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RESEARCH ARTICLE

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Cochlear implantation for children with single-sided deafness: parents' perspectives

Abbey L. Hooper[a] and Holly F. B. Teagle[a,b]

[a]Department of Audiology, The University of Auckland, Auckland, New Zealand; [b]The Hearing House, Auckland, New Zealand

ABSTRACT

Historically, cochlear implantation is reserved for those with bilateral severe to profound hearing loss. However, indications have expanded to include Single-Sided Deafness (SSD) because of the known benefits of binaural hearing and the limitations of unilateral hearing, especially for children developing linguistic and cognitive skills. This study aimed to provide a qualitative perspective of lived experiences of children with SSD who use a cochlear implant (CI), as perceived and reported by their parents. An online questionnaire was developed and distributed to evaluate outcomes of cochlear implantation in children with SSD residing in New Zealand and the United States. Qualitative content analysis of open-ended questions identified themes, including: (1) motivating factors; (2) benefits of amplification; (3) challenges associated with the CI journey; and (4) advice to parents. Parents described benefits and challenges as a result of cochlear implantation, such as access to sound and academic and psychosocial development, as well as subjective improvements in spatial hearing, reduced listening fatigue, enhanced academic performance, and changes in quality of life. The difference that bilateral hearing makes to a child's development is difficult to precisely define but parental insights offer valuable perspective to healthcare providers when considering what some consider an elective procedure.

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Introduction

Single-sided deafness (SSD) is a form of unilateral hearing loss characterised by the presence of severe-to-profound sensorineural hearing loss (SNHL) in one ear and normal hearing in the contralateral ear (Deep et al. 2021). From an intervention standpoint, the hearing loss in the affected ear is so severe that traditional amplification is not useful (Snapp and Ausili 2020; Park et al. 2021). For decades, it has been recognised that children with Single Sided Deafness (SSD) face social, cognitive, educational, and behavioural challenges despite having normal hearing in one ear (Bess and Tharpe

CONTACT Holly F. B. Teagle holly.teagle@auckland.ac.nz

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1984; Oyler et al. 1988). The auditory deficits resulting from monoaural hearing create a cascade of barriers to higher auditory development (Bilecen et al. 2000; Liu et al. 2023). Some of these challenges occur due to the loss of spatial hearing benefits necessary to localise sound and understand speech in noise (Snapp and Ausili 2020), as well as loss of benefits from head shadow effect (Bakal et al. 2021). In the absence of early intervention with a hearing technology, single-sided auditory input begets the inability to process binaural cues and, therefore, can have a profound and long-lasting impact on the developing auditory system and higher-level functions (Liu et al. 2020; Ramos Macías et al. 2019). Furthermore, the auditory deficits associated with SSD have been shown to adversely impact children's communication and quality of life outcomes relative to their normal-hearing peers (Griffin et al. 2019; Brown et al. 2022).

Historically, cochlear implantation has been reserved for those with bilateral, severe to profound hearing loss; however, indications have expanded in many countries to include SSD. Providing direct electrical stimulation of the deafened ear via a cochlear implant (CI) offers several advantages over traditional rehabilitative options, which reroute sound from the impaired side to the normal hearing ear. The primary advantage of using a CI is the ability to stimulate both auditory pathways and, potentially, generate or restore binaural functionality. Following the United States Food and Drug Administration (FDA) approval in 2019, there has been growing interest in the therapeutic application of a CI for children with SSD. Clinical management, referring to these children's audiological and auditory rehabilitation, has been described in the literature (Greaver et al. 2017; Park et al. 2022) and there is an increasing body of literature that describes speech perception, localisation and spatial release from masking changes post-implant for this population (Corbin et al. 2017; Park et al. 2021; Gordon et al. 2023; Park et al. 2023)

Emerging evidence from recent case studies and clinical trials suggests that CIs can improve speech understanding in noise, sound localisation and quality of life for children with SSD (Benchetrit et al. 2021; Park et al. 2022). There is even evidence that CIs can restore bilateral auditory input (Polonenko et al. 2017) and reverse cortical reorganisation (Sharma et al. 2016; Lee et al. 2020). Despite a growing body of evidence supporting the use of CIs for children with SSD, currently, there is limited public funding available for this population in New Zealand. A small cohort of children with SSD have used private financing or funding through Accidental Compensation Corporation (ACC) to access a CI, which has created a unique opportunity to contribute a New Zealand perspective to this growing body of literature. Since parents are the primary decision-makers for cochlear implantation, the insights captured by this study regarding parent perception of outcomes could assist clinicians when providing counselling and support to families of a child with SSD. This work offers the parental perspective that supplements the existing body of literature on the importance of binaural auditory input and how a cochlear implant can rapidly restore bilateral auditory input to the auditory cortex compared to alternative treatments (Polonenko et al. 2017).

While the exact prevalence of children with SSD in New Zealand is unknown, a report from The New Zealand Deafness Notification Database (Digby et al. 2022) indicated that SSD accounts for 6% of all reported hearing loss cases in children between 2010 and 2020. One previous study in New Zealand focused on a case study of a child with unilateral hearing loss who received a CI (Cañete et al. 2021); however, no research to date has specifically investigated a larger cohort of parents' perceived benefit of cochlear implantation in children with SSD. At the time of this investigation, a small number of children have received an implant for SSD in New Zealand, with the Northern Cochlear Implant Program (NCIP) reporting a total of 10 cases since 2014 (D. Bos, personal communication, February 15, 2021) and the Southern Cochlear Implant Programme (SCIP) reporting 8 cases between 2018 and 2022 (J. Mustard, personal communication, April 17, 2022). The purpose of this study was to collect and thematically review the experiential impressions and perspectives of parents whose children have undergone cochlear implantation for SSD.

Methods

This study was approved by the Auckland Health Research Ethics Committee (AHREC) on 5 August, 2021. A mixed methods research design was used to explore parents' perspectives of cochlear implantation for children with SSD. Qualitative methods are commonly employed in health research to analyse behavioural patterns, describe lived experience, evaluate interventions and inform clinical practice (Renjith et al. 2021; Crombie and Davies 1996). Open-ended questions encourage the acquisition of rich, meaningful data by allowing respondents to express themselves without the constraints imposed by quantitative techniques (Schuman et al. 1981). This approach provides researchers with a contextualised understanding of human experiences and allows for unforeseen narratives to emerge from the data (Fowler 1995). In the modern environment of person-centred care, the qualitative perspective can inform clinical decisions and enrich the personal experience of healthcare delivery. Due to the limited number of cases in NZ, the questionnaire was also circulated in the United States. The incidence of and practices regarding CIs for SDD varies among countries, however, it was reasoned that differences in locale would not impact parents' perceptions.

Survey development

Based on the current literature, a questionnaire was designed by the investigators and reviewed by two paediatric cochlear implant audiologists with over 12 years of combined experience, an adult SSD CI recipient, and an experienced qualitative researcher who was not a co-author of this study. To maximise reliability and validity of responses, questions were developed to be 'brief, relevant, unambiguous, specific and objective' (Peterson 2000). The experienced qualitative researcher was consulted to assist with the construction of open-ended questions. The final questionnaire included 14 questions arranged in three sections and was designed to take 15–20 minutes to complete (see Appendix). Section one (Q1-Q6) included a series of demographic questions about the child and their hearing loss. These questions examined factors known to affect CI outcomes in children with SSD, including aetiology, onset of deafness and device use (Park et al. 2023).

The second section evaluated changes noted by parents after the child's cochlear implant, as well as parental satisfaction or 'happiness with their decision'. This was measured on a five-point rating scale ranging from one being 'extremely unhappy' to five being 'extremely happy'. Seven items relating to changes experienced because of receiving a CI were combined to create a scale for overall outcome benefit. These items were: (1) emotional wellbeing, (2) willingness to engage socially, (3) mood or disposition, (4) listening effort or fatigue, (5) attention and ability to focus, (6) speech and language development and (7) ability to communicate in noisy environments (Figure 2). Parents were asked to indicate whether after receiving a CI their child had experienced a positive change (+1), negative change (−1), or no change (0) for each item. These items were used to create a composite perceived change score for the purpose of identifying correlational trends. (Higher score corresponds to positive perceived outcomes and lower scores reflect negative perceived outcome). Outcome scores were plotted as a function of CI experience to investigate whether the parents of children with more CI experience reported improved outcomes. The relationship between CI experience and outcome scores is shown in Figure 3.

The next section included two open-ended questions presented using customised display logic. These questions asked participants whether their child had experienced any challenges or academic impacts after receiving their CI. Those who answered 'yes' to either question were taken to an open-ended response field and asked to explain their answer. The last section of the questionnaire asked participants the following open-ended questions: (1) What advice would you give to other parents/caregivers considering a CI for their child with SSD? and (2) Do you have any other comments you would like to share about your child's experience with their CI?

Recruitment approach and participants

Participants were recruited through newsletters and social media outlets managed by paediatric cochlear implant centres in the United States and New Zealand over a period of 6 months in late 2021 and early 2022. A web-based survey platform (Qualtrics, Provo, UT) was used to create, distribute, and collect survey responses. The participant information sheet, consent form and inclusion criteria were targeted to parents of children with SSD who had undergone cochlear implantation. A total of 23 participants completed the online questionnaire.

Data analysis

Survey responses were recorded online through Qualtrics and exported as a data file into Microsoft Excel (2022). Each respondent was assigned a unique identifier and incomplete responses were excluded from analysis. Demographic data including age at onset of deafness, age at implantation, and etiology were compiled. Responses to the questionnaire were analysed using a general inductive approach (Thomas 2006). This approach describes a systematic procedure used to analyse qualitative data and identify key themes based on specific research objectives. Data files were initially cleaned and organised into a common format. Phrases or meanings within the data were used to identify and define common codes. Formalised definitions of each code were developed into a code book and used as a guide for data analysis to avoid definitional drift. Similar quotes were assigned into codes using NVivo 12 software. The coding framework was subsequently revised to link or combine codes with similar meanings into themes and analysed until no new themes were identified (Thomas 2006).

A reliability analysis was carried out on these subtopics or themes: (1) emotional wellbeing, (2) willingness to engage socially, (3) mood or disposition, (4) listening effort or fatigue, (5) attention and ability to focus, (6) speech and language development and (7) ability to communicate in noisy environments. The reliability analysis of the seven themes items yielded an overall Cronbach's alpha of (α = 0.859), which demonstrates good internal reliability. A corrected item-total correlation was used to assess the reliability of individual scale items. All item-total correlations were greater than 0.5, indicating that no individual item was poorly related to the others.

Quantitative results

The mean age of the 24 children in this sample was eight years (SD = 3.4) ranging from (1.0–15.0 years). The mean age at which children received their CI was 6.3 years (SD = 3.2) and the mean duration of CI experience was 1.9 years (SD = 2.1). Figure 1 shows the distribution of age at the time of CI.

As shown in Table 1, the majority (37.5%) of children in this sample had an unknown aetiology of hearing loss. Twenty-five percent (n = 6) experienced SSD secondary to congenital CMV infection, and one child was determined to have enlarged vestibular aqueduct syndrome. Over half (54.2%) of the sample had a congenital onset of deafness, and five children developed SSD after birth but before two years of age. Regular device use, as defined by Wiseman et al. (2021), was reported for all children, with 83% (n = 20) using their CI for more than 8 hours/day. Twenty percent (n = 5) of the questionnaire responses were received from New Zealand participants and the remaining 79% were from the United States of America.

The distribution of responses to each item queried is shown in Figure 2. Seventy-four percent of parents indicated that their child experienced a positive change in their ability to communicate in background noise after receiving a CI. Fifty-seven percent reported a positive change in their child's attention/ability to focus and willingness to engage socially. Similarly, 62% of parents reported a positive change in queries related to their child's speech and language development, as well as their emotional well-being.

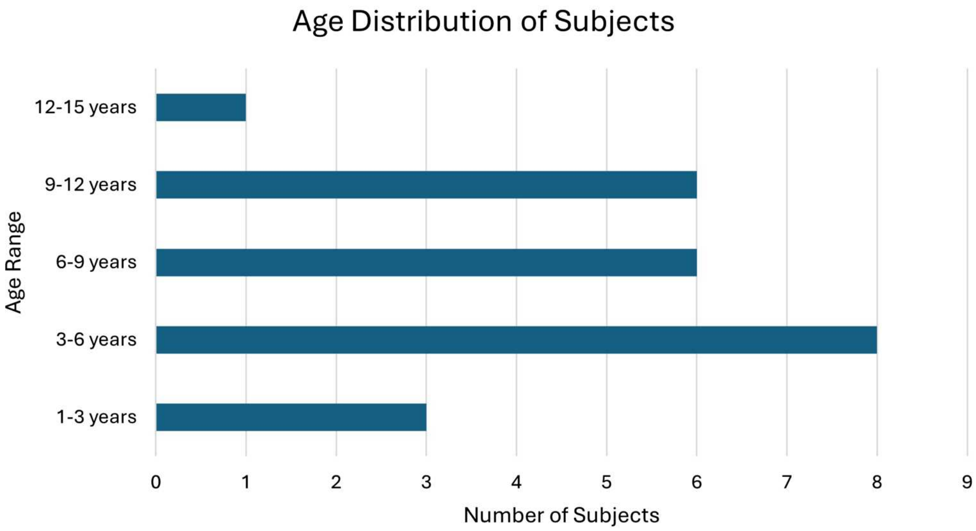

Figure 1. Age-distribution of children at age of implant. Children were combined into 3-year age intervals.

Table 1. Characteristics of children (frequencies and percentages).

Characteristics	Frequency	%
Aetiology		
Cochlear nerve deficiency	1	4.2
Congenital CMV	6	25.0
Meningitis	1	4.2
Head trauma	4	16.7
Idiopathic SSNHL	2	8.3
Unknown	9	37.5
Other	1	4.2
Onset of deafness		
Congenital	13	54.2
Onset after birth and before 2 years	5	20.8
Onset between 2–4 years	2	8.3
Onset after more than 4 years	4	16.7
Daily device use		
More than 8 hours per day	20	83.3
Less than 8 hours but more than 5 hours per day	4	16.7
Country		
New Zealand	5	20.8
United States of America	19	79.0

Sixty-one percent of parents reported a positive change in their child's listening effort. Finally, 43% reported a positive change in their child's mood or disposition.

The relationship between CI experience and outcome scores is shown in Figure 3. A correlational analysis was not conducted due to the distribution of the data; however, a trend was evident that outcome scores were related to CI experience. In general, children with more CI experience had moderate to high outcome scores (meaning more positive response), while those with less experience demonstrated poorer outcome scores (meaning less positive response). A few recently implanted children exhibited high outcome scores, indicating that some parents perceived their child to gain immediate benefit from their CI.

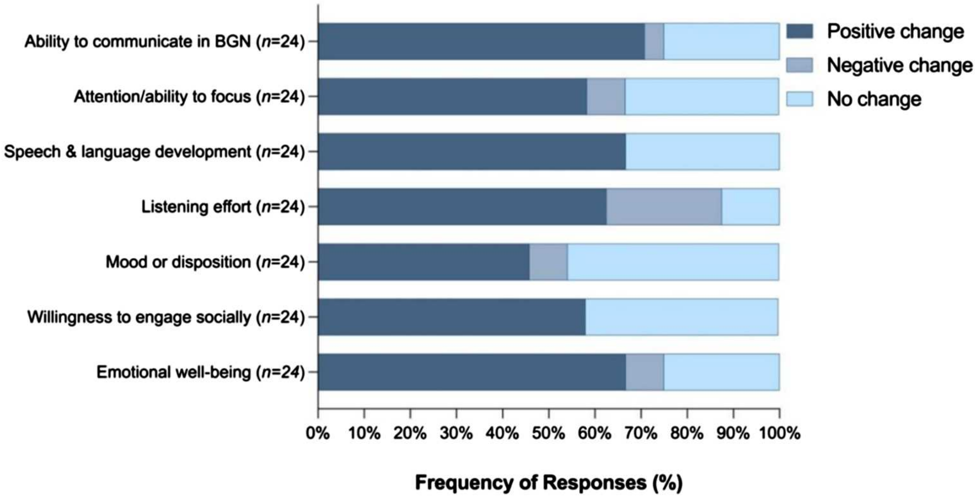

Figure 2. Seven items, shown above, were queried. Parents were asked to rate whether their child experienced a positive change, negative change, or no change after receiving their CI for each of the seven items. These were used to create a composite perceived change score for the purpose of identifying correlational trends. BGN = Background noise.

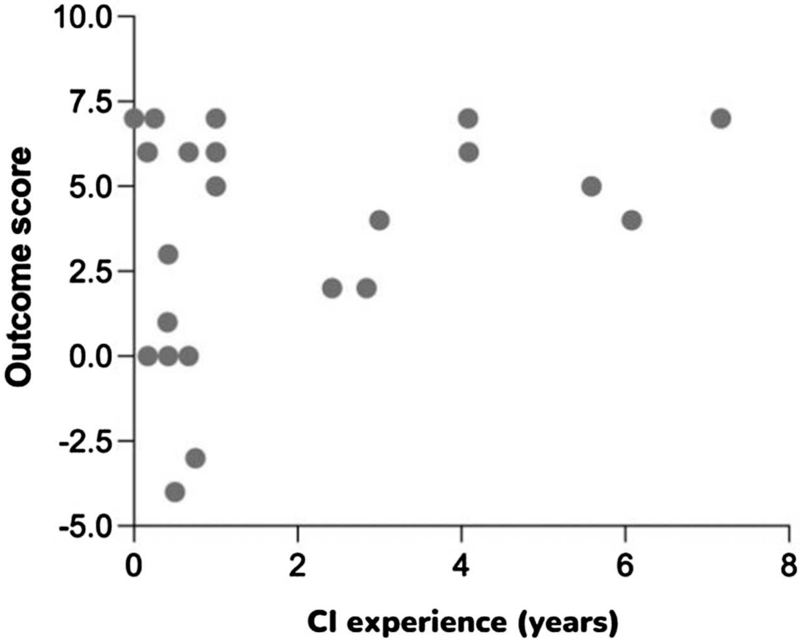

Figure 3. Relationship between years of CI experience and CI outcome scores. Along the continuum from − 5 to 10, the higher score corresponds to positive perceived outcomes and the lower scores reflect negative perceived outcomes.

Qualitative results

Four key themes related to parental experiences of cochlear implantation for children with SSD were identified during data analysis of the open-ended responses: (1) motivating factors; (2) perceived benefits of increased access to sound; (3) challenges associated with the CI journey; and (4) advice to parents. Subthemes were also developed to better understand the breadth and complexity of data captured in each of the key themes. The final organisation of themes and subthemes is represented in Figure 4 and explanations of each subsection follow.

Theme One: Motivating Factors

While parents typically described the process as iterative and complex, the following key motivating factors were identified: psychosocial impacts, long-term consequences, safety concerns, and future-proofing. See comments by parents related to these subthemes in Appendix 1.

Psychosocial impacts

Despite the common misconception that one normal hearing ear is enough, several parents expressed concerns about the potential impacts of untreated SSD on their child's psychosocial development. Children were frequently described as feeling

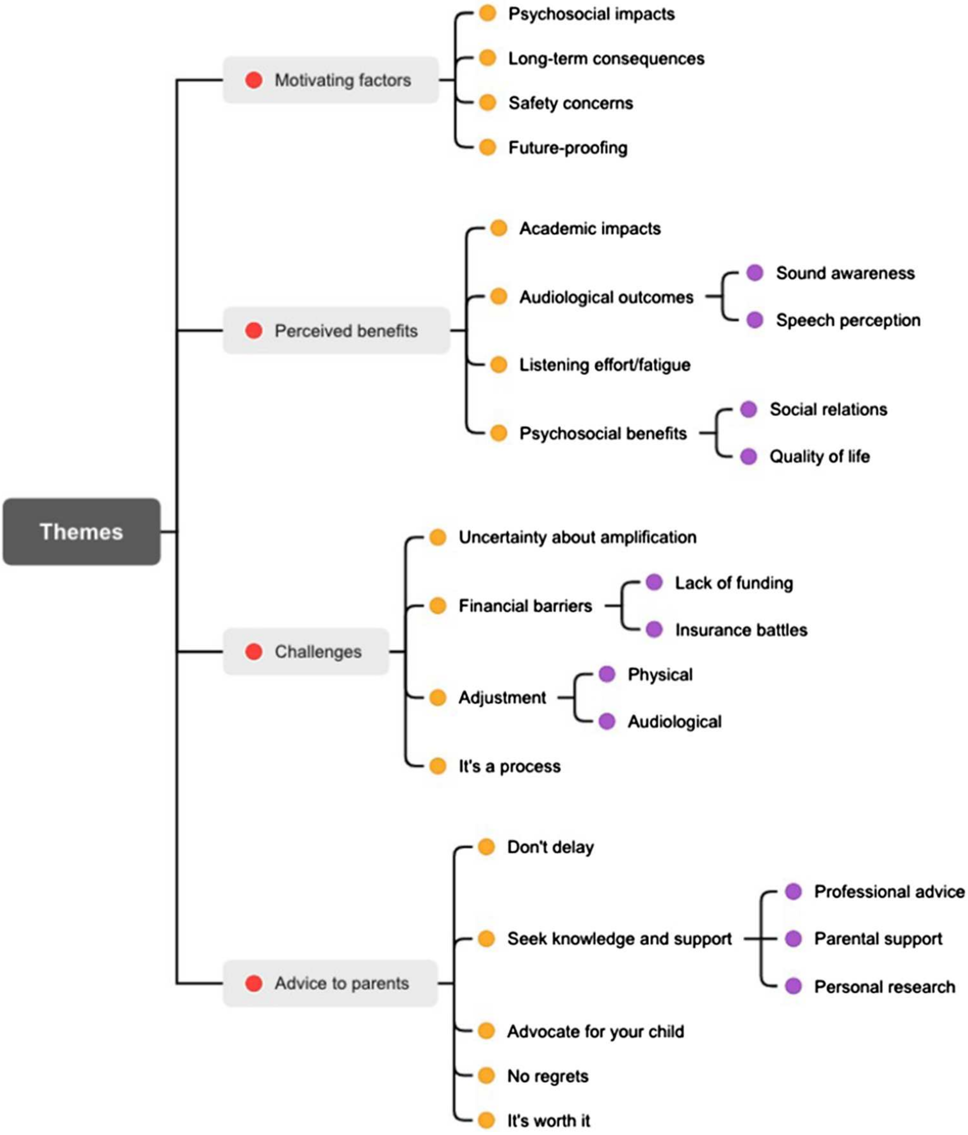

Figure 4. Organisation of themes and subthemes from qualitative data analysis.

'anxious' and 'isolated' in social settings due to their inability to localise sound and understand speech in background noise.

Long-term impacts

The long-term consequences of untreated SSD were identified as a key factor influencing parents' decision to pursue a CI for their child. Although children were often reluctant to receive a CI, parents were cognizant of how SSD could potentially impact their child's academic success and social development. From this perspective, many parents considered the CI as 'a long-term investment' in their child's future. One parent believed that having a CI would enable their child to participate in mainstream education and provide a broader range of vocational opportunities in the future.

Safety concerns

For many parents, safety considerations were paramount in their decision to pursue a CI for their child. Spatial hearing deficits associated with monaural hearing can lead to significant concerns about children's safety, primarily their inability to localise sounds in potentially dangerous environments. One parent reported a recent experience of their child being struck by a car that precipitated their decision to pursue the CI.

Future-proofing

Future-proofing, or the process of anticipating future events and developing strategies to minimise negative effects, was cited by several parents as the motivation to pursue an implant for their child. In part, their rationale was based on the unpredictable nature of SSD and the concurrent risk of bilateral involvement. When viewed from this perspective, CIs were seen to provide a level of assurance that children would continue to have access to sound regardless of other changes in their circumstances. Other parents noted that underlying their decision to proceed with an implant was the concern that if they did not act swiftly, their child would miss the opportunity to develop binaural hearing.

Theme two: increased access to sound

The second key theme outlines the perceived benefits of increased access to sound afforded by the CI as reported by parents. These include academic impacts, listening effort, sound awareness, speech perception, and psychosocial benefits, with one parent describing these benefits as 'life altering'. Comments related to these subthemes are shown in Appendix 2.

Academic impacts

Parents were asked whether their child's academic performance had been impacted by their hearing loss, with 50% ($n = 12$) of parents indicating an affirmative response. According to these parents, children demonstrated a significant improvement in their learning and academic achievement after receiving a CI. The restoration of bilateral functionality was also seen to enhance children's capacity to comprehend verbal information, enabling them to perform academically at a level consistent with their normal hearing peers.

Listening effort

Following cochlear implantation, parents also perceived a significant reduction in their child's listening effort compared with their preoperative performance. As a result of the reduced listening effort, their child became more enthusiastic about learning while also experiencing less cumulative fatigue over the course of the day.

Parents also reported that the provision of a CI improved their child's energy levels, disposition and willingness to engage socially after school.

Sound awareness

Consistent with the restoration of binaural cues, many parents observed a significant improvement in their child's ability to localise sounds with a CI. As evident in the comments, cochlear implants were perceived to enhance spatial awareness, enabling children to become more engaged with their surroundings. This perceptual advantage was most apparent in complex auditory environments characterised by high levels of background noise.

Speech perception

Another frequently cited benefit of amplification was enhanced speech perception. A number of parents reported marked improvements in their child's ability to understand speech and distinguish similar sounds with a CI. These comments include noticing small differences in the child's ability to perceive individual phonemes and gestalt differences in general communication.

Psychosocial impacts

In many cases, parents observed improvements in their child's social interactions and quality of life within a few weeks of device activation. Specifically, parents described their children as being more 'confident', 'self-sufficient', and 'happier' after receiving their CI. Beyond the immediate psychosocial benefits, parents also associated CI use with improvements in their child's overall growth and development.

Theme three: challenges

While parents reported a range of benefits associated with cochlear implantation, several challenges with the CI process and postoperative period were also identified. When explicitly asked if their child had experienced any challenges after receiving their CI, 45.8% (n = 11) of parents responded 'yes'. These challenges were classified into the following subthemes and together constitute the third major theme of this qualitative analysis: uncertainty about amplification, financial barriers, adjustment, and it's a process. Comments that capture these subthemes are shown in Appendix 3.

Uncertainty about amplification

During the early stages of the diagnostic process, parents described feeling 'nervous' and 'anxious' about their decision to pursue a CI for their child. For some, this apprehension was fuelled by inconsistent professional advice regarding the consequences of SSD and potential benefits of amplification. As evident in the extracts shown in Appendix 3, parents felt that some professionals dismissed their concerns and minimised the importance of their child's hearing loss. Parents also identified that difficulties associated with accessing reliable information regarding treatment options for SSD contributed to their uncertainty about amplification:

Financial barriers

Funding the implant and managing the ongoing financial obligations post-implantation were frequently cited by parents as one of the more significant challenges associated with the CI process. These challenges typically fell under two main subthemes: lack of funding and difficulties obtaining insurance approval. The lack of CI funding available for children with SSD was perceived by some parents as a lack of equity in access to healthcare. Combined with the prohibitive costs associated with accessing private services, the lack of funding not only created a barrier to treatment but also imposed a significant financial burden on families.

Adjustment and accepting the process

Parents also noted a range of challenges in the post-operative period as their child adjusted to using a CI. The challenges experienced during the adjustment period were generally transient and could be categorised under two main subthemes: physical and social adjustment and audiological adjustment. Although some parents perceived benefits shortly after the device was activated, most acknowledged that it took time for the full benefits to be realised.

Theme four: advice to parents

The final theme captures advice that parents would give to other families considering a cochlear implant for their child with SSD. From this advice, the following four main subthemes were identified: don't delay, seek knowledge and support, advocate for your child, and it's worth it. Comments from parents on these subthemes are included in Appendix 4.

Seek knowledge and support

Parents encouraged other families to research the potential benefits and risks associated with CIs to enable them to make an informed decision and better support their child through the process. In addition, parents described the benefit they obtained from meeting with other families and encouraged those contemplating a CI to contact families who had been through the process to learn more about their experience.

Don't delay and advocate for your child

When reflecting on their experiences, parents encouraged other families, who had completed their due diligence, to act promptly in order to maximise the potential benefits of binaural hearing. Specifically, parents discussed the positive impact of early intervention on both the training and recovery time after surgery. While acknowledging that 'sometimes the experts don't get it right', parents advised others to challenge the advice they received and to continue advocating for their child.

No regrets/ its's worth it's

When asked how happy they were with the decision to pursue a CI for their child, on a five-point scale ranging from one being ('extremely unhappy') to five being ('extremely happy’), all parents (n = 24) indicated that they were extremely happy and advised that they had no regrets about their decision to proceed with the CI. Finally, despite their initial scepticism and all the challenges they faced, parents ultimately concluded that getting a CI for their child was a worthwhile investment.

Discussion

Bilateral cochlear implantation is the standard of care for children with bilateral, severe-to-profound hearing loss (Wanna et al. 2012) and has been the accepted practice in New Zealand since 2014. The 2019 US FDA approval of cochlear implantation for SSD for children resulted in increased awareness of SSD, greater access to CIs, and subsequent research findings on outcomes for this population. The aim of this study was to investigate how parents perceived their child’s outcomes following cochlear implantation, as well as the challenges of the process using parent-proxy measures. The questionnaire distribution format was an effective means of gathering data. It allowed for quantitative parent ratings to be collected and for analysis of open-ended qualitative responses intended to reflect real-world behaviours and outcomes. By offering the parent perspective on cochlear implantation for SSD, these findings may offer clinicians additional counselling support for whānau to support family decision making and may support policy changes regarding funding of CIs for SSD.

Overall, parents reported positive outcomes following cochlear implantation and were happy with their decision to pursue a CI for their child. These findings are consistent with previous research by Thomas et al. (2017) who reported high levels of parental satisfaction, noting that 84.2% of parents would choose a CI again for their child with SSD. According to the distribution of scores on the itemised and composite CI outcome scale shown in Figure 2, the majority of parents perceived benefit from the CI in all of the queried situations or domains. Three children received a scaled score of zero, indicating that their parents perceived no change in their overall outcome following cochlear implantation. Two parents reported a negative scale score, indicating their perception that the CI had negatively impacted their child’s performance outcomes. These two children were recently implanted, so it may be possible that their experiences were related to challenges and adjustments associated with receiving a CI.

In general, children with a longer duration of CI experience had more positive outcome scores, while those with less experience reported poorer outcome scores. Additionally, in the case of children with more than two years of CI experience, the reported outcomes were always positive. These findings are comparable with what is observed in traditional paediatric CI candidates, wherein progress improves over time (Pulsifer et al. 2003). Longer time since surgery, shorter duration of deafness and higher average daily use times have been shown to correlate with open set word understanding in the ear of implant for children with SSD (Park et al. 2023). However, it is important to recognise the unique differences between traditional CI recipients and those with SSD. Compared to bilateral deafness, brain plasticity with a unilateral deficit presents a different set of dynamic factors. Binaural integration may occur more readily in children with SSD because they have a normal hearing ear as a comparison; however, brain reorganisation to support binaural integration may be slow if there has been a long period of SSD (Arras et al. 2024). Emerging evidence in children with

SSD suggests that consistent device use can reverse some of the cortical impacts of monaural deprivation and promote the development of binaural auditory pathways (Sharma et al. 2016; Lee et al. 2020). Although the sound quality from the CI is inferior to that of the normal hearing ear, which may pose concerns for its acceptance, use, and value, some parents perceived that their child to gain immediate benefit from their CI.

A recent systematic review of cochlear implantation in children affected by SSD by Santopietro et al. (2024) identified four studies where CI use (hours per day) of patients were reported. These studies divided users into two major subgroups: those using a CI more than 8hrs/day and those using a CI less than 8hrs/day. In this study the reported use of CI is more than 8 hours/day in 70% of cases, and less than 8 h hours/day in 26%; three children (4%) had been reported to be non-users. Another recent study has shown that paediatric CI users with SSD experience improved speech recognition with increased daily device use (Park et al. 2023). However, unlike the current study, objective rather than subjective or qualitative outcomes were reported.

Seven questions assessed outcome change. For each, parents were asked to indicate whether their child had experienced a positive change, a negative change or no change at all. Most parents indicated their child experienced a positive change (Figure 2). The biggest improvement was in their ability to communicate in background noise, with 71% of parents reporting a positive change. An improvement in their child's social interactions and academic performance due to better comprehension in a classroom setting was specifically highlighted. Since most children live and learn in environments with abundant background noise, this is a significant finding. Importantly, 67% of parents reported a positive change in their child's emotional well-being and speech and language development. While children who learn to communicate by relying on only one ear can become competent communicators, the extra effort, social anxieties and educational challenges of single-sided listening are barriers that parents want to help their children overcome. Listening effort was the third highest ranked item with 63% of parents reporting a positive change. A reduction in listening fatigue when combined with an improved ability to communicate in background noise impacted positively on their child's engagement at school and academic performance.

Interestingly, 25% of parents reported a negative change in their child's listening effort after receiving a CI, which may reflect increased auditory fatigue associated with listening and processing sound through the CI, especially for recently implanted children who are still adapting to the new input. When asked to assess their child's attention/ability to focus and willingness to engage socially 58% of parents reported improvements. Finally, 46% of parents reported a positive change in their child's mood or disposition, 42% reported no change and 8% reported a negative change. Based on previous evidence (Park et al. 2023), this may improve over time as children become more comfortable with the physical device and have increased experience with processing auditory input. Overall, these findings indicate that children with SSD obtain benefit from a CI in their non-hearing ear across a variety of domains.

The original intent of this study was to investigate the outcomes of cochlear implantation in children with SSD, however, what became clear in the open-ended narratives were some of the motivating factors behind the decision parents made to pursue a CI for their child. This has not previously been explored in the literature on SSD and was a significant finding of this research. Broadly speaking, the results of this study suggest parents were strongly motivated to pursue a CI for their child to give them the best possible start in life and viewed cochlear implants as 'a long-term investment' into their child's future. Motivating factors included keeping their child safe, reducing the impact of untreated SSD on academic success, social development and maintaining access to sound in the event of bilateral involvement.

The most significant qualitative benefit identified related to audiological outcomes, including enhanced sound awareness and improvements in speech perception, which is consistent with the published literature (Ehrmann-Mueller et al. 2020; Brown et al. 2022). Spatial hearing benefits led to a range of subjective improvements including enhanced social interactions, a reduction in listening effort and improved academic outcomes.

Parents identified several challenges that arose during the decision-making process and following implantation. This is another insightful finding that presents an opportunity to consider how audiologists and otolaryngologists could counsel and advise parents considering a CI for a child with SSD. The reported lack of consistent advice and difficulty accessing information regarding treatment outcomes often led to uncertainty regarding the benefits of amplification. This finding identifies a need for more awareness among clinicians and highlights the need for accessible information regarding current treatment options and outcomes. Financial concerns also represented a significant challenge and were perceived by some as leading to inequalities in healthcare access. Though adjustment issues were reported, parents noted that the challenges associated with physical and audiological adjustments resulted in positive change, ultimately.

Parents were effusive in their praise regarding the benefits of cochlear implantation for children with SSD when asked how their experience could help to support other families considering a CI for their child. Acknowledging their own uncertainties, parents encouraged other families contemplating a CI to supplement professional advice with their own research and to seek out other parents who had been through this process. Finally, parents in this study highlighted the importance of advocating for their child and urged other families to do the same thing.

It is important to consider the potential bias associated with only using parent proxy measures to evaluate outcomes of cochlear implantation in children with SSD. Imperfect agreement between self-report and parent proxy-reports has previously been documented in research examining children with hearing loss (Zhang et al., 2022). Given that this study did not collect self-reported data or performance measures from children, the outcomes reported by parents were not able to be verified, therefore, parents may have underestimated or overestimated the actual benefit experienced by their child.

A limitation of this study was the retrospective nature of the questionnaire, which relied on parents' memories of previous events, introducing the possibility of recall bias. A retrospective questionnaire was utilised as no standardised pre-implant data were available for the participants in this study. Parents' memories of past events may either be more or less favourable than what actually occurred, potentially distorting their perception of the benefit obtained by their child following cochlear implantation. Additionally, factors such as the child's age may have impacted the results, as older children may demonstrate less auditory fatigue and better speech perception outcomes than younger children due to age and experience, rather than due to the benefits provided by their CI.

Conclusion

While there may be inherent biases and many possible motives to defend the choice to pursue CI for their child with SSD, parental perceptions of their children's use of a CI can be summarised as overwhelmingly positive, yielding benefits that can be observed in day-to-day natural listening environments. These findings offer support to clinicians when counselling families and guiding shared decision-making regarding cochlear implantation. The collection of international data helps to validate local findings and position the results of this study in a global context. Additionally, the qualitative component provided valuable insight into both the experiences and opinions of parents.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Author contributions

AH developed study design, collected and interpreted data, organised and wrote content; HT developed study design and wrote content.

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