in a lot of patient care settings, sometimes these possibilities are just not viable. So I will implore you to do just these three things. The first is to think about how weird it is to the patient that we describe the audiogram as hearing. So they're coming to us talking about hearing as an experience. I can't hear my friends at a restaurant, Right?

That's an experience. And then we tell them, your hearing is normal. What you actually mean is they have normal sensitivity to sound. And they wouldn't argue with that. So these folks know that they don't have a problem hearing quiet sounds, but when we use the word normal hearing, we're contradicting their experience of hearing.

So we're telling them that their hearing is normal when they just told us their hearing is not normal. And I think that that's where those feelings of COVID or unintentional dismissal are coming from.

And the second thing is to admit to the patient that the tests that we have available to us us are not perfect, and they cannot detect many of many disorders of the ear. And just because we didn't find anything today doesn't mean that nothing is wrong or that we don't believe them.

And then finally telling the patient that there are many others like them. And this is an unfortunately common problem, but there are people who are working to figure this out, and hopefully we will have answers in the future.

So I really want to thank you for sticking it out and listening to me for an hour and being here today. I really, really appreciate all of you.

Thank you. Hand this back to Carolyn. Thank you, Dr. Kamerer. I had so many, like, wow, moments in there. I was shocked by the ENT referral was actually, like, negative.

And I understand how patients could feel like passing off. Like, this was an amazing course. We have a couple questions there, so I didn't know if you wanted to look those over. And while you're doing that, I'll just let folks know. Just a reminder, the exam expires within a week.

It'll be available in about 15 minutes after the course closes. It's super easy. Take five minutes, finish that exam if you're earning CEUs. Okay. Questions would you recommend oral rehabilitation as a part of the treatment plan for patients with hidden hearing loss?

This is a great question and I think that this actually needs to be studied quite a bit more. There have I. As far as I know there hasn't been a whole lot of research on oral rehabilitation in this population. There

has been, there is really just now starting to be research or start research coming out on fitting these folks folks with low gain hearing aids. There has been one study that was interesting that came out on providing communication strategies in a military population on folks with self reported speech and noise difficulties but normal audiograms.

And interestingly those folks did not find communication strategies very helpful or at least did not find that counseling very helpful to them. But I am not very aware of the effectiveness of oral rehabilitation on this patient population.

Thank you Dr. Kamerer. See if there's another one. Here are many of unexplained hearing loss with normal audiograms. Is it often assumed to be APD or is it often apd? This is such a great question.

I have very strong personal opinions about apd so I'll just go into it. I guess this is what my thoughts on APD are. Auditory Processing disorder. My worries about Auditory Processing Disorder are that it is not. Auditory Processing disorder is not diagnosing a site of lesion.

Auditory Processing disorder could be caused by anything anywhere from the cochlea to the cortex. It could be an attentional problem. So it could be maybe strongly not even in the auditory system. So just like saying unexplainable hearing concerns, it's not actually explaining anything about what's wrong in the auditory system. So the worry that I have when clinicians diagnose Auditory Processing disorder is now we've said oh I know what it is now, when in fact we don't actually know what it is.

The Auditory Processing disorder. The assessments that are done are all of these different psychoacoustical assessments. We're measuring frequency sensitivity, we're measuring temporal sensitivity, we're measuring binaural processing. We can get, get at certain psychoacoustic aspects and like where you know, those things may break down but again it's difficult to then treat those certain aspects. And a lot of the research on treating those like if you have an app, if you have an app that

works on training gap detection, a lot of these people get really good at gap detection but it often doesn't translate into them being better at understanding speech and noise in a restaurant.

And so I think that it could, I mean I, I, so I guess this is a long roundabout way of me saying that I don't really see the difference between saying someone has auditory processing disorder and someone as having unexplainable hearing concerns.

Thank you for that. I mean I love how in just a short amount of time you went through like the rationale, the history, the research and really practical takeaways. I love the examples you showed of like the person centered statements we can make. And I feel like you turned a lot of things things inside out in a really clear way. So thank you so much for this.

I hope we can do a follow up with you in the future. And now I'm already thinking like we need a grand rounds on this where people can bring in cases of unexplained hearing loss, those that went wrong, those that were successful. So again, thank you. So cool. All right, let's do it.

Yes, I would love that. Well, thanks again. Thanks to everybody for participating, for showing up, for asking great questions. And since I am from New York, I do need to end with GO KNICKS! Thanks everybody.

Have a great rest of your day.