Auditory and Vestibular Research

Barriers and facilitators to cochlear implantation among children in Karnataka, India

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Highlights

- **Early CI referral strongly increases likelihood of implantation in children**
- **Cost, fear of surgery, and family influence delay cochlear implant uptake**
- **Awareness exists, but decisions are driven by risk perception and beliefs**

Abstract:

Background and Aim: Cochlear implants (CI) offer significant benefits in speech-language and auditory development for children with severe to profound sensorineural hearing loss. However, in countries like India, barriers to accessing CI surgery persist, influenced by factors including financial constraints and societal perceptions.. Therefore, the study aimed to investigate barriers and facilitators to CI uptake in Karnataka.
Methods: A cross-sectional questionnaire-based study was conducted among parents of children who underwent cochlear implantation (CI group, n=82) and those who did not (non-CI group, n=102), in Karnataka, India (n = 184). The questionnaire was developed through expert focus group discussion, literature review, and pilot testing, and included sections on facilitators and barriers to CI uptake. Content validity was established using expert ratings (CVR and CVI), and demographic variables included parental education and socioeconomic status.
Results: The logistic regression model was significant [$\chi^2(4) = 71.25, p < 0.001$]. Higher parental education (aOR = 0.56, $p < 0.001$) and earlier age at recommendation (<3 years; aOR = 0.26, $p = 0.001$) were significant predictors of CI uptake, while income and gender were not ($p > 0.05$). Key barriers were financial burden, concerns about surgical complications, family opposition, caregiving responsibilities, and pandemic-related disruptions.
Conclusion: Facilitating CI uptake requires financial support, tailored counselling, and early detection initiatives. Government initiatives should be supplemented with subsidized CI spare parts. . Addressing parental concerns and increasing awareness among healthcare professionals and policymakers are crucial to improve accessibility and outcomes for children with hearing loss.
Keywords: Cochlear implants, parental decision-making process, financial constraints, societal perceptions.

Introduction

Advancements in hearing devices technology have significantly boosted the development of auditory abilities, speech and language skills in children with bilateral severe to profound sensorineural hearing loss. Cochlear implants (CI) enhance speech perception outcomes, sound localization, and the capacity to hear in noisy environments compared to hearing aids in individuals with hearing loss [1,2]. Despite this, in a developing country like India there are several hindrances for CI uptake. International guidelines from the World Health Organization and the Joint Committee on Infant Hearing emphasize that parents are the primary decision-makers in paediatric implantation, with decisions informed by professional counselling, family values, cultural beliefs, and expectations regarding developmental outcomes [3].

During the intricate and uncertain process of decision-making, parents commonly seek supplementary guidance and support from diverse sources including professionals, families of CI recipients, and the deaf adults [4]. The parental decision-making process is notably influenced by professional advice and the assessment of their child's eligibility for CI [5]. However, for certain parents, factors beyond eligibility, such as parental preferences, goals, values, and beliefs, also play a crucial role in determining the course of action [5]. Another study has reported that the most common service delivery-related barrier was the lack of timely and appropriate referrals; the most common social issues-related barrier was the lack of awareness [6].

Cultural beliefs and societal attitudes toward deafness differ markedly across nations, profoundly influencing parental choices about cochlear implantation. In numerous high-income countries, the procedure enjoys broad acceptance within medical and rehabilitative paradigms; however, in various low- and middle-income contexts, decisions are shaped by stigma, religious convictions, familial structures, and divergent views of deafness—as either a disability or a cultural-linguistic identity [1,3,6].

In India, the government provides CI device and surgery for free-of-cost through two principal schemes: the Rashtriya Bala Swasthy Karyakram (RBSK) and the Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP). Despite the availability of these schemes, a substantial number of children with bilateral severe to profound sensorineural hearing loss continue to use hearing aids, even when they offer limited benefit. This suboptimal parental decision significantly impacts the child's speech-language development, academic performance, and overall quality of life. Hence, a deeper understanding of the multifaceted factors involved can assist in devising targeted strategies to boost referral and surgery rates for cochlear implantation among those who could benefit from this technology [7,8].

The current study was an attempt to investigate several aspects that impact parental decision-making process within the framework of India, a nation with a distinct socio-cultural environment and medical system. This investigation aimed to elucidate the intricacies inherent in making consequential life-altering decisions, offering insights that may aid healthcare providers, policymakers, and support groups in effectively guiding families through this journey.

Methods

Study design and participants

The study employed a cross-sectional design and utilized questionnaires for data collection. Respondents, comprising either mothers or fathers of children who underwent CI surgery, constituted the CI group. Similarly, parents of children who did not undergo CI surgery formed the non-CI group. All the participants were residents of Karnataka state, India.

Development of Questionnaire

The questionnaire was developed using a structured, multi-step process. Initially, a focused group discussion was conducted with five experienced clinical audiologists to define the construct of interest and to identify its key underlying dimensions relevant to parental decision-making for cochlear implantation. Based on this discussion and a review of relevant literature, preliminary domains were generated, including awareness-related, social, time-related, and financial factors. An initial pool of items was drafted to reflect each domain.

Before the actual administration of the questionnaire, the most commonly reported barriers for CI uptake and facilitators for CI surgery were listed and given to five parents of children without and with CI, respectively. Those parents were asked to provide feedback on the questions to ensure that the questions were clear, and they were asked to suggest additional barriers to undergoing CI surgery. Following the pilot study, wordings were amended, and an additional question was added (Question 13, Table 1).

The questionnaire consists of two sections. The first section consisted of facilitators and was answered by those parents whose children had undergone CI surgery. The second section had barriers that were applicable to those parents whose children did not undergo surgery. The demographic details, including educational qualification and financial status, were also collected during questionnaire administration.

Content validation

Five expert audiologists independently reviewed all items on relevance, grammar, familiarity, simplicity, and unambiguity, using a two-point scale of ‘Yes’ and ‘No’. To quantify expert agreement on item relevance, the Content Validity Ratio (CVR) and Content Validity Index (CVI). CVR was determined based on the number of experts who rated each item as 'Yes' relative to the total number of experts, while CVI represented the proportion of 'Yes' ratings obtained for each item.

With respect to expert agreement on item relevance, all 10 items in Section 1 showed complete agreement, with all five experts rating each item as relevant, resulting in CVR and CVI values of 1.

In Section 2, most items also demonstrated high agreement, with CVR and CVI values of 1. However, Questions 2 and 7 were rated as relevant by four out of five experts, resulting in a CVR value of 0.6 and a CVI value of 0.8. According to Lawshe's criteria [9] for a panel of five experts, a minimum CVR value of 0.99 is required, and therefore these items did not meet the strict cutoff. However, considering the acceptable CVI values and the qualitative feedback provided by the experts, these items were retained with modifications to improve clarity and relevance.

Demographic information was obtained from parents using a structured questionnaire and included parental education and family income. Parental education was categorized based on completion of the 10th grade, with reliable verification obtained through presentation of official certificates. The 10th-grade cutoff was chosen as it represents the minimum educational level at which accurate, verifiable information could be consistently collected. Family income was classified as below poverty line (BPL) or above poverty line (APL) based on government-issued BPL certification and income criteria commonly used in public welfare schemes in India.

Questionnaire administration

The list of children for whom the recommendation for CI was advised was retrieved from the institute's database repository. A total of 184 parents of children with hearing loss were interviewed using a structured telephone interview method. The structured telephone interview method was chosen for its practicality in reaching a diverse sample of parents across geographical locations, within Karnataka. Before the interview, informed consent was obtained from all participants, ensuring ethical considerations were met. The responses were fed into google sheet to analyze further. Demographic details of participants are presented in Table 2.

Data analysis

Statistical analyses were executed utilizing IBM SPSS Statistics version 22. Descriptive analysis was used to investigate the frequency of occurrence of a particular factor among CI and non-CI groups. Binary logistic regression analysis was performed to identify demographic factors associated with cochlear implant (CI) uptake. CI uptake (yes/no) was entered as the dependent variable, with uptake coded as the event of interest. Parental education, child's age at CI recommendation, family income, and gender were included as predictor variables and were categorized for analysis. Odds ratios were adjusted for all variables included in the model, and adjusted odds ratios (aOR) with 95% confidence intervals and corresponding p-values are presented. Statistical significance was set at $p < 0.05$.

Results

This study aimed to analyze the barriers and facilitators to the uptake of CI from the parental perspective in a region of India.

Predictors of cochlear implant uptake

Binary logistic regression analysis was performed to identify factors associated with cochlear implantation (CI) uptake (CI uptake = 1; non-uptake = 0). The reference categories were parental education above the 10th grade, age at recommendation <3 years, above poverty line income, and male gender (Table 3).

The overall model was statistically significant [$\chi^2(4) = 71.25$, $p < 0.001$], indicating that the included predictors reliably distinguished between children who underwent CI and those who did not. The model demonstrated good fit (Hosmer–Lemeshow test, $p = 0.728$) and explained a moderate proportion of variance (Cox and Snell $R^2 = 0.32$; Nagelkerke $R^2 = 0.43$). This indicates a moderate explanatory power of the model. No multicollinearity was observed among predictors (Variance inflation factor < 5). The overall classification accuracy was 77.2%, with higher sensitivity for identifying CI uptake (85.3%) than non-uptake (67.1%).

Within the adjusted logistic regression model, parental education and timing of CI recommendation were independently associated with CI uptake.

Overall, factors associated with reduced odds were considered potential barriers, whereas those associated with increased odds were considered facilitators of CI uptake.

Facilitators and Barriers to CI Uptake

Parental responses regarding factors facilitating and hindering CI uptake among the CI and non-CI groups are summarized in Table 1 and Figures 1 and 2.

Facilitators reported by the CI Group

Parents of children who underwent cochlear implantation consistently reported positive perceptions regarding CI outcomes. All parents indicated that CI provided better long-term benefits and superior speech perception in noise compared to hearing aids. A substantial proportion of parents (75.6%) identified government-supported schemes such as ADIP and RBSK as key facilitating factors, underscoring the role of public funding in enabling access to CI services.

Despite these favorable perceptions, only 23.2% of parents expressed plans for bilateral implantation, with 76.8% not considering implantation on the contralateral side. This finding may reflect limited awareness regarding the benefits of binaural auditory input for speech perception in noise and spatial hearing.

Barriers Reported by the Non-CI Group

Parents in the non-CI group reported multiple barriers influencing their decision not to pursue cochlear implantation. The most frequently reported barrier was concern regarding long-term CI maintenance costs (90%), followed by difficulty in arranging funds for pre-implant evaluation or surgery (75.5%). Medical concerns were also prominent, with fear of post-surgical complications and apprehension about the need for re-implantation in the event of device failure reported by 70.6% of parents.

Family-level factors further contributed to non-uptake, with objections from other family members reported by 50% of parents. Additional contextual barriers included disruption due to the COVID-19 pandemic (48%), uncertainty regarding CI outcomes (47.1%), and the birth of a second child (45.1%). Importantly, concerns related to the birth of a second child reflected increased financial and caregiving burden.

Notably, lack of awareness was not a predominant barrier. The majority of parents (86.3%) were aware of cochlear implantation as a management option, indicating that informational access alone did not determine CI uptake. These findings suggest that financial, medical, familial, and psychosocial constraints—rather than lack of awareness—were the primary factors limiting cochlear implantation uptake.

Discussion

The present study aimed to identify and quantify parent-driven facilitators and barriers influencing cochlear implant (CI) uptake among children with hearing impairment.

In the adjusted logistic regression model, parental education and timing of recommendation emerged as significant predictors of CI uptake.

Lower parental education was associated with significantly reduced odds of CI uptake, suggesting that limited awareness, access to information, and understanding of intervention benefits may act as barriers. This aligns with previous literature indicating that higher parental education is associated with earlier age at implantation [10]. In contrast, studies from other healthcare contexts, such as California, have reported no significant association between parental education and CI uptake [11]. These differences may reflect variations in healthcare systems, financial coverage, cultural attitudes, and access to information. From a decision-making perspective, higher education may enhance health literacy, improve understanding of benefits, and reduce uncertainty, thereby facilitating informed choices. These findings highlight the importance of structured counselling and targeted awareness programs for parents with lower educational levels.

The Timing of recommendation emerged as a strong facilitator, with early recommendation significantly increasing the likelihood of CI uptake. Although the present study focused on parental decision-making rather than post-implant outcomes, this finding aligns with evidence showing that early implantation, particularly before 24 months of age, is associated with improved speech, language, and educational outcomes [12–14]. Early identification and timely referral may enhance parental confidence, reduce decisional delays, and improve acceptance of surgical intervention. In contrast, delayed recommendation may contribute to uncertainty, missed critical periods, and reduced motivation for implantation.

In contrast, family income and gender were not significantly associated with CI uptake in the adjusted model ($p > 0.05$), indicating that these factors did not independently influence implantation decisions in the present cohort.

Beyond model-based predictors, parents reported several perceived barriers and facilitators influencing their decision-making. Financial burden was one of the most frequently reported barriers; however, it did not emerge as a statistically significant independent predictor of CI uptake. Parents highlighted concerns related to pre-implant assessments, post-surgical maintenance, and replacement of device components. These findings are consistent with previous studies reporting reduced CI usage due to delayed replacement of damaged components resulting from financial constraints [15,16], as well as increased parental financial stress associated with long-term CI use [17]. Although government schemes often cover implantation, ongoing costs remain largely out-of-pocket [18]. These financial demands may function as perceived barriers that delay or discourage CI uptake despite awareness of its benefits.

Fear of surgical complications was another prominent barrier. Parents expressed concerns regarding procedural risks, surgical outcomes, and the child's ability to tolerate surgery, consistent with earlier reports [19,20]. Parental perceptions also appeared to be influenced by experiences shared by other families [21], with prior literature indicating that peer interactions provide emotional reassurance and practical insights [22,23]. This underscores the potential value of structured parent-to-parent mentoring programs integrated within clinical counselling [23]. Additional barriers included opposition from family members, competing caregiving responsibilities, pandemic-related disruptions, and uncertainty regarding CI outcomes. Similar concerns have been documented previously, highlighting the role of surgical risk, outcome variability, and financial burden in parental decision-making [24]. Addressing these concerns requires individualized, family-centred counselling that incorporates both clinical and sociocultural factors.

Interestingly, lack of awareness was not a predominant barrier in the present study, contrasting with findings from earlier reviews [25]. Instead, financial concerns and perceived risks related to the device and surgery were more prominent, suggesting that affordability and risk perception may outweigh access-related challenges in this population.

These findings emphasise the importance of a multidisciplinary CI care model involving otolaryngologists, audiologists, speech-language pathologists, psychologists, and social workers. Such teams can support shared decision-making by addressing informational, emotional, and financial concerns comprehensively. Increasing awareness among healthcare professionals regarding technological advances and available government schemes may further strengthen counselling practices [9,26]. The findings align with established decision-making frameworks, including the Health Belief Model and shared decision-making approaches [27,28], wherein parental decisions are shaped by perceived benefits and barriers, health literacy, and sociocultural influences [28,29].

Finally, the limited presence of large-scale national awareness initiatives on hearing loss and CI represents a critical public health gap. Compared to other chronic conditions, hearing loss receives relatively less public attention despite its long-term impact on communication, education, and quality of life [26]. Coordinated awareness efforts targeting the public, clinicians, and policymakers may improve early identification, reduce stigma, and facilitate timely intervention, ultimately enhancing CI uptake. These findings highlight the need for structured early referral systems and targeted parental counselling strategies in resource-limited settings

Limitations

The study has several caveats. First, the sample was drawn from a specific region of India, limiting generalizability due to potential regional variations in healthcare access, socioeconomic status, and cultural factors. The use of self-reported data, particularly through yes/no questionnaires, along with the retrospective analysis of responses, introduces the risk of response and recall bias. A more detailed response format, such as a Likert scale, could have better captured the complexities of parental decision-making. Further, the small expert panel size made the CVR highly sensitive, where even a single disagreement reduced its value. Additionally, the absence of longitudinal data restricts understanding of how decision-making evolves over time or in response to long-term factors. Moreover, the study focused solely on parental perspectives, excluding the views of other key stakeholders, such as healthcare professionals. Finally, unmeasured confounding variables, such as regional healthcare infrastructure or parental health literacy, may have influenced the results.

Conclusions

The decision to pursue CI surgery is highly personalized and influenced by a multitude of factors. The financial implications associated with CI surgery are being mitigated by government initiatives such as the RBSK and ADIP schemes. Moreover, there is a potential for additional governmental support through the provision of subsidized spare parts for CI devices, aimed at enhancing the uptake of CI procedures. Further, the development of individualized and tailored counselling strategies is imperative, necessitating a case-by-case approach to effectively address the diverse needs and concerns of parents considering CI surgery. Additionally, efforts to lower the age of identification of hearing loss are crucial in facilitating early intervention and increasing the uptake of CI among children. Universal newborn hearing screening and follow-up are crucial to lower the age of identification and intervention.

In summary, a comprehensive approach encompassing financial support mechanisms, personalized counselling strategies, and early detection initiatives is essential in promoting greater accessibility and uptake of cochlear implantation.

Data availability statement

The data generated and analyzed in this study are presented in the form of tables and figures. Individual participant data can be made available upon request to the corresponding author.

Ethical considerations

The study adhered to the Ethical guidelines for bio-behavioral research involving human subjects with the number bearing No.DOR 9.1/Ph.D/SP/872/2020-21 dated 12.11.2022.

Authors' contributions

CC: Study design, acquisition of data, and drafting the manuscript; PS: Interpretation of the results, statistical analysis, and drafting and critical revision of the manuscript; PM: Study design and supervision, interpretation of the results, and critical revision of the manuscript;

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Table 1. Percentage of responses obtained in Cochlear implant (CI) group (Section 1) and non-CI group (Section 2)

Section 1: CI group (n=82)			
	Questions	**Percentage of responses**	
		Yes (%)	**No (%)**
1.	Did your child get implant because he/she fit under any government schemes for free surgery of CI?	75.60	24.4
2.	Do you feel CI is better than HA on a long run?	100	0
3.	Did you choose CI for your child with the expectation that it would enhance their speech and language skills?	100	0
4.	Did you choose CI with an expectation of that child will have good speech intelligibility/production?	98.78	2.44
5.	Did you choose CI, because it provides better speech understanding in noise?	100	0
6.	Did you opt for CI considering it as a one-time investment, unlike hearing aids which need to be replaced at least once every 8 years?	100	0
7.	Did you feel the child is old enough to be undergoing a surgical procedure?	57.32	42.68
8.	Do you plan on getting implant on other side?	23.17	76.83
9.	Were proper referrals made by other professionals like Doctors or Nurses?	63.7	36.3
10.	Did you have sufficient information regarding the surgical and follow up procedures?	63.7	36.3
Section 2: Non-CI group (n=102)			
		Yes (%)	**No (%)**
1)	Were you aware about the available management options like CI?	86.3	13.7
2)	Were you worried about the cosmetic appeal and social acceptance following the procedure?	39.22	60.78
3)	Did you have doubts on outcome or success of CI?	47.10	52.94
4)	Did you feel there is a possibility of betterment in hearing as the child grows?	27.45	72.55
5)	Did child take a long time to get used to hearing aids?	39.02	60.98
6)	Did you had trouble in arranging funding or money for pre-implant tests or surgery?	75.50	24.50
7)	Did having another baby lead to neglecting the first one?	45.10	54.90
8)	Do you live in faraway place hence couldn’t complete the testing?	23.53	76.47
9)	Were there any objections from the family members?	50	50
10)	Were there any financial issues as the other child in the family is implanted before?	8.82	91.18
11)	Did covid-19 pandemic affect the plans of getting the surgery done?	48	52
12)	Are you afraid of getting re-implantation in case of surgery failure?	70.60	29.40
13)	Are you afraid that your child does not maintain the device and is at risk of getting hit on the head frequently?	39.22	60.78
14)	Are you scared of the maintenance expenses like procuring cable or speech processor etc after CI?	90	10
15)	Were you frightened about surgery and post implant complications?	70.6	29.4

Table 2. Demographic details and the number of samples in each category. Total number of samples in cochlear implant (CI) and non-cochlear implant (CI) groups was 82 and 102 respectively

	Demographic details	Cochlear Implant (CI) Group (%)	Non-CI group (%)
Children	**Age**		
	Below 3 years	29 (35.36)	9 (8.82)
	3 to 5 years	51(62.19)	77 (75.49)
	Above 5 years	2 (2.45)	16 (15.69)
	Gender		
	Male	50 (60.97)	57 (55.88)
	Female	32 (39.02)	45 (44.12)
Parents	**Income**		
	Below poverty	46 (56.09)	96 (94.11)
	Above poverty	36 (43.90)	6 (5.89)
	Education		
	Below 10th grade education	38 (46.34)	95 (93.13)
	Above 10th grade	44 (53.66)	7 (6.87)

CI; Cochlear Implant

Table 3. Demographic variables and results of binary logistic regression predicting cochlear implant uptake

Predictor variable	Category	Adjusted Odds ratio[*]	95% CI (Lower–Upper)	*p*-value
Education level of parents	Above 10th grade education (n = 51)	1 [Reference]		
	Below 10th grade education (n = 133)	0.556	0.406–0.762	<0.001[†]
Child's age at cochlear implant recommendation	Less than 3 years (n = 39)	1 [Reference]		
	3 to 7 years (n = 145)	0.262	0.119–0.576	0.001[†]
Family income	Above poverty line (n = 42)	1 [Reference]		
	Below poverty line (n = 142)	0.382	0.113–1.302	0.124
Gender	Male (n = 107)	1 [Reference]		
	Female (n = 77)	0.856	0.411-1.779	0.676

CI; Confidence Interval.

[*] Odds ratios represent the likelihood of belonging to the CI group (CI = 1). Values greater than 1 indicate higher odds of undergoing cochlear implantation relative to the reference category, [†] $p < 0.05$

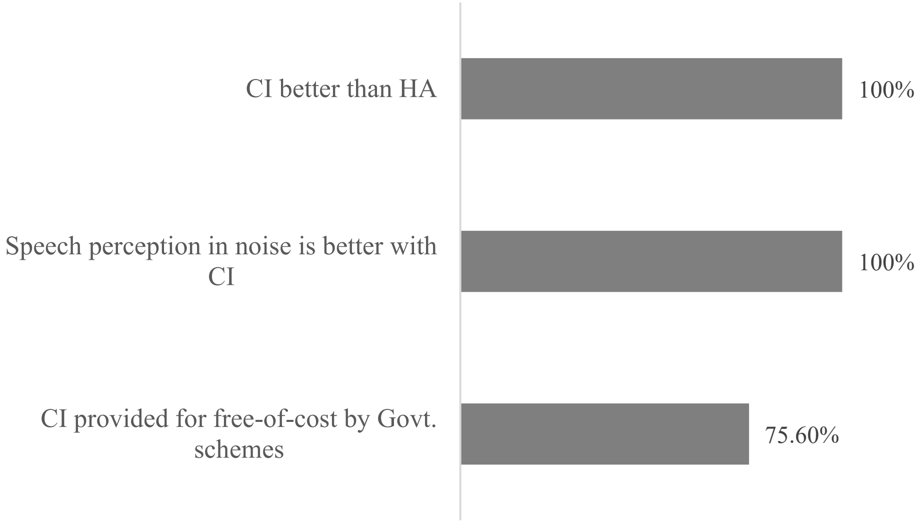

Fig 1. Percentage of responses from parents indicating perceived facilitators for Cochlear Implant (CI) uptake

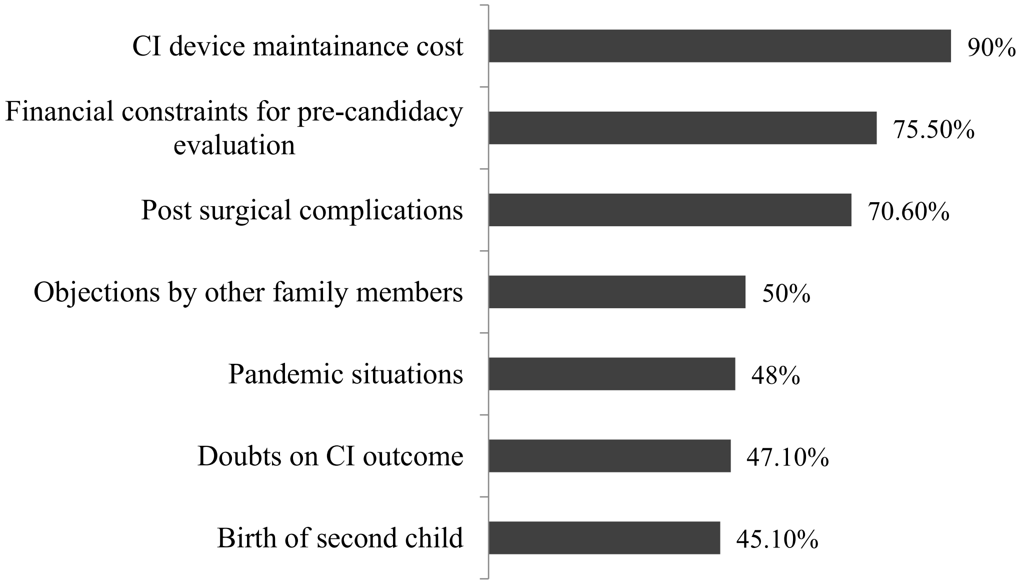

Fig 2. Percentage of responses from parents indicating perceived barriers for Cochlear Implant (CI) uptake