

Family-centered Care: Working with Partners Reporting "Incongruent" Hearing Aid Outcome

What to do when the patient's and family member's perceptions of the hearing loss differ

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Discussing the opinions of a person with hearing loss whose perceptions about their hearing differs significantly from their family's perceptions can be awkward. However, these situations can be used to positively share experiences and change perspectives when addressed in a supportive environment. Here's how.

You were feeling good—you have incorporated family centered care into your practice by following the first three steps in the Phonak Position Statement: Family-centered Adult Audiologic Care.¹ That is, you have:

- Routinely been inviting a family member along to your patients' audiologic appointments, and explaining to your patients why this is advantageous;
- Rearranged your office so that family members and the patient can now be equally included in the consultation, and
- Begun each appointment by letting the patient and their family member know that input will be sought from *both* of them—the patient first and then the family member.

You are also a believer in evidence-based practice, and so you've begun using a hearing aid outcome measure that can be completed by both the patient and their family member. You routinely use the International Outcome Inventory for hearing aids (IOI-HA) and the significant other companion version (IOI-HA SO),² but know that there are other options you could choose, such as the Hearing Handicap Inventory (HHI)^{3,4} paired with the HHI for significant others (HHI-SO),⁵ the Self-Assessment of Communication (SAC) paired with the Significant Other Assessment of Communication (SOAC),⁶ the Quantified Denver Scale (QDS) paired with the Quantified Denver Scale-Modified (QDS-m) for significant others,⁶ or the Communication Profile for the Hearing Impaired (CPHI)⁷ paired with the CHPH proxy.⁸ These pairs of questionnaires assess the hearing-impaired person's perception of their own difficulties or outcome (self-report), and the spouse's/family member's perception of the difficulties or outcome of their spouse/family member with hearing impairment (proxy report).

Authors' Note: Although the pairs of questionnaires in this article are not specifically designed to assess third-party disability (ie, the impact of the hearing loss on the spouse/family member's day-to-day functioning), some of the proxy versions do include a small number of items which do. The impact of the hearing loss on family members is without doubt a critical consideration in family-centered care because of the importance of acknowledging both the person with the hearing loss and their family as recipients of care, and thus the entire family may be considered when measuring outcomes.⁹ However, a discussion of third-party disability is not the focal point of this article, but for the interested reader here are some references in which third-party disability is discussed in depth: Kamil & Lin¹⁰; Scarinci et al¹¹; Scarinci et al¹²; Preminger et al¹³; Stephens et al.¹⁴ Similarly, here are some questionnaires that can be used to assess third-party disability: Hearing Impairment Impact-Significant Other Profile (HII-SOP)¹⁵; Significant Other Scale for Hearing Disability (SOS-HEAR).¹⁶

However, at your last appointment you encountered something uncomfortable, and were unsure how to address it: the patient's responses on the IOI-HA were very different to those given on the IOI-HA-SO by the accompanying family member. You concluded that, evidently, these two people disagreed about the outcomes of the hearing aids. How awkward.

So, what should your approach be? What might be the best way to handle these "incongruent" responses?

First and foremost, just because a patient and a family member have different opinions, it does *not* indicate a problem and it shouldn't make you uncomfortable. Think of it as providing the perfect opportunity for discussion;



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it is a chance to increase a shared understanding of communication and can hopefully prevent conflict and frustration down the line.

Let's get a little more specific here and consider a couple of hypothetical scenarios:

Scenario 1. Jane & Peter

Jane is a 56-year-old executive at a large company. She recently obtained hearing aids for her moderate hearing loss. Her husband, Peter, also age 56, has normal hearing and joined her at her hearing aid follow-up appointment. They completed the IOI-HA/IOI-HA-SO. Their scores are shown in Figure 1.

With the exception of Q1, Jane's scores are higher than Peter's, suggesting that she has a higher opinion of the hearing aids than does Peter. In this situation, the dispensing professional might ask Jane and Peter why they gave the responses they did and then discuss the replies. Here are some hypothetical answers given by Jane and Peter.

Explanation of scoring from Jane: "I've been using the hearing aids pretty much all the time both at work and at home, so I gave Q1 a rating of 5 (>8hr/day). I feel as though a weight has been lifted from my shoulders, my quality of life is so much better, so I gave Q7 a rating of 5 (very much better) too. I would say I am much more outgoing at work these days—I am enjoying that I can take part in meetings without worrying I will say something silly. When I get home, I am not nearly as tired as I used to be, and aside from when Peter tries to talk to me while I am watching TV, I can hear him very well, so I answered 5 to Q2 (helped very much) and 4 (slight difficulty) to Q3 because, although the hearing aids really help me, I still don't hear perfectly. I am also more relaxed now. I think Peter must see the change in me, so I gave Q6 a score of 4 (Bothered slightly). In fact, I have so much energy these days that I suggested we have some friends over to dinner next weekend. That is something I have really missed but I haven't done because it would have been too stressful, so I answered 5 (affected not at all) to Q5. All in all, I am thrilled to have these hearing aids so Q4 gets a 5 (very much worth it) too."

Explanation of scoring from Peter: "Well, the hearing aids certainly help Jane, and she wears them all the time—at least when I am around, so I gave a 5 (>8hr/day) to Q1. I answered a 3 (helped moderately) for Q2 because things are definitely better, but they are far from perfect. For example, as Jane said

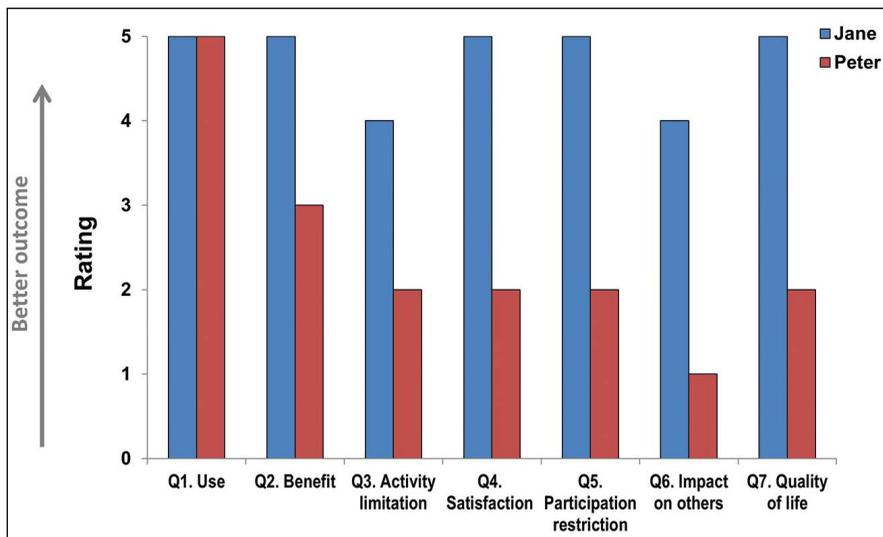


Figure 1. IOI-HA and IOI-HA-SO data for Jane (blue bars) and Peter (red bars).

just now, she still doesn't hear me when she is watching TV—and forget it if I try to talk to her from the kitchen while I am cooking. It's true that she hears me when we are sitting at the dinner table, and she hears her cell phone ring more often these days. This is why I answered 2 on Q3 (quite a lot of difficulty), Q4 (slightly worth it), and 5 (affected quite a lot). I also answered 1 on Q6 (bothered very much) and 2 on Q7 (no change) since for me, this is all really quite disappointing and frustrating."

These discrepancies in perceptions demonstrate the usefulness of proxy reports. Much like an "empathy belly" (Figure 2) promotes empathy for the pregnancy experience, completing a questionnaire can alert a partner about the day-to-day experience of living with hearing loss. Peter's answer to Q7 indicates that, despite Jane experiencing improvements in her quality of life as a result of the hearing aids, the hearing aids have not improved Peter's enjoyment of life; his answer to Q6 also indicates that he is still bothered quite a lot by Jane's hearing difficulties.

This would be a good time to explore further with Peter what ongoing difficulties he is continuing to experience as a result of Jane's hearing loss (ie, further explore his third-party disability). By asking Peter to share this, Jane will be able to consider the ongoing impact of her hearing difficulties on Peter's everyday life, and you, as the clinician, could facilitate a discussion on strategies the couple might implement together to reduce his third-party disability.

The incongruence on the IOI-HA on Q2

and Q3 also indicates that Peter may not be aware of the "invisible" benefits Jane is experiencing from the hearing aids (feeling more energetic, less tired, and less stressed). This would be a good time to encourage Jane to share this with Peter so he can better understand that her perspective goes beyond simply hearing better.

A tool to further this discussion is the Hearing Handicap Inventory (HHI),^{3,4} a measure of the social and emotional consequences of hearing loss, and the proxy version, the HHI-SP.⁵ Whereas the HHI asks the person with hearing loss "Does your hearing problem cause you to feel embarrassed when meeting new people?" the HHI-SP asks "Does your hearing problem cause your significant other to feel embarrassed when meeting new people?" In a number of studies, the HHI and the HHI-SP have been administered to



Figure 2. Screen capture from Amazon.com of an Empathy Belly Pregnancy Simulator (from Birthways) which is designed to help partners understand the experience of pregnancy.

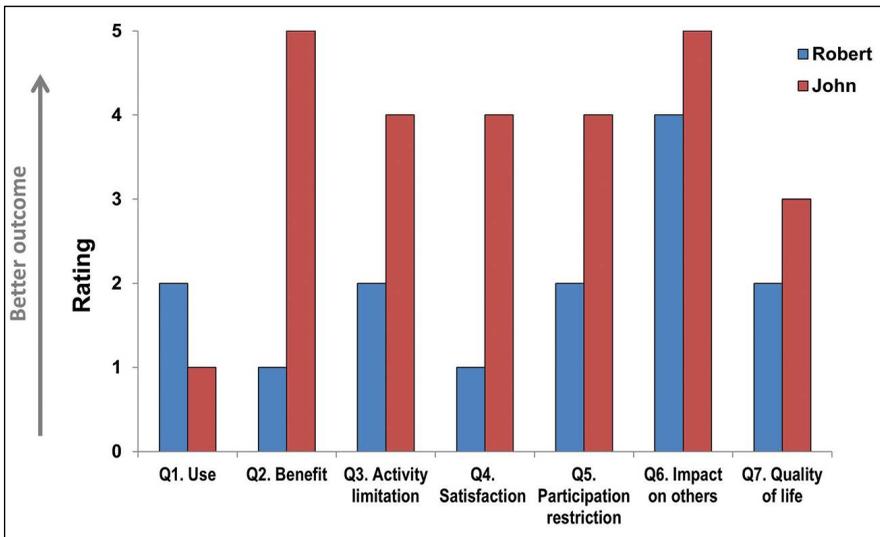


Figure 3. IOI-HA and IOI-HA-SO data for Robert (blue bars) and John (red bars).

spouse couples in which one member has a hearing loss. In an evaluation of 52 couples in which one member was a hearing aid or cochlear implant user and the other member had normal or near-normal hearing, three different patterns emerged:

- 1) There are couples in which the partner without hearing loss underestimates the hearing disability faced by the spouse with hearing loss (50% of couples);
- 2) There are couples in which the partner without hearing loss overestimates the hearing disability (12%), and
- 3) There are couples in congruence who report similar amounts of hearing disability.¹⁷

In other words, in most couples in which one member is a hearing aid user and there is incongruence, the spouse often does not recognize that participation restrictions and activity limitations remain after one partner begins wearing a hearing aid. This demonstrates the usefulness of inquiring about the experience of each member of the couple, as in this case the perceptions that Jane and Peter share are in the minority.

Getting back to Jane and Peter, in the post-IOI-HA-SO discussion, it is apparent that Peter is underestimating Jane’s hearing aid benefit. Once this is pointed out to Peter, it is likely that his perspective regarding the benefits of the hearing aid to Jane will change. Peter also brings up his frustration and disappointment with the hearing aids. This is not a proxy report. Rather, Peter is reporting his

own third-party disability; in other words, the impact Jane’s hearing loss has on him.¹¹

Furthermore, the discussion with Jane and Peter suggests they are not using effective communication skills much of the time—such as when trying to communicate from different rooms in the house and while one or both of them are distracted by the TV. This is an ideal opportunity for you, the hearing care professional, to discuss the impacts that hearing loss has on all family members, not just the person with hearing loss. It is also a time to provide communication strategies advice and training.

Often, starting this discussion on what is working well (ie, pointing out that their communication at the dinner table is successful as the listening situation is good) can be a good place to start, as it helps to keep the discussion positive, and then offers the opportunity to further explore situations where there are communication difficulties.

Finally, Peter notes that “I assume she too must know that she still can’t hear perfectly” suggests that he thinks perfect hearing is a possibility. In other words, his expectations about the hearing aids may be higher than is realistic. Here is an opportunity to discuss the matter.

Scenario 2. Robert & John

Robert is 68. He has had his hearing aids for just over 3 weeks. His son John has accompanied him to his hearing aid follow-up visit. Their IOI-HA and IOI-HA-SO scores are in Figure 3 below.

Robert’s scores are in blue, John’s are in

red. On all items, Robert’s scores are lower than John’s, suggesting he rates his hearing-aid outcome less positively than John. Here are their “stories”:

Explanation of scoring from Robert: “I am not enjoying these hearing aids; I find they don’t work very well, and so I only wear them when I have to, like when I am with John or his brother, and when I am out playing backgammon with my mates. Other than that, I don’t use them because they don’t help much, and really I can’t take the continuous noise I hear when I am wearing them. This is why I answered 1 or 2 for nearly all the questions—except for Q6. I answered 4 for that because my hearing isn’t very bad anyway.”

Explanation of scoring from John: “I know Dad doesn’t like the hearing aids and he says they don’t work, but I don’t agree. When he does wear them he hears a lot better—he hears my questions and what my kids, his grandchildren, share with him. This is why I answered 4 or 5 to most of the questions. Of course, I only gave a 2 (<1hr/day) to Q1, as from what he says, he doesn’t wear them much. I don’t know why he thinks they don’t help. I’d love to figure out a way to show him that they do.”

The incongruence in this pair of descriptions is that Robert is struggling with the hearing aids, but his son John is noticing benefit that evidently Robert is not. This seems to be a case in which Robert’s hearing aid use has successfully reduced John’s third-party disability, but has not reduced Robert’s own hearing disability.

A discussion of these findings is important for both father and son to understand the benefits and drawbacks of hearing aid use. The clinician can help John explain to his father how the hearing loss impacts him and his children, and how they all enjoy spending time with him—especially when the hearing aids make communication easier.

The clinician can also help Robert tell John how background noise remains a problem, even after a successful hearing aid fitting. This is an opportune time, once again, to discuss realistic expectations and effective communication strategies. John can plan events with his father and his children where they are in ideal communication situations, so that they all can benefit from the hearing aid use.

Additionally, the hearing care professional can talk with both Robert and his son about hearing aid adjustment, and suggest that they work together to plan a schedule in which

Robert gradually increases his hearing-aid use time. It is important for both of them to understand that hearing aid success is often a process that happens over time.

It is important for hearing care professionals and their patients to understand that hearing loss can cause disability in the person with hearing loss and third-party disability in their family members. Similarly, successful hearing aid use can reduce this disability in all family members. Hearing aid success most often occurs when all members of the family understand the benefits and limitations of hearing aid use, and the simple steps that can be taken to promote good communication.

As we have hopefully illustrated above, discussing incongruent opinions of a person with hearing loss and his/her family can be used to positively share experiences and change perspectives when addressed in a supportive environment. ▀

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