

Patient-Provider Partnerships Lead to Better Outcomes

Implementing Shared Decision Making in Tinnitus Care

By Helen Pryce, MSc, PD (Health)

Shared decision making is a core feature of evidence-based healthcare and its practice. The National Institutes of Health states that it is a process by which “healthcare professionals and patients make healthcare decisions together.” The basic tenet of shared decision making is that where there is more than one clinical option available to manage a health condition (including doing nothing), the patient has an active role in deciding which clinical option best fits his or her individual values and preferences. Victor Montori, MD, from the Mayo Clinic defines this process beautifully:

“Shared decision making is an empathic conversation by which patient and clinician think, talk, and feel through the situation and test evidence-based options against the patient’s situation ... Shared decision making is a human expression of care.”¹

What Currently Informs Care?

Within audiology, there are clinical guidelines for tinnitus and practice documents to inform practitioners.² These derive evidence from population averages to determine what on the whole works for whom on the whole. What’s lacking in the guidelines and guidance is how to engage

with patients in conversations about their care, as well as how to understand their preferences for both the outcome of treatment and for the type of treatment itself.

Recent criticisms of evidence-based healthcare are that strict adherence to guidelines has resulted in a “tyranny” of evidence, e.g. doing whatever the trial said worked best, regardless of the preferences and values of the individual patient.^{3,4}

The problem with this is that the best intentions to use the right treatment (in other words, what works well for most people most of the time) can lead clinicians to prescribe, rather than negotiate, treatments. If this is not negotiated with the individual who will have to live and work with the prescribed treatment, there is a risk of “silent misdiagnosis.” This phrase describes how one can unwittingly cause significant harm to quality of life by misdiagnosing – not the original condition, but what someone wants to *do* about the condition.⁵ The individual who is affected is the one required to do the work of treatment, to use a device regularly, or engage in a talking therapy of some sort.⁶

Rarely do patients with silent misdiagnoses bother their clinicians. Rather, they become dissatisfied, possibly seek help elsewhere, and remain “silent,” leaving clinicians unaware that they have failed in any way.

Hand on heart, most clinicians can reflect on scenarios where this may have been the case. The patient who didn’t return for follow up. The patient who constantly complained. The patient who went home and never used the hearing aid again.

What is needed is a way of integrating best evidence, clinical expertise, and patient values and preferences. In other words, a return to real evidence-based healthcare.^{7,8}

What’s missing is guidance for people with tinnitus so that they can inform the discussion by adding what will help this individual patient in these individual circumstances.

Happily, there is an alternative.

Our team has been working on projects to determine what currently happens in tinnitus care in the United Kingdom and how to ensure that patient preferences are recognized in decision making. The British Tinnitus Association (BTA) funded research projects, including the development of the tinnitus care decision aid, that enable both patients and clinicians to work from consistent information. Put simply, it can help a clinician practice shared decision making by ensuring that both parties to the encounter are well informed.

How can we build shared decision making into tinnitus care?

There are some well-documented stages in the clinical encounter:

Build a relationship.

This is the bedrock of all change. We need to trust, believe, and value our clinicians. They earn trust, belief, and value by being explicitly interested in us. That means fully attend-

ing. In other words, not looking at computer screens, paperwork, or anything else when a patient is with you. Full and undivided attention is a great starting point. Open questions are what you need.

Great listeners are amongst the most efficient case history takers in the world. Just try talking on one subject

to an interested person uninterrupted for two minutes, and you'll see for yourself. You cover vast amounts of information. By all means, check facts afterwards; but, be present and fully attend to what people are telling you.

It's a challenge for a clinician to manage his or her own feelings during these moments. People who become audiologists generally want to help and dealing with a chronic problem can leave them feeling powerless. But listening is the most important thing to do, even if it makes you uncomfortable. Even if you can't fix it. Even if you don't like it. You will do more good than you realise. People seek help more often to be heard and validated than to be fixed.

It also is easier to pick up what the preferences and values of this individual are, when you actively listen. There often are indirect allusions in what is described that tell us about preferences. We can also use open questions to explore this, e.g., *"What matters to you most about this?"*

In this relationship, it is straightforward to negotiate that you will make a decision together. It's worth pointing this out *"so there are different approaches we can take to this, and together we need to find what's best for you."*

Present choices.

There always are choices in tinnitus. There always are choices in hearing loss. Your preferences as a clinician are important to acknowledge, but it is more important to hear what your patient prefers. The patient will be living with the consequences of the decision made, not you.

This is where the decision aids really help. They are available to

Tinnitus Decision Aid

Evidence Document Summary

Talking therapies

Martinez-Devesa P, Perera R, Theodoulou M & Waddell A. *Cognitive behavioural therapy for tinnitus*. The Cochrane Database of Systematic Reviews, 2010: Issue 9.

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Westin V, Hayes SC & Andersson, G. Is it the sound or your relationship to it? The role of acceptance in predicting tinnitus impact. *Behaviour Research and Therapy*, 2008a: 46(12), 1259-1265.

Philippot P, Nef F, Clauw L, Romrée M & Segal Z. A randomized controlled trial of mindfulness-based cognitive therapy for treating tinnitus. *Clinical Psychology & Psychotherapy*, 2012: 19(5), 411-419.

McKenna L, Marks EM, Hallsworth C & Schaette R. Mindfulness-Based Cognitive Therapy as a treatment for chronic tinnitus: a randomised controlled trial. Submitted to *Psychotherapy and Psychosomatics*, 2017.

Ostermann T, Boehm K & Kusatz M. Evaluation of 5536 patients treated in an integrative outpatient tinnitus treatment center—immediate effects and a modeling approach for sustainability. *BMC Health Services Research*, 2016: 16(1), 377.

Sound

Hoare DJ, Edmondson-Jones M, Sereda M, Akeroyd MA & Hall D. *Amplification with hearing aids for patients with tinnitus and co-existing hearing loss*. The Cochrane Database of Systematic Reviews, 2014: Issue 1.

Hobson J, Chisholm E, & El Refaie A. *Sound therapy (masking) in the management of tinnitus in adults*. The Cochrane Database of Systematic Reviews, 2012: Issue 11.

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Group support

Thompson P, Pryce H & Refaie E. Group or individual tinnitus therapy: What matters to participants? *Audiological Medicine*, 2011: 9(3), 110-116.

Foster G, Taylor SJ, Eldridge SE, Ramsay J & Griffiths CJ. (2007). Self-management education programmes by lay leaders for people with chronic conditions. The Cochrane Database of Systematic Reviews, 2007: Issue 4

Webel AR, Okonsky J, Trompeta J & Holzemer, WL. A Systematic Review of the Effectiveness of Peer-Based Interventions on Health-Related Behaviors in Adults. *American Journal of Public Health*, 2010: 100(2), 247-253. <http://doi.org/10.2105/AJPH.2008.149419>

Henry JA, Loois C, Montero M & Kaelin C. Randomized clinical trial: group counseling based on tinnitus retraining therapy. *Journal of Rehabilitation Research and Development*, 2007: 44(1), 21.

Jakes SC, Hallam RS, McKenna L & Hinchcliffe R. Group cognitive therapy for medical patients: an application to tinnitus. *Cognitive Therapy and Research*, 1992: 16(1), 67-82.

British Tinnitus Association. Find a Tinnitus support group [online]. Available from <https://www.tinnitus.org.uk/find-a-support-group> (last accessed 11/07/2017)

Information

Vollmann M, Kalkouskaya N, Langguth B & Scharloo M. When the ringing in the ears gets unbearable: Illness representations, self-instructions and adjustment to tinnitus. *Journal of Psychosomatic Research*, 2012: 73(2), 108-111.

Greenwell K, Sereda M, Coulson N, El Refaie A, & Hoare DJ. A systematic review of techniques and effects of self-help interventions for tinnitus: Application of taxonomies from health psychology. *International Journal of Audiology*, 2016: 55(sup3), S79-S89.

Sereda M, & Hoare DJ. Self-Help Interventions for Tinnitus. In Baguley DM & Fagelson M. (eds) *Tinnitus: Clinical and Research Perspectives*, Plural Publishing, 2015: 227.

National Institute for Health and Care Excellence. *Clinical Knowledge Summaries: Tinnitus. Scenario: Management*. [online] Available from <https://cks.nice.org.uk/tinnitus#!scenario> (last accessed 11/07/2017)

TINNITUS CARE OPTIONS

Use this decision aid to help you and your healthcare professional(s) talk about evidence based tinnitus care options. If you have a hearing loss as well, see the Hearing loss: hearing technology options Option Grid www.optiongrid.com

Frequently asked questions	Options for tinnitus care			
	Understanding tinnitus	Talking therapies	Using sound	Group support
Will this option mean I hear my tinnitus less or cure it?	Understanding tinnitus may not make it go away, but getting a better grasp of tinnitus can mean that you notice it less.	Following talking therapy, some people don't hear tinnitus as much. Whilst some people may find that they hear it just as much, others often describe their tinnitus as becoming less bothersome.	Some people find playing sound through various devices helps them hear the tinnitus less. Sound is unlikely to make your tinnitus go away completely. If you have hearing loss and tinnitus some people find hearing aids can help reduce awareness - see the Hearing loss: hearing technology options Option Grid.	This probably won't mean that you hear your tinnitus less, but sharing experiences can be supportive, especially in helping you to understand tinnitus and feel less alone. This may mean that you notice tinnitus less.
What does this do to tinnitus?	Tinnitus is often made worse by worrying about what it is and what it means. Understanding tinnitus and what influences it can help you manage tinnitus better.	Tinnitus is often made worse by higher levels of stress, and talking therapies can help by reducing stress. Talking therapies also focus on changing how you respond to tinnitus. You learn to change how you think and act and how much attention you give to it.	Tinnitus is influenced by other sounds around you. By listening to external sounds, you're likely to hear your tinnitus less. It can be helpful to focus your attention onto another sound.	Groups can help people find support from others. People swap ideas about what helps them with their tinnitus.
How does this approach help tinnitus?	Making sense of the causes of tinnitus and what keeps people noticing it, can help people cope with tinnitus. Most people find discussing tinnitus information with an Audiologist or Hearing Therapist is helpful.	Talking therapies have been shown to reduce distress caused by tinnitus. People who have talking therapy for tinnitus can find that they notice it less.	Some people find it helpful to put a radio on in the background when they come into a quiet setting. Others may use relaxing sounds to help get to sleep at night. Various devices and apps are available for this.	Many people find it helpful to meet others who are in the same position. Groups provide information and support. Groups are unlikely to make tinnitus go away but understanding that you are not alone might help.
How do I access this option?	You can get tailored advice from your Audiologist. Your GP can refer you. The British Tinnitus Association produce clear information on all aspects of tinnitus.	There are different types of talking therapies. You can access this type of help from a psychologist, therapist or even online. Talk to your GP about referral.	An Audiologist or Hearing Therapist can advise on this. Your GP can arrange a referral.	The British Tinnitus Association has information on tinnitus groups in the UK. Alternatively your local audiology service may be able to guide you to a group.
Can I choose more than one option?	Yes	Yes	Yes	Yes

(T) British Tinnitus Association

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download freely and can be given to patients before they meet with you so that they can consider them with their family and friends.

The decision aids we developed meet the international consensus for decision-aid standards, meaning both the options and the frequently asked questions are derived from evidence. They are structured not just to present some options, but to weigh the pros and cons for them.

There are important differences between those who would like group support, those who would like a device, and those who would like counseling or talk therapies. The decision aid helps people decide on the approach that suits them best.

Our research found a really important role for the clinician here. Patients described really wanting curated information, tailored for them. They wanted someone off whom they could bounce their thoughts about management. This is where clinicians can shine! It's a misconception of shared decision making that simply giving a list of treatment possibilities will suffice. Rather, we need to explore the pros and cons.

Make the decision in partnership.

The decision making is then the integration of the preferences and values the patient holds, coupled with the expertise of the clinician. In practice, this can mean having a conversation in which a thought experiment tries out the various options. What would it involve in practice to seek talk therapy in your area? How does someone access a group? What's the commitment in time, traveling, cost, etc.?

These finer points are discussed in this phase of the decision. These points may make all the difference between an evidence-based option in theory and one that actually is feasible for the individual to access or engage.

Also, it's worth remembering that this is not fixed. Circumstances change over time, and preferences may change too. Letting people know that, as a clinician, you'll be there to have another discussion when things change is important too.

Sharing control of decisions in the treatment of tinnitus is about providing care. It's the ultimate expression that something can be done and that the individual patient has the authority and ability to have a say. As Atul Gawande – doctor, *New Yorker* writer, and public health researcher – puts it:

“You may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them.” 

Resources & Tools

Tinnitus Care Options & Tinnitus Decision Aid are available for download on the British Tinnitus Association's website at www.tinnitus.org.uk/decision-aid.

The decision aid was developed in accordance with the consensus on International Patient Decision Aid Standards (IPDAS), which means it went through iterative development with input from many patients, experts in the field, clinicians, and researchers.⁹ The aids also have been through user-testing procedures and readability testing.^{10, 11}



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