

## Viewpoint

# Incorporating Patient Narratives to Enhance Audiological Care and Clinical Research Outcomes

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**Purpose:** The engagement of patients as key stakeholders in their experience of care processes is a critical component of quality improvement efforts for both clinical care and translational research. Increasingly, health care systems are soliciting input from patients on care processes and experiences through surveys, patient interviews, and patient video narratives. The purpose of this viewpoint article is twofold: (a) to describe the increasing role of patient narratives about their experiences with adverse health conditions to inform patient-centered research and quality

improvement efforts and (b) to present three patient narratives that highlight the real-world impacts of hearing loss and tinnitus, the life enhancing impacts of aural rehabilitation, and the importance of prospective ototoxicity monitoring in individuals with complex health conditions.

**Conclusion:** Patient narratives provide individual patient perspectives that can be used to build awareness of the range of experiences and impact of hearing disorders, and to explore patient preferences for when and how to implement hearing-related clinical services.

Increasingly, U.S. policymakers (Epstein et al., 2010) and quality improvement initiatives seek to incorporate, and be responsive to, the needs, values, and preferences of patients and their families (Baker, 2001; Fix et al., 2018; Frampton et al., 2017). Concepts such as patient-centered care, patient engagement, and patient activation abound in the literature and have become an important centerpiece across a range of health care delivery improvement initiatives (Epstein et al., 2010). Focusing on patients' experiences with clinical care, or providing patient-centered care, is posited to improve health care quality outcomes, increase clinical care efficiencies (Ahmed et al., 2019;

Levesque et al., 2013; Stewart et al., 2000) and, thus, enhance patient health outcomes and quality of life (Kaplan et al., 1989).

Patient-centered care is defined as “health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own health care” (Hurtado et al., 2001, p. 7). The way in which patient surveys have been used to improve health care has expanded over time. Surveys were initially designed to assess patient satisfaction. In efforts to systematically collect data on patients’ experiences with care processes, quantitative surveys, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS), were developed. The CAHPS and other publicly accessible patient surveys provide health care systems with incentives to collect survey data on patients’ experiences with clinical care processes (Grob et al., 2019; Huppertz & Smith, 2014; Schlesinger et al., 2015). More recently, evidence-based research on health care services and systems has expanded the modality through which patients’ experiences are rendered through the production and use of patients’ narratives (Zaharias, 2018; Schlesinger et al., 2015). Patients’ narratives are defined as stories told by patients (or “health care consumers”; Pullman et al., 2005) about their care experiences and reflections on an

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array of health conditions. While the methodologies and models for incorporating narrative evidence into clinical practice are still relatively nascent (Ash et al., 2015; Schlesinger et al., 2015), several studies have examined how narratives can enhance medical education consultation skills (Epstein et al., 2010; Pandhi et al., 2019; Snow et al., 2016), support patient education and decision making with chronic diseases (e.g., oncology patients; Atkinson & Rubinelli, 2014), inform quality improvement initiatives (Tsianakas et al., 2012), and inform the diffusion of innovations in health care (Findlay, 2016).

An important, innovative application of patient narratives for research involves the development of a repository of patient stories for primary and secondary research (Ash et al., 2015). Twenty years ago in the United Kingdom, an international group of academics, nonprofits, and clinicians created a video repository called the Database of Individual Patients' Experiences (DIPEX; DIPEX International, n.d.). DIPEX houses videos of patients' narratives on health and illness experiences across a range of health conditions that can be accessed free-of-charge by the public, medical education programs, and quality improvement teams. Importantly, these videos on chronic diseases can build awareness on range of treatment issues and can reveal important contextual information on patients' experiences and care quality outside of traditional quantitative metrics (Schlesinger et al., 2015).

There is increasing attention to implementing patient-centered care models into the audiology scope of practice (American Speech-Language-Hearing Association [ASHA], 2018; Jones, 2018). Furthermore, the National Institute on Deafness and Other Communication Disorders' (NIDCD) 2017–2021 Strategic Plan identifies a critical need in auditory research to include patient-centered outcomes (NIDCD, 2017). Self-reported measures and the elicitation of patient narratives could enhance the care team's knowledge and awareness of important contextual factors that could inform treatment decisions. As in other medical disciplines, there is also acknowledgement that treating patients holistically is good practice and can improve health outcomes because the values, preferences, and needs of patients are taken into account by care providers (ASHA, 2018; Berwick, 2009).

In the context of whether to provide prospective hearing loss surveillance (i.e., hearing screening before an individual recognizes symptoms, such as in individuals exposed to loud noise or those receiving treatment with an ototoxic drug), it is recognized that audiological testing and treatment brings little to no harm. However, there is a lack of evidence on the patient's perspective to inform hearing health-related decisions in these contexts (Baguley & Prayuenyong, 2020). From an organizational standpoint, patients' perspectives or narratives about their chronic conditions, experiences with care processes, service gaps, and general satisfaction with care processes can be leveraged to inform quality improvement initiatives (Grob et al., 2019) and to enhance provider awareness about the constellation of factors, such as psychosocial functioning, problems with referrals, or other quality issues that may not be captured by

traditional surveys (Epstein et al., 2010). This article presents narratives by patients who participated in a recent conference on auditory damage from exposures to noise or ototoxicity. The goal of this viewpoint article is to highlight the power of patient narratives for illustrating the impacts of so-called "invisible" disabilities, such as hearing loss and tinnitus, that manifest primarily in reduced social–emotional well-being (as opposed to overt physical changes).

In September of 2019, researchers at the National Center for Rehabilitative Auditory Research at the VA Portland Health Care System held a biennial conference called, "Ototoxicity and Noise Damage: Translating Pre-clinical Findings to Audiological Management." One innovative aspect of the conference was a "Patient Voices" session in which recorded and live patient testimonials were presented to share the patients' perspective on key issues related to the burden of hearing loss and tinnitus resulting from exposure to noise or ototoxic drugs. All patients who participated provided consent to publish their names and narratives. By presenting patient testimonials, conference organizers posited that clinicians and researchers would be able to leverage patients' narratives to devise improved rehabilitative and pharmaceutical interventions shaped not only according to specific auditory symptoms and sites of lesion, but also based on the priorities of individual patients. Through each personal account, a layered backstory is revealed that highlight both the internal struggles that can arise from these so-called "invisible" auditory disabilities and the life enhancing impacts that can come from rehabilitation to optimize auditory function. Two of the three accounts also address the importance of prospective ototoxicity monitoring in individuals with complex health conditions. These personal accounts can and should drive our approach for understanding and treating hearing-related problems. To see video clips of patients' stories, please see <https://www.ncrar.research.va.gov/PatientVoices/Index.asp>.

### ***Hearing Loss and Aural Rehabilitation in a Patient With Cystic Fibrosis: Allyson's Story***

Diagnosed with cystic fibrosis (CF) as a child, Allyson had become resistant to most antibiotic treatments by the time she reached her 20s. After starting a broad-spectrum ototoxic aminoglycoside antibiotic (Amikacin), Allyson experienced severe hearing loss for which she was unprepared. The drug was a necessary treatment to stave off infection following lung transplant surgery. However, when she was not able to hear following the surgery, this contributed to her anxiety and disorientation. She eventually sought help to address what she thought might be ear wax, which was ruled out as a cause of her hearing problems. She still struggled with her hearing and described herself as feeling isolated, lonely, and emotionally exhausted after attempts at listening and communication. It was not until she participated in research at Oregon Health & Science University that she was diagnosed with a profound sensorineural hearing loss and referred for clinical audiological management. Allyson was initially provided

hearing aids for her hearing loss; however, she continued to have significant communication difficulties. She was ultimately referred for a hybrid cochlear implant. Now with both a cochlear implant and a hearing aid, Allyson is able to more successfully engage in social situations again. She discussed how her nurses often warned about the ototoxic potential of her frequent vancomycin treatments, but she did not recall her health care team ever talking to her about the possibility of hearing loss with aminoglycosides (Tobramycin or Amikacin). She recommends that all patients ask about auditory side effects before starting a new medication and request routine hearing tests and monitoring for hearing loss during ototoxic treatments. Allyson describes the impact of her hearing loss on her quality of life in this way, “I felt like I couldn’t go anywhere. I couldn’t go to school. I couldn’t get most jobs. I had no social life. Even just stuff around the house, like, I couldn’t hear the microwave. I couldn’t hear the smoke alarm. You know, everything was just way more difficult.”

### ***Auditory Complaints in a Patient With Borderline Normal Hearing Following Treatments for CF and Colon Cancer: Mike’s Story***

Mike is an audiology graduate student with CF who has tinnitus and difficulties understanding speech in noise despite having borderline normal hearing. Mike also has a history of colon cancer treated with oxaliplatin. Mike reported not having his hearing tested until recently even though he would be considered at high risk for hearing loss and tinnitus due to his history of receiving ototoxic medication for treatment of cancer and frequent CF-related bacterial lung infections. He also was a drummer but did not know about the synergistic effects of noise and ototoxic drugs at the time of his treatment. Although Mike has normal hearing with a mild loss at 8 kHz, he shared several specific instances in which he felt he struggled to hear, as well as the first time he realized he had tinnitus. In the video, Mike expressed how his hearing prevents him from fully participating in conversations. He also shares his hopes that clinical practice in CF clinics improves to include education on the risks of hearing loss, noise exposure, and ototoxicity. As Mike stated,

“How is it that a person with a history of cystic fibrosis and chemotherapy never had a hearing test until he was 23 years old? How is it that this person had to connect all the dots alone, where the potential of adverse auditory consequences had never been discussed at annual health visits? It is my hope that my video testimony, presented at the conference, has the chance to inspire new protocols for patients with CF and/or going through chemotherapy.”

### ***Noise Exposure, Hearing Loss, and Bothersome Tinnitus: Brian’s Story***

Brian is a Navy Veteran with hearing loss and bothersome tinnitus. Brian reported high noise exposure on an

aircraft carrier from jet engines, high-caliber weapons fire, and a “catapult” that sounded like “two freight trains hitting each other.” He participated in tinnitus research at the NCRAR to find ways to deal with his tinnitus, which he describes as “hell” in a quiet space. Through a comprehensive audiologic evaluation, Brian learned he also had significant sensorineural hearing loss. He was subsequently fit with bilateral hearing aids and underwent tinnitus and audiologic counseling. Brian reported that amplification provides tinnitus relief and considerable improvement in communication with his wife. He also uses cognitive behavioral therapy and meditation as tinnitus reaction management. Brian’s story emphasizes how individuals with significant hearing loss may not recognize they have it. Brian was surprised at the stress on his marriage from miscommunication that he now attributes to his previously untreated hearing loss. Brian poignantly described the impact that tinnitus has had on his life in the following way, “. . . tinnitus is an “invisible disability” that “affects your wellbeing, your way of life, your mood, your psychological state.” In emphasizing the need for preventative measures to reduce tinnitus in the military, Brian said: “It’s not worth having if you can prevent it.”

## **Discussion**

Patient-centered care has become an exemplary model for improving health care outcomes and patient satisfaction in the United States. Incorporating patients’ perspectives and experiences with clinical care processes has the potential to improve health outcomes (Ahmed et al., 2019; Levesque et al., 2013; Stewart et al., 2000). Conversing with patients about their personal health experiences is crucial for optimizing this type of care model, likely to improve the outcome of their personal care, and possibly elucidate critical gaps in interdisciplinary clinical collaborations and shortcomings in referral networks.

Utilizing a patient-centered model in audiology is also useful to establish a partnership between patients, families and the clinical care team. Audiology, as a field, would benefit from improving communication and disseminating hearing health care information across clinical disciplines that may not have a protocol to capture hearing, tinnitus, or balance issues in their patients. For example, the narratives presented highlight the significant quality of life impacts that late-identification had on patients with tinnitus and/or hearing loss. These narratives also demonstrate that hearing and tinnitus were actionable items for these patients when they received and processed guidance on their conditions. The patients’ stories elucidate the need for properly implementing hearing health care into specialty clinics to identify patients and cue the initial physician referral for a diagnostic hearing and/or vestibular evaluation. All three individuals experienced significant struggles and impacts on quality of life due to their acquired auditory issues. Some of these impacts may have been mitigated with earlier identification of hearing issues, proper counseling, and prompt aural rehabilitation.

## ***Interdisciplinary Collaboration***

Allyson and Mike's stories highlight the need for better care coordination and communication processes among specialty care providers, which is a persistent problem in a health care system where providers often work in silos (Sunderland & Hellsten, 2017). As part of "ASHA's Envisioned Future: 2025" (ASHA, n.d.), there is increasing emphasis on integrating interprofessional educational practice and interprofessional practice (IPP) models to enhance health care quality and outcomes. In the IPP framework, teams of more than two medical professionals learn from each other and work with each other to provide comprehensive health care to patients and to facilitate collaboration. Since auditory issues affect a range of psychosocial issues, audiologists are well positioned to increase awareness among other health care specialties regarding the impact of auditory dysfunction. Having audiologists as part of an IPP team would positively effect patient outcomes by influencing the proper identification, monitoring, and management of auditory issues. The ASHA website provides rich resources on strategies to align IPP care models with current reimbursement models.

Patients' narratives have the potential to point out areas in which IPP teams could work collaboratively to develop education materials about the referral process and time points in which patients should expect to have their hearing tested, especially in situations where people are taking medications that have ototoxic effects. Ideally, these materials would be developed for a range of patient literacy levels and graphically demonstrate the impact of medications on auditory or vestibular function, as well as depict the optimal referral process among primary care and specialty providers. Such materials could be posted in a multitude of clinical settings, including both primary care and specialty practices, with the goal of increasing patient awareness and motivation to take an active role in their health care.

## ***Proactive Surveillance of Auditory Function***

The stories presented describe how Allyson and Mike secured auditory rehabilitation by chance, rather than through the appropriate point-of-care referral pathways. In light of the profound impact of hearing loss and tinnitus on patients' quality of life, accidentally stumbling onto appropriate rehabilitation services is unfortunate. For example, Allison and Mike are patients with CF who did not recall their health care providers warning them about the ototoxic side effects of life-saving aminoglycoside antibiotic treatments. This is not surprising given that less than 26% of CF centers in the United States monitor for aminoglycoside-induced hearing loss (Prescott, 2014). Additionally, hearing monitoring has yet to be included in the Cystic Fibrosis Foundation's clinical care guidelines for patients treated with aminoglycosides and/or other known ototoxic agents. This also suggests that the U.S. national audiology guidelines for ototoxic monitoring programs (e.g., ASHA, 1994; American Academy of Audiology, 2009), which have been in place for over 20 years, are not

influencing or reaching clinical specialties that need audiology services. On a positive note, there have been a plethora of recent publications in the area of clinical ototoxicity monitoring (e.g., Garinis et al., 2017; Maru & Malky, 2018; Vijayasingam et al., 2020), as well as the development of professional working groups such as the International Ototoxicity Monitoring Group (National Center for Rehabilitative Auditory Research, n.d.) that will promote the inclusion of audiologic care for patients receiving ototoxic medications, and improve communication between audiology and clinical specialty groups needing hearing health care services.

## ***Consequences of Noise Exposure***

Brian's vignette illustrated that he was unaware of the impact of military noise on his auditory system, which ultimately caused his tinnitus and hearing loss. After the appropriate diagnosis and rehabilitation to improve his hearing health-related function, Brian reported great improvement in his quality of life. Due to Brian's experiences, he was motivated to share his story and educate other patients and veterans who may suffer from noise-induced auditory impacts and are unaware there may be help for their symptoms. Unfortunately, Brian's case is also typical, in that military service members and veterans are exposed to excessive noise (e.g., firearms, aircraft engines, mortars) and tend to have auditory complaints at higher rates than the general population (Theodoroff & Konrad-Martin, 2020). Furthermore, it is important to recognize the co-occurring mental conditions that may exacerbate these auditory symptoms in combat Veterans, such as posttraumatic stress disorder, depression, and blast exposure (Theodoroff et al., 2015). Monitoring of hearing and other physical and mental comorbidities is critical in the Veteran population to ensure proper identification and management of hearing issues.

The collection of patient narratives along with quantitative data has the potential to reveal significant information that may not be achieved with quantitative data alone. While the frameworks and models for incorporating patients' narratives into quality improvement initiatives is emergent (Bergerum et al., 2019; Schlesinger et al., 2015), there is some practical guidance on ways to incorporate elements of patients' narratives into audiological practice. First, during medical intake, Bergey (2017) suggests that asking patients' open-ended questions about their medical history or medical concerns in "their own words" to gain greater understanding of the contextual factors that are at play in a patient's life as well as to understand a patient's treatment goals and preferences. As the patient's story unfolds, paying attention to clinically relevant information and listening (Goyal et al., 2008) to what is meaningful to a patient will help clinicians to work with the patient on setting realistic and meaningful medical goals. Open dialogue is also important to develop rapport between the patient and clinician, before targeting specific health concerns (e.g., hearing loss) are addressed, which they may not discuss during initial conversations. In the context of using narratives

in cancer care, Atkinson and Rubinelli (2014) describe the impact of patients' narratives on oncology care as follows,

“Cancer narratives indicate areas for health professionals to consider in developing more patient-centered care. Information can help support patient coping strategies and cancer narratives have shown the need for information and support that goes beyond a narrow concept of medical care as the illness experience affects all aspects of patients' lives, including functional capacity, financial strain, and stress on relations with friends and family” (p. 3).

As this quote indicates, listening to patients' stories about their illnesses provides important contextual information on the elements of health that might remain invisible to care teams. To elicit patient stories, research across a range of clinical topics indicates that patients are often most comfortable having conversations about their health with someone they trust (Fuzzell et al., 2018; Ganzini et al., 2013), which is often a nurse or medical assistant.

Finally, researchers could include some open-ended, qualitative questions in research protocols to gain greater understanding of the challenges associated with hearing loss and strategies that patients use to manage it. These data, coupled with the perspectives of clinical team members, could be used to inform quality improvement initiatives. For example, in a recent Veterans Affairs–lead systematic review on polypharmacy/deprescribing, the first author (K. C.) and collaborators (Christensen et al., 2021), conducted qualitative interviews with patients on their experiences with the deprescribing process, their physicians, and other care team members (e.g., pharmacists) to create deprescribing, web-based, interactive stories to accompany the results of the traditional systematic review. The findings from our evaluation on provider ratings of the stories indicate a narrative based approach has the potential to influence clinical practice.

## Conclusions

The engagement of patients as key stakeholders in their experience of care processes is a critical component of quality improvement efforts. Increasingly, health care systems are soliciting input from patients on care processes and experiences through surveys, patient video narratives for medical education, patient narratives to improve care delivery, and quality improvement initiatives to increase the quality of care and patient satisfaction. The patient narratives in the present report provide individual patient perspectives that can be used to build awareness of the range of experiences and impacts of the symptoms of hearing loss due to ototoxicity and/or noise and explore patient preferences for surveillance and management.

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