

Conversations in Tinnitus

with Helen Pryce, MSc, PD (Health)

Transcription:

- S1 00:00 Welcome to *Conversations in Tinnitus*, a podcast of the American Tinnitus Association. The American Tinnitus Association is a nonprofit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. *Conversations in Tinnitus* podcasts are an extension of ATA's magazine *Tinnitus Today*, the only publication dedicated to educating the public and practitioners about ongoing research, treatments, and management of the condition. [music]
- S1 00:48 Welcome back to *Conversations in Tinnitus*. Our first talk and our first guest of 2018. I'm John Coverstone, along with my cohost Dean Flyger who is traveling this week, so joining us via our video conference. And also joining us – our very special guest that we are very happy to have with us on this podcast – is Dr. Helen Pryce, who is a senior lecturer in audiology at the School of Life and Health Sciences, Aston University, in Birmingham, United Kingdom. And, so, thank you for joining us and welcome, Dr. Pryce.
- S2 01:27 Thank you very much for having me. It's great to be here.
- S1 01:30 You are currently doing a lot of work in the area of clinical decision-making for tinnitus, and you've been doing much research in different areas of hearing care and related disorders for many years. But, of course, that's our primary interest here is talking about tinnitus on this program, and so you have gone out and started looking at how we're making decisions as we're providing tinnitus care. Dean and I have talked a little bit about this in the past on both of our podcasts, because we think this is a very important area that's emerging as we're starting to find out more and more about the options that we have and trying to link those to different presentations of tinnitus. So, tell me at this point, what it is that you're specifically looking at and what you're finding, knowing that you're just starting to get some of this information out there.
- S2 02:28 Great. Well, we have been doing a series of different link studies, really, to investigate what preferences people who experience tinnitus have for their care. We've been also interested in looking to see how well those are articulated during clinical encounters. We've done a series of kind of ethnographic observations of different clinicians working with patients to see how they communicate when they're making decisions and to see how patient preferences around not just the outcomes for their treatments for tinnitus, but also the preferences for the treatments themselves are articulated and communicated. And then finally, those two strands have kind of led us towards a series of iterative kind of projects to develop a Tinnitus Decision Aid. So, to help us to condense, I guess, what we know in the evidence about what's likely to work and to be helpful for people with tinnitus, and to condense that into a series of kind of described approaches. But to describe it in a way that enables people to weigh up the pros and cons of those different approaches, and to consider what's likely to work best for them as individuals. So, in a way, it's a means of sharing information with people who have tinnitus about what's available and about what can help. So, it's, I guess, an attempt to overturn that kind of frequent complaint that nothing can be done, and to illustrate very clearly that there are things that can be done. But

depending on the individual and the kind of needs, and preferences, and lifestyle they're living, there are going to be some approaches that are going to be more effective than others for them. And it's to help clinicians to really start to reach out and bring the patient, the person, into the clinical encounter in a more active way. So, to help them to empower the patient to form part of the decision-making team.

S1 04:37

Yeah. And you talk about that in some of the writings that you've done, some of the articles you're working on at this point. And you talk about this concept of shared decision-making. And I'm not sure we as clinicians necessarily always stop to think about how we're making the decisions. We talk about it sometimes, but you've looked much more in depth into this. But there is a process to the decision-making and there are different ways to go about that. And what are you finding [that] is really effective as we go through that process with someone that has tinnitus?

S2 05:12

Well, I guess the work around shared decision-making has highlighted, I think, what Professor Glyn Elwyn at Dartmouth College refers to as the neglected second half of the clinical encounter. We know that clinicians on a whole are really good at going through the preliminary information gathering phases and investigating the symptoms that people present with, when they're presenting their health with hearing difficulties and with tinnitus. And we know that they're quite good at gathering information and piecing it together and coming up with some ideas about what might help. What they're less good at doing is then moving on to structuring the second half of the encounter, which is about, "Now, what do we do? Now, what happens? What's our plan of action from here?" And what tends to happen at the point is that, very often, clinicians wind up becoming quite prescriptive. So, they tend to favor treatments that they are comfortable with or that they have been trained in a particular way to do or feel more confident using; but, without really having the vital conversation about whether those treatments are the right thing to do for that individual at that point in time. And that's, I guess, really what we're going to try and encourage people to sort of stop and reflect on. And so part of this is about a kind of slight shift in the way in which we conduct some clinical encounters, so that we move away from a kind of, I guess, sort of a questioning approach towards using slight more open questions, to gathering more rounded information. Not only about symptoms and about problems and about kind of biological signs, but also about what are your preferences. What's going to work for you, what matters most to you at the moment.

S2 07:07

So, broadening it into a kind of, I guess, look at the whole person and their lifestyle, partly at the questioning point, but then also moving on to frame a conversation around, "Look, there is more than one thing we could do now. What's going to be the best thing for you?" And to help explore that through looking at information about the different approaches that are available and weighing those up with somebody. So that can mean having a bit of kind of a thought experiment about what would it be like for you if we were to do this? A talking therapist approach, for example. What would that mean in practice for you? What would it mean in practice for you if we were to go down there using sound to help? What would that involve? And it would help therefore to really engage individuals much more with the whole process of choosing an intervention that's going to help.

S1 08:07

Sure. Sure.

S3 08:08

Dr. Pryce, what has your feedback been, or are you to the point where you're getting a sense of how the practitioners or the clinicians are reacting to this approach? Because in some ways this is changing our behavior as well to serve the patient in a different way. And you're going to lay down a very nice road map that, for a person like me, is very comforting to have a kind of a general way of following a path to help

a patient. Have you noticed that there's been good acceptance, or have you guys been to that point yet with the information you're gathering?

S2 08:53

Well, from the feedback that we've had on the Tinnitus Decision Aid and that approach, so far the feedback has been quite positive from clinicians. So what people, I think, find useful is having a tool to use in the clinical encounter that summarizes a lot of the information they would like to communicate. So, having something that kind of moves the conversation on, because it's already there on paper. And we tend to suggest that people use decision aids, sending them out of the post in particular before somebody comes in for an appointment. So they've had a chance to discuss the different approaches, to consider them in the context of what their friends and family think is going to work and so on, before they come in to the clinical encounter. So that, I think, has had some very positive feedback. The Tinnitus Decision Aid itself was developed alongside a range of different clinicians. So, we have clinicians' use to testing it in clinic as part of its development process, and partly that was to look at logistics and practical issues to do with the wording, and how things were interpreted, and how they were used and so on. Was it readable? Was it intelligible [laughter] in that context [laughter]? And the feedback from that was quite positive, but we're at the stage now where we're hoping to roll it out. What we're trying to do is to support the [Tinnitus] Decision Aid itself with a series of short films that we produced, which sort of illustrate how it is that clinical encounters very often happen and where the opportunities are for extending those into greater involvement of the patient in the process, so greater shared decision-making being included in the process.

S2 10:45

But it is hard, because I think all these things are really difficult to take on when you're a clinician who's been working very often in quite challenging circumstances. And it's always a challenge to be asked to change your behavior, because that's a tough thing to do. That's a very learned process, and it's hard to suddenly change behavior. But what we do notice is that when people do adjust their approach and they bring the patient into the encounter more, that both they and the patient report much higher degrees of satisfaction with that. So, we're just trying to quantify that at the moment through a series of service evaluations around England, where we'll be using different services that are already used in the [Tinnitus] Decision Aid routinely. And we're trying to get a measure of a kind of broad before-and-after level of decisional satisfaction the patients have, as a result of the shifted emphasis within the encounter. So, there's a number of things we're trying to do to kind of adjust that, but I guess the process of moving clinicians towards a slightly different model is going to be an ongoing piece of work.

S1 11:57

Sure. You know, what I keep thinking of is we're talking about a more collaborative model, which is the current trend in healthcare to collaborate with your patients and not just direct them; and that's what we're talking about. But we're only half of the equation in that case, and I know this isn't specifically what you're looking at in this case. But if we shift over and talk to our patients, which is really the majority of our audience anyway, patients coming in – and we all know patients come in with all kinds of ideas ... It's a different world out there for patients coming in to see any healthcare provider, because we've got the internet and we've got all kinds of information, and they're seeing advertising. And it's good and it's bad because they can come in more informed, but they can also come in misinformed. I kind of have my thoughts, but I want to hear what yours are. In your mind, for the patients – so you're talking to a patient – who is not your patient, but just someone who is experiencing tinnitus – needs to go seek help, finally has that appointment maybe to go see someone and is going down that path to get help. What would you say to them, or what do you think the patient can do to prepare, or have a good mindset for what you're seeing is the type of an appointment or conversation, I guess, with a clinician?

- S2 13:32 Well, one of the things [crosstalk] we did was ...
- S1 13:34 And I know you weren't expecting that question, but I [laughter] can't help but think about it [laughter].
- S2 13:38 Okay. Yeah. I know. It's a really good question. I mean one of the things we did as a precursor to this work, as a way of developing the [Tinnitus] Decision Aid, was to have a series of indepth interviews with people who had sought help for tinnitus and were at different stages of the help-seeking process. And we asked them about that, we asked them about what information do you currently use, and what do you know at the moment, and what are you looking for from your clinician? What would you like to get from your encounter? And the thing that people kept telling us was that they wanted information, but they found it really difficult to know what information to trust and what not to trust. They were nervous about information they came across on the Internet, either because they found some of it to be very negative, or because they weren't sure about the validity of the source and how reliable it might be. But more interestingly as well, they wanted information that was bespoke. So they wanted the information that their clinician gave them not only to be a kind of general description about mechanisms and the way in which things work, but how things might work for them. So, it's really difficult to make that leap between understanding that cognitive behavioral therapy might work this way, and is cognitive behavioral therapy actually right for me? And in order to engage with that kind of treatment approach, you need to undergo that middle stage of a bit of a thought experiment to go, "Well, what would that involve? What would it take? What would they offer me? What do I do well at the moment that I can build on? What is going to be best [for] me to my particular circumstances?"
- S2 15:17 So, it's really this curated information that people were after from their clinicians. So, a kind of bespoke approach, a kind of curated approach. And that's why the clinicians are so vital in this, because that really is where they bring the expertise. They bring the knowledge of what works, and they also bring years and years of professional experience about how it might work and what it might look like in practice. And they can give the patient access to them, and that's really critical stage. So, from the point of view the people we had, they said very clearly that they did want a choice. They would want to be involved, and they would want to be involved in making a choice of treatment. They expected that really, which I think as you say part of the more general kind of approach to healthcare provision that we have now. But they wanted help in making that choice, and they wanted the clinician to provide them with bespoke and tailored information to help them make that choice.
- S1 16:24 And you're looking kind of the decision process. But I think, well, it seems like it would really help us as we're just almost on a monthly basis getting more information, more research coming out, about how we can tailor the plan for each patient based on how their tinnitus is presenting – the intake and the diagnostic process – and then using that information. In the past, to be very honest about it, there are many times where just a couple of options available to clinicians for how to address tinnitus. And we have more options than ever before, and so we're in this position of having to decide which option is right for this patient. And there was actually an article that came out very recently, talking about how the general approach right now is, "Well, let's try this," and it may kind of be the clinician's favorite, or one they've had a lot of success with or are comfortable with. And then if that doesn't work, try something else and kind of go on down the ladder and try different things. But I'm hoping - and I think your approach is helping - that we will get more to a point where we have enough information where we can say, "This is what I see for you. This is how your tinnitus-- how your hearing, your tinnitus, and what kind of hearing loss you have maybe and what the possible ideologies are, and what your psychological state is and such." And

then say, "This is what I think would work best for you," and be a little more targeted in that approach. And it seems like what you're finding will help with that process, as we get more information to do that. Does that make sense [laughter]?

S2 18:10

I hope so. I mean, I think the challenge is that ... is to move away perhaps from the idea that we are necessarily prescribing to, and rather negotiating with patients in terms of the treatment that we eventually go for. And I think it's about informing patients about what the pros and cons of those different options are and enabling them to be autonomous participants in the process. Because certainly adults are perfectly capable of making an informed decision about what is likely to work best, once they know what the way in which that might operate in the local setting. So I think that does help. I think the risk is – is a well-known phenomenon in this – were around something called the *silent misdiagnosis*, which is probably something we've had quite a lot of in audiology in general. Which is where we misdiagnose not the original condition and not the medical side, but we misdiagnose what somebody wants to do about that condition. And that is a very problematic experience, because we can damage somebody's quality of life by prescribing something to them that doesn't fit with their values and preferences. And then in turn, then damages that quality of life. It can be, arguably, every bit as harmful as if we had misdiagnosed the condition itself. So we're very keen to avoid that.

S2 19:43

The reason the silent misdiagnosis is referred to as silent is because we very often don't know that we've done it. So very often, the people who are misdiagnosed in the sense of having their preferences and values misdiagnosed, are the people who just don't turn up to appointments again or they opt out. So, they say, "Thanks very much," then they go off and they seek help from somebody else. As so quite often, we as the clinician may not be aware that there's been anything wrong there at all. But that's the real danger. So most of us would have some sort of experience, hand-on-heart in our time, when we can think of people where we either have some break down in communication with them, or where we think that something we have prescribed heavily or pushed heavily to them has not been acceptable to them and they have simply broken the communication after that. And that's a perfect example, I think, where silent misdiagnosis takes place. So I think we need to reflect hard on that experience, and to think about different ways in which we could communicate in those moments. Different, more open approaches to communication that don't necessarily prescribe in the same way.

S1 20:55

Sure.

S3 20:57

Yep. And I want to interject and reflect back to a prior podcast we had with Dr. David Baguley. And when he was presenting his information, he was saying, "Look, to have tinnitus and to have this as a chronic condition is very emotional." Auditory input is very emotional, and so it seems to me that what you're putting together here engages the patient in a way that is collaborative and empowering them. So maybe we can harness some of that emotion for positive, and kind of focus the clinician to have the conversations to figure out what the patient's preferences is for overall success. So, I'm very impressed with what I'm hearing from you [laughter].

S2 21:52

Oh, [inaudible], thank you very much. I think the thing is we may not be able to control whether or not we have tinnitus. But if we can control what we do about it and we can control it even in the moments where we're having an encounter with a clinician who knows a lot more about tinnitus than we do, then that's an important part of coping actually. And certainly, the people who – the patient participants who – we had involved in the different stages of the study, and then later on, particularly with the focus groups we ran, as part of the development process for the [Tinnitus] Decision Aid. Because it's not something we just dreamed up, it's kind of an iterative

process going back and forth, different patient groups and getting input from different individuals. And certainly the individuals who have been through the process and have used it, felt that it was a much more satisfactory experience than they had previously encountered. Because they were able to have a say, they were able to be actually engaged in the process, and that in itself is a form of stimulating coping. You get a degree of control back over circumstances around you.

S1 23:02

Well, and you just touched on what I was thinking about next. And that was it seems like this process we're talking about would also create a greater investment by the patient. And I think all of us clinicians get frustrated sometimes because [we think], "Oh, that darn patient didn't follow through on what we wanted them to do, because I know that'll help them." But then you have to step back and say, "Well, wait a second. I mean, is it just because they're not following through because they don't get it?" or whatever the case may be. Maybe it's because I – and I'm not afraid to turn this around and look at me internally and say – maybe I didn't make the right recommendation, or maybe in this since it's right to what we're talking about, maybe we didn't involve the patient enough. And, so, it certainly seems that if we follow this approach that you're talking about, then the patient – and I'm asking you actually – did you find patients more likely to follow through long term in this case?

S2 24:07

Okay. I have to declare we do not have at the moment data on long-term choices and satisfaction with those choices long-term. So, I cannot say hand-on-heart for sure that it makes a substantial difference there. But what I do know is that if I look across into other fields where they have incorporated shared decision-making and decisional support – so decision aids of this sort in other fields – then, on the whole, yes, that's exactly what you see is a greater satisfaction with the decision that's been made. And you see a greater uptake and the use of devices, whether a device is involved, and a good engagement in self-management, where that's involved, and so on. So, all of those sort of positive long-term health behaviors we would hope for. In other words, that somebody's undertaking to manage their own experience by utilizing some approach is more likely to be successful if we use shared decision-making. So, we have plenty of evidence from lots of other fields for that. But obviously the [Tinnitus] Decision Aid is brand new, so I can't say that we definitely have the information for tinnitus yet [laughter].

S1 25:20

No, I know you haven't gotten there yet. But yeah, I was just kind of curious if that's the trend that you were seeing. And you mentioned that that's what other research has born out in other areas, so we would think it would – we would hope it would – carry over here, because that's certainly a positive outcome. You also talked quite a bit in the information that's coming out here with the British Tinnitus Association about talking therapies, and that's not a term that I think we've seen a lot in publications. And so can we talk a little bit, so to speak, about talking therapies. Are you, in that case, looking just at established therapeutic processes with your psychologists, such as CBT things, such as that, or is it a bit broader than that?

S2 26:11

Yes. I mean, again, this is an approach I guess that we're sign-posting people to. And then within that approach there will be conversations to be had with local clinical providers about both what's available and what's likely to work. So, yes, I mean, at the moment as you'll be aware, one of the strongest of evidence-based interventions for tinnitus that we have is CBT, and mindfulness-based CBT is also proving very promising. And so it is likely that for some people that is going to be the right approach. Now, how that's delivered locally is going to vary. So, for some people that may rely on internet-based resources to deliver CBT. Because it's not as easy as all that to necessarily stumble into a psychologist who's available to deliver your [laughter] targeted CBT for tinnitus any time soon. But if you can, that's great. And then increasingly, we have therapists as well in the UK, for instance. In our context,

we have a community of hearing therapists ,who are audiological clinicians, who are concerned entirely with rehabilitative audiology, and come with an array of counseling skills in particular. And in some cases also have particular skills in cognitive behavioral therapy as well, are trained to use cognitive behavioral therapy approaches as well. So, there are a range of different options, I guess, within that approach. And it's going to rely on local providers to be able to sign-post people to the most appropriate and accessible option for them. But within talking therapies, and I guess the phrase was used because it is easier to access and easier to read for some people than words like cognitive behavioral therapy, which are quite technical and quite difficult to use. But it's as a broader approach about psychological adjustment that's very much obviously one of our most promising interventions.

S1 28:15

Sure. Sure. So, when will this information be out? I believe you're in the process of publishing this right now, is that correct?

S2 28:22

Yeah. So, we've got three papers that underpin the [Tinnitus] Decision Aid itself that are at different stages of the review process with different journals at the moment. The [Tinnitus] Decision Aid itself is published on the British Tinnitus Association website. And supporting it on the British Tinnitus Association website, there are also videos to illustrate how in practice conversations happen between clinicians and patients, and how those can be modified to incorporate the [Tinnitus] Decision Aid. So it's a way of kind of illustrating it in practice if you like as well. So that's available there, and I understand that the American Tinnitus Association are in the process of looking at the [Tinnitus] Decision Aid and looking at ways of adjusting it for the US context as well.

S1 29:11

Sure. And I did find some of those videos online, and I believe I looked at a couple of them at least. I'm not sure how many there are at this point, but they're fairly short. And so they're real easy to access and look at, you're not sitting down watching an hour length film [laughter] to do this. But they were interesting, I enjoyed watching them, and that's a nice way to present some of that material. To illustrate it, so that people can see that. Yeah, I think that was a really nice way to do that. And so you can find that ... the British Tinnitus Association website is not on the tip of my tongue, but it probably should be.

S2 29:52

It's www.tinnitus.org.uk.

S1 29:56

There we go [laughter]. There we go. So, we've been speaking with Dr. Helen Pryce at the School of Life and Health Sciences at Aston University in Birmingham, UK. And I just want to thank you so much for joining us, and we really look forward to all this information coming out because I know there's more on the way. And for you to just help us with this process, so that we can have better interactions and hopefully have better outcomes with our patients.

S2 30:22

Thank you so much for having me. [music]

S1 30:37

The American Tinnitus Association is a nonprofit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. Gifts and donations to ATA are used to support research for a cure and other critical missions described on our website at www.ata.org.