

Family-Centered Adult Audiologic Care: A Phonak Position Statement

Recommendations for moving toward a family-centered model in hearing healthcare

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The authors propose an audiologic treatment shift from a site-of-lesion focus to a family-centered care perspective as a means of increasing the value of our services and the uptake of hearing devices.

Editor's note: As reported in The Hearing Review online news (November 6, 2015), Phonak has convened a select group of hearing healthcare experts to provide evidence-based recommendations to hearing care providers on how to better engage family members. Chaired by Dr Louise Hickson, the objective of this group is to facilitate family involvement throughout the hearing remediation process. This is the first paper from their work.

It stands to reason that hearing loss affects not only people who are hard-of-hearing but their significant others as well. Indeed, there has been longstanding recognition within the audiology community of the negative psychosocial consequences of hearing loss on family members and the third-party disability

experienced by significant others.¹⁻⁴ (For a review, see the 2015 article by Kamil and Lin.⁵)

Remarkably, the field has only recently recognized the many benefits associated with engaging family members in the audiologic rehabilitation process. This paper will consider both an historical and modern framework of audiologic rehabilitation, then follow with a brief review of relevant research on family engagement and social support. We conclude by proposing that, in order to provide optimal service for our patients, audiologic care must integrate new research that emphasizes both patient and family involvement during treatment, the relationship between the patient and family and the healthcare professional, and the context in which rehabilitation is provided.



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Audiology Past & Present

Audiologic care for adults with hearing loss is largely provided along a continuum book-ended by two perspectives: a “site-of-lesion” perspective and, more recently, a “family-centered” perspective. The site-of-lesion perspective, described in greater detail by Pichora-Fuller and Singh,⁶ considers the auditory system as consisting of functionally discrete anatomical units that are connected in a largely bottom-up serial fashion. When audiologic care is provided from a site-of-lesion perspective, the role of the audiologist is to determine the location or type of “lesion” (eg, conductive, sensorineural, retro-cochlear, etc), to quantify the magnitude of a hearing loss (eg, mild, severe, etc), and to develop an appropriate set of treatment recommendations (ie, continued monitoring, referral to other medical professionals, use of hearing assistive technology, etc).

The site-of-lesion perspective has greatly advanced the field by equipping audiologists with the ability to perform diagnostic tests, the results of which are linked to specific treatment recommendations. However, clinicians and researchers have come to recognize several limitations of this framework. Chief among them are the failures of the site-of-lesion perspective to consider a person holistically and to underemphasize the cognitive, emotional, motivational, and social factors that contribute to treatment success. Furthermore, a site-of-lesion perspective overemphasizes the role of technology in audiologic rehabilitation⁷ rather than considering it as a component of the care necessary for treatment.

The second perspective, family-centered care, describes the implementation of healthcare that considers the individual using healthcare services and his/her family members as partners in the planning, execution, and monitoring of treatment. Family-centered care is an extension of patient-centered care that places greater emphasis on the role of family. A discussion of the distinctions between family- and patient-centered care is beyond the scope of this article; however, both frameworks underscore similar core concepts discussed below. Because hearing loss affects both the person with hearing loss and significant others, we suggest the term “family-centered care” is better suited for audiology and will use this term throughout the paper.



What Does Family-Centered Care Mean?

From a family-centered care perspective, patients and family members are both considered experts who work along with the clinician whenever decisions are to be made. This is a particularly key concept because no one understands their needs better than they do. Although there is no globally accepted definition of family-centered care, we favor the following description from the Institute of Medicine:

Family-centered care provides care to patients and family members that is respectful of and responsive to individual patient and family preferences, needs, and values, and ensures that patient and family values guide all clinical decisions.⁸

Importantly, in family-centered care, the needs of both patients and family members are recognized, with both the patient and family considered central in any clinical exchange.⁹ “Family” includes two or more people who are related in any way, be it through a continuing biological, legal, or emotional relationship. Thus, family is a broad and encompassing concept that includes any individual who plays a significant role in a patient’s

life.^{10,11} Patients themselves define the components of their “family” and it can range from including just themselves to including partners, friends, and children in their treatment.

Recent research looking at the preferences of those attending audiology appointments all point to the same conclusion—that both patients¹²⁻¹⁴ and family members^{15,16} report a clear preference for greater involvement of patients and family members during the audiologic care process. Note that this does not imply that all information and decision-making is shared with the patient. A basic tenet of patient-centered care is that together, the provider and patient must come to an agreement about the role of the patient (and family) in selecting treatment options.¹⁷

One common misconception about family-centered care is that its broader adoption would be problematic because of the concern that it may be inappropriate for some individuals. For example, there are those patients who prefer to provide minimal input regarding their care and treatment, while others may prefer not to involve family members.¹⁸ Critically, when care is provided from a family-centered care perspective, an attuned clinician will

10 Recommendations to Implement Family-Centered Care

- 1) **Invite a family member along to audiologic appointments.** When making appointments say: "Our experience is that it is very helpful if you can bring a friend or a loved one along to the appointment. Who would that be?" If patient asks for more information, you could say "There is a lot to discuss and it helps to include family and friends in the process." This information should be reinforced in any written information provided to patients regarding appointments.
- 2) **Set up the physical environment so that family are comfortably included in the consultation** rather than being relegated to a seat at the back of the room. An inclusive physical environment fosters a sense that everyone can equally provide their thoughts and perspectives.
- 3) **Start the appointment by letting the patient and the family member know that input will be sought from both of them**—patient first and then the family member. The clinician could say "We are going to do a lot today. For the next 10 minutes, I want to find out about your hearing and communication (directed to the patient) and then I want to find out about this from your perspective [directed to the significant other]." The goal is to listen so as to attain an integrated understanding of the patient's and family's physical, social, and emotional needs.
- 4) **Set joint hearing and communication goals with patient and family.** Discuss what they would both like to achieve (eg, TV at a lower volume, easier conversation) and prioritize together. The Client Oriented Scale of Improvement (COSI)⁴⁸ could be used or the Goal-Sharing Partnership Strategy (GPS).⁴⁹
- 5) **Present options for rehabilitation that address the needs and goals of both the patient and the family.** For example, whereas a hearing aid alone can address the problem of communicating with one's spouse at the dinner table, a hearing aid and a remote mic can be used when trying to communicate across greater distances.
- 6) **When developing the treatment plan, aim for shared decision-making,** with patient, family, and clinician as equal partners in the process. Use decision aids to guide discussions about options for hearing rehabilitation (see Laplante-Lévesque, Hickson, and Worrall⁵⁰). Decision aids provide a simple summary of all options and the advantages and disadvantages of each. Confirm there is a mutual understanding of all communication goals.
- 7) **Remember that the patient and the family are the experts.** They live with the hearing loss every day. For example, the patient and family could be asked "What do you want to do about your hearing loss?"
- 8) **Actively encourage involvement of the family at all stages of the care process** (eg, history taking, rehabilitation planning, hearing aid fitting, follow up, and annual reviews).
- 9) **Measure outcomes of interventions for both the patient and the family.** You could revisit the goals identified at the start by both patient and family and find out how much the treatment has affected those goals. There are many outcome measures for patients and a smaller number for family that could also be helpful: the Significant Other Scale—Hearing (SOS-HEAR)⁵¹ and the Hearing Impairment Impact—Significant Other Profile (HII-SOP).⁵²
- 10) **Make the entire clinic family-centered with buy-in from all stakeholders** (executives, managers, clinicians, and front office staff). Put family-centered care on the agenda of regular staff meetings.

be responsive to individual needs and will always provide treatment that respects the wishes of the patient.

Benefits for the Patient from Family-Centered Care

Family-centered care has become internationally recognized as a dimension of high-quality health provision. While most research has been conducted outside of audiology, the broad consensus is that family-centered care results in superior health outcomes, particularly along dimensions such as patient well-being (less symptomology), adherence to treatment recommendations, and satisfaction with medical services¹⁹ (see Rathert et al²⁰ for a review).

Similarly, research conducted in audiology has demonstrated that outcomes are improved when family is engaged. For example, the family of patients with hearing loss can encourage help-seeking and advocate for the adoption of hearing instruments,^{13,21,22} provide instruction on the proper use and care of devices,²³ increase a person's confidence that they can manage their hearing loss,²⁴ decrease hearing handicap when accompanying patients to audiologic rehabilitation classes,²⁵ and reinforce the importance of adhering to treatment recommendations.^{26,27} Correlational evidence also suggests that the involvement of family best differentiates successful users of hearing aids from unsuccessful users of hearing aids²⁸ and is the best predictor of hearing aid satisfaction.²⁹ In a recent study, audiologists also identified a number of benefits to involving family members in audiological care, including: increased family member input and support into rehabilitation decision-making, improved provision of information to both patients and family members, and importantly, the provision of emotional support for the patient.¹⁶

Benefits for the Family from Family-Centered Care

The literature suggests that there are both direct and indirect benefits for family and communication partners attending and participating in audiology appointments. Direct benefits include greater awareness of the effect of hearing impairment for

the patient³⁰ and less reported third-party disability³¹ following audiologic rehabilitation. Because involvement of family and social networks increases treatment uptake and improves the outcomes of audiologic care, the downstream indirect benefits for family members include improved relationship quality and quality of life.³²

Benefits for the Clinician from Family-Centered Care

Research conducted both in audiology and other areas of healthcare suggests several positive outcomes when care is provided using concepts consistent with family-centered care. Preminger et al³³ suggest that shared decision-making fosters trust and improves the patient-provider working relationship. The importance of trust is underscored by research suggesting that when trust is present between a patient and practitioner, recommendations are followed 90% of the time but only 50% of the time when trust levels are described as “low.”³⁴ In addition, it has been found in other areas of healthcare that fewer medical malpractice claims³⁵ and greater job satisfaction³⁶ are observed when care is provided from a family-centered perspective.

Benefits for the Business from Family-Centered Care

In light of the broad pattern of positive effects associated with the provision of family-centered care for patients, families, and clinicians, it stands to reason that family-centered care should also be associated with a higher rate of hearing aid uptake. Although this relationship was not directly tested, new evidence in a submitted paper by Singh and Launer³⁷ finds support for this hypothesized relationship. They report on data collected on 63,105 individuals with hearing loss who did not own hearing aids and who received a recommendation for at least one hearing aid. In contrast to the 50% of individuals who purchased a hearing aid when they attended the appointment alone (n = 35,188), 64% of individuals purchased at least one hearing aid when they attended the appointment with a family member or significant other (n = 29,917).

While it may be tempting to draw a causal connection between hearing aid uptake and the delivery of care that is inclusive

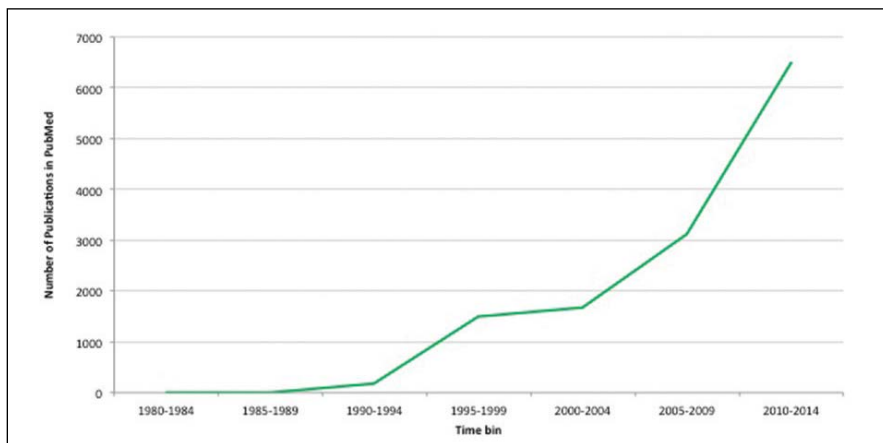


Figure 1. The total number of publications returned from PubMed for the term “Patient-Centered Care” in each of seven 5-year periods.

of family, it is important to note that the study did not employ random assignment to condition. Nevertheless, this study is the first to provide quantitative evidence that attendance at audiology appointments with significant others—a key recommendation of family-centered care—is positively correlated with hearing aid uptake.

Is Audiology Implementing Family-Centered Care?

To date, there are no survey data describing the extent to which family-centered care is implemented in audiology clinics. We suspect that audiology is experiencing a transition away from a site-of-lesion perspective and towards family-centered care. Unfortunately, there is also reason to suspect that, on balance, hearing healthcare practitioners do not currently provide care from a family-centered care perspective with high fidelity. Several recent studies report that communication between patients and practitioners during initial appointments is largely controlled and structured by the clinician,³⁸ family members minimally participate in audiology appointments and are typically not invited to join the conversation,^{15,16} and that shared decision-making rarely occurs when treatment plans are being developed.³⁹

At this point you may be asking, if family-centered care represents a “win” for all involved, why is it not being practiced more regularly? Three points are worth mentioning. First, much of the research about family-centered care was only published in the 2000s (Figure 1), with only a small fraction coming from audiology.

Thus, it is relatively recent that audiologists have recognized the importance of family-centered care for better healthcare outcomes.

Second, and probably most importantly, it is inherently challenging to transform healthcare delivery, particularly when professional development time is limited and the availability of training materials is not widespread. To address this issue, audiology could benefit from learning and incorporating lessons on how best to implement behavior change in clinicians.⁴⁰

Third, it may be possible that audiologists believe they *already deliver* family-centered care in the clinic. There is considerable evidence, much of it led by Nobel-prize winner Daniel Kahneman, that when observers are asked to reflect on their own abilities, they tend to become biased and self-serving.⁴¹⁻⁴³ We suspect that such biases may also apply to well-intentioned clinicians and researchers (ourselves included) when asked to judge clinical efficacy. This inability to fully self-assess clinical competencies brings to mind the classic observation that most drivers (ie, 93%) rate their driving skills as better than average.⁴⁴ Indeed, in an analysis of 326 studies investigating how well clinicians adhere to recommended guidelines, clinicians, on average, tend to overestimate their adherence rate by 27%.⁴⁵

Looking Forward: Key Recommendations for Audiology

Table 1 contains 10 suggestions for the implementation of family-centered audiologic care. It is well known, however, from research on knowledge translation

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and optimal ways to implement behaviour change in clinical settings, that to try to do “too much too soon” is a recipe for noncompliance and disappointment (for example, see article about Knowledge Translation at <http://www.cihr-irsc.gc.ca/e/29418.html>).⁴⁶ We therefore recommend starting with just 3 of the 10 suggestions, as follows:

- 1) Invite a family member along to audiologic appointments, reinforcing the reasons why they should attend.
- 2) Set up the physical environment so that family are comfortably included in the consultation rather than being relegated to a seat at the back of the room.
- 3) Start the appointment by letting the patient and the family member know that input will be sought from both of them—patient first and then the family member.

As can be seen from this Top 3 list, the implementation of family-centered care requires buy-in from all stakeholders including executives, managers, clinicians, support staff, and of course from patients and their significant others.

In light of the changing landscape in audiology—most notably the increased commoditization of audiologic services, the entry into the market of “big box” retail, and potential regulatory changes such as those suggested by the President’s Council of Advisors on Science and Technology⁴⁷—it will be incumbent upon audiologists to continue to develop and to increasingly demonstrate our value as clinicians. We propose that the provision of audiologic treatment shift from a site-of-lesion focus to a family-centered care perspective as a means to achieve this goal and increase the value of our services. ■

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