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Cochlear implant recipient volunteer partnerships: perceptions of an adult peer community

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ABSTRACT

Purpose: To describe adult cochlear implant (CI) recipient volunteer partnerships, as perceived by CI volunteers, in terms of support and informational counselling. By exploring the dynamics of these partnerships, valuable insights are gained into the effectiveness of volunteer support systems, contributing to peer-based interventions and the overall well-being of CI recipients navigating the complexities of cochlear implantation.

Materials and methods: Focus group discussions were conducted with eight adult CI volunteers, and qualitative data were thematically analysed.

Results: Four overarching themes were identified: (1) Sharing personal experiences, (2) Information broker, (3) Providing support, and (4) Recommendations for CI volunteer partnerships.

Conclusions: Insights from CI volunteers highlight the value of peer support in enhancing person-centred audiological care. The study identifies a need for structured volunteer involvement in CI programs and marks an initial exploration of CI volunteering and mentoring.

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IMPLICATIONS FOR REHABILITATION

- Collaboration between CI volunteers and hearing healthcare professionals highlights the importance of CI programs providing comprehensive informational counselling.
- Counselling should integrate technical aspects of CIs with personal experiences shared by CI volunteers, addressing both clinical and human dimensions of the CI journey.
- CI volunteers play a critical role in providing emotional support throughout the CI journey, suggesting the need to integrate peer mentoring into rehabilitation programs to sustain CI recipients' psychological well-being.
- CI programs should involve CI volunteers in advocacy efforts to raise awareness and foster supportive CI communities.

The prevalence of significant, acquired hearing loss (HL) is rising annually in adults [1]. When individuals present with severe, profound or moderate sloping to profound sensorineural hearing loss, demonstrate inadequate benefit from conventional (non-invasive) hearing aids [2] and have limited aided speech perception abilities [3], cochlear implants (CIs) might be a viable hearing solution. Therefore, rather than relying solely on the severity of HL, CIs are often considered when speech perception is not adequately improved by conventional hearing aids, regardless of the degree of hearing loss [3]. CIs are electronic devices surgically implanted to bypass the damaged hair cells in the cochlea by directly stimulating the auditory nerve's functional neurons to provide the brain with access to sound [4].

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Adult cochlear implantation results in enhanced speech and auditory perception skills and positively affects adult CI recipients' self-esteem, social functioning, vocational and educational opportunities [5]. Despite the remarkable outcomes that can be achieved, cochlear implantation is a challenging journey, especially in adults who had normal hearing and now have to regain auditory function *via* a CI [6]. Bleckly et al. [7] explored how late-deafened adults reconceptualize their identity following cochlear implantation, revealing diverse identity transformations. While some maintained or regained a hearing identity, others experienced identity confusion, feeling neither fully deaf nor hearing. These findings underscore the impact of self-perception on healthcare decisions and rehabilitation engagement [7].

The CI journey refers to the processes and experiences that patients undergo during the course of HL diagnosis and treatment [1]. Globally, adult CI recipients experience challenges prior to- and during the CI journey, such as concerns about loss of residual hearing, fear of surgery, being uneducated about the process of CI assessment, how the CI device functions and the procedure of eventual cochlear implantation [8]. In addition, they have concerns about leave-of-absence for CI surgery and rehabilitation, the irreversibility of the CI procedure and the status of the sound signal after implantation [9]. Adult CI recipients reported that improved information and communication throughout the CI process aid in overcoming the challenges experienced prior to- and during the CI journey [10]. Furthermore, adult CI recipients value socialising with other CI recipients and obtaining their testimonials [11], as it enables them to obtain first-hand information about CIs and consequently provides increased social support [1]. Literature has reported that CI recipients value access to CI mentors/volunteers during the CI journey and at key points along the journey, such as during referral for CI candidacy assessment [1]. While volunteering in healthcare offers many benefits, its impact varies by culture. In societies where hearing loss is stigmatised (such as the hard of hearing community), volunteers can help reduce stigma and encourage CI acceptance [3]. However, CI outcomes can vary, and some adults may not benefit, with factors like device settings, surgical placement, and individual characteristics influencing results [3]. In rare instances, certain hearing loss aetiologies or a history of prelingual hearing loss may be associated with reduced long-term device use [3]. Volunteering is often described as offering help and time to others without pay [12]. Individuals personally affected by a disaster or tragedy tend to identify more strongly with it, making them more likely to volunteer than those less affected and with weaker identification [12]. Volunteer activities encompass peer education, sharing information to influence behavioural changes and peer support, providing physical, social and emotional assistance based on shared experiences [13]. Thus, imagining the adverse circumstances of others may enhance the desire to volunteer [12]. Volunteer programs offer essential non-medical care and play a crucial role in overcoming staff- and resource barriers in patient care [14]. In general, volunteering in health care is shown to have several benefits, such as facilitating improvements in patient-professional interactions and relationships, filling the gaps in service provision and delivering services which are more responsive to patients' local needs [15].

Within the field of cochlear implantation, adult CI recipients value access to other CI users [10] and are also shown to be motivated after implantation to assist other CI recipients in their CI journey, and consequently gain a sense of empowerment in return [1]. Fortunately, within the field of cochlear implantation, CI manufacturers attempted to become focal points for the adult CI peer community by designing volunteer programs that address the need of adult CI recipients to have access to CI advocates/users. These volunteer programs include *the Bionic Ear Association (BEA) Mentor's Programme* facilitated by Advanced Bionics, the *Cochlear^{TM} Volunteer Program* facilitated by Cochlear, and the *HearPeers Mentor Programme* facilitated by MED-EL [16]. All three of these programs strive to provide support to CI recipients throughout their CI journey by connecting them to someone who had a similar experience with hearing loss and consequent CI treatment [16]. The volunteers from the current study were skilled and experienced with a Cochlear™ hearing solution and willing to assist Southern ENT and Cochlear™ without any compensation.

Patient care in healthcare service delivery models has shifted from a practitioner-centred to a patient-centred approach [17]. ASHA [18] defines patient-centred care (PCC) as actively involving individuals with HL in the management of their condition, leading to improved outcomes across various health conditions, including HL [19]. PCC fosters patient empowerment and independence throughout the hearing care journey [20]. Athalye et al. [21] found that CI recipients prefer service delivery based on joint decision-making between the healthcare team and the user. Consequently, services for adult CI recipients should integrate scientific evidence, patient values and clinical expertise [17]. This approach promotes empowerment, shared control and active involvement in decision-making and HL management [22].

Despite the transformative impact of cochlear implantation on individuals with HL, a clear understanding of the dynamics within CI recipient volunteer partnerships remains limited and the motivations, challenges and perceived benefits of such partnerships remain underexplored. Hence, the outcomes- and perceptions of those who joined these volunteer programs have not yet been reported in the literature. Although the positive impact of CI volunteering and mentorship has been widely acknowledged on social media platforms, there remains a dearth of published evidence in this type of research regarding volunteerism [23] and how CI volunteers and adult CI recipients perceive these partnerships. A greater understanding of how CI recipients perceive CI volunteer partnerships should inform evidence-based audiological service delivery within a person-centred care (PCC) framework since, throughout the CI journey, CI recipients prefer service delivery that is based upon decisions that are jointly made by the CI team and the CI user [21]. Consequently, this study aimed to describe CI recipient volunteer partnerships as perceived by CI volunteers. By unravelling the intricacies of these partnerships, valuable insights into the effectiveness of volunteer support systems can be provided, contributing to the enhancement of peer-based interventions and the overall well-being of CI recipients.

Materials and methods

Study design

This study employed a descriptive, qualitative design, and data were collected through focus group discussions. Within the field of audiology, qualitative approaches to research are increasingly utilised, as they provide better insights into the perspectives of individuals with hearing loss [4]. Furthermore, focus group discussions enable the incorporation of participants' own concerns and experiences, making focus groups a gold standard in person-centeredness [24]. This qualitative research paradigm facilitated an in-depth exploration of CI volunteers' perspectives, fostering participant interaction and discussion. Ethical clearance was obtained from the Research and Ethics Committee of the Faculty of Humanities, University of Pretoria, South Africa (HUM036/0522). Written informed consent was provided by all participants before the commencement of data collection. Furthermore, this study was conducted with the understanding that the experiences of individuals with hearing loss are diverse and multifaceted. We recognise the importance of cultural and social factors in shaping attitudes towards hearing impairment and we have approached the research with respect for the autonomy and perspectives of these communities.

Participants

A specific cohort population, namely adult (≥18 years of age) CI recipients, was included in this study and was sampled using non-probability, purposive sampling. Five South African CI volunteers were recruited from the South Africa Cochlear™ Global Volunteer Program in partnership with Southern ENT, and three United Kingdom CI volunteers from the United Kingdom Cochlear™ Global Volunteer Program. Cochlear™ is a medical device company and a global leader in implantable hearing devices [25] and Southern ENT the sole distributor of Cochlear™ hearing devices in South Africa. The *Cochlear™ Global Volunteer Program* developed by Cochlear, strives to provide hearing implant recipients and candidates with the opportunity to speak and meet with someone "like them" by training volunteers to support them along their hearing journey [25]. According to the *Cochlear™ Global Volunteer Handbook*, a Cochlear Volunteer is defined as an individual who has experience with a Cochlear™ hearing solution, is willing to freely assist Southern ENT and Cochlear™ in attaining their mission without compensation and is accepted by Southern ENT and Cochlear™ to participate in the Cochlear™ *Global Volunteer Program* (Supplementary Appendix B).

To join the *Cochlear™ Global Volunteer Program*, CI volunteers were required to complete and sign the "*Volunteer Expression of Interest Form*" (Supplementary Appendix B). Thereafter, when their application was successful, they were approved by Southern ENT and Cochlear™ to participate in the *Cochlear™ Global Volunteer Program* [25]. Therefore, the participating adult CI volunteers were skilled and experienced with a Cochlear™ hearing solution (CI devices specifically) and approved by Cochlear™ as a "Cochlear Volunteer" through quality controls and standardised checks.

All participants were literate and competent in English, as all data collection procedures were conducted in English. Three participants were experienced in providing volunteer support (had more than three years volunteering experience) and five were newly trained, with limited experience in providing volunteer support (less than one year volunteering experience). The self-reported characteristics of the CI volunteers who participated in this study are summarised in Table 1.

Data collection material and procedures (focus group discussions)

Three focus group discussions were undertaken for this study: two sessions involved South African CI volunteers, with three and two participants respectively, and one session included United Kingdom CI volunteers, with three participants. Prior to the commencement of the focus group discussions, participants were required to provide informed consent and to complete a demographic questionnaire. The quantitative data obtained from the demographic questionnaire provided the researcher with participant background information and assisted in contextualising the collected data for more effective data analysis [26].

The Cochlear™ volunteer managers from the *Cochlear™ Global Volunteer Program* in South Africa and the United Kingdom received an informed consent letter detailing the study's purpose and rationale. Both volunteer managers granted permission to recruit CI volunteers from the program. CI volunteers meeting the selection criteria were approached by the SA and UK volunteer managers and invited to participate. The contact details of CI volunteers who agreed to participate were then provided to the researchers. CI volunteers who indicated they were willing to participate in the study were contacted three to four weeks before the focus group discussion to establish a date and time for the discussion. A week prior to the discussion, participants were contacted again to confirm their attendance. One focus group discussion with South African CI volunteers was held in-person/face-to-face at the Department of Speech-Language Pathology and Audiology, University of Pretoria, and the remaining two focus group discussions (one with South African CI volunteers and one with United Kingdom CI volunteers) were conducted online *via* the Microsoft Teams meeting platform.

The primary researcher/principal investigator (CD) acted as moderator for each focus group discussion and created an environment where participants felt comfortable expressing their views. Follow-up prompts were used when needed. The notetaker (TIR or LP) was responsible for operating the recording device and objectively making notes during the discussion to ensure that no verbal or non-verbal

Table 1. Self-reported characteristics of participating cochlear implant volunteers ($n = 8$).

Participant characteristics	n (%)
Mean age at data collection (years)	59 years (SD: 11.5, range 42–75 years)
Gender	
Female	6 (75%)
Male	2 (25%)
Mean duration of CI use at the time of data collection	5 years (SD: 2.6, range: 3–10 years)
• Participant 1	3 years
• Participant 2	10 years
• Participant 3	3 years
• Participant 4	5 years
• Participant 5	3 years
• Participant 6	8 years
• Participant 7	6 years
• Participant 8	6 years
Employment status	
Employed	5 (63%)
Not employed	3 (37%)
Cochlear implant configuration	
Bimodal (cochlear implant with hearing aid in the non- implanted ear)	4 (50%)
Bilateral (cochlear implants in both ears)	3 (37%)
Unilateral (cochlear implant with no hearing aid in the non-implanted ear)	1 (13%)
Onset of hearing loss	
Congenital/ early onset	3 (37%)
Acquired	5 (63%)
Nationality	
South Africa	5 (63%)
United Kingdom	3 (37%)

information was overlooked or forgotten. A focus group guide was employed for each discussion (Supplementary Appendix A) to capture diverse perspectives on the research topic and to foster a comfortable environment for participants to articulate their views [27]. Additionally, the guide ensured consistency across the different focus groups [28]. The focus group guide contained one introductory-, three guiding- and one concluding open-ended questions that were carefully designed and determined with input from the South Africa Cochlear™ volunteer manager from the *Cochlear™ Global Volunteer Program*. The content of the questions asked to participants was based upon specific themes (support and informational counselling) related to the research aim.

The duration of each focus group discussion was approximately 60–90 min. Each discussion was audio-recorded and transcribed verbatim. Given that all the participants presented with significant hearing loss, effective communication strategies for individuals with hearing loss were utilised during each discussion to prevent any communication breakdown, thereby facilitating optimal communication [29]. Real-time subtitles were presented on Microsoft Teams during the online focus group discussion by using the "Turn on Live Captions" setting. Printed questions were provided before the commencement of each in-person focus group discussion for additional visual support [1]. Data collection continued until saturation was reached, signified by the absence of new codes in the focus group data and new emergent themes compared to previous sessions [30]. After each focus group discussion, participants received a verbal summary of the session content, allowing them to engage in critical discussion and summarise the key points and occurrences to ensure the accuracy of interpretation.

Data analysis

A Microsoft Excel spreadsheet was used to capture the participants' demographic data as obtained from the demographic questionnaire, and analysed descriptively using descriptive statistics (frequency counts, means and standard deviations) to describe the sample population. For the transcription process, "Otter.ai" was used to generate initial verbatim transcripts of the focus group discussions. These transcripts were then manually reviewed and refined for accuracy. Thereafter, the qualitative data obtained from each focus group discussion were analysed using Braun and Clarke's Reflexive approach to Thematic Analysis [31] as outlined in Table 2. Despite the focus group discussions being recorded, the transcribed notes did not contain any information that allowed individual participants to be linked to specific statements, thereby ensuring confidentiality. Reliability and validity were assessed by sharing the coding manual/transcripts with an experienced qualitative data analyst (TIR). The study results were subsequently verified, discussed and interpreted. The researchers addressed inter-coder discrepancies and achieved data saturation by generating new codes collaboratively.

Results

The inclusion of information in this research article was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ-32) checklist. This approach was employed to augment the focus groups' data comprehensiveness, rigour and credibility, ensuring thorough- and transparent reporting among the researchers [32]. During the focus group discussions, the CI volunteers shared diverse and meaningful perspectives on CI volunteer partnerships. Four primary themes were identified from which fourteen specific subthemes emerged, as illustrated in Figure 1.

A comprehensive explanation of these themes and subthemes, including excerpts from the focus group discussions, is provided in the following section.

Theme 1: sharing personal experiences

This theme encapsulates the perspectives of CI volunteers regarding their personal encounters with CIs and underscores the valuable insights these volunteers can contribute to facilitating the cochlear implantation process for future CI recipients. Four distinct subthemes emerged within this theme, each representing unique perspectives related to personal experiences.

Table 2. Six-phase process to reflexive thematic analysis according to Braun and Clarke [30].

Phase	Name	Researcher(s) involved:	Description
Phase 1	Data familiarisation	Primary researcher (CD)	During this phase, the author familiarised herself with the data by: • Listening to all the audio-recordings once before transcribing each recording. • Thereafter, transcribing each audio-recording verbatim and then reading, and re-reading the transcripts. • Making notes on the initial analytical insights and observations concerning each data item (focus group guide) and in relation to the dataset. This also included the identification of any omissions or errors in the transcripts and to correct them as much as possible.
Phase 2	Coding the data	Primary researcher (CD)	During this phase, data were organised systematically and meaningfully by generating concise labels (codes) that capture important aspects of the data and address the research question. It involved the following: • Inductive coding of the entire data set with two or more rounds of coding. • Thereafter, relevant data extracts and all the codes were combined for the later stages of data analysis.
Phase 3	Generating initial themes	Primary researcher (CD)	This phase involved the following: • Examining the combined data and codes to start developing potential themes. • Thereafter, data relevant to each potential theme were combined to review the viability of each potential theme.
Phase 4	Developing and reviewing themes	Primary researcher (CD) Notetaker (TIR)	During this phase, the potential themes were reviewed against the coded data as well as with the entire data set. This was done to ensure and determine whether the potential themes address the research question. Therefore, themes were further developed, discarded, or combined during this phase.
Phase 5	Defining, refining, and naming themes	Primary researcher (CD) Notetaker (TIR)	This phase involved: • The development of a detailed analysis of each theme. • Deciding on an informative name for each theme. • Determining the focus and scope of each theme. This phase also included the recognition of any possible subthemes and how they relate to- and interact with the main theme.
Phase 6	Write-up of results	Primary researcher (CD) Notetaker (TIR)	All the data extracts and analytic narratives were collated during this phase. The analysis was also contextualised in relation to current literature.

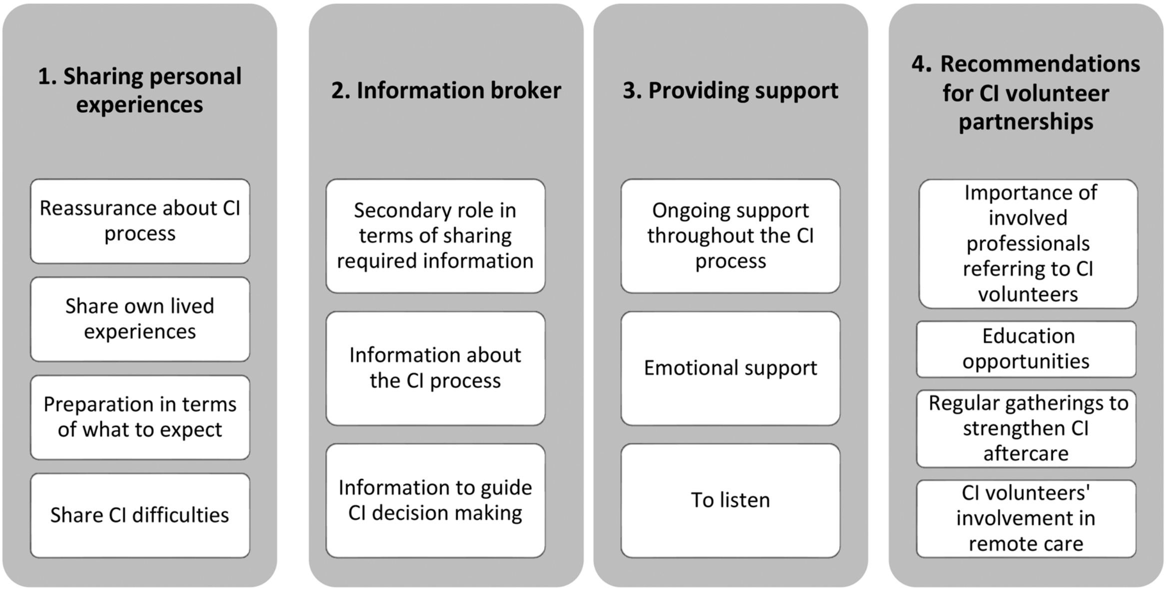

Figure 1. The generated themes and subthemes from the focus group discussions.

Subtheme 1.1: reassurance about the CI process

Several CI volunteers emphasised their ability to draw upon personal experiences with a CI to offer reassurance to prospective CI recipients who are apprehensive and uncertain regarding the CI process. By acknowledging the common fears and uncertainties, CI volunteers position themselves as channels of reassurance. By sharing the details of their personal journeys, CI volunteers aim to alleviate concerns and instil confidence in future CI recipients, providing them with first-hand insights and perspectives that serve to demystify the CI process.

> "You get all sorts of questions about what the operation was like. Mine was 6 years ago, and when I woke up from the operation, I thought it hadn't been done because I couldn't feel anything. And they found that hard to believe. Lots of people are concerned about the operation, so I think it's important to have people who've had implants talking to candidates - I think that's very important."

> "I have found that after some people had their implants, they find certain things difficult and then I can give them the benefit of my experiences. And that gives them a lot of reassurance to cope with their own problems."

> "It is nice to speak to someone to have that reassurance that it is not a scary experience…" (participant 1)

CI volunteers reported that it is also important to share the positive outcomes of cochlear implantation in order to create excitement and expectation in terms of what prospective CI recipients can expect.

> "…give them just something to look forward to or motivate them and assist them and show them there's a lot more that they can look forward to than the position that they were in." (participant 5)

> "…make them excited to continue with this whole process…" (participant 4)

Subtheme 1.2: share own lived experiences

CI volunteers conceptualised CI volunteer partnerships as a platform for imparting their personal encounters with CIs to prospective CI recipients. A prevalent sentiment among CI volunteers is the belief that the act of sharing their own lived experiences proves to be both beneficial and persuasive for current and prospective CI recipients. This sub-theme underscores the pivotal role played by first-hand narratives in the peer support dynamics.

> "…giving them guidance and support from a personal viewpoint. I think I was once told that we actually humanise it." (participant 2)

> "Yes, you have your audiologist and the ENT that can assist, but, that personal experience is important." (participant 3)

CI volunteers made it clear that they are not involved in CI decision-making, but that they rather make their personal experiences available to prospective and current CI recipients.

> "I mean, we are never involved in which implant they should accept… We just make our experiences available to people." (participant 6)

CI volunteers further conveyed the dissemination of their own insights into CIs and the knowledge they have acquired, drawing from their personal experiences as experienced CI users throughout their CI journey.

> "… by sharing … what we know and what we learned throughout this process…" (participant 8)

> "… how we can enrich their lives… with our knowledge that we've gain." (participant 4)

Subtheme 1.3: preparation in terms of what to expect

By sharing their personal experiences, CI volunteers reported that they could help prospective CI recipients prepare for cochlear implantation by setting expectations for both the CI procedure and the sounds they can expect to hear with their newly activated CI device(s). For CI recipients who have acquired hearing loss and still retain memories of sound, shared experiences are crucial in setting realistic expectations regarding hearing improvements.

> "…to make it easier for a future CI recipient to know what is waiting for them…" (participant 1)

> "But, especially to guide those future recipients in what to expect…" (participant 6)

> "We can give advice on what to expect when the CI device is switched on…" (participant 3)

> "I think it is important to especially give people who acquired a hearing loss later in their life, realistic expectations about what to expect from hearing with a CI." (participant 7)

Recognising the unique value of first-hand insight and relatability, CI volunteers assert that the most effective source for conveying expectations related to the CI experience is an individual who has undergone cochlear implantation themselves.

> "The doctors, audiologists and the clever people…, with all respect, they can tell you what to expect, but the people to best explain what to expect is an actual CI recipient whose already has gone through that process…" (participant 2)

> "I didn't have anybody to speak to and I didn't know what to expect, so the CI operation was terrifying, because I didn't know what to expect. Thereafter, I reached out to other people with cochlear implants. It helps to speak to somebody about what to expect." (participant 5)

CI volunteers emphasised the importance of sharing personal experiences regarding the CI process and device outcomes. This can help establish realistic expectations post-implantation, addressing any potential disparities between expectations and actual outcomes.

> "…how did I experience the process… and how does that correlate in terms with the process - as it was explained, and what actually happened. Because, there might be a difference between the two." (participant 4)

> "…the outcome which I had I want to share with the future recipients, so that he/she is realistic about expectations. That is important." (participant 3)

Subtheme 1.4: share CI difficulties

Given the array of emotions associated with cochlear implantation, CI volunteers emphasised the significance of also sharing their personal experiences, including the difficulties they've encountered throughout the CI process.

> "Just to share… all the difficulties, because there's a lot of stuff that you go through and a lot of emotions." (participant 6)

> "There's a lot that you go through and a lot of unknowns." (participant 8)

Theme 2: Information broker

CI volunteers believe that, within CI volunteer partnerships, their role is not primary when it comes to supplying information about audiological service delivery. Instead, they recognise their capacity to share personal experiences related to the CI process and focus primarily on providing guidance during the decision-making process concerning CIs. This theme captures the viewpoints of CI volunteers regarding their informational contribution within the context of audiological service delivery and CI volunteer partnerships. CI volunteers believe that CI device-related information and technical support should be provided by the hearing healthcare professionals involved. The following three subthemes illustrate these perspectives in terms of providing information to CI recipients.

Subtheme 2.1: secondary role in terms of sharing required information

CI volunteers perceive their role in sharing necessary information about CIs as secondary to that of hearing healthcare professionals. Providing essential information about CIs such as maintenance, care and the technical aspects thereof to CI recipients, remains the primary responsibility of hearing healthcare professionals.

> "It's my humble opinion that in terms of providing information, I have a secondary role. The primary role is with the ENT surgeon, the audiologist and CI team. We are not the medical experts. We receive training and we should have some background, but I don't see it as my primary role to provide information." (participant 1)

CI volunteers noted that their role in providing information about the CI process is confined to sharing their personal experiences. The primary responsibility for disseminating information about the CI process remains with hearing healthcare professionals.

> "…what is the actual process? That should actually be explained by either the ENT surgeon and/or the audiologist. I can just add sort of what I went through." (participant 3)

> "…the CI process, … the steps before the actual implant, although that should have been covered by the medical people." (participant 5)

In addition, CI volunteers perceive their role in providing necessary information during CI decision-making as secondary to that of the hearing healthcare professionals. CI volunteers believe that it is the primary responsibility of the engaged hearing healthcare professionals to share essential information with CI recipients in the context of decision-making for CIs.

> "We are not qualified to advise people on which CI they should go for." (participant 4)

> "It's not for us to recommend or disagree with any of the experts…" (participant 7)

The majority of CI volunteers viewed their role in offering CI device-related information and technical support as secondary to that of hearing healthcare professionals. They emphasised that hearing healthcare professionals are primarily responsible for providing CI device-related information and technical support. While CI volunteers are willing to share their personal experiences with their CI devices, they do not feel equipped to provide technical support or CI device-related information.

> "…we do have Southern ENT as a backup to assist us with any technical or detail that we might need to share." (participant 8)

> "The audiologist should be giving the technical support/information mostly…" (participant 5)

> "…anything sort of technical I do urge them to go and speak to the clinic. I'm not qualified and it's a different sort of relationship I'm trying to build with those people." (participant 4)

> "I can't provide any technical information. I'm not qualified to do so." (participant 2)

Nevertheless, CI volunteers have conveyed their eagerness to share the resources at their disposal with potential CI recipients. Their goal is to assist individuals in obtaining accurate information about CIs and establishing connections with hearing healthcare professionals, ultimately contributing to a more seamless CI journey for those individuals.

> "If they struggle with something, I would assist them to get to the right people." (participant 3)

> "…just show them where to go. Just give them the right contact information and the people to talk to." (participant 1)

> "So I think just use those resources that's available to you and to share them if they don't know where to go and look for or where to go and search on the Cochlear website to get all those technical details that they need to know about." (participant 7)

Subtheme 2.2: information about the CI process

CI volunteers expressed their willingness to share insights from their personal experiences with the CI process with future CI recipients. This information encompasses positive outcomes, challenges faced during the CI process, approaches to managing the process and setting realistic expectations.

> "…how did I experience the process, did it go well, or were there hiccoughs and so on." (participant 8)

> "to guide those future recipients about the process of CI and how to handle it." (participant 6)

> "Provide information in terms of the actual process, what you went through…" (participant 7)

Subtheme 2.3: information to guide CI decision making

CI volunteers expressed their readiness to offer guidance and share information derived from their personal experiences when making decisions about CIs. Their intention is to support CI recipients in the decision-making process by providing relevant information and guidance regarding CIs.

> "We need to not tell them what to do but sort of guide them into helping them make decisions that they are happy with." (participant 1)

> "…people who are trying to make up their minds which then go along to meet us and ask questions." (participant 3)

> "…just helping people know what their options and possibilities are." (participant 4)

Theme 3: providing support

CI volunteers view the CI volunteer partnership as a means of providing support to prospective CI recipients. This theme encompasses the perspectives of CI volunteers regarding the support they can provide to facilitate the CI process for these individuals. The following three subthemes represent these perspectives regarding the specific type of support a CI volunteer can provide.

Subtheme 3.1: ongoing support throughout the CI process

CI volunteers have repeatedly emphasised the significance of providing continuous support throughout the CI process. The importance of having a supportive presence throughout the entire CI journey is considered a fundamental principle in CI volunteer partnerships.

> "Just to be there through the whole process and not letting them down in the middle of the whole process, but to see through to the end." (participant 2)

Subtheme 3.2: emotional support

CI volunteers shared that having emotional support during their own CI process would have significantly eased their experiences. Consequently, they consider the provision of emotional support by a CI volunteer to a potential CI recipient as crucial throughout the entire CI process.

> "The support is amazing that you can get from people and it's a lot to go through. So, I think if I had the emotional support, it would have been easier for me." (participant 8)

> "Having someone there after the operation would have been important for me, which I didn't have. So, I think emotional support is important." (participant 7)

Moreover, CI volunteers highlighted that they can act as "personal support" for individuals who lack emotional assistance or aid from relatives. They are readily available for those in need of a sympathetic ear or a shoulder to lean on.

> "…just be there for someone who maybe doesn't have anybody." (participant 5)

> "…you can be the person support - someone you can message and speak to." (participant 1)

CI volunteers are of the belief that providing support is beneficial, especially in terms of offering comfort and alleviating the CI process for recipients who may be emotionally distressed.

> "…give support or comfort them when they are down." (participant 3)

> "I can assist them and help them to keep calm…" (participant 4)

Subtheme 3.3: to listen

Having someone to listen to your concerns, thoughts and beliefs throughout the CI process was also identified as a key factor in providing support to CI recipients, as reported by the CI volunteers.

> "…just to be there and to listen, share and assist where I can." (participant 7)

> "It's best if we can listen to the people and listen to their concerns and then respond accordingly." (participant 8)

CI volunteers also emphasised their capacity to serve as a sounding board for CI recipients during the adjustment phase when they are adapting to living with their CI. They are available whenever recipients need to share any concerns encountered with their CI device or throughout the CI process.

> "You can also be sort of a sounding board for the person in the adjustment phase…" (participant 6)

> "…unload some of the things that are on their minds and that they're concerned about." (participant 1)

Theme 4: recommendations for CI volunteer partnerships

CI volunteers provided numerous meaningful and insightful recommendations regarding CI volunteer partnerships for future prospects and efficacy. This theme outlines the recommendations made by the CI volunteers, and the following four subthemes provide detailed insights into these recommendations.

Subtheme 4.1: importance of involved professionals referring to CI volunteers

CI volunteers emphasised the importance of multidisciplinary teamwork when referring CI recipients to CI volunteers. The involvement and engagement of hearing healthcare professionals are deemed necessary for the efficacy of CI volunteer partnerships.

> "…the ENT surgeon or the audiologist should inform the future recipient that there is a programme where you can contact somebody…" (participant 2)

> "…how many of those patients were told about the volunteers and offered the opportunity to engage with a volunteer…" (participant 5)

Subtheme 4.2: education opportunities

CI volunteers have also communicated a future prospect of CI volunteering, which involves offering support to both teachers in educational settings and learners with CIs. They aim to achieve this by sharing their personal experiences, recognising that teachers may have limited knowledge about CIs and how to optimise the learning environment in the classroom for students with CIs.

> "I think another role we can play, if it's wanted, is to offer support to teachers and students to present a user view – especially people working with children, because there are some of the pitfalls and difficulties, particularly. So, it's sort of sharing experience, but I do think we've got things to offer in that sort of field as well." (participant 6)

Another future prospect mentioned by CI volunteers is providing guidance and support from a personal viewpoint to hearing healthcare professionals, considering that these professionals may have limited knowledge about CIs.

> "…another thing I've quite been involved with is zoom calls with audiology departments, because it's quite surprising how little audiologists know about cochlear implants. So that's something I've been involved with answering their questions…" (participant 7)

> "…it's also with the hearing professionals as well, giving them guidance and support from a personal viewpoint." (participant 8)

Subtheme 4.3: regular gatherings to strengthen CI aftercare

CI volunteers highlighted the importance of regular follow-ups for CI recipients to monitor their performance with their CI device. They emphasised the need for explanations or orientations if any difficulties arise. A suggested future initiative in CI volunteering involves organising regular gatherings with CI recipients to provide ongoing support and enhance aftercare for their CI devices.

> "So many people are elderly when they get their implants, and they all dropped through the system for various reasons. So, we're going to try and strengthen the system by using volunteering. One of it was to have coffee mornings to which people who were in the pipeline to get an implant or referred for one, could go to listen to other people in the groups. There would be a hearing therapist or rehabilitation therapist in charge, and they would do some sort of discussion." (participant 1)

> "…there isn't that follow-up and explanation of how to wear them, especially with older people." (participant 4)

Subtheme 4.4: CI volunteers' involvement in remote care

A CI volunteer mentioned that a future prospect of CI volunteering is to provide remote care to CI recipients, involving CI volunteers as part of this initiative.

> "But the main thrust would be to support people through remote checks and then remote tuning in due course, so I thought, well, if you've got somebody sitting beside you - this might be a trained volunteer or

> technician who has a remote phone or console, which a lot of people don't have - and say, yes, that's what we do and listen to them. And if you're worried, you say yes, you need to go back to the clinic with that or no, that's fine, everybody has that problem. So, we're working towards introducing that…" (participant 8)

Discussion

The study highlights the invaluable contributions of CI volunteers in providing holistic support to CI recipients and suggests strategies to improve collaboration among CI volunteers, hearing healthcare professionals and CI recipients for improved rehabilitation outcomes and the delivery of PCC. CI volunteers play essential roles by sharing personal experiences, providing emotional support and serving as information resources throughout the CI process. However, it is important to acknowledge that this study captures only the perspectives of CI volunteers, not those of the CI recipients who receive their support. Consequently, the findings do not provide insights into the practical impact of volunteer contributions from the CI recipients' point of view.

The study findings align with existing literature, which emphasises the importance of peer support in healthcare settings [1]. Within the context of cochlear implantation, peer support is considered an important element of patient care, aiming to increase access to reliable information and uptake of appropriate CI referrals and to ease the patient's transition to CIs [1]. However, some distinctions arise, particularly in CI volunteers' secondary role in providing CI-related information, underscoring the need for a nuanced understanding of their contributions to the CI process and journey. CI volunteers who participated in this study emerged as valuable resources, providing diverse insights into their roles in CI volunteer partnership and their perceived impact on individuals undergoing the CI journey. The four main themes: "Sharing personal experiences", "Information broker," "Providing support" and "Recommendations for CI volunteer partnerships," collectively shed light on how CI volunteers contribute to person-centered audiological service delivery.

One of the primary roles of the CI volunteers as identified in this study, is the sharing of personal experiences. CI recipients' perceptions of cochlear implantation are commonly influenced by their experiences with other CI recipients [33]. Many CI recipients find engaging with other CI recipients helpful, seeking practical advice and real-life perspectives through social groups, community connections and online sources [33]. A study by McRackan et al. [24] suggested that the pre-implantation expectations of CI recipients could influence their quality of life after CI surgery. Hence, it is important that hearing healthcare professionals prioritise the assessment of prospective CI recipients' expectations prior to implantation [24]. However, this study's results confirmed that the CI volunteers who participated in this study recognise the power of lived experiences in humanising the CI journey, providing prospective CI recipients with relatable insights. By offering narratives about their own experiences of the CI process, the CI volunteers from this study aim to prepare prospective CI recipients for what can be expected, ensuring realistic expectations and dispelling fears related to surgery and post-implantation challenges.

Recognising the unique value of first-hand insight and relatability, CI volunteers in this study emphasised that the most effective source for conveying expectations relating to the CI experience is an individual who has undergone cochlear implantation themselves. Meeting other CI recipients and hearing their testimonials strongly facilitate potential CI candidates considering CIs [11]. This perspective highlights the perceived efficacy of peer support, emphasising the importance of shared lived experiences in providing nuanced guidance and understanding for those considering- or undergoing cochlear implantation. The emphasis on social interactions with other CI recipients and access to testimonials underscores the crucial role of peer support [1,11].

Moreover, CI volunteers play a pivotal role in providing reassurance, particularly as adult CI recipients often report a lack of education about the CI assessment process [8]. By acknowledging the common fears and uncertainties surrounding the CI process, the participating CI volunteers act as a source of comfort, instilling confidence and demystifying the surgical- and adjustment phases. As confirmed by the results obtained in this current study, the positive and negative CI aspects shared by CI volunteers serve not only to inform, but also to inspire and motivate future CI recipients, by emphasising positive outcomes and the transformative impact of CI on their lives. Sharing positive outcomes has been shown to be influential in encouraging hearing aid users to consider CIs for enhancing their auditory skills, as observed in the findings of Dowell et al. [34].

In the context of CI support, the participating CI volunteers play a central role in sharing personal experiences while acknowledging the importance of information provided by hearing healthcare professionals. The participating CI volunteers position themselves as complementary sources rather than replacements for medical experts, with a focus on guiding decision-making during the CI process and referring CI recipients to relevant resources or professionals for technical CI device-related details. CI recipients place a high value on the source of information, underscoring the importance of having diverse and high-quality resources available [2]. Pryce et al. [33] and Vieira et al. [35] have demonstrated that access to information plays a critical role in the CI decision-making process, providing participants with hope, strength and motivation to continue their CI journey. Importantly, CI recipients' perceptions about CIs are significantly influenced by information received from various sources, including healthcare professionals, peers, and the media [4].

The collaborative approach between CI volunteers and hearing healthcare professionals ensures that CI recipients receive a comprehensive understanding of the CI process. CI volunteers in this study underscored the primary role of medical experts in providing technical CI-related information, showcasing a clear understanding of their own scope of expertise and responsibilities within the prospective patient's CI journey. Audiologists specifically play a pivotal role as the first point of introduction to CIs [1], therefore comprehensive written and verbal CI related information provided by CI teams is crucial to align expectations with reality [35], with audiologists acting as key gatekeepers [36]. Recognising the potential challenges in the CI journey, improved communication and information-sharing are deemed essential [10]. Both patients and hearing healthcare professionals express the importance of access to CI information and support, with some healthcare providers admitting a lack of confidence in their knowledge about CIs [9]. This collaborative and comprehensive approach aims to address the multifaceted needs of individuals undergoing the CI process.

Numerous discoveries within this study substantiate the significance of emotional support that should be provided to prospective- and newly implanted CI recipients throughout the CI journey. The participating CI volunteers are instrumental in providing consistent and ongoing support, particularly emotional support. CI volunteers provide essential personal support for individuals who may lack support and assistance from their relatives. During the CI adjustment phase, CI volunteers from this study prioritise listening and acting as sounding boards. This emotional support is deemed essential for easing the overall CI experience and aiding CI recipients in navigating the challenges associated with adapting to life with a CI. In a study by Rapport et al. [1], adult CI recipients reported that the opportunity to offer and receive support creates a sense of empowerment for CI recipients. Furthermore, feeling supported is vital in helping patients come to terms with changes in their hearing loss and needs [1]. Mindful emotional support and counselling is pivotal in facilitating the adjustment process for CI recipients and are emphasised as integral components for achieving optimal outcomes [37]. A study by Gfeller et al. [38], exploring adult CI recipients' perspectives on music in daily life, unveiled the essential roles of personal motivation and social support in fostering self-initiated rehabilitation efforts. The results from this study emphasised the importance of CI recipients' attitudes and behaviours in optimising CI benefits beyond basic device maintenance and programming [38]. Support for CI recipients is identified as a necessity at earlier stages of the CI journey [1]. Support from other sources, such as family and friends, plays a significant role in CI recipients' ability to cope during the CI journey [33]. In summary, the findings of this current study collectively stress the enduring role of CI volunteers in providing emotional assistance and highlight the broader importance of emotional support from various sources in optimising the CI experience.

The participating CI volunteers offered insightful recommendations for the enhancement of CI volunteer partnerships. They stress the importance of involved professionals referring prospective- and current CI recipients to CI volunteers, emphasising the need for multidisciplinary teamwork. Such a collaborative CI approach is acknowledged for fostering enhanced understanding among CI recipients and their families regarding the broader implications of cochlear implantation and optimal strategies for seamless integration of the CI device into daily life [4]. Educational opportunities for both teachers and school-going learners with CIs have also been proposed by the CI volunteers in this study, showcasing a forward-looking approach to expanding the impact of CI volunteering. A study by Punch et al. [39] found that teachers reported a lack of liaison with CI clinics and insufficient professional development about CIs. Close liaison between CI centres and teachers has thus been deemed essential to ensure the best management and continuing use of CIs [39]. Recognising the value of ongoing follow-ups and support for CI recipients, CI volunteers suggested regular gatherings with CI recipients with the purpose of strengthening CI aftercare.

The initiative of CI volunteers' involvement in remote care emerged as a potential avenue to provide continuous assistance and support to CI recipients, especially in situations where in-person visits may be challenging. This has implications for enhancing accessibility to CI support and care, particularly for individuals who may face barriers to frequent in-person interactions. These recommendations by the participating CI volunteers align with the findings of Rapport et al. [1], who explored the hearing healthcare experiences of older adults with severe SNHL on their journey to CI. The study highlighted the significant role played by non-specialist professionals in the context of CI support [1]. It underscored the importance of documenting both patient and professional desires for enhanced support, increased educational opportunities about CIs for professional growth, and improved access to referral resources developed in collaboration with CI specialist teams [1]. In this study, CI volunteers emphasised the need for improved education to empower adults with HL in understanding their intervention options earlier on, ensuring access to improved information, and advocating for enhanced CI services. Similarly, study results also highlighted the importance of health promotion campaigns to raise awareness of HL and the necessity for an improved support infrastructure and services [1].

A strength of this study is the established Cochlear™ Global Volunteer Program, which enabled quicker rapport building among participants. This familiarity with each other led to increased attendance during the focus group discussions [40], which in turn fostered spontaneous discussions and shared experiences [41]. Furthermore, the insights gained from this study may inform improvements in patient care and support programs, suggesting potential areas for expanding volunteer initiatives in the field of cochlear implantation. CI rehabilitation programs can offer a more holistic range of information, including technical details about CIs as well as personal experiences shared by CI volunteers. Furthermore, CI rehabilitation programs should also recognise and integrate emotional support mechanisms, possibly through peer support groups or counselling services, to address the emotional needs of individuals throughout their CI journey. By involving CI volunteers in advocacy efforts, CI rehabilitation programs can leverage their personal experiences and insights to educate the public, healthcare professionals and policymakers about the benefits of CIs and the challenges faced by individuals with HL. By valuing the lived experiences of CI volunteers, the healthcare system can adopt a more holistic approach that integrates personal narratives into the decision-making and support processes.

Study limitations include a small sample size ($n=8$) from only one specific CI volunteering program (Cochlear™ Global Volunteer Program) and may not be generalisable to CI volunteer programs managed by other CI manufacturers or organisations, as volunteer program structures and -activities may vary significantly. The reliance on self-reported data introduces the possibility of response bias, where participants may provide socially desirable responses or inaccurately recall their experiences [42]. Furthermore, the study sample included participants that did not have equal experience as CI volunteers and were mainly adults (did not represent all age groups). Acknowledging these limitations is crucial when considering transferability to other research contexts.

Future research could address these limitations by targeting a larger sample size that is more representative by including CI volunteers from other CI volunteer programs. Different CI volunteer programs may have unique characteristics, support systems and approaches to rehabilitation. Including participants from various CI volunteer programs would allow exploration of how these differences might impact outcomes such as language development, quality of life or educational attainment. Furthermore, future research could also include newly implanted CI recipients who are receiving volunteer support from a CI volunteer, to obtain evidence on the real- world impact of volunteer support on newly implanted CI recipients. Similarly, future research could also include the paediatric CI population, as considering the perspectives of children with CIs and their parents may provide valuable insights into the lived experiences and challenges that they face. By including a wider range of participants from diverse CI programs and backgrounds, research can yield findings that better represent the CI population. This diversity will enhance the generalisability of results, making them more applicable in clinical settings.

This study emphasises the value of PCC within the context of CI service delivery, suggesting integrating personal narratives into decision-making and support processes to enhance well-being. CI volunteers play a pivotal role in informing and preparing CI recipients for the CI journey, providing emotional support to address psychological aspects. Collaboration between CI volunteers and healthcare professionals is key, with suggestions to expand volunteer programs and engage in remote care for increased accessibility to support for CI recipients. Regular gatherings between CI volunteers and CI recipients, as well as ongoing support, strengthen CI aftercare. The study underscores the importance of multidisciplinary teamwork in referring prospective and existing CI recipients to CI volunteers, and advocates for comprehensive audiological services that prioritise informed decision-making and CI recipients' well-being.

Conclusions

While this study offers valuable insights into how CI volunteers perceive volunteering partnerships, further research with a larger and more diverse sample is necessary to inform evidence-based CI service delivery within a PCC. The study suggests a need for CI volunteer support for adult CI recipients and offers nuanced insights into the roles and challenges of CI volunteers, and recommendations for CI volunteer partnerships. By illuminating these dynamics, the findings contribute valuable insights for optimising peer-based interventions, ultimately enhancing the well-being of CI recipients. The collaborative efforts of CI volunteers and healthcare professionals align with PCC principles in audiological service delivery.

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