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Understanding, Measuring, and Managing Listening-Related Fatigue in Adults and Children with Hearing Loss

Presented in partnership with Vanderbilt University

Presenter: Benjamin Hornsby, PhD

- Okay, welcome, everyone, to today's course, Understanding, Measuring, and Managing-Listening Related Fatigue in Adults and Children with Hearing Loss, in partnership with Vanderbilt University. We're so glad you're joining us here for the next hour. I want to welcome Dr. Ben Hornsby, who is an associate professor in the Department of Hearing and Speech Sciences at the Vanderbilt University School of Medicine. If you'd like to learn more about our presenter, additional information and bios are on the course registration page. And at this time, I'm gonna hand over the mic to you, Dr. Hornsby.

- Okay, well, thank you, Farzana. I appreciate it. And for everybody out there, I appreciate you joining me this Friday afternoon for a talk about fatigue. And when I say that, it just makes me think maybe the timing isn't the best for that, so I hope you've had your coffee, and we'll try to make the best of it. So when I give a talk like this, I try to start off by giving people an idea of why we think the issue of fatigue and hearing loss is important. And I think that people with hearing loss can make that case better than I can. And so, I've pulled a couple of quotes, some from articles people have written in blog posts and one from a interview that we did with a child here at Vanderbilt, that sort of highlight those issues.

So they're on this front slide, if you look at the top one. "Since I lost most of my hearing, I've had periodic bouts of tiredness that are deeper and of a different quality than I ever experienced before." That's from an adult who developed severe profound hearing loss late in life, at sudden onset. The bottom quote is from an adult that has had longstanding severe to profound hearing loss. "I go to bed most nights with nothing left. It takes so much energy to participate in conversations all day that I'm often asleep within minutes." And then the middle quote is from a child that we interviewed as part of the research program we've had here, talking about her experience of fatigue in the classroom.

And it's just a simple quote. "My brain needs a rest from listening." So quotes like this and hearing people with hearing loss tell me these sorts of things. That's what really got me interested in this area. And it's clear from these quotes that while fatigue may not be an issue for every patient you see, that comes in, there's a subset of people with hearing loss for which it's a significant issue, that it affects their quality of life. And if that's the case, then we think we ought to be able to measure it precisely and hopefully move to intervene and help them with those issues. And so, that's what I'll be talking about today. Before I get to the main talk, we'll do our housekeeping.

Here are my disclosures. You can review those. And then the learning outcomes that we'll cover today. Again, so hopefully this will be clear as we move through. I also need to acknowledge that although I'm the one here doing the talking, I wouldn't have much to say if it wasn't for the contributions of many, many other people. I've listed some here that have been working on this project. I'd like to especially acknowledge Dr. Fred Bess, who really has been a driving force in this area for many years. So this is the information that I'd like to cover today. I'll give you a brief overview of what fatigue is and why we think it's important, why hearing loss increases risk for fatigue.

So we'll talk about a model for fatigue that we think is relevant in that area. And then, very briefly, give you some evidence from the literature that supports that idea that having hearing loss does increase risk for fatigue. And then we'll move into a tool that we've developed really specifically to target fatigue due to listening difficulties. We call it the Vanderbilt Fatigue Scale. And we think it may be useful for both clinic and research purposes. I'll talk about how you might be able to use that clinically, and score it, and interpret scores. And then we'll have a brief discussion, a brief section on management options. It turns out that research in that area is very limited, so I'll share some stuff with you, but it's an area where work is ongoing and more work's needed.

So let's get everybody on the same page. What is fatigue? You'd think that would be a simple thing to get everybody to agree on, but it turns out there's not a universally accepted definition, and researchers vary on how they'll define it. But there's a couple of ways that it has been, over the years, routinely measured and defined in the literature. One of the ways is using physiologic tools, like EEG, pupillometry, cortisol, galvanic skin response, and other measures to look at the physiologic mechanisms that are associated with a fatigued state and how those change as fatigue develops. This is important. It gives us a better idea of what's going on in the body when we develop fatigue.

Researchers have also used behavioral techniques to look at fatigue. We know in a fatigued state that our performance is less than optimal. Think of the athlete that you asked to run a hundred-yard dash. They can run it very quickly once, but if you ask them to do it two, three, four, five, six times, their performance will go down. Their performance will be less than optimal. And the same is true for cognitive performance in a fatigued state. We don't think as quickly, we don't make decisions as quickly. And so, researchers have monitored both physical and cognitive performance over time and used that as a way to measure and define fatigue. So both of these are important measurement approaches.

They provide us with good information. But in my mind, fatigue is most intuitively thought of as a subjective construct. It's a feeling, it's a mood state. It's a feeling of tiredness, exhaustion, a lack of energy. You just don't want to continue doing what you're doing, whatever that goal or task is. You run out of desire. And if we're interested in subjective fatigue, and that's gonna be the focus of the talk today is subjective fatigue, then you're gonna get information about that by using questionnaires, and surveys, or interviews. So there's a lot of things that can influence whether fatigue is gonna develop and how severe it is, and I'm gonna talk about more of them later. But one thing that's sort of universal is the application of effort.

We don't tend to get tired if we don't apply much effort. So if we are applying effort towards a listening task and fatigue develops, we call that listening-related fatigue. And we think that's particularly important for people with hearing loss. So if I could see you all out there, and I'd ask you to raise your hand if you have ever experienced fatigue, everybody would raise their hand. It's ubiquitous. It's something we all experience. But the kinds of fatigue that a typical healthy population experiences tends to be mild and transient. So you work hard at something, you get fatigued, you take a break. The fatigue resolves and it has no long, lasting consequences. But that's not the kind of fatigue I'm talking about.

I'm talking about fatigue that's more severe in nature. It occurs more frequently. And it occurs in response to situations that don't necessarily lead to fatigue in a healthy population, things like listening. That kind of severe, recurrent fatigue is actually quite common in individuals who have some sort of chronic health condition, and I've listed a few here. Cancer, AIDs, Parkinson's, multiple sclerosis, rheumatoid arthritis, diabetes, obesity. Fatigue is a primary complaint for many of these disorders. And recent research has supported the idea that hearing loss is another chronic condition for which fatigue can be a primary complaint, again, at least for a subset of people. So what's the big deal about fatigue? Well, severe, recurrent fatigue can have cognitive consequences.

Research suggests that in that fatigued state, we have trouble maintaining attention and concentration. We're not able to think things through quickly, make mental decisions quickly, so we make poor decisions. And so, it's not uncommon in working adults that they tend to be less productive and more prone to accidents if you're suffering from fatigue than when you're not. And in fact, we know from investigations of industrial accidents, so think Three Mile Island, or Chernobyl, Exxon Valdez, people my age are aware of those terms, these are major industrial accidents. And investigations

into those accidents and others like them routinely identify fatigue as a contributing factor. It's not the only thing that causes the accident, but it's routinely found as a contributing factor.

And it's not just working adults that these cognitive consequences can impact. Older adults who aren't working tend to be less active, more socially isolated, and less able to take care of themselves when they're suffering from severe fatigue. And these effects aren't just present in adults, and they impact children as well. You could imagine how difficulty with attention, concentration, poor mental processing, speed of processing deficits, those things would affect children in school settings. And the research supports that. A lot of this work comes from children suffering from chronic health conditions who are experiencing fatigue. These kids tend to do poorer in school. They're more likely to have to repeat a grade. And they're more likely to miss school.

And this is not due to their treatments for their disease, but it's for fatigue-related issues. So the consequences of fatigue, when it's severe, can be significant and impact quality of life in both adults and kids. So why do we get fatigued? Well, there's multiple models that talk about the purpose of fatigue. But one that we think is relevant for people with hearing loss was developed by Robert Hockey. It's called the Motivation Control Theory of Cognitive Fatigue. And Hockey treats fatigue, or looks at fatigue, as an emotional response. So here, think as a subjective feeling, a feeling of tiredness, exhaustion. And his idea is that that feeling serves an emotional, I'm sorry, an adaptive goal-directed function.

And by that, I mean that that feeling directs where we apply our effort and energy towards some task. Fatigue is a kind of an uncomfortable feeling that forces us to answer the question, do I really wanna keep doing what I'm doing? So think of the person pushing this boulder up the hill. They're applying lots of effort. And as they apply that effort, they're gonna start to develop fatigue. And that forces them to answer

the question, do I really wanna keep pushing this boulder up the hill? So in that sense, fatigue can act as a protective mechanism to make sure we're not applying effort for unrewarding things. So I mentioned that effort plays a role in how much fatigue develops, but other factors play a role too, and I've listed two here.

Feelings of control are important and your motivation to do well on a task. How important is it for you to achieve that goal? These things work together to impact the risk for fatigue and its magnitude. So the example I use here is, think of the assembly line worker whose job is to put a widget in a box. And these things are coming down in assembly line quite fast. And so, to get the widget in the box and then get to the next one, it takes a lot of effort. So the worker's applying a lot of effort. And on top of that, so that's gonna bump up their risk for fatigue, but on top of that, they can't control the pace of those things coming down the assembly line.

They're coming as fast as they're coming and they have no control over it. That increases their risk for fatigue. And then the worker, if they, like, can't keep up, and stuff starts coming on the floor, and a big mess is made, and the supervisor comes over, they get yelled at, they may lose their job, right? So it's important to them that they continue to achieve their goal, that is, get the widget in the box, and there's negative consequences if they don't. So all those things work together to make that setting high risk for fatigue. So I'd like us to stop for a second and think now about how these things might apply to someone with hearing loss, right?

So do people with hearing loss have to apply more effort in listening tasks? And the answer's obviously yes. There's decades of research now showing that. People with hearing loss have limited control over their ability to hear well. You know, they can do some things to improve their setting, but once they're in a setting, if they're not hearing well and they've done their strategies to try to improve it, they can't change their hearing loss, right? So they've got limited control over that. Communicating well is

important to people, right? We're not communicating with somebody because we don't want to. In many cases, we want to know what they're saying. It's important to us if it's friends, or family, or maybe job-related.

And there's negative consequences when we don't communicate well. All of us have had patients come in and tell us about feelings of frustration or embarrassment when communication breaks down. So there are negative effects when they're not able to communicate well. So all of these things will add together to increase the risk for fatigue for people with hearing loss. At least that's what the model would predict. So we can ask the question then, is fatigue a problem? Our model suggests it is. We've got anecdotal reports, I showed you these here, they're on this slide, that sort of suggest that it is. Has there been any research to support this? And if so, how is it measured? And the answer is yes.

There's been a fair amount of work, more over the past 5 or 10 years than, it's sort of recently picked up interest. But there have been scales for measuring subjective fatigue that have been around for many, many, many years. And I've listed several here that have been around for a while and have also been used to assess fatigue in people with hearing loss. Now, none of these scales were designed specifically with people with hearing loss and their fatigue issues in mind, but they've been used for people with hearing loss. I've used the Profile of Mood States, the POMS. It looks at multiple moods, anxiety, depression, but the two that I've used it for are fatigue and vigor. It's a generic fatigue scale in that it's not designed to assess fatigue in any one chronic health condition.

It's been used with athletes, people with hearing loss, college students, cancer, lots of different populations. Another one we've used is the Pediatric Quality of Life-Multidimensional Fatigue Scale, or the Peds-QL. That's designed to assess fatigue in children, okay? Also a generic measure, so it's been used in lots of different

populations. Other scales are designed or developed specifically to assess fatigue in a given chronic condition. For example, some scales are designed to assess cancer-related fatigue, okay? So scales can be either generic or disease-specific. Until the development of our scale, there was no disease-specific scale for assessing fatigue associated with hearing difficulties. So we can ask the question, what do these existing generic measures tell us about fatigue in people with hearing loss?

And I'm gonna highlight a couple of studies that we've been involved in. The broad answer to that question though is that the results are mixed. The findings are, in general, tend to show that people with hearing loss do report more fatigue, but there's some studies that have some caveats with that. So I've put a few citations here if you want to kind of dig into those. But I'll highlight some of them as I go throughout the talk. So this is a study that we did looking at fatigue in adults, published it back in 2016. And we used the Profile of Mood States and pulled out the fatigue and vigor subscales for them. And we had 116 adults that had come into our clinic with complaints of hearing problems.

So they were gonna get a hearing aid or they just wanted a hearing test 'cause they felt like they were having hearing trouble. And the nice thing about the POMS is it's been around for many years, so there's normative data, there are means. And in addition, the developers of the POMS have identified what they call cut-points for severe problems, that is, problems that are unusual for the general population. And the cut-points for them are 1 1/2 standard deviations above the means of their normative data. So we call that severe fatigue problem, scores that were greater than the 1 1/2 standard deviation. Fatigue scores that were greater, we said that severe fatigue or vigor scores, lower is worse for vigor scores that were less than that 1 1/2 standard deviation cut-point was a severe vigor deficit.

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And we compared the percentage of adults that came into our study, of our 116, who had severe problems to what we see in the normal distribution. And so, that's what this figure is showing. The red bars are the percentage of people who reported severe fatigue or severe vigor that had hearing loss. And then the blue bars are the normative data. And what we found was people with hearing loss were more than twice as likely to report severe fatigue and more than four times as likely to report severe vigor deficits. So it suggests sort of consistent with what the anecdotal reports were telling us. And we've done work like this with children as well. I said we used the Peds-QL to look at kids.

And so, this figure is from a 2021 study where we sort of summarized some of the work we'd done with children. And as part of that, we wanted to compare the fatigue experienced by children with hearing loss to fatigue experienced by children with other chronic health conditions. And so, that's what this figure is showing you. The fatigue for children with hearing loss come from a 2017 study where we looked at 60 kids who had a mild to moderately severe bilateral sensorineural hearing loss. And the Peds-QL is part of a suite of quality of life measures, so it's a little unusual in that lower values are bad. So here, more fatigue is a lower value. So the black circle here is the mean fatigue score for the children with hearing loss.

And then on the x-axis, I'm showing these fatigue scores for children with other chronic health conditions that we pulled from the literature. So these were people who were studied at other places, not here, not by us at Vanderbilt. We just pulled it out of the literature. So any symbol that falls above the line means the children in that study had less fatigue. Any symbols below the line, they reported more fatigue. And you can see that almost all the symbols are above the line. The asterisk show significant differences. So what I'm saying here, and the types of disorders on the x-axis is cancer, obesity, diabetes, rheumatoid arthritis, and others. So I'm not saying by any stretch that having hearing loss is a bigger problem than having cancer if you're a kid.

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I'm not saying that at all. What I'm saying is that the fatigue experienced by children with hearing loss is significant. It's comparable to the fatigue experienced by kids with other chronic health conditions for which fatigue is a primary complaint. So it's a big deal. It's not just a little thing. So these generic measures give us some good information, but sometimes we find things that don't make sense to us. So, for example, one of the things we expected to see was that there would be a correlation between degree of hearing loss and the magnitude of fatigue that someone's experiencing. You know, the more hearing loss you have, the more communication trouble we would expect, the more effort you'd have to apply, so based on our model, we would expect more fatigue.

But we didn't see that. This is the data from the children with hearing loss, the 60 kids with hearing loss in that prior study I was talking about. No correlation at all. And we saw the same thing with adults. This is from that 2016 study. It's a different fatigue scale, another generic scale, but the data from the POMS looks the same. As degree of hearing loss increases, we expected fatigue to increase, but there's no correlation. So seeing things like that made us ask the question, are generic measures optimal? And we think that they may not be. And this study by Bob Dwyer sort of gets at that and helps make that point. So this was a study conducted here at Vanderbilt.

I was a part of this study as well. And the study had many purposes. I'm only gonna talk to you about a little part of it, and that is the subjective measures that were included. It's a small study. There were only eight young adults with hearing loss. They had severe to profound hearing loss. And they were in AuD programs around the country. And so, once they were identified, they then recruited someone within their class cohort to be a control subject. So although it's a small n, it's a nice case control study. And we felt like this was gonna be a high stress environment, and if there was

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anywhere we were gonna see effects of hearing loss, it would be among young college students who were in a high stress program.

So we did, like I said, did lots of things, but what I'll talk about is we gave them the POMS, so a generic fatigue scale. And then we created some questions that asked about listening fatigue issues. And we had them complete both. Well, we saw absolutely no difference on the POMS between the normal hearing control group and the hearing loss group. But when we asked them about listening-specific questions related to fatigue, we saw large and significant differences for each item. So this was our first pass at sort of coming up with ways to ask about listening-related fatigue. So some of us sat around, and we talked about questions, and we came up with three that we thought were reasonable.

Difficulty listening causes me to become physically or emotionally tired. Fatigue and low energy due to difficulty listening are major problems in my life. And how often do you feel physically or emotionally tired? And so, you know, more problems are higher values here in the black bars or the control group, the gray bars are the hearing loss group. And you can see large, significant differences for each item, right? So depending on how you ask the question, you get different results. So are generic measures optimal? We don't think so. We think that we can get good information from them, they're useful for some things, but they may underestimate the magnitude of fatigue experienced by people with hearing loss.

And so, this and other things motivated us to develop our own scales, the Vanderbilt Fatigue Scales. These were the scales that were designed specifically to measure listening-related fatigue in both adults and kids. And while our focus in developing them was on hearing loss, and so they were designed to get at fatigue in people with hearing loss, we actually think they're gonna be very appropriate to use with children or in adults with other issues. Anyone that has trouble with auditory disorders or

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communication problems may be at risk for listening-related fatigue, so people with APD, second language learners, TBI, attention deficit disorder. We think this scale may be useful for a wide range of clinical populations.

So I'm gonna introduce you to the scales and then we'll talk about how you can use them and maybe use them in clinic. So we have two versions for adults, a 40-item version that really is appropriate for research purposes. We don't think it's gonna be useful for clinic, it's just too many items. And we don't think it's required for clinical purposes. It gives you a total score, and also, you can calculate subscale scores on different domains of fatigue, physical, cognitive, social, and emotional. But to make a scale that would be more appropriate for clinical use, we took the 40 items and we extracted 10 very high information items and used those to create a 10-item unidimensional scale that we think is appropriate for clinical use.

And actually, it's been appropriate for research use as well. Then we have three scales that are appropriate for assessing fatigue in children. We call the suite of scales the VFS-Peds, the Pediatric Vanderbilt Fatigue Scales, appropriate for kids for 6 to 17, although the age range varies depending on the scale. There's a child self-report scale. This is unidimensional, 10 items. So all of these are just a small number of items, so all appropriate for clinic or use in school settings. And then there are two proxy report scales. One that you give to the teachers, the VFS-T, the teacher fills it out regarding fatigue of the child. And then a parent scale that is multidimensional. It provides two scores, a score for physical fatigue and for mental fatigue.

All of these scales assess what we call long-term listening-related fatigue. So I'm not getting at how tired are you right at this minute or right after this activity. We ask the adult or the child to think back over a typical week about their fatigue experience over that week when they're answering their questions, so we get a broader view of a more long-term fatigue. All of the scales use a five-point Likert frequency response format for

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responding to test items, that is, you'll read an item and then you'll answer the question, you know, how often is that a problem for you? Never a problem, rarely, sometimes, often, or almost always. And then this is scored, you score one of those with zero through four.

So the VFS-Peds, all of them use this response format. The 10-item adult scale uses this response format. And 31 of the 40 items on the 40-item research scale use this format. The last nine items use an agreement scale. It's just the way the items were worded in agreement scale was clearer, but it works the same way. You read the item and then you respond to that. You know, how well does that describe my fatigue experience? I strongly disagree, that's not my experience. or I strongly agree, or, you know, increments in between. But again, scored on a zero to four scale, five-point scale. There are two options for scoring the scales. One is simple sum scoring. We think this is gonna be most appropriate for clinical purposes.

Now, you just add up, if it's a 10-item scale, you add up all of the responses to the different items and you get a total summed score. So the maximum score that you get will vary depending on the number of items. And that varies across scales. One issue with this approach is that it requires that all items be responded to. The scale is not validated to allow you to skip an item and, like, average it to fill it in, right? So it's gonna be important, if you administer a scale and you wanna score it, that you look at it before the patient leaves. And if they miss an item, you ask them to go ahead and make their best stab at responding to it.

The other option which we think is most appropriate for research purposes is to calculate IRT scale scores. IRT stands for item response theory. You can think of an IRT scale score as a weighted standardized score, like a Z-score, like in standard deviation units. So minus three would be very low, plus three would be very high. The advantage of IRT scale scoring is that it allows you to take advantage of the fact that the different

test items are weighted differently in terms of their power for discriminating fatigue of a certain severity. Some items are very good at discriminating someone with severe fatigue. Some are very good with mild fatigue. And so, you can take those individual item weights and incorporate them when you do the scoring, and that gives you a more precise estimate of any individual's fatigue.

The challenge with this is that it requires a dedicated computer software, specialized statistical software, and really an understanding on your part of IRT statistics. So we don't think it's appropriate for clinical use. We think it's very relevant for research purposes. In terms of administering the scales, I'll just state the obvious here, they were developed for people who use spoken language, who listen to spoken language and respond auditorily. So for English speakers, individuals with very severe hearing loss who use sign language also struggle with fatigue, but that's associated more with visual straining. And that's not the purpose of the scale. It's not designed for that. So when we administer this scale to adults, most adults can complete the 10-item scale on their own, read the instructions, it's very simple, very straightforward, and complete it five minutes or less, no problem at all.

The 40-item scale, maybe 15 to 20 minutes. But again, adults can typically do that on their own without much of an issue. For children, it varies depending on the scale. For the child self-report scale, we normed that and validated it using a population of kids from 6 to 17, but the vast majority of the kids were aged 10 to 17. And now, as we've been using it in schools and getting feedback from clinicians, our experience is that, really, it's most appropriate to use for kids 11 to 17. Younger kids struggle with some of the concepts. And some of the older kids may as well, so we think it's important that you either read it to them directly so that you're ensuring that they're getting the correct material but also sort of confirming comprehension as you administer the scale.

And you can get details about this process and our current recommendations by going to a website we've developed to distribute the scales and information about the scales. The link is down here. We've got a user's guide for the child scales. For the teacher proxy scale, that can be used with children as young as 6 up to 17. The teacher should be someone that, or the person that is filling out the scale should have direct knowledge of the child's behavior in a wide range of settings. So that's typically gonna be the general education educator, the general educator. You know, easier for younger kids when they're not moving classrooms. Sometimes more challenging for high school kids that are going to multiple classrooms.

But it's important that the individual completing the scale have information about the child in a wide range of settings in order to be able to answer the questions. And then for the parent, also appropriate for kids 6 to 17, you're gonna wanna have the parent that spends the most time with the child outside of school complete the scale. So those are the scales. If you'd like to see copies of them, you can go to the original articles where we describe 'em. They're available there. But as I said, we've also developed a website. They're available for free download. Just Google Vanderbilt Fatigue Scales, or I provided you with the link. We've also been working with researchers around the world.

There's been strong interest in developing the scales and translating them into other languages. If you need it in Spanish, Italian, Indian, or Mandarin, those versions are available on the website. And then we listed some other programs we're working with now that, it's ongoing work. So we hope to have these other languages available shortly. So if you get the scale, you decide you wanna use it, how are you gonna use it? Well, I think there are three ways that you can use it. One, and probably most intuitively, is as a tool to identify an individual who's got fatigue-related issues that are significant enough that you may wanna do something about it. In addition, we think it's

important to use that opportunity when you administer the scale as a time to counsel and educate individuals on listening-related fatigue, adults, kids, parents, teachers.

We think that's gonna be an important component in management actually. And then finally, if you've identified someone who's having significant problems, then we should make attempts to intervene, to try to assist 'em with that. And if we do that, then we wanna be able to measure changes over time, so we can use the scale as an outcome measure. So I'm gonna start off with the identification question. And the thing we're answering here is, what score warrants monitoring or intervention? You know, how do you know when to intervene? You'd think that that would be an easy number to come up with, but it turns out it's not a trivial task. And so, what I'll share with you today is our sort of best guess on that.

This is ongoing work in our lab, and we hope, now that the scale is developed, that other researchers will look at this as well and try to develop validated metrics that can make the scales' information as useful as possible to clinicians. So one way we can do that is by interpreting the score that we get qualitatively based solely on frequency of complaints. Remember that most of the items asked about how often fatigue is occurring or how well the fatigue issue describes your experience. And our feeling on this is that anyone who is experiencing fatigue-related issues often to almost always, that's a problem, right? That's not typical in individuals who don't have some sort of health condition.

Sort of following up on this qualitatively as well, we can not only look at a total score in terms of frequency of complaints but look at individual items and any items where issues are occurring often to almost always are potentially problematic. So we're gonna suggest that, and this is especially true for children, that we do follow up questioning about any items where individuals are reporting problems occurring often to almost always. And with children, we're really gonna be looking for direct examples of the

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functional impact of their fatigue because that'll give us targets for intervention. And then finally, we can take a statistical approach, and this is what's commonly used. We can calculate means and standard deviations on normative data and then just come up with cut-off points, one or two standard deviations above the mean, and say scores that are higher than that are unusual for individuals who don't have hearing loss.

So I'll walk through some of those approaches, starting off with the sort of frequency of fatigue-related problems. So here, I'm actually showing you, this is our 10-item adult scale, so 10 items, the response options or the frequency of response format. So they'll read an item, I feel worn out from every day listening, and then they answer, you know, how often is that true for me? Never, almost never, or almost always. So if they go down through each of these items and say never to all of them, they'll get a total score of zero. If they say almost always to all of 'em, they get a total score of 40, and then everything in between. Point being that, as you are circling more problems, your sum score gets higher, okay?

So this is data from a hypothetical adult, hearing aid user, they have severe hearing loss. And you can see that, 5 out of the 10 items, they said these problems are occurring almost always, three, they're occurring often, and two, just sometimes. You sum up those scores, you get a score of 33. So if you look on our scale here, 33 is falling in this range where problems are occurring, suggesting that problems are occurring often to almost always. Really, scores of 25 to 30 or higher, the only way you get that score is if you have circled lots of these often to almost always responses. So in our mind then, regardless of anything else, this person is saying these problems are occurring very frequently, and hence they may warrant intervention.

And we can go the opposite direction and try this logic, and it works for a bit, but it's not complete, right? So we could say scores of 10 to 15 or less imply that fatigue really is not much of a problem. It occurs rarely. And that could be true but not in every case.

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So here, our hypothetical adult with mild to moderate hearing loss, most items, they said fatigue issues never occurred. Some rarely, one sometimes. But there were 3 out of the 10 where they said these situations are occurring often or almost always. I feel worn out from everyday listening, often. Struggling to listen and understand makes me feel tired, often. And it takes a lot of energy to listen and understand, that's always.

So is that too much of a problem for that individual? Well, I think that's where the conversation needs to come in. So we think, in addition to looking at the summed score, it's important to look at the items and follow up on items where fatigue issues are occurring often to almost always. And we think, again, this is gonna be critical for children. And so, this next example is actually data collected at a school, from a 13-year-old girl with bilateral hearing loss. And the information was actually used in her IEP program, her IEP report. So she had a sum score of 20. So this is the child's self-report, it has 10 items as well. So some scores will go from 0 to 40 just like before.

And a score of 20 would imply, on average, that she has fatigue sometimes. That's not too bad, everybody has fatigue sometimes. But if you look at the items, there are 3 of the 10 where she says issues are occurring often or almost always. Trying to listen at school stresses me out, almost always. And so, what we recommend is that you review this with the child and then you follow up on this. So tell me about this, when does this happen to you? What does this look like when you say, it stresses me out? What's going on? Other questions. I give up trying to listen when I get tired, almost always. And I feel worn out when I have to listen carefully, often.

So think about this at school. The child gets worn out when they have to listen carefully often while they're at school. And when they get tired, they give up, right? That's not a good thing at school. So we would say, ask the child about this. You know, what's going on when you say you feel worn out when you have to listen carefully? What are the conditions about it? And when you say you give up trying to listen when you get

tired, what does that look like? What do you do? And so, you take that information from the child, and that can be very helpful in IEP meetings because it highlights the functional impact of the child's fatigue and targets specific issues or areas, or gives you at least some specific issues or areas, to try to intervene at.

So the the other approach then would be a statistical approach, that is, just develop norms and then take somewhat arbitrary cut-off point, one or two standard deviations is common, and use that as a, any scores higher than that would be a flag for intervention. And so, this is routinely done, and we've actually have data that allow us to do this. We don't have population-based norms. The data that we have are from adults who have self-reported, they have no hearing loss or additional disability and then children who, by a parent report, don't have hearing loss or any additional disability. The sample sizes vary, from 68 for our teacher norms to a 220 for our 10-items scale.

So, you know, we're gonna give you the best information we have with these data, but we are hoping that more can be collected and these cut-points can be validated further. So this approach, we think, works well for adults, but it's problematic for kids. So I'll just walk you through why that happens. So this is showing a histogram of our 10-item adult scores. So this is from the VFS-A-10. So scores go from low to high. And then the y-axis is the percentage of those 220 adults who had scores that fell in this range, like zero to four, five to eight, that bend. So you can see that most of the scores are skewed way to low values.

So in adults who don't have hearing loss, most of them have very low scores. The median is five, and so that means the one and two standard deviation cut-points are gonna be low here, 13 and 19 respectively. And then importantly, there were no adults out of the 220 that completed this scale that had a score higher than 26. So none of them that are reporting fatigue-related issues occurring often to almost always. When I

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plot the distribution for adults with hearing loss, this is 366 adults with hearing loss, you can see they look very different, as you would expect. It's a much broader distribution. Now there are a portion of people with hearing loss, fatigue's no big deal to them, okay?

So that happens. But there are many, in fact about 70%, that score higher than the one standard deviation cut-off for norms and 50% higher than the two standard deviation cut-off. So fatigue is clearly more common in adults with hearing loss, and a 25% of them are reporting fatigue-related issues occurring often to almost always. Remember, none for those adults without hearing loss. So the quotes that I showed you on that front slide may have come from people falling into this range of scores. So, to us, this suggests that having a standard deviation cut-point is a reasonable approach for adults. Nothing is easy with kids, right? They're not little adults. So this is the distribution of typically developing children without hearing loss or any other disability.

And you can see right away the distribution looks very different. It's 120 kids. It's a broader distribution, and it's shifted to the right compared to adults. The median is 15 compared to 5. And so, because of that, the one and two standard deviation cut-offs are very high, 27 and 37. 12 1/2 percent of typically developing kids are saying they have fatigue-related issues often to almost always. So kids at school, in those settings, they're in challenging settings, right? So even typically developing kids, fatigue-related issues can be significant. And we're 0% for adults. When we overlap the distribution of kids with hearing loss, this is 116 kids with hearing loss, you can see it's shifted to the right. So the median is 20 versus 15, but there is a lot of overlap here, right?

And so, that's a real challenge. About a third of kids with hearing loss have scores that exceed the one standard deviation cut-point for normal hearing kids. And remember, that point was 27, that's in the range of fatigue problems are occurring often to almost always. So a third of kids with hearing loss are having those sorts of issues.

Remember, 25% with adults. But only 1% exceed the two standard deviation cut-off. And that's 'cause it's 37 outta 40. You know, very few have that high, high score. So using a two standard deviation cut-point would be totally inappropriate, because you would miss all of these children, both those with and without hearing loss, that are saying fatigue-related issues are occurring often to almost always.

So we think interpreting scores statistically works well for adults. And in this table, I provide the cut-offs for one and two standard deviations for the adults. For the children, I've taken the two standard deviations out because I don't think they're appropriate. And so, I showed you the data for the child self-report. It looked similar for the parent and teacher data. So I've provided the one standard deviation cut-points, but we think, again, regardless of the score, it's easy to interpret if they're exceeding that one standard deviation cut-point. That's in the often to almost always range. But even if they're not, then it's important that you look at the items and see which items that are saying fatigue-related issues occur often to almost always.

And follow up with those. And again, details for this, you can find in our user's guide and in the 2023 paper for the adult data. Okay, so the last thing I wanted to talk about was, well, I'm sort of skipping over counseling 'cause I'm gonna get to that in a little bit in the outcome measure part. And whenever you administer the scale, we think that there's an opportunity for counseling there, to talk about the issues that are occurring as you go through each item. But if you've identified someone that's got significant problems with fatigue, you think you want to offer them suggestions for ways they might help reduce that, well, you're gonna wanna measure later to see if you've had any effect.

So it would be nice if I could tell you these are the interventions that you should use, but there isn't much in the way of empirical work to support any one intervention. But if we look at the broader fatigue literature and our model of fatigue, we can make some

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predictions. And the prediction would be that any intervention that reduces effort or improves control should have, or we would predict that it would have some benefit for fatigue. So when we talk about children, you're gonna do things that are part of standard of care, right? To reduce effort, set up the classroom to optimize listening, preferential seating, good visual cues, good acoustics. Make sure they have their devices, right?

'Cause these things, together, should reduce effort. Now, you'll see I've got, make sure they're using their device with a caveat because we, actually, let me take a step back here. The information that I'm giving you here in terms of interventions for children, this is not based on studies that have looked at these approaches and validated their successfulness, their effectiveness, because those studies haven't been done. Where we get this information from is from children with hearing loss, their teachers, their parents, people who've worked with these kids. Through focus groups and interviews that we've held, we've asked them about their fatigue and how they manage it. And so, these are things that are being used already to address fatigue issues for kids with hearing loss.

Now, how successful or effective they are, we're looking to develop studies that will show that, but they don't exist at this point, so this is sort of our best guess at this point. So consistent uses of their assistive device, that's intuitive, but we also know from the focus groups and interviews that listening is demanding. Listening through hearing aids or cochlear implants is demanding. And children need breaks from that sometimes, otherwise fatigue is very problematic. So some educators will build these into their day, schedule it into their day, into IEP plans. Children may have a space that they can go to where they just can take a break from listening, whether they leave their device on or off.

So if you want some details about these things, like I said, you can look at the citations down here. That's where we describe the focus groups and interviews where we got this information from. The other thing that we think is really important is education. So I've mentioned this a couple of times, where I say counseling and education is an important component. We learned from talking to young adults with hearing loss, so this is college-aged adults, and asking them about their fatigue experience as children versus now in college, several have told us that, you know, when I was little, I just thought that's the way that it was. You know, I thought everybody took naps after school.

I didn't know. It wasn't until I got to college that I could make the connection between the hearing difficulties I was having and the fatigue I was experiencing. So we think it's important to educate the children, the parents, and teachers about this because this will enhance feelings of control over the situations that they're in. And then based on model predictions, we should be able to help with fatigue. So details on these, we have a handout on our website for management strategies for kids. For adults, same things apply, based on the same model, listing breaks, education, using their devices. But for adults, there is some recent data that I can share with you that actually supports the idea that using hearing aids and cochlear implants can reduce long-term listening-related fatigue.

There's a study by Jack Holman that came out in 2021 that used our 40-item adult scale. Actually, it wasn't published at that time. They contacted us ahead of time, just knew that we were working on this and had seen the work presented at other research meetings, and we shared it with them prior to publication. And they used it to look at fatigue in adults that were coming in to get their first hearing aids. So these were adults with mild to moderate sensorineural hearing loss. A group came into a clinic, they said, yep, you guys need hearing aids, and they got hearing aids. Others came into the

clinic, they said, you need hearing aids, and they didn't get it, that was the control group.

And they had them fill out our fatigue scale at baseline, right? And then two weeks after the fitting, for the control group, it was three months later, but both of 'em were about three months after the baseline setting. And then again three months after that, and three months after that. So fitting and then out to about six months after the fitting. And what they found was that fatigue in the hearing aid group decreased two weeks after fitting and then remained lower out to nine months. But the control group showed no change. So hearing aids helped reduce their long-term fatigue. And our scale was sensitive to that. Interesting point is they also used two generic measures, or another generic measure, I forget which one.

And the generic measures they used were not sensitive. They didn't see any difference between groups. So the disease-specific scale, or our scale designed to look at listening-related fatigue, was more effective at showing benefits for that situation. And then we have done work here at Vanderbilt asking the same question about cochlear implants. And so, this has been a long-term study. We've submitted it for publication in Ear and Hearing. Got back a set of reviews recently. I think they're manageable, so we're hopeful that this should be eventually accepted for publication. So the question was, does getting a cochlear implant impact fatigue? And if so, what's the time course? And so, we had two groups. One group was what we call our experimental group, it's about 50 people.

They came in for a CI workup, and we said, yep, you can get a CI, and they got one implanted, either just a unilateral one or there were two subjects that were simultaneously implanted. So got one in for both ears. And so, participants were recruited at Vanderbilt but also at the University of Colorado as well. And then our control group consisted of about a hundred adults, about 50 that had one implant and

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50 that had two implants, and had been wearing them for at least a year. So we collected data on our experimental group before they got the implant, two weeks after it was activated, one month, two months, three months, six months, and a year, so out to a year.

And then for the control group, we did it twice, once when they entered the study and then again three months later to kinda look at stability. Collected a lot of data. I'm only gonna show you the fatigue data. And that's what I'm showing you here. So we used the 40-items scale. So I'm showing some score here. So the scores go from 0 to 160, and I've put the frequency count here to kind of orient that to you. So zero is never, almost never. 160, problem is almost always. 80, problems are occurring sometimes. 120, often. And then the x-axis is the time. So pre-implantation scores were a little over a hundred, about 105, so somewhere between sometimes and often on average.

So fatigue's an issue for people before they get a cochlear implant. Two weeks after implantation, scores decreased significantly, continued to decrease out to three months, and then they were stable out to 12 months when it was equivalent to that of our experience control groups, the unilateral or bilateral control groups. So cochlear implants have a rapid and large impact on fatigue. So that's good news. The bad news is that if we look at what's fatigue in normal hearing listeners, they're at about 22. So about 40 points higher even a year out, right? Even experienced CI users, fatigue's still a problem compared to listeners without hearing loss. And then the other thing I'll show you is, you know, just to be upfront here, the mean data looks really good, but as with anything with hearing loss, there's just a lot of variability.

So here, I'm showing you the individual variability. Some people had these really large changes, like from almost 160 down to that 20 range, and then it stayed down there. Others' fatigue was high, and it stayed high. Some were low and stayed low. So lots of variability. Our work today, we haven't identified any factors that can explain that well,

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but work's ongoing. Okay, so we've covered a lot. I hope you understand better now what fatigue is and why we think it's important. If you're gonna use the fatigue scales, this is kind of your next steps here. Evaluate, use the information to identify individuals who need some help. Educate and advocate for them and then intervene as appropriate. So I think we're running out of time.

That's it for me. So.

- All right, well, thank you so much, Dr. Hornsby, for sharing your expertise with us today. We'll go ahead and open up the floor for questions. So please use the Q&A chat box to type in your question at this time. And I see that we do already have a couple of questions in the queue, so I'll start with our first one. Do you find that this fatigue holds true for individuals with auditory processing disorder versus attention deficit hyperactivity disorder? This person is thinking there may be a correlation of APD with a significant co-occurrence of ADD with ADHD diagnosis.

- Yeah, no, that's a great question. And that's a wonderful area of research but not one that we've done. So what we do have, and I didn't have time to show you any of this, is we've looked at how having any additional disability. And so, when you look at the child's report and it lists their multiple disabilities, having any additional disability other than hearing loss increases risk for fatigue. It's certainly, we would predict, based on our model, that disabilities that affect communication function or auditory processing would have a larger impact than ones that might, say, affect physical issues.

- Okay. All right, next question. Does using the word struggling in VFS-A-10 add any bias to the question?

- Well, if they're not struggling, they can certainly put never, right? But it's a good point in, like, where did the questions come from? So I didn't have time to talk about how the

scales were developed and validated, but it was a long process. It took many years to do that. But we started the process by these focus groups and interviews, transcribed, we asked people with hearing loss about their fatigue-related issues. And then we took their quotes and used those to make out, so every item in a scale came from someone with hearing loss talking about their fatigue. So whether it is a negative bias or a positive bias, you know, I'm not quite sure about that, but I do know that the items are relevant to the target population because that's where they came from.

- Okay, thank you for that. All right, next question. This is referring to physical exercise that helps with physical fatigue and focusing on increasing energy. So the question is, are there any sound exercises that individuals with a hearing loss can apply themselves to help increase with the management of sound information?

- That's another question that I'm afraid I don't know the answer to. So I can't talk about sound exercises. There is work in the broader fatigue literature, certainly, that, as you were suggesting, physical activity is helpful. You know, for chronic fatigue syndrome, the advice early on was rest. Well, that's no longer the advice for people with chronic fatigue syndrome. It's actually get up and get active, because that helps reduce our fatigue. But in terms of a sound exercise that would be similar, there's nothing that I'm aware of. What I know from what people with hearing loss told us in our focus groups is that listening is a challenge, especially in noise. And that process of continuing to strain to listen can lead to fatigue.

Now, whether you can strengthen somebody to overcome that or not, I don't know the answer to that question.

- Okay, all right. And then we'll wrap up with our last question here. This is referring to many post-fitting, there are many post-fitting questionnaires available to measure subjective benefit. Adding a pre and post-fitting questionnaire to measure a reduction in LRF may be too much for some patients. Do you think using the VFS-A for all adult patients is helpful or a specific subset of patients?

- So that's a great question. And I am hopeful, and I don't know that it's appropriate for, right, there's about 30% that are having problems often to almost always. You can identify them in five minutes, right? So there may be a way to screen before you give the scale, I'm not sure. But whether it would be useful for other reasons, I think that it may be, and I know that people are doing work in this area. It's not published yet, but I know that some researchers have shown, and they've presented these data at other meetings, that the fatigue scale is predictive of hearing aid satisfaction. So there may be other reasons that it will provide information that will turn out to be beneficial.

But they've just gotten out and published, and so, hopefully, now, people will use them to help provide more information to answer that question.

- All right, perfect. That is all the questions we have at this time, and we are right at the hour. So we'll go ahead and wrap up. I wanna thank you again, Dr. Hornsby, for your expertise today and to our audience for joining us today. Have a great rest of your day, everyone, and take care. Thank you.

- Thank you too. Bye.