Health Literacy and Patient-Centered Care in Audiology – Implications for Adult Aural Rehabilitation

Jennifer Gilligan and Barbara E Weinstein

Graduate Center, CUNY, New York, USA

Abstract

A fundamental principle in adult audiological rehabilitation should be the incorporation of patient preferences and health literacy into the counseling, intervention and management of older adults with hearing impairment. However, there is a lack of field-specific research to help guide audiologists in delivery of gold standard, evidence-based practice in this arena. This is a pressing concern, given the demographic shift to an aging population in which hearing impairment is increasing in both prevalence and severity. This paper examines how Patient-Centered Care (PCC) and health literacy form the interlocking foundations that can greatly influence an individual’s decision making, adherence to treatment, health outcome and overall health status. A brief review of the literature is included, together with a discussion of relevant resources for clinicians who wish to integrate health literacy and PCC into rehabilitative practice.

Patient-Centered Care (PCC)

Audiologists are slowly being viewed as integral members of interdisciplinary health care teams bringing a holistic perspective to the diagnostic and management process. Moving away from a physician centered approach to patient care with a focus on the “ear”, to a patient centered approach wherein we are concerned with the patient’s unique understanding of his/her illness, has been an integral part of the evolution of audiologists. The need for a paradigm shift away from the delivery of health care based in the medical model has been explicit in the medical literature since the late 20th Century. A driving force behind “patient-centered care” was Harvey Picker, Ph.D, founder of the Picker Institute, who pioneered the concept that outstanding medical care must include sensitivity to a patient’s personal beliefs and comfort level. Dr. Picker’s advocacy has been far-reaching and ground breaking. His original vision for PCC, “understanding and respecting patient’s values, preferences and expressed needs”, was derived from multiple decades of research [1] and forms the rational core around which coalitions of clinicians, researchers, patient advocates, institutions and policy makers are aiming to reshape the future of healthcare.

Based on a survey of older hearing aid users regarding their experiences and preferences for patient centered rehabilitation in a clinical setting, Grenness, Hickson, Laptaine-Lévesque, & Davidson [2] proposed a preliminary context for patient-centered hearing health care. A therapeutic relationship is integral to patient centered care and individualizing care is an overarching theme. Grenness et al. [2] stated that components of a therapeutic relationship include trust and loyalty among stakeholders. The audiologist must engender trust in order to facilitate a relationship conducive to long term loyalty. If an audiologist is to be trusted, he/she must possess technical competence and excellent interpersonal skills, communication and professionalism. The opportunity for information exchange, shared decision making and problem solving are salient clinical processes expected in the context of delivery of patient centered audiological rehabilitation. Patients reported preferences for a variety of ways of accessing information about hearing health care, such as written material to supplement counseling, and reliable internet resources that are integral to patient centered care.

The elements of PCC described by Weinstein [3] dovetail with those of Grenness et al. [2] and include patient-centered practices such as: involving the patient in the process by eliciting information about the psychosocial context in which they operate; inquiring about the patient’s needs, expectations and health status; establishing a therapeutic relationship; and facilitating decision making concordant with the patient’s values and motivations which allows for the sharing of power and responsibility on the part of the patient and family members.

Recent, widespread recognition of the importance of PCC in geriatric medicine is encouraging; however, PCC is still far from being fully realized and implemented by healthcare professionals throughout the United States. The Institute of Medicine [4] has identified a “quality chasm” wherein the current healthcare system is ill equipped to manage increasingly prevalent chronic conditions, particularly in the elderly. The report cited poor co-ordination of services, lack of interdisciplinary collaboration, and an imbalanced focus on acute care as obstacles to patient centered care with a focus on positive patient outcomes. Among the recommendations for improvement, the IOM envisions bridging the chasm through a shared responsibility to reduce the burden of illness, injury, and disability, and to improve the health and functioning of the people of the United States. Included in this is the delivery of PCC that is not only respectful of and responsive to individual patient preferences, needs, and values, but also ensures that patient values guide all clinical decisions in an equitable way regardless of age, gender, ethnicity, geographic location or socioeconomic status. PCC is also the focus of the American Geriatric Society’s Task Force aimed at optimizing the health of older individuals [5], to ensure that every one receives high-quality, patient-centered health care. Therefore, delivery of PCC, together with an awareness of the current
shortcomings, is highly relevant to audiologists evaluating and treated older patients with hearing loss.

Integral to PCC is the concept of health literacy, which is defined by US Department of Health and Human Services [6] as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions". For healthcare providers, health literacy awareness encompasses the provision of clear, comprehensible communication, to ensure that patients get plain, unbiased and culturally appropriate information that will equip them to better understand their condition and make educated choices about their treatment. It is very important to deliver patient information at the appropriate health literacy level, in an accessible format and using a range of modalities.

**PCC and Health Literacy**

The National Assessment of Adult Literacy [7] found that about 33% of all people have limited health literacy, and only 12% have proficient health literacy. This translates to an estimated 90 million Americans with low Health literacy. Of the 30,000 Americans assessed by the NAAAL, up to 40% of all Americans and 65% of those over 65 years of age had low Health literacy. According to the findings, the elderly and those who did not finish High School are at the greatest risk for low health literacy. On a more global level, nearly half of all Americans with low Health literacy. Of the 30,000 Americans assessed them effectively. Further, hearing loss and its consequences are considered unimportant, tendency on the part of physicians to dismiss hearing loss complaints, lack of appreciation regarding hearing aid options, and pricing are deterrents to help seeking [14,15]. The extent to which health literacy accounts for underutilization and lack of acceptance of hearing aids as a treatment option remains unknown.

In an effort to explore the link between health literacy and hearing aid use, Nair and Cienkowski [16] conducted a study to quantify the health literacy of older patients receiving rehabilitative audiological services. They sought to establish the baseline level of health literacy of older hearing aid users, and to determine if a significant difference existed in the language level used by these patients and the average reading level of American adults. Further they explored whether in fact a difference existed in level of language among audiologists, patients, and patient education materials (i.e. hearing aid instruction guides). Participants included 12 adults with hearing impairment (eight male, four female, mean age 70.6 years) with a mean Pure Tone Average (PTA) of 36.1 dB HL. Five were first-time hearing aid users; seven were experienced hearing aid users. Each person participated in a hearing aid orientation appointment. Three different audiologists with different levels of graduate experience participated (two of whom had completed graduate-level counseling courses). Counseling dialogs videotaped and transcribed. For selected participants, the counseling involved distribution of printed educational materials, hearing aid informational brochures included in the packaging of hearing aids and required by the FDA to be read by consumers [17].

The videotaped sessions and informational brochures were analyzed by transcription of dialog and printed materials into Microsoft Word, using the Flesch-Kincaid grade level formula [18]. According to ReadabilityFormulas.com as cited in AHRQ [19] FKGL outputs a U.S. school grade level which the average student in that grade level can read. For example, a score of 7.4 indicates that the text is understood by an average student in seventh grade. Based on the analyses from the counseling sessions, each of the 12 participants had a predicted health literacy level that was below a fourth grade reading level. The audiologist’s FKGL was found to be significantly higher than the patient’s FKGL, and significantly lower than the FKGL in the hearing aid instruction guides (which had a mean FKGL of 7.9). Nair and Cienkowski [16] concluded that many hearing aid users have a triple disadvantage in that access to information starts with being able
to hear, then ask questions, and understand the responses from the audiologist. Poor understanding resulting from disparities in language level can be costly, time consuming and frustrating to the most important stakeholder, namely the person with hearing loss. Patients may need to make additional appointments for clarification of hearing aid function which is time consuming and in the future may be costly when audiologists begin to unbundle and charge for services related to the hearing aid fitting. The cascading effects of a lack of understanding due to hearing loss and health literacy are likely to have far-reaching effects, including a negative impact on overall health and difficulty navigating the health system.

Counseling and PCC

The American Speech-Language Hearing Association (ASHA) places emphasis on making effective communication a human right, accessible and achievable for people of all ages and from all cultural and socioeconomic backgrounds. This includes advocacy for individuals and families through community awareness, health literacy, education, and training programs to promote and facilitate access to full participation in communication, including the elimination of societal, cultural, and linguistic barriers. For the audiologist involved in the rehabilitation of older adults, much of the delivery of PCC and advocacy for improved health literacy relates to the provision of effective and appropriate informational counseling.

Counseling is a critically important aspect of audiological practice. It is broadly defined by the American Counseling Association [20] as "a professional relationship that empowers diverse individuals, families, and groups to accomplish wellness goals." The American Academy of Audiology (AAA) and The American Speech-Language-Hearing Association (ASHA) scope of practice criteria define counseling for hearing aid users as part of a rehabilitation and management plan that is patient centered, culturally appropriate, and psychosocially focused, as well as educational and informative. Amplification counseling includes “fitting ...dispensing, and educating the consumer and family/caregivers in the use of sensory aids” as well as helping a person adjust to sensory aids and coping with the consequences of the loss. Additionally, the AAA scope of practice calls for audiologists to develop counseling materials for use with patients/consumers which are at appropriate healthcare literacy levels. However, there is currently no hearing aid industry standard for ensuring the readability of informational brochures.

Historically, a paternalistic approach was taken to intervention and counseling, wherein top-down advice was delivered and the patient was expected to comply with the recommendation [3,21]. More recently, a shared decision making approach has gained favor in geriatric medicine and allied health practice. Considered to promote intervention adherence, the shared intervention decision making approach takes into account the clinician’s and patient’s expertise [22]. The clinician has the technical expertise and knowledge of the disease, prognosis, treatment options and outcomes, whereas the patient’s expertise lies in their experience of illness, social-environmental factors, risk adversity, and individual values and preferences [23]. Decision aids based on the clinician’s expertise help to present information about hearing health care intervention options and outcomes and this helps to inform the patient’s decisions. Like instructional materials developed to accompany hearing aid provision, decision aids must be at the appropriate literacy level of the patient if they are to be helpful to the patient.

The need for appropriate informational materials has been highlighted in a recent assessment of hearing aid manuals by Caposecco, Hickson & Meyer [24]. Caposecco et al. [24] analyzed the content, literacy demand, readability, graphic content, layout, interactivity and cultural appropriateness of 36 printed hearing aid user guides from nine manufactures to determine their suitability for older adults. Readability was assessed using four reading ease/grade level algorithms (including FKGL), and was also judged using the Suitability Assessment of Materials [25]. The SAM is an instrument developed at Johns Hopkins School of Medicine under NIH funding to systematically assess the suitability of health information across domains of content, literacy demand, graphics, layout/type, learning motivation and cultural appropriateness. Each domain can be rated as “superior”, “adequate” or “not suitable” depending on objective criteria included in the instrument [25]. Caposecco et al. [24] reported that 69% of the guides were unsuitable for their intended audience, based on the parameters measured with these assessment tools.

Specifically, the reading level was too advanced in all of the hearing aid user guides, with a mean US grade level of 9.6, and in more than 90%, excessive technical jargon and uncommon vocabulary was used in lieu of simpler terminology. In terms of scope, 90% of the guides included information about a range of different hearing aid styles and technologies as the informational brochures tend to be generic and not always specific to the model being used by the patient. Summary sections and overviews of main hearing aid functions were not included in 33% of the guides, and graphics were rarely described with captions. Content and design issues were also identified in the majority of the guides. In 100% of the guides, the font was too small, with the majority having fonts less than 12 points in size. Layout was described as “cluttered”, with insufficient white space and poor text-to-paper contrast in many examples, resulting from inappropriate selection of gloss or semi gloss paper stock. Separately, these factors may each contribute to lack of understanding: together, they may negatively impact self-efficacy and preclude successful outcomes, resulting in dissatisfaction, increased healthcare costs and longer follow up appointment times. Here, the importance of the patient being at the center of care was unheeded by producers of the FDA-required printed informational guide that is integral to all hearing aids dispensed.

Based upon the findings, it is abundantly clear that it is not only crucial to be aware of patient health literacy levels, but it is also critical that all resources used with patients during orientation and counseling sessions must be at the appropriate level for patients at risk for low Health literacy.

The Agency for Healthcare Research and Quality (AHRQ) commissioned Dewalt et al. [19] to develop and test Health literacy Universal Precautions Toolkit that provides step-by-step guidance and 20 tools for assessing clinical practice and making changes in order to connect with patients of all literacy levels. It is a comprehensive resource with empirically derived methods for healthcare providers to improve spoken and written communication, facilitate patient self-management, build trust and empowerment, and develop supportive systems, all of which relate to PCC and Health literacy in the Audiological Rehabilitation context.

Dewalt et al. [19] provide guidelines in the AHRQ health literacy toolkit for producing easy-to-read printed materials. These include using a large, high-contrast font, and chunking information together using clearly defined headings, bullet points, and breaks between sections, with areas of white space on the page. Sentence structure
should be simple. Active voice and first-person pronouns are preferred, while multi-syllable words, jargon and medical terminology should be avoided. The use of simple, captioned graphics can enhance the message. Bolded key words and simple glossary definitions are also helpful.

**Summary**

At the heart of PCC, is spoken communication which is critical for audiologists, who deal on a regular basis with older adults who have hearing impairment and multimorbidity affecting cognitive function and the ability to process what is being communicated. According to Dewalt et al. [19], clear oral communication strategies help insure that patients are more involved in their healthcare and may increase likelihood of adherence to treatment plans. While most audiologists and other communication disorders professionals are likely to already employ suggested strategies such as warm greetings, eye contact and slow, audible speech, it is very important to consider the use of plain, non-medical language free from jargon during the intake and counseling and to be especially cognizant of this in the resources they share. AHRQ provides a “plain language thesaurus” as well information from the American Medical Association (AMA) on health literacy and patient safety. Implications for the way in which oral information is prioritized and grouped are also discussed. The AHRQ health literacy toolkit recommends limiting information per visit, beginning only the most important information, and using repetition and summarization of no more than 3-5 key points using concrete and specific conversation, rather than generalizations.

According to studies on patient memory [26] and retention [27], 40-80% of all medical information received is forgotten immediately, and nearly half of the information retained is incorrect. The National Patient Safety Foundation [28], an independent, non-profit patient advocacy organization has developed a program called “AskMe3” which encourages patients to ask healthcare providers, “What is my main problem? What do I need to do? Why is it important for me to do this?” These questions are intended to facilitate PCC and Health literacy, and translate very well into the audiological setting.

Another technique to engage patients and their family members in PCC is utilizing the “teach back” method. This approach is not an assessment of a patient’s health literacy, but rather a tool for the clinician to assess whether instructions have been properly understood. Used increasingly by geriatricians, this technique is comprised of three simple steps: explain a key point, check for comprehension, and re-explain if needed. The teach-back method can serve as a valuable tool during hearing aid orientation, when a patient is learning a new skill that requires comprehension and retention. According to research by West et al. [29], use of the “teach-back” method in a prospective cohort study of heart failure patients over age 65 resulted in increased retention of self-care information.

Health literacy impacts overall health status and the health care encounter. Poorer outcomes are more common in patients with low Health literacy [12]. Addressing low health literacy and employing strategies to increase it will reduce disparities in overall health outcomes, leading to a healthier and more empowered aging population. Audiologists should strive to increase patient’s health literacy, as this is integral to delivery of patient-centered care. By building upon Picker’s PCC principles, considering the IOM’s recommendations for improvement, and utilizing existing resources, clinicians involved in the audiological rehabilitation of older adults can incorporate all the relevant elements into diagnosis, treatment and management.

**Acknowledgement**

Portions of this paper were presented as a Clinical and Teaching poster session at the American Academy of Audiology (AAA) 2014 conference “AudiologyNow”, and as a seminar at the American Speech-Language-Hearing Association (ASHA) conference in November 2013.

**References**


