User Awareness and Perspectives Survey on Privacy, Security and Usability of Auditory Prostheses

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1 Motivation

According to the World Health Organization, over 466 million people worldwide suffer from disabling hearing loss, with approximately 34 million of these being children [1]. Auditory prosthetic devices, such as hearing aids (HA) and cochlear implants (CI), have become indispensable tools for restoring hearing and enhancing the quality of life for individuals with hearing impairments [2, 3].

The adoption of HA and CIs has been on the rise. Clinical research and consumer studies indicate that users of HA and CIs report significant improvements in their daily lives, including enhanced communication abilities and social engagement and reduced psychological stress [4–9]. Other studies focusing on stress evaluation have shown that auditory prostheses can considerably alleviate the mental strain associated with hearing loss, thus contributing to better mental health outcomes for users [10–12]. Accessibility remains a critical area of focus, with efforts aimed at making these devices more affordable and widely available, particularly in low- and middle-income countries [13–15].

Modern auditory prosthetic devices are more advanced and interconnected with digital networks to add functionality, such as streaming audio directly from smartphones and other devices, remote adjustments by audiologists, integration with smart home systems, and access to artificial intelligencedriven sound enhancement features [16–18]. With this interconnectivity, issues surrounding data privacy and security have become increasingly pertinent. Despite the growing relevance in the domain of auditory prostheses, there is a notable gap in the literature regarding consumer awareness of privacy and security concerns related to these technologies. Studies have highlighted the lack of cybersecurity in private medical practices in audiology, indicating increased risks of cyberattacks and security breaches involving sensitive personal information in CI and HA devices [19–21]. This underscores the critical need for consumer awareness of potential vulnerabilities.

There is limited research on the usability perceptions of current HA and CI models from the perspective of end-users. Usability is directly linked to privacy and security because if users find the devices complex or unintuitive, they may not effectively manage privacy settings or recognize security threats [22]. Therefore, enhancing usability can improve consumer awareness and practices related to privacy and security. This underscores the importance of understanding user experiences and concerns.

In addition, no studies have investigated consumer mental models during the purchasing process, particularly which factors they prioritize when selecting a device. Understanding these factors is crucial for ensuring that the devices not only meet auditory needs but also align with the expectations and concerns of the users. By connecting these aspects—technological advancement, consumer awareness, usability, and purchasing behavior—we can better address the comprehensive needs of end-users, ensuring their safety, satisfaction, and overall well-being.

To this end, our work-in-progress study aims to gain insight into consumer perceptions and awareness concerning privacy and security matters associated with cochlear implants and hearing aids by answering the following research questions:

- RQ1 How satisfied are consumers with their current cochlear implants or hearing aids?
- RQ2 What is the perceived level of importance of different factors like performance, durability, and price while making a purchase decision?
- RQ3 How informed are users about privacy and security practices?
- RQ4 What strategies might be helpful to increase consumer awareness about privacy and security features?

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This work contributes to the field by addressing gaps in user perceptions of HA and CI usability, identifying key factors in consumer purchasing decisions, and highlighting the need for improved privacy and security awareness and education among users.

2 Methodology

We developed a survey on the Research Electronic Data Capture (REDCap) platform [23,24]. The survey encompassed 45 questions grouped in multiple sections covering demographics, device details, usage satisfaction, mobile app security, privacy, cybersecurity awareness, improvements, and purchase decisions. The survey includes Likert scale questions and open-ended questions.

The survey study was approved by the Duke University Institutional Review Board. We recruited participants by posting advertisements and flyers in private social media groups dedicated to CI/HA users. The participants were compensated 10 USD for successfully completing the survey. We recruited 27 participants, comprising 12 cochlear implant users and 15 hearing aid users. Participant demographics are summarized in Appendix Figure A.1. Details about participants' brand of auditory prosthetic device and duration of device usage are summarized in Appendix Figure A.2.

3 Results

A subset of participant survey results is reported here. We assessed participants' satisfaction levels on the importance of various features of their auditory prosthesis. The device features included: *performance* of the CI/HA in improving hearing and communication; *reliability* in consistent functioning; *durability* of the device to withstand wear and tear; *customer support* from the manufacturer, *privacy and security* of personal data; *usability* in everyday life; and *flexibility* in the number device settings based on the listening environment. 44% of participants reported complete satisfaction with performance, while 48% expressed complete dissatisfaction with flexibility (Appendix Figure A.3) (RQ1).

Participants were also asked to rank the device's features based on their perceived level of importance when deciding which device to purchase (RQ2). Comparable to satisfaction levels, 48% of participants considered performance to be the most important factor when making a purchase decision. Reliability (52%), durability (48%) and usability (22%) were the next highly ranked factors. Interestingly, price (30%) and recommendations from healthcare professionals (22%) were ranked the least important factors by most participants, while privacy, security, and customer support garnered mostly neutral sentiments (Appendix Figure A.4).

Most participants (23 out of 27) were found to be uninformed about privacy and security practices (such as password usage and data privacy) associated with the devices, Figure 1 (RQ3). When queried on strategies that could be adopted to enhance user awareness and education on privacy and security issues related to their devices, the most common responses



Figure 1: Participants' responses when asked questions on device privacy and security: *Have you come across any information regarding privacy and security practices (like usage of passwords, and information on data protection) associated with your cochlear implant or hearing aid?* (top) and *What do you believe could be done to enhance consumer awareness and education regarding privacy and security issues associated with cochlear implants or hearing aids?* (bottom)

were receiving regular email updates from manufacturers (18/27) and enhanced data security features in their devices (16/27). Other practices that participants selected included accessibility to online resources and videos (13 out of 27), availability of user-friendly mobile apps and security tips (13 out of 27), more informative user manuals and guides (11 out of 27), improved communication from healthcare providers (9 out of 27), and collaborative efforts with patient advocacy groups (9 out of 27), Figure 1 (RQ4).

4 Discussion

Our study highlights that users of CI and HA devices express a strong satisfaction with their device performance in enhancing their hearing and communication abilities, which significantly influences their decision-making process when purchasing these devices. However, a significant gap in awareness regarding privacy and security practices was evident. Participants expressed interest in obtaining guidance to augment their understanding of privacy and security matters, emphasizing the need for comprehensive knowledge dissemination. Our findings underscore the importance of bolstering privacy and security settings while ensuring user-friendliness, ultimately contributing to the safety and satisfaction of CI/HA device users. Given the increasing integration of wireless technology into CI/HA devices, enhancing user awareness about privacy and security issues related to their auditory prostheses is important. Future work could involve developing educational programs to enhance user knowledge of privacy and security practices, investigating the impact of this awareness on device adoption and usage, and designing more secure and user-friendly features for HAs and CIs. Additionally, exploring the long-term effects of improved privacy measures on user satisfaction and potential regulatory implications could foster valuable collaborations.

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References

- World Health Organization. Deafness and hearing loss. https://www.who.int/news-room/fact-sheets/ detail/deafness-and-hearing-loss, 2021.
- [2] Robert P. Carlyon and Tobias Goehring. Cochlear implant research and development in the twenty-first century: A critical update. *JARO: Journal of the Association for Research in Otolaryngology*, 22:481 – 508, 2021.
- [3] Ulrich Hoppe and Gerhard Hesse. Hearing aids: indications, technology, adaptation, and quality control. *GMS Current Topics in Otorhinolaryngology, Head and Neck Surgery*, 16, 12 2017.
- [4] Theresa Hnath Chisolm, Carole E Johnson, Jeffrey L Danhauer, Laural J P Portz, Harvey B Abrams, Sharon Lesner, Patricia A McCarthy, and Craig W Newman. A systematic review of health-related quality of life and hearing aids: final report of the american academy of audiology task force on the health-related quality of life benefits of amplification in adults. *Journal of the American Academy of Audiology*, 18(2):151–183, 2007.
- [5] Burak Kabiş, Nuriye Yıldırım Gökay, Hakan Tutar, Recep Karamert, and Bülent Gündüz. The challenges encountered by conventional hearing aid and/or cochlear implant users during the covid-19 pandemic. *American Journal of Audiology*, 32(1):81–89, 2023.
- [6] Emily Kay-Rivest, Jamie Schlacter, and Susan B Waltzman. Cochlear implantation outcomes in the older adult: a scoping review. *Cochlear Implants Int*, 23(5):280–290, 2022.

- John Marinelli, Sarah Sydlowski, and Matthew Carlson. Cochlear implant awareness in the united states: A national survey of 15,138 adults. *Seminars in Hearing*, 43:317–323, 12 2022.
- [8] Susana Marcos-Alonso, Cristina Nicole Almeida-Ayerve, Chiara Monópoli-Roca, Guillermo Salib Coronel-Touma, Sofía Pacheco-López, Paula Peña-Navarro, José Manuel Serradilla-López, Hortensia Sanchez-Gomez, José Luis Pardal-Refoyo, and Ángel Batuecas-Caletrío. Factors impacting the use or rejection of hearing aids—a systematic review and meta-analysis. *Journal of Clinical Medicine*, 12, 2023.
- [9] Robyn M. Cox, Jani A. Johnson, and Jingjing Xu. Impact of hearing aid technology on outcomes in daily life i: The patients' perspective. *Ear and Hearing*, 37:e224–e237, 2016.
- [10] Rebecca J Kamil and Frank R. Lin. The effects of hearing impairment in older adults on communication partners: a systematic review. *Journal of the American Academy of Audiology*, 26 2:155–82, 2015.
- [11] Tilottama Mukherjee, Anindita Chaudhuri, Nilanjana Mitra, Dibyangana Biswas, and Sukanya Chowdhury. A delve into the psychosocial experiences of adults with mild to moderate hearing loss using leventhal's selfregulatory model. 02 2021.
- [12] Nader Saki, reza bahadori birgani, Hossein Bagheripour, Soheila Nikakhlagh, Golshan Mirmomeni, Sara Saki, and Arash Bayat. The impact of cochlear implantation on sound quality and quality of life in postlingually deaf adults: A prospective study. *Egyptian Journal of Ear*, *Nose, Throat and Allied Sciences*, 2023.
- [13] Tess Bright and Hannah Kuper. A systematic review of access to general healthcare services for people with disabilities in low and middle income countries. *International Journal of Environmental Research and Public Health*, 15, 2018.
- [14] Helen Goulios and R Patuzzi. Audiology education and practice from an international perspective. *International journal of audiology*, 47:647–64, 11 2008.
- [15] Bolajoko Olusanya, Katrin Neumann, and James Saunders. The global burden of disabling hearing impairment: A call to action. *Bulletin of the World Health Organization*, 92:367–73, 05 2014.
- [16] Nafisa Zarrin Tasnim, Aoxin Ni, Edward Lobarinas, and Nasser Kehtarnavaz. A review of machine learning approaches for the personalization of amplification in hearing aids. *Sensors*, 24(5), 2024.

- [17] Nicholas Lesica, Nishchay Mehta, Joseph Manjaly, Li Deng, Blake Wilson, and Fan-Gang Zeng. Harnessing the power of artificial intelligence to transform hearing healthcare and research. *Nature Machine Intelligence*, 3:840–849, 10 2021.
- [18] Michail Athanasopoulos, Pinelopi Samara, and Ioannis Athanasopoulos. A journey to hear: The evolution of cochlear implants. *Encyclopedia*, 4(1):125–136, 2024.
- [19] Josiah Dykstra, Rohan Mathur, and Alicia D.D. Spoor. Cybersecurity in medical private practice: Results of a survey in audiology. 2020 IEEE 6th International Conference on Collaboration and Internet Computing (CIC), pages 169–176, 2020.
- [20] Capkun Srdjan and Daniel Bodmer. On the security and privacy risks in cochlear implants. 2010.
- [21] Panagiotis Katrakazas and Dimitrios D. Koutsouris. A (lack of) review on cyber-security and privacy concerns in hearing aids. 2018 IEEE 31st International Symposium on Computer-Based Medical Systems (CBMS), pages 223–226, 2018.
- [22] Francesco Di Nocera, Giorgia Tempestini, and Matteo Orsini. Usable security: A systematic literature review. *Information*, 14(12), 2023.
- [23] Paul A. Harris, Robert Taylor, Robert Thielke, Jonathon Payne, Nathaniel Gonzalez, and Jose G. Conde. Research electronic data capture (redcap) - a metadatadriven methodology and workflow process for providing translational research informatics support. *Journal of biomedical informatics*, 42 2:377–81, 2009.
- [24] Paul Harris, Robert Taylor, Brenda Minor, Veida Elliott, Michelle Fernandez, Lindsay O'Neal, Laura McLeod, Giovanni Delacqua, Francesco Delacqua, Jacqueline Brothier, and Stephany Duda. The redcap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, 95:103208, 05 2019.

A Appendix



Figure A.1: Participants demographics. Gender (left) and age-groups of the participants (right).



Figure A.2: Distribution of participants across various brands of cochlear implants and hearing aid devices (left) and duration of device usage among participants (right).



Satisfaction ratings of the features of current cochlear implant or hearing aid

Figure A.3: Survey participants' responses when asked: *How satisfied are you with the features of your current cochlear implant or hearing aid?*



Importance of different factors while making a purchase decision

Figure A.4: Survey participants' responses when asked: When deciding to purchase a cochlear implant or hearing aid, what factors are most important to you? Please rank them in order of importance, with 1 being the most important and 9 being the least important. Please assign a unique rank to each option.