PERSON-CENTEREDNESS & COCHLEAR IMPLANT USERS

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If you have suggestions for future research summaries on the topics of person-centered care and cochlear implants, please send them to ke3@uakron.edu.

> Person-centeredness, *defined*: engaging with individuals, their families and their communities as equal partners in promoting and maintaining their health[1]; sharing control and power in healthcare decisions and management; actively involving the individual in decision-making[2]

1. **Athalye, S., Archbold, S., Mulla, I., Lutman, M., & Nikolopoulous, T. (2015). Exploring Views on Current and Future Cochlear Implant Service Delivery: The Perspectives of Users, Parents and Professionals at Cochlear Implant Centres and in the Community. Cochlear Implants International, 16(5), 241–253.**

This study was designed to collect input from relevant CI stakeholders regarding current service delivery and its challenges, as well as thoughts about future services. A 22-item online survey was created with open-ended and closed questions, and then uploaded to the Internet with a dedicated link. The link was emailed to users, parents and professionals registered in CI databases within the UK, and also promoted on several websites and social media platforms.

The call for participants resulted in 748 responses (80 users; 138 parents/carers; 495 professionals; 35 no response). Regarding the topic of person-centeredness, the majority of CI users and parents expressed a desire for change: specifically, a shift from implant team decisions made behalf of users and parents/carers, to a model where decisions are made jointly by the team and the user or parent/carer. One comment describes the need for this change: “Parents’ views are completely ignored, even when they have valid concerns or wishes” (p. 246). Notably, half of the CI professionals (implant team members) felt that users and families were in fact involved in decision-making, which is not only at odds with users and families, but also raises the question, why only half?

Key Insights: In this study, CI users and parents clearly indicated their preference to be actively involved in decision-making. Although the term was not used, the end-users of CI services (users and parents) were requesting a change in services to person-centeredness. The following two research summaries demonstrate how person-centeredness has been put into action.

The abstract of this article is available here: https://doi.org/10.1179/1754762815Y.0000000003

2. **McRackan, T.R., Velozo, C.A., Holcomb, M.A., … Dubno, J.R. (2017). Use of Adult Patient Focus Groups to Develop the Initial Item Bank for a Cochlear Implant Quality-of-Life Instrument. JAMA Otolaryngology-Head & Neck Surgery, 43(10), 975-982. DOI: 10.1001/jamaoto.2017.1182**

At the time of this study, no validated instrument had been developed to assess quality of life (QOL) outcomes for adult cochlear implant users. The authors therefore recruited 23 adult CI users to participate in one of three focus groups to create items for a QOL questionnaire, noting that "the use of focus groups to better understand patient perspective is vital" (p. 980).

Within their focus groups, participants responded to open-ended questions and also introduced new topics. Discussions were transcribed with professional Communication Access Real-time Translation (CART) to ensure comprehension and also to save as a record for analysis. From the focus group discussions, several quality of life themes emerged, including communication and environmental sounds, listening effort, social isolation, emotional health, independence, and work performance. Ultimately, CI users developed, reviewed, and approved 101 questionnaire items, which are now being used to evaluate CI outcomes relative to quality of life.

Key insights: Focus group input is considered a gold standard in person-centeredness, since the process incorporates participants' own experiences and concerns into a product. Because CI users co-created this assessment, it is far more likely to accurately represent the adult CI user experience, and consequently will increase understanding of how cochlear implant use affects quality of life.

The complete article is available at:
https://jamanetwork.com/journals/jamaotolaryngology/fullarticle/2645910

3. **Philips, B., Smits, C., Govaerts. P.J., Doorn, I., & Vanpoucke, F. (2018). Empowering Senior Cochlear Implant Users at Home via a Tablet Computer Application. American Journal of Audiology, 27(3S), 417–430.**

This study was informed by previous studies indicating CI users' expressed preferences to manage and make their own decisions about appointments, treatments, accessory maintenance, etc., rather than rely solely on their (often distant) CI centers. Since CI users are asking for a more patient-centered role in their care, and since the wide availability of tablet technology lends itself to this type of active engagement, the authors created an app for personal tablets, based on input from focus groups. The MyHearing App included six components: My Hearing Tests, My Environment, My Hearing Journey, Tip of the Day, Recipient Portal, and Program Use and Features.

To test the app's usefulness, ease of use, and perceived value, 16 experienced CI users (ages 61-80) were recruited to explore the app in their homes for 4 weeks. The majority of the participants went online every day to explore the features; at the end of the trail period, the app was described as accessible, motivating and stimulating. Ninety-three percent of the participants reported they would like to continue using the app, and that access to the app had increased the quality of their CI care.

Key insights: The participants in this pilot study expressed their preference to "take more responsibility for and to become a more active actor in their own hearing care" (p. 417) if provided the right tools. The MyHearing App was based on person-centered principles, by empowering CI users to self-manage important components of their hearing care.

The complete article is available at: https://pubs.asha.org/doi/pdf/10.1044/2018_AJA-IMIA3-18-0014?casa_token=FR8W7co9R4gAAAAA:gcduo76-jWIWB14WPEl-AR6-W2AuQd_SkACELjlms0Fwn1IyfZUF3qe0hnyDF2j9He8NY9C0Nihwvrk

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[1] Institute of Medicine. (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press.

[2] Morgan, S., & Yoder, L.H. (2012). A Concept Analysis of Patient-Centered Care. Journal of Holistic Nursing, 30(1), 6-15.