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Citation

Philpott, N., Nijmeijer, H. G. B., Philips, B., Kaandorp, M. W., Frijns, J. H. M., Mol, B. M., ... Huinck, W. J. (2025). Beyond hearing: the impact of Cochlear implantation on the quality of life of users and their communication partners after 1 year. *International Journal Of Audiology*. doi:10.1080/14992027.2024.2441332

Version: Publisher's Version

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Downloaded from: <https://hdl.handle.net/1887/4245385>

Note: To cite this publication please use the final published version (if applicable).

ORIGINAL ARTICLE

 OPEN ACCESS

Beyond hearing: the impact of Cochlear implantation on the quality of life of users and their communication partners after 1 year

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ABSTRACT

Objective: To assess the impact of cochlear implantation (CI) and speech perception outcomes on the quality of life (QoL) of adult CI users and their communication partners (CP) one-year post-implantation.

Design: This research is part of a prospective multicenter study in The Netherlands, called SMILE (Societal Merit of Intervention for hearing Loss Evaluation).

Study sample: Eighty adult CI users completed speech perception testing and the Nijmegen Cochlear Implant Questionnaire (NCIQ). Fifty-four CPs completed the Hearing Impairment Impact – Significant Other Profile (HII-SOP).

Results: CI resulted in a large improvement in the QoL of both users and CPs. Despite this, some users still reported difficulties in the NCIQ sub-domains Social Interactions, Activity Limitations and Self-esteem. Similarly, some CPs still reported moderate and severe third-party disability on the HII-SOP. Additionally, the correlation between speech perception results and self-reported QoL was weak to negligible for both groups.

Conclusions: Speech perception in quiet is not an accurate measure of real-life success with a CI. A subset of CI users and CPs still experience substantial QoL challenges regardless of speech perception performance. To improve counselling and intervention, QoL measures should be a standard part of the CI care pathway for CI users and their CPs.

ARTICLE HISTORY

Received 20 August 2024

Revised 4 December 2024

Accepted 7 December 2024

KEYWORDS

cochlear implants;
communication partners;
quality of life; speech
perception

Introduction

Cochlear implants (CIs) significantly enhance speech perception in quiet for the majority of individuals with post-lingually acquired severe-to-profound sensorineural hearing loss (Boisvert et al. 2020). Beyond the improvement in communication ability, Mäki-Torkko et al. (2015) demonstrated that CIs can elevate the well-being and satisfaction of both users and their communication partners (CPs; which typically includes significant others, close friends and caregivers) particularly in terms of enhanced autonomy, a sense of normalcy, and increased social engagement in everyday life. Clinically, outcome measures with a CI primarily focus on speech perception, testing the perception of words, sentences, or a combination, in both quiet and noise (Boisvert et al. 2020). There is also an interest in functional benefits associated with CIs, often captured using validated Patient-Reported Outcome Measures (PROMs), such as quality of life (QoL) questionnaires, and focus on more person- and societal-related outcomes (McRackan, Bauschard, Hatch, Franko-Tobin, Droghini,

Veloza, et al. 2018). Societal-related outcomes relate specifically to the health-related quality of life (HRQoL) of persons with hearing loss and CI users and, less routinely captured, the third-party hearing loss-related quality of life (HLQoL) of their CPs.

Barker, Leighton, and Ferguson (2017) make the important point that neither hearing loss nor coping with hearing loss happens in isolation. Scarinci, Worrall, and Hickson (2009) first explored the concept of third-party disability, defined by the World Health Organisation as the “study of disability and functioning of family members due to the health condition of significant others” (World Health Organization 2001), in the hearing loss domain. The World Report on Hearing (World Health Organization 2021) repeatedly emphasises the significant impact of hearing loss not just on the individual experiencing it, but also on their family and CPs. A systematic review of the impact of hearing loss in older adults on CPs concluded that the QoL and social functioning of CPs are detrimentally affected by their partner’s hearing loss (Kamil and Lin 2015). This is in addition

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 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/14992027.2024.2441332>.

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to greater caregiver burden and negative impacts on family relationships, especially when the CP has normal hearing, which may lead to a snowball effect of isolation and frustration for both parties as a result of the hearing loss.

Research generally shows a positive impact of CI on speech perception in CI users (Boisvert et al. 2020) and QoL outcomes of both users (McRackan, Bauschard, Hatch, Franko-Tobin, Droghini, Nguyen, et al. 2018) and their CPs (Mistry et al. 2014). However, as with clinical outcomes, a large variability in post-implantation QoL for CI users and their CPs has also been reported (McRackan, Bauschard, Hatch, Franko-Tobin, Droghini, Nguyen, et al. 2018). While the impact of CI on QoL is not a novel concept, our study uniquely examines pre- and post-implantation QoL as perceived by newly implanted adult CI users and their CPs. Understanding the impact of CI on both users themselves and their CP is important for two reasons: (1) For many individuals, one of the primary reasons for CI uptake is for improved communication (and ultimately social connection) with those around them, including their CPs, and (2) post-lingually deafened CI users and their CPs have been living with the psychosocial impact of hearing loss for many years. Keidser et al. (2020) argue that the reduced ability to communicate is the most disabling result of living with hearing loss. Understanding to what extent CI users and CPs still experience the impact of hearing loss on QoL after implantation can provide important insights into additional avenues for counselling, support, and expectation management opportunities for both parties. Our study explores these QoL outcomes in the context of pre- and post-implantation speech perception. We expect that while QoL generally improves post-implantation for both users and partners, this may be impacted by the speech perception performance of the CI user. In other words, higher QoL will be reported in cases where the CI user has higher performance.

Previous research into the correlation between QoL ratings of CI users using the Nijmegen Cochlear Implant Questionnaire (NCIQ; developed by Hinderink, Krabbe, and Van Den Broek 2000) was limited to experienced CI users, leading the authors to suggest future research that explores whether similar relationships between speech perception and QoL exist for CI candidates at pre- and post-implantation timepoints (Vasil et al. 2020). The Hearing Impairment Impact – Significant Other Profile (HII-SOP) was designed as a scale to measure third-party QoL (in life partners) of individuals with hearing loss (Preminger and Meeks 2012). Although it has been established as a validated and reliable measure of third-party disability in the hearing loss domain, to our knowledge, its use in the context of CI is lacking.

The present study aimed to assess the impact of CI on the self-reported QoL of newly implanted CI users and their CPs. We also evaluated the QoL ratings of both parties in relation to post-implantation speech perception outcomes.

Specifically, we evaluated:

1. The extent to which both CI users and CPs still experience the impact of hearing loss on their QoL one-year post-implantation.
2. Whether the QoL experienced by CI users and their CPs correlates with post-implantation speech perception in quiet.
3. Whether CI users and their CPs have similar trends in their pre- and post-implantation QoL ratings.

Materials and methods

This research constitutes a component of the SMILE study (Societal Merit of Intervention for hearing Loss Evaluation;

Nijmeijer et al. 2023), an observational multi-centre study designed to explore the impact of moderate/severe-to-profound hearing loss on societal participation and autonomy in adults. The study also evaluates the effects of CI on these outcomes at 1-, 2-, and 3-years post-implantation. The study was submitted to the local Medical Ethics Review Board of each participating university medical centre in The Netherlands, where each local Medical Ethics Review Committee provided a letter of no objection for the conduction of the study (Radboud university medical centre ethics committee file number 2019–6057).

Adults with a post-lingual bilateral onset of severe-to-profound hearing loss, eligible for a CI according to the Dutch quality standards for CI (CI-ON 2013), were eligible for study inclusion. A comprehensive description of the study protocol and participant inclusion process is available elsewhere (Nijmeijer et al. 2023). Recruitment concluded in December 2022, with 232 participants enrolled after providing informed consent at each participating centre. As of 1 February 2024, 152 adults have undergone implantation of which 111 are at least one-year post-implantation.

Speech perception was assessed during clinical visits at the CI centre and QoL questionnaire data of CI users and their CPs were collected through secure online surveys using the Castor Electronic Data Capture (EDC) platform (Castor EDC 2019).

Speech perception

Speech perception in quiet testing was conducted in a sound-treated room with the Interacoustics Affinity audiometry system. Speech materials consisted of consonant-vowel-consonant words from the Nederlandse Vereniging voor Audiologie (NVA) word lists (Bosman and Smoorenburg 1995). Testing conditions were:

1. aided per ear (1 list per ear at 45, 55 and 65 dB SPL in free field) with the contralateral hearing aid removed and, where necessary, the contralateral ear masked (using masking principles outlined by the NVA)
2. best-aided (2 lists at 45, 55 and 65 dB SPL in free field).

Testing took place pre-implantation at CI trajectory intake with hearing aid(s) and one-year post-implantation with CI and (where applicable) a hearing aid. The best-aided condition reflects the listening condition as applied in daily life. For some participants, this condition combined the CI and contralateral hearing aid. For other participants, the best-aided condition was with their CI only, as they did not receive additional benefit from a hearing aid as indicated by speech perception testing.

Quality of life

QoL outcomes are assessed using the NCIQ (Hinderink, Krabbe, and Van Den Broek 2000) for CI users and the Hearing Impairment Impact – Significant Other Profile (HII-SOP; Preminger and Meeks 2012) for CPs.

NCIQ

The NCIQ is a validated self-report instrument to measure HRQoL in CI users. It comprises 60 questions in three domains: (1) Physical (encompassing sub-domains *Basic Sound Perception*, *Advanced Sound Perception*, and *Speech Production*), (2) Psychological (encompassing a *Self-esteem* sub-domain), and (3) Social (encompassing sub-domains *Activity Limitations* and *Social*

Interactions). For each question, participants are given the following response options: 1 = Never, 2 = Sometimes, 3 = Regularly, 4 = Usually, 5 = Always or Not Applicable (N/A), which are then quantified after completion. Interpreted per domain, higher scores indicate a better QoL.

HII-SOP

The HII-SOP is a validated scale to measure third-party HLQoL in spouses (life partners), or CPs, of individuals with hearing loss. It contains 20 items across three subscales, measuring: (1) *Relationships and Emotions* (the emotions that arise when having a partner with hearing loss as well as the impact of the hearing loss on the relationship), (2) *Social Impact* (the impact of the hearing loss on the social life of the CP), and (3) *Communication Strategies* (communication strategies used by the CP). For each question, participants are provided with the following response options: *Yes, Sometimes or No*, which are then quantified after completion. Interpreted by the *Total score*, 20–39 reflects mild third-party disability, 40–59 reflects moderate third-party disability, and >60 reflects severe third-party disability related to hearing loss. While the original HII-SOP was developed and validated in English, it was translated into Dutch, without re-validation, for use in the present study.

Statistical analyses

For audiological outcomes, the primary objective was to evaluate changes in speech perception from pre-implantation to one-year post-implantation. The best-aided condition at 65 dB SPL was selected as the outcome of interest for comparison with QoL, as this is the condition that most participants use for daily life listening and the intensity at which speech perception outcomes are mostly monitored in the clinic. Data were extracted from patient files, following Good Clinical Practice guidelines, into the secure Castor EDC database. Data cleaning and preparation were performed in R-studio v4.3.1 (R Core Team 2023).

For NCIQ, where participants had more than 3 responses indicating “Not Applicable” within a given sub-domain, these sub-domains were subsequently excluded from the analysis, in line with the recommended procedure of Hinderink, Krabbe, and Van Den Broek (2000). Given that the HII-SOP questionnaire was specifically designed for life partners, responses from individuals who were not life partners (such as other family, caregivers, friends, neighbours, or colleagues) were excluded from the analysis. Reference to CPs in the context of our study therefore only refers to life partners.

This is an observational, explorative study with no power calculation or hypothesis testing. As such, a specific statistical significance level was not set. Cohen’s *d* was used to measure effect sizes, facilitating a standardised comparison of pre- and post-implantation QoL scores with 95% confidence intervals. An effect size (*d*) of 0.2 was considered small, 0.5 was considered medium, 0.8 was considered large, and ≥ 1.3 was very large (Cohen 1988). Spearman’s correlation (r_s) analysis explored the relationships between CI user and CP QoL ratings, and between QoL ratings and speech perception outcomes. A correlation coefficient between 0.00 and 0.10 was considered negligible, 0.10 to 0.39 weak, 0.40 to 0.69 moderate, 0.70 to 0.89 strong, and greater than 0.90 very strong (Akoglu 2018).

Results

The results presented here are from a cohort of participants in the SMILE study. As of February 2024, 80 participants are one-

year post-implantation and have completed the pre-implantation and post-implantation NCIQ and 54 CPs (after excluding 26 non-life partners) have completed the HII-SOP at both time-points. Demographic information of all participants included for analysis can be found in Table 1.

Speech perception outcomes

Pre- and post-implantation speech perception outcomes are presented in Table 2. On average, the aided pre-implantation phoneme score in the to-be-implanted ear was 23.8% (*SD* = 23.8) and improved to 83.2% (*SD* = 12.9) post-implantation. Most CI users experience clear benefits in speech perception in quiet in their daily aided listening condition (mean best-aided score of 86.2% at 65 dB SPL), with only five of 81 CI users scoring <70% in this testing condition.

The impact of hearing loss and CI on quality of life outcomes

Domain-specific results of the NCIQ and HII-SOP are presented in Figure 1a and 1b, respectively (more details relating to effect size, significance and 95% confidence intervals are provided in Supplementary 1). For the NCIQ (Figure 1a), a very large effect (Cohen’s *d*) of CI is observed in all sub-domains, except for *Speech Production* (*d* = 0.75), with the largest effects observed for *Basic Sound Perception* (*d* = 1.79), *Activity Limitations* (*d* = 1.74) and *Social Interactions* (*d* = 1.6). While an improvement in QoL is observed across all domains post-implantation, some participants still experience difficulties in the *Social Interactions*, *Activity Limitations* and *Self-esteem* sub-domains.

For the HII-SOP (Figure 1b), a large effect of CI is observed for the *Communication Strategies* (*d* = −1.15) domain and the *Total score* (*d* = −0.94). As with the group of CI users, an improvement in QoL is observed across all domains and in the *Total score* post-implantation. While total scores on a group level improve from moderate third-party disability pre-implantation to mild third-party disability post-implantation, some individuals still experience moderate (*n* = 17) and even severe (*n* = 6) third-party disability one year after their partner has received a CI.

Correlations between post-implantation QoL outcomes of CI users and CPs are reported in Table 3. Moderate correlations are observed between the post-implantation HII-SOP total score and the *Activity Limitations* ($r_s = -0.49$; $p < 0.001$), *Social Interactions*

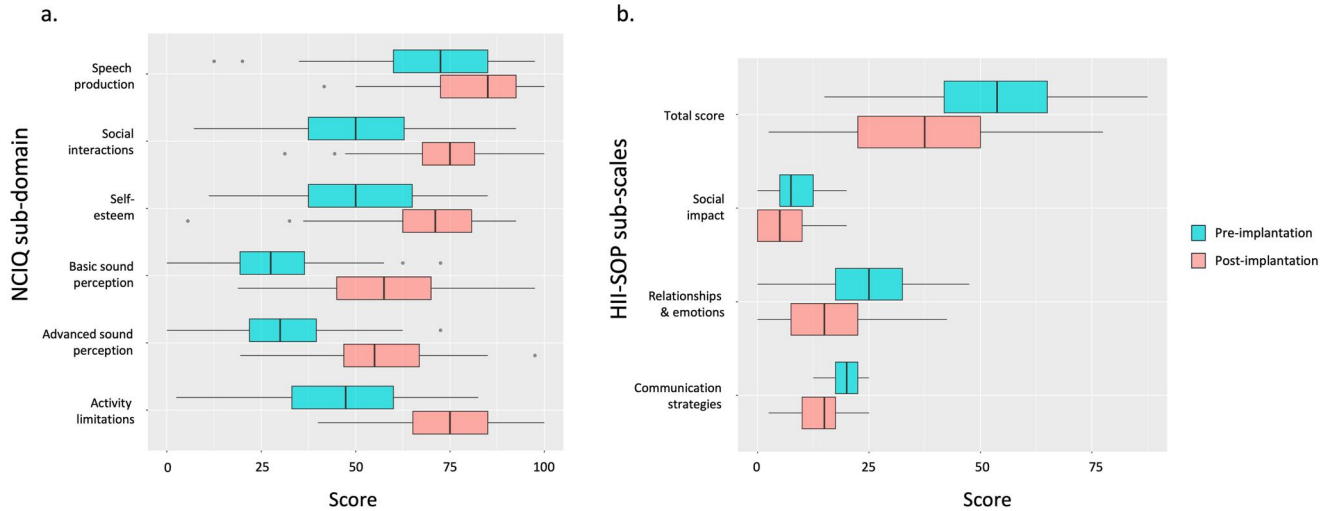
Table 1. Demographics of included CI users.

Demographics	N = 80
Age at study inclusion (years)	
Mean (SD)	65.0 (10.5)
Sex	
Male	45 (56.3%)
Female	35 (43.8%)
Duration of hearing loss (years)	
Mean (SD)	23.8 (14.3)
Missing	3 (3.8%)
Hearing loss aetiology	
Unknown	50 (62.5%)
Genetic	12 (15%)
Meniere’s Disease	5 (6.3%)
Acquired	5 (6.3%)
Otosclerosis	5 (6.3%)
Sudden deafness	3 (3.8%)
Living situation	
Alone	13 (16.3%)
Not alone (with partner, children, etc.)	67 (83.8%)

Table 2. Pre- and post-implantation audiological data ($n = 80$).

Pre-implantation (mean, SD)		1-year post-implantation (mean, SD)	
Hearing aid use in at least 1 ear	79/80	Hearing aid use in non-CI ear	68/80
Aided TBI ear phoneme score at 65 dB SPL	23.8 (23.8)	Aided CI ear phoneme score at 65 dB SPL	83.2 (12.9)
Bilateral aided phoneme score at 65 dB SPL	59.3 (20.5)	Bimodal aided phoneme score at 65 dB SPL	86.2 (12.5)

Bilateral = two hearing aids; Bimodal = cochlear implant and contralateral hearing aid; CI = cochlear implant; SD = standard deviation; TBI = to-be-implanted ear.

**Figure 1.** Quality of life outcomes for the NCIQ and HII-SOP.**Table 3.** Correlations for post-implantation NCIQ, HII-SOP and speech perception data.

NCIQ	HII-SOP total score	CI phoneme score
Basic Sound Perception	$R = -0.38$ ($p = 0.003$)	0.12 ($p = 0.32$)
Advanced Sound Perception	-0.41 ($p = 0.001$)	0.32 ($p = 0.006$)
Speech Production	-0.14 ($p = 0.28$)	0.26 ($p = 0.026$)
Self-esteem	-0.33 ($p = 0.01$)	0.16 ($p = 0.18$)
Activity Limitations	-0.49 ($p < 0.001$)	0.19 ($p = 0.1$)
Social Interactions	-0.56 ($p < 0.001$)	0.26 ($p = 0.025$)
HII-SOP		CI Phoneme Score
Communication Strategies	–	-0.34 ($p = 0.012$)
Relationships & Emotions	–	-0.17 ($p = 0.21$)
Social Interactions	–	-0.12 ($p = 0.39$)
Total Score	–	-0.25 ($p = 0.073$)

($r_s = -0.56$; $p < 0.001$) and *Advanced Sound Perception* ($r_s = -0.41$; $p = 0.001$) sub-domains of the post-implantation NCIQ, and weak correlations with the *Basic Sound Perception* ($r_s = -0.38$; $p = 0.003$) and *Self-Esteem* ($r_s = -0.33$; $p = 0.01$) sub-domains. No correlation is observed with *Speech Production*.

Correlating (changes in) speech perception with (changes in) quality of life

Correlations between post-implantation speech perception outcomes (best-aided at 65 dB SPL) and NCIQ sub-domains are shown in Table 3. Weak correlations were only found for *Speech Production* ($r_s = 0.26$; $p = 0.026$), *Advanced Sound Perception*

($r_s = 0.32$; $p = 0.006$) and *Social Interactions* ($r_s = 0.26$; $p = 0.025$). Changes in speech perception from pre- to post-implantation (not shown) also showed negligible to weak correlations with changes in NCIQ sub-domain scores between these timepoints. Table 3 also reports the correlations between post-implantation best-aided speech perception and HII-SOP scores. No correlation is seen with the HII-SOP *Total score* and a weak correlation ($r_s = -0.34$; $p = 0.012$) is only observed for the *Communication Strategies* domain. Changes in speech perception from pre- to post-implantation (not shown) also showed a weak correlation ($r_s = -0.35$; $p = 0.03$) with the change in HII-SOP *Total score* between these timepoints.

Discussion

One of the most devastating consequences of hearing impairment, especially for individuals with more severe hearing impairment, is the breakdown in effective communication with those around them. Consequently, one of the primary motivations for CI uptake in adults is enhanced communication ability, and ultimately social connection, with their CPs. This study explores the self-reported QoL of 80 CI users and 54 of their CPs while examining its correlation with speech perception.

Quality of life outcomes

For the cohort of participants in our study, questionnaire data show a positive change in the QoL of both CI users and their CPs post-implantation across all sub-domains. While our NCIQ findings are in line with prior studies which have demonstrated improvements in CI users' QoL post-implantation (McRackan, Bauschard, Hatch, Franko-Tobin, Droghini, Nguyen, et al. 2018; Plath et al. 2022), our study provides unique insights into the impact of CI on CPs, highlighting the effects on third-party disability both pre- and post-implantation. Findings relating to third-

party disability post-implantation are also in line with prior literature, where CPs of CI users also reported improved QoL as a result of implantation (Lambinon et al. 2024; Shao, Moberly, and Ray 2020; Völter et al. 2022). Specifically, the HII-SOP data in our study shows a large reduction in third-party disability, which improved from moderate levels pre-implantation (52.4, SD = 16.7, range = 15–87.5) to mild levels post-implantation (35.8, SD = 18.4, range = 2.5–77.5). These positive changes underscore the potential benefits of CI not only for the user, but also for their CP, whose QoL can improve as a result of reduced caregiver burden, enhanced communication, and greater autonomy of the CI user.

Furthermore, we examined the post-implantation correlation between the QoL of CI users and their CPs. Our findings show a moderate correlation between improvements in the QoL of CI users and reductions in third-party disability among their CPs, specifically when correlating the HII-SOP Total Score to the *Activity Limitations*, *Advanced Sound Perception* and *Social Interactions* sub-domains. These correlations underscore the interconnected nature of QoL outcomes within the user-partner dyad, where improved hearing and social participation for CI users contributes to positive changes in CP's experiences. These findings highlight the importance of improved communication and social engagement as key contributors to enhanced subjective well-being for both parties. However, while a CI may bring improved communication ability for both the user and their CP, this newfound improvement may impact partner dynamics, where a CP who may have previously spent years living with, assisting with and compensating for their partner's hearing loss now finds themselves navigating a new way forward. This change in dynamics may be related to previous activity limitations and participation restrictions, such as a shift in a sense of responsibility (always answering the telephone for the person with hearing loss), or communication compensation (avoiding certain social situations that hamper good communication for the person with hearing loss).

Although overall reduction in third-party disability among CPs is encouraging, our data show that some CPs continue to experience moderate and even severe levels of third-party disability even one-year post-implantation. It is important to consider the lasting impact on partners of individuals with hearing loss, who often experience third-party disability due to their partner's hearing loss (Scarinci, Worrall, and Hickson 2012) and which may persist even after CI (Völter et al. 2022). Third-party disability may remain higher in CPs who also experienced a higher pre-implantation burden related to their partner's hearing loss. Experts in the field have recommended expanding post-implantation rehabilitation to include CPs, who may benefit from continued intervention and support even with the newfound benefits of their partners' CI (Manchaiah et al. 2012; Völter et al. 2022). Völter et al. (2022) argue that more emphasis should be placed on including CPs from the beginning of the CI trajectory and throughout the post-implantation auditory rehabilitation trajectory. Shao, Moberly, and Ray (2020) also recommend including CPs in early post-implantation rehabilitation sessions, during the CI users' journey to a new way of hearing. Coupled with our own findings, this warrants a change in the current CI care pathway that moves beyond a person-centred approach, to a family-centred approach (Lambinon et al. 2024).

The relationship between speech perception and quality of life outcomes

QoL sub-domains of CI users and their CPs had negligible to weak correlations with speech perception outcomes in quiet,

one-year post-implantation. These correlations remained negligible when looking at the impact of changes in speech perception on changes in QoL ratings. While overall findings are positive, a considerable subset of CI users and CPs continue to report at least moderate impacts of the hearing loss on HRQoL and HLQoL even one-year post-implantation, irrespective of post-implantation speech perception outcomes in quiet. Vasil et al. (2020) only found moderate correlations with some NCIQ sub-domains when using more complex speech tests, such as audiovisual tasks or AzBio sentences. However, in their study, all testing was performed in quiet and therefore possesses limited ecological validity. Other studies have also concluded that typical clinical speech perception assessments poorly predict QoL in CI users (Dorismond et al. 2023; McRackan, Bauschard, Hatch, Franko-Tobin, Droghini, Nguyen, et al. 2018) and their partners (Aylward et al. 2022). Our data shows that some CI users with high speech perception scores still had low scores in the *Social Interaction*, *Activity Limitation* and *Self-Esteem* domains, domains that capture daily living beyond the sound-proofed walls of the clinic. Hearing amplification users have also previously provided feedback that standard tests used in CI evaluation fail to capture their daily experiences, often characterised by noise and multiple talkers (Bierbaum et al. 2020). The negligible to weak correlations between speech perception and QoL in CI users and their CPs in our study suggest that post-implantation improvements in QoL should be evaluated beyond improvements in clinical speech perception alone. Standard clinical measures often lack the depth to capture experiences in daily listening environments, warranting a more comprehensive exploration of additional factors contributing to the multifactorial nature of subjective CI outcomes. Instead of focusing on QoL measures that correlate with speech perception outcomes, QoL measures from CPs can be further used to enhance the counselling and intervention services offered to both parties during the post-implantation phase, especially if these measures are captured early on and allow for timely support to be offered.

There is a considerable body of literature evaluating more ecologically valid measures of speech perception that are suitable for use in the clinical setting. Keidser et al. (2020) define ecological validity in hearing science as the degree to which research findings reflect daily hearing-related function, activity and participation. The DiapixUK task, for example, allows for evaluating communication difficulties in a more spontaneous, ecologically valid setting (Baker and Hazan 2011; Van Engen et al. 2010). Hey, Mewes, and Hocke (2023) point out that despite the relevance of complex listening situations in daily life, standard clinical protocols do not routinely use complex interfering noise signals (e.g. fluctuating noise or a cocktail party situation) as part of their testing. The authors showed that a reduced speech perception test battery in the S0N90 setup (speech from the front of the participant at 0 degrees, noise from the side at 90 degrees) has proven to be clinically feasible and more ecologically valid than traditional speech perception testing setups. To facilitate the creation of interventions that effectively address communication hurdles, it is crucial to continuously relook at speech audiometry protocols (Hey, Mewes, and Hocke 2023) and think about creative interactive or conversational paradigms to elicit communication situations that individuals experience in daily life (Carlile and Keidser 2020). In line with recommendations from Skidmore et al. (2020), the inclusion of cognitive, top-down assessments may also contribute to a better understanding of QoL outcome variability. As innovative at-home, self-test technologies evolve as alternatives to standard clinical testing, there

is an opportunity to prioritise ecological measures during clinical appointments. This shift in testing may shed light on how CI candidates and users leverage auditory cues in real-world conversations and social interactions, allowing for individualised interventions and counselling. Utilising remote care resources to conduct at-home diagnostic testing and monitoring can allow valuable clinical time to be used for more complex assessments and meaningful conversations with users and their partners about navigating the daily challenges they may experience around living with a CI.

Limitations

Firstly, clinical outcomes in our study primarily centred on speech recognition in quiet. Challenges arose in collecting speech-in-noise data (digits-in-noise) across participants due to various factors, including time constraints, limitations in testing room conditions, poor reliability (as indicated by a high standard deviation during testing) and participant fatigue. It is plausible that speech-in-noise assessments may yield stronger correlations with HRQoL ratings, as this test, although not fully ecological, better approximates real-world listening situations in noisy environments. While the use of sentences for speech testing may seem more ecological, previous research has shown that digits-in-noise testing is more feasible and reliable than sentences-in-noise testing, especially for CI users, where the use of sentences is often too complex (Kaandorp et al. 2015). At-home testing options may be a viable solution to overcome clinical and resource constraints for conducting speech-in-noise testing. Secondly, our study's evaluation of third-party ratings of HRQoL was restricted to life partners of CI users. Consequently, insights into the QoL experiences of other caregivers, family members, colleagues or friends, remain beyond our scope. Given the absence of a validated questionnaire for assessing broader proxy HRQoL, Aylward et al. (2022) modified the Significant Other Scale for Hearing Disability (SOS-HEAR) to accommodate a wider audience in their study. While promising, this approach has the challenging task of capturing the diverse interactions individuals have with different types of CPs within a single questionnaire. Lastly, post-implantation outcome measures were collected one-year post-implantation. It may be that QoL ratings continue to evolve as individuals gain more experience with their new hearing implant. The SMILE study follows CI users up to 3 years post-implantation and speech perception and QoL ratings at this timepoint will be reported in a future study.

Conclusions

This study highlights the impact of hearing loss and CI on the QoL of newly implanted adults and their CPs. While our results generally indicate positive QoL outcomes, they also show persisting QoL challenges for some CI users, but especially their partners. Contrary to our expectations, post-implantation speech perception demonstrated limited correlation with QoL (sub-) domain ratings. Based on our findings, clinicians and therapists should consider (1) placing more value on CI user QoL measures to gain more comprehensive feedback on daily living experiences with a CI and provide intervention and support on what CI users are reporting and, (2) incorporating third-party QoL measures in the CI care continuum, to recognise and support the needs of individuals who regularly interact with CI users. Relying solely on speech perception outcomes as a success metric is insufficient and fails to address the broader challenges users

and their partners face due to hearing loss. In recognising the impact of hearing loss on both parties, further exploration into the multifaceted contributors to post-implantation QoL in CI users and their CPs is important. Integrating these factors into the CI care pathway will facilitate enhanced counselling, comprehensive assessment, realistic expectation management and ongoing satisfaction monitoring for CI users and those who walk the hearing loss journey with them.

Disclosure statement

BP is employed by Cochlear Ltd, although her role in this manuscript was strictly related to the supervision of NP's PhD work as part of the MOSAICS project. The authors have no additional competing interests to declare.

Funding

The SMILE study is investigator-initiated research and received funding from the Heinsius Houbolt Fund - an ENT-related funding organisation in The Netherlands. NP's research within the SMILE study is part of the MOSAICS project, funded by the European Union's Horizon 2020 framework programme for research and innovation under the Marie Skłodowska-Curie grant agreement No 860718, in which EM, WH and BP are involved as supervisors.

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Data availability statement

SMILE is an ongoing longitudinal study for which data is still being collected. Upon termination of the study, data will be stored in line with the FAIR principles and available for reasonable request at the discretion of the project leaders.

References

- Akoglu, H. 2018. "User's guide to correlation coefficients." *Turkish Journal of Emergency Medicine* 18 (3):91–93. <https://doi.org/10.1016/j.tjem.2018.08.001>.
- Aylward, A., S. A. Gordon, M. Murphy-Meyers, C. M. Allen, N. S. Patel, and R. K. Gurgel. 2022. "Caregiver Quality of Life After Cochlear Implantation in Older Adults." *Otology & Neurotology: official Publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology* 43 (2):e191–e197. <https://doi.org/10.1097/MAO.0000000000003427>.
- Baker, R., and V. Hazan. 2011. "DiapixUK: task materials for the elicitation of multiple spontaneous speech dialogs." *Behavior Research Methods* 43 (3):761–770. <https://doi.org/10.3758/s13428-011-0075-y>.
- Barker, A. B., P. Leighton, and M. A. Ferguson. 2017. "Coping Together with Hearing Loss: A Qualitative Meta-Synthesis of the Psychosocial Experiences of People with Hearing Loss and Their Communication partners." *International Journal of Audiology* 56 (5):297–305. <https://doi.org/10.1080/14992027.2017.1286695>.
- Bierbaum, M., C. M. McMahon, S. Hughes, I. Boisvert, A. Y. S. Lau, J. Braithwaite, and F. Rapport. 2020. "Barriers and Facilitators to Cochlear

- Implant Uptake in Australia and the United Kingdom." *Ear and Hearing* 41 (2):374–385. <https://doi.org/10.1097/AUD.0000000000000762>.
- Boisvert, I., M. Reis, A. Au, R. Cowan, and R. C. Dowell. 2020. "Cochlear Implantation Outcomes in Adults: A Scoping Review." *PLoS One* 15 (5): e0232421. <https://doi.org/10.1371/journal.pone.0232421>.
- Bosman, A. J., and G. F. Smoorenburg. 1995. "Intelligibility of Dutch CVC Syllables and Sentences for Listeners with Normal Hearing and with Three Types of Hearing Impairment." *Audiology: Official Organ of the International Society of Audiology* 34 (5):260–284. <https://doi.org/10.3109/00206099509071918>.
- Carlile, S., and G. Keidser. 2020. "Conversational Interaction Is the Brain in Action: Implications for the Evaluation of Hearing and Hearing Interventions." *Ear and Hearing* 41 (Supplement 1):56S–67S. <https://doi.org/10.1097/AUD.0000000000000939>.
- Castor EDC. 2019. "Castor Electronic Data Capture." [online]. <https://castor-edc.com>
- CI-ON. 2013. "Veldnorm Cochleaire Implantatie." Dutch CI implant guideline.
- Cohen, J. 1988. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale, N.J.: L. Erlbaum Associates.
- Dorismond, C., A. Patro, J. T. Holder, and E. L. Perkins. 2023. "Correlation Between Quality of Life and Speech Recognition Outcomes Following Cochlear Implantation." *Otology & Neurotology: Official Publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology* 44 (10):1015–1020. <https://doi.org/10.1097/MAO.0000000000004029>.
- Hey, M., A. Mewes, and T. Hocke. 2023. "Speech Comprehension in Noise-Considerations for Ecologically Valid Assessment of Communication Skills Ability with Cochlear Implants." *HNO* 71 (Suppl. 1):26–34. <https://doi.org/10.1007/s00106-022-01232-3>.
- Hinderink, J. B., P. F. Krabbe, and P. Van Den Broek. 2000. "Development and Application of a Health-Related Quality-of-Life Instrument for Adults with Cochlear Implants: The Nijmegen Cochlear Implant Questionnaire." *Otolaryngology-Head and Neck Surgery: Official Journal of American Academy of Otolaryngology-Head and Neck Surgery* 123 (6):756–765. <https://doi.org/10.1067/mhn.2000.108203>.
- Kaandorp, M. W., Cas. Smits, P. Merkus, S. T. Goverts, and J. M. Festen. 2015. "Assessing speech recognition abilities with digits in noise in cochlear implant and hearing aid users." *International Journal of Audiology* 54 (1):48–57. <https://doi.org/10.1177/2331216517743887>.
- Kamil, R. J., and F. R. Lin. 2015. "The Effects of Hearing Impairment in Older Adults on Communication Partners: A Systematic Review." *Journal of the American Academy of Audiology* 26 (2):155–182. <https://doi.org/10.3766/jaaa.26.2.6>.
- Keidser, G., G. Naylor, D. S. Brungart, A. Caduff, J. Campos, S. Carlile, M. G. Carpenter, G. Grimm, V. Hohmann, I. Holube, et al. 2020. "The Quest for Ecological Validity in Hearing Science: What It Is, Why It Matters, and How to Advance It." *Ear and Hearing* 41 (Suppl. 1):5S–19S. <https://doi.org/10.1097/AUD.0000000000000944>.
- Lambinon, C., T. Le Roux, R. H. Eikelboom, and R. J. Bennett. 2024. "Impact of Adult Cochlear Implantation on the Partner Relationship: A Conceptual Framework Informed by Cochlear Implant Recipient and Partner Perceptions." *Disability and Rehabilitation* :1–15. <https://doi.org/10.1080/09638288.2024.2396061>.
- Mäki-Torkko, E. M., S. Vestergren, H. Harder, and B. Lyxell. 2015. "From Isolation and Dependence to Autonomy - Expectations Before and Experiences After Cochlear Implantation in Adult Cochlear Implant Users and Their Significant Others." *Disability and Rehabilitation* 37 (6):541–547. <https://doi.org/10.3109/09638288.2014.935490>.
- Manchaiah, V. K. C., D. Stephens, F. Zhao, and S. E. Kramer. 2012. "The Role of Communication Partners in the Audiological Enablement/Rehabilitation of a Person with Hearing Impairment: An Overview." *Audiological Medicine* 10 (1):21–30. <https://doi.org/10.3109/1651386X.2012.655914>.
- McRackan, T. R., M. Bauschard, J. L. Hatch, E. Franko-Tobin, H. R. Droghini, S. A. Nguyen, and J. R. Dubno. 2018. "Meta-Analysis of Quality-of-Life Improvement after Cochlear Implantation and Associations with Speech Recognition Abilities." *The Laryngoscope* 128 (4):982–990. <https://doi.org/10.1002/lary.26738>.
- McRackan, T. R., M. Bauschard, J. L. Hatch, E. Franko-Tobin, H. R. Droghini, C. A. Velozo, S. A. Nguyen, and J. R. Dubno. 2018. "Meta-Analysis of Cochlear Implantation Outcomes Evaluated With General Health-Related Patient-Reported Outcome Measures." *Otology & Neurotology: Official Publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology* 39 (1): 29–36. <https://doi.org/10.1097/MAO.0000000000001620>.
- Mistry, D., J. Ryan, H. Maessen, and M. Bance. 2014. "Differences in Perception of Hearing Handicap between Cochlear Implant Users and Their Spouses." *The Laryngoscope* 124 (5):1199–1203. <https://doi.org/10.1002/lary.24404>.
- Nijmeijer, H. G. B., W. J. Huinck, S. E. Kramer, A. R. T. Donders, G. J. van der Wilt, and E. A. M. Mylanus. 2023. "Changes on Clinical and Participatory Outcomes in People with Severe-to-Profound Hearing Loss after Cochlear Implantation: Protocol of a Multicentre Prospective Observational Cohort Study - Societal Merit of Intervention on Hearing Loss Evaluation (SMILE)." *BMJ Open* 13 (6):e072689. <https://doi.org/10.1136/bmjopen-2023-072689>.
- Plath, M., T. Marienfeld, M. Sand, P. S. van de Weyer, M. Praetorius, P. K. Plinkert, I. Baumann, and K. Zaoui. 2022. "Prospective Study on Health-Related Quality of Life in Patients Before and After Cochlear Implantation." *European Archives of Oto-Rhino-Laryngology: Official Journal of the European Federation of Oto-Rhino-Laryngological Societies (EUFOS): Affiliated with the German Society for Oto-Rhino-Laryngology - Head and Neck Surgery* 279 (1):115–125. <https://doi.org/10.1007/s00405-021-06631-w>.
- Preminger, J. E., and S. Meeks. 2012. "The Hearing Impairment Impact-Significant Other Profile (HII-SOP): A Tool to Measure Hearing Loss-Related Quality of Life in Spouses of People with Hearing Loss." *Journal of the American Academy of Audiology* 23 (10):807–823. <https://doi.org/10.3766/jaaa.23.10.6>.
- R Core Team. 2023. *R: A Language and Environment for Statistical Computing*. Vienna, Austria: R Foundation for Statistical Computing. <https://www.R-project.org/>.
- Scarinci, N., L. Worrall, and L. Hickson. 2009. "The ICF and Third-Party Disability: Its Application to Spouses of Older People with Hearing Impairment." *Disability and Rehabilitation* 31 (25):2088–2100. <https://doi.org/10.3109/09638280902927028>.
- Scarinci, N., L. Worrall, and L. Hickson. 2012. "Factors Associated with Third-Party Disability in Spouses of Older People with Hearing Impairment." *Ear and Hearing* 33 (6):698–708. <https://doi.org/10.1097/AUD.0b013e31825aab39>.
- Shao, D., A. C. Moberly, and C. Ray. 2020. "Quality of Life Outcomes Reported by Patients and Significant Others Following Cochlear Implantation." *American Journal of Audiology* 29 (3):404–409. https://doi.org/10.1044/2020_AJA-19-00101.
- Skidmore, J. A., K. J. Vasil, S. He, and A. C. Moberly. 2020. "Explaining Speech Recognition and Quality of Life Outcomes in Adult Cochlear Implant Users: Complementary Contributions of Demographic, Sensory, and Cognitive Factors." *Otology & Neurotology: Official Publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology* 41 (7):e795–e803. <https://doi.org/10.1097/MAO.0000000000002682>.
- Van Engen, K. J., M. Baese-Berk, R. E. Baker, A. Choi, M. Kim, and A. R. Bradlow. 2010. "The Wildcat Corpus of Native- and Foreign-Accented English: Communicative Efficiency Across Conversational Dyads with Varying Language Alignment Profiles." *Language and Speech* 53 (Pt 4): 510–540. <https://doi.org/10.1177/0023830910372495>.
- Vasil, K. J., J. Lewis, T. Tamati, C. Ray, and A. C. Moberly. 2020. "How Does Quality of Life Relate to Auditory Abilities? A Subitem Analysis of the Nijmegen Cochlear Implant Questionnaire." *Journal of the American Academy of Audiology* 31 (4):292–301. <https://doi.org/10.3766/jaaa.19047>.
- Völter, C., L. Götze, I. Ballasch, L. Harbert, S. Dazert, and J. P. Thomas. 2022. "Third-Party Disability in Cochlear Implant Users." *International Journal of Audiology* 62 (11):1059–1066. <https://doi.org/10.1080/14992027.2022.2125913>.
- World Health Organization. 2001. *Classification of Functioning, Disability and Health*. Geneva: World Health Organization.
- World Health Organization. 2021. "World Report on Hearing." <https://www.who.int/publications/i/item/9789240020481>