

# Survey of Demographic Features of Prelingually Deaf Children Using Cochlear Implants in Pakistan

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## ABSTRACT

**Background:** Hearing loss affects 1.5 billion individuals globally, with profound implications of disability, manifest in delayed speech-language development, difficulty securing mainstream education, and social integration, particularly in children. In Pakistan, challenges such as consanguineous marriages, insufficient healthcare infrastructure, and environmental factors exacerbate the prevalence of pediatric hearing impairments.

**Methods:** This retrospective survey aims to establish the demographic character of children with congenital or prelingual hearing loss, given cochlear implants (CIs) in Pakistan. It investigates intervention timelines, family and educational language status, and outcomes of cochlear implantation in terms of aural rehabilitation and enrolment at school. Data was collected from 81 participating parents of CI children, using a questionnaire that revealed trends in the age of cochlear implantation, linguistic diversity, speech-language therapy given to CI children, and educational integration post-implantation. The data (e.g., multiple-choice questions) was analyzed using methods in descriptive statistics (means, percentages) for the different groups.

**Results:** While advancements in CI technology show promise, the results of this survey show limited accessibility and financial constraints as significant barriers to aural rehabilitation. The majority of the CIs were given to 2, 0-4; 0-year-old children. 90.12% of children in this study received speech and language therapy, of which 49.38% were enrolled in mainstream schools, while 38.27% attended other schools. 43.21% of the children received a donation for their CIs.

**Conclusion:** The study emphasizes the need for subsidized programs, enhanced public awareness, robust post-implantation support, and integration of hearing care into primary health systems to maximize the benefits of early intervention in multilingual settings.

**Keywords:** Aural rehabilitation, Children, Cochlear implant, Early Intervention, Hearing impairment.

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## INTRODUCTION

Disabling hearing loss refers to a hearing impairment more significant than 35 dB in the better hearing ear, significantly affecting an individual's ability to communicate and interact with their environment<sup>1-2</sup>. Hearing loss is a significant global health issue, affecting over 1.5 billion people worldwide, with nearly 430 million

experiencing disabling hearing loss<sup>3-4</sup>. It is particularly impactful in children, as hearing is critical for the development of verbal communication and education. Without early detection and intervention, children with hearing loss may face speech, language and cognitive development delays, leading to academic



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challenges and social isolation<sup>5</sup>. This can negatively affect their quality of life, limiting their ability to fully engage with peers and achieve their potential<sup>6</sup>. The prevalence of hearing loss is compounded in low- and middle-income countries, where access to hearing care services is often limited, underscoring the urgent need for improved awareness, prevention, and intervention strategies<sup>4,7,8</sup>.

Globally, in 2021, approximately 97.83 million children and adolescents under the age of 20 suffered from hearing loss, contributing to about 3.91 million years lived with disability (YLDs). Over the period from 1990 to 2021, the prevalence of hearing loss increased from 3,537 cases per 100,000 to 3,711 cases per 100,000. This rise was characterized by an estimated annual percentage change (EAPC) of 0.15% (95% confidence interval: 0.12–0.17)<sup>9</sup>.

Hearing health in Pakistan faces significant challenges, with a substantial portion of the population affected by hearing loss due to limited access to healthcare, insufficient awareness, and a lack of robust infrastructure for early diagnosis and intervention<sup>10-12</sup>. Approximately 3% of children are born with some form of hearing impairment, and the number of children experiencing hearing loss has increased by about 30% over the past three years<sup>13-16</sup>. Contributing factors include cousin marriages, high-grade fever, birth-related issues, and infections caused by improper infant care during feeding. Environmental factors such as noise and air pollution also play a substantial role, particularly in urban areas like Karachi, Lahore, and Faisalabad. These cities are among the world's most polluted, exacerbating noise-induced hearing loss and ear infections<sup>17-20</sup>.

It is estimated that millions in Pakistan experience some degree of hearing impairment, with congenital causes, untreated ear infections, and noise pollution being common contributors. Children are particularly vulnerable, as undiagnosed hearing loss can hinder language development, education, and social integration<sup>16, 21</sup>. Rural areas face the most acute challenges, where healthcare resources are scarce, and awareness about hearing care is minimal<sup>11-14,22</sup>. Additionally, the availability of audiologists,

hearing aids, and cochlear implant services is limited, making effective treatment inaccessible to many<sup>23</sup>. This underscores the urgent need for government and private sector initiatives to enhance public awareness, expand healthcare services, and integrate hearing care into primary health programs to address this pressing issue<sup>10</sup>. Despite advancements in cochlear implant (CI) technology, limited data exist on the effectiveness of early intervention programs in children with prelingual hearing loss, especially in multilingual countries like Pakistan<sup>24-29</sup>. The situation of CIs in Pakistan highlights both progress and significant challenges. CIs are increasingly recognized as practical tools for treating severe to profound hearing loss, particularly among children. However, their accessibility remains limited due to high costs, low awareness, and inadequate healthcare infrastructure<sup>2,5,10,30</sup>. The average cost of a cochlear implant ranges between \$15,000 and \$35,000, including surgery and post-operative care. This makes them unaffordable for most families in Pakistan, where the per capita income is relatively low<sup>3,31</sup>. In urban centres such as Lahore, cochlear implantation programs are available but not widespread. These programs have shown positive outcomes in improving speech and auditory skills among recipients. However, the volume of surgeries remains low, primarily due to financial barriers and the lack of government-funded initiatives<sup>10,30</sup>. For instance, most cochlear implant recipients globally are in wealthier countries, while developing countries like Pakistan struggle to integrate such programs into their public health systems. Efforts like charity-based funding and private-sector involvement have facilitated some access, but these initiatives are not enough to meet the country's needs. Further challenges include the scarcity of trained audiologists and ENT specialists and limited post-implant rehabilitation services, which are crucial for the effective use of implants. Increasing public awareness and implementing subsidized programs are essential to expanding the availability and impact of CIs in Pakistan<sup>6,10,32-35</sup>.

This retrospective survey aims to analyze the demographic features of the age of cochlear implantation and the linguistic and educational status of children with prelingual hearing loss receiving CIs. Understanding these factors is

critical in tailoring rehabilitation strategies for prelingually deaf children in a linguistically diverse population. The study identified children with CIs through vendor records and parent support groups, providing a unique dataset that could improve early intervention strategies and aural rehabilitation programs, particularly in multilingual settings, ensuring better integration of children with prelingual hearing loss into educational and social environments.

## METHODOLOGY

A questionnaire was designed for parents of children using CIs to extract information relating to various demographic features that could potentially make an impact in the life of a child with a hearing impairment from the time s/he received the CI, followed by speech-language therapy, and finally, enrolment in school. These features included the following;

- i. **Gender**
- ii. **Age when the child received the CI**
- iii. **Native language and other languages spoken in the child's home and surroundings**
- iv. **Provision of speech and language therapy, (v) enrolment at school**
- v. **Financial cost of CI**

The residence of the children receiving the CI was also established, though it was not considered in the statistical analysis with the other demographic features. This survey was based on the questionnaire designed by Mumtaz, Saqlain and Babur<sup>11</sup>. It was distributed to eligible children's parents using various messaging service platforms. The responses to the questions were gathered through the same online platform and exported into CSV files to analyze the data.

### Ethical Review

The institutional approval of the described study was taken from the ERC of Ziauddin University with ERC reference code 5330422ASSLT.

### Selection of Candidates and Study Size

The subjects who were parents of children with CI were approached through the vendors (MED-EL, Cochlear, and Advanced Bionics) supplying CIs to

the potential candidates and through parent support groups for this retrospective survey study.

The eligibility for enrolment of parents of children with CI was based on a comprehensive set of criteria, including the age at which their children received the CI, multi/bilingualism, typical developmental milestones, and the absence of co-morbidities in children. These factors were chosen to ensure that the children using CIs were representative of the target population and to minimize potential confounding variables that could affect the outcomes of cochlear implantation.

Since the children had already received their CIs, no assessment was done to determine eligibility. From a total of (N=148), 83 parents of children using CIs were enrolled in this survey. However, (n=81) participated in the data collection process, as two of them had missing records, and their responses were excluded. The study was conducted from January 2023 to July 2023.

### Statistical Analysis and Results

The data (e.g., multiple-choice questions) was analyzed using descriptive statistics (means, percentages) and cross-tabulation methods to compare different subgroups, such as Microsoft Excel.

## RESULTS

### Gender Distribution

Of the 81 participants included in the study, 47 (58.02%) were males, and 34 (41.98%) were females.

### The Age at Which the Children Received CI

Another important factor was the age of the children when the implant was given. Table-2 shows a frequency distribution table where the age is divided into five classes in increments of two years, and the number of individuals within that age group is listed. From the collected data, the minimum age when the implant was given was 1 year, and the maximum age was 10 years, with a mean of  $3.48 \pm 1.79$  years.

Table-1 Age of Participants

Age Bracket	Number of Participants	Percentage
0 ----2	17	20.99%

2----4	43	53.09%
4----6	13	16.05%
6----8	6	7.41%
8----10	2	2.47%

### Native Language of Child's Mother and other Languages Spoken at home

Urdu was the dominant native language for the mothers of the children included in the study (58.02%), as shown in Figure-1, and Sindhi was the second most common native language. The other native languages used in the children's homes were Pushto, Punjabi, Saraiki, Gujrati, Hindko and Balochi.

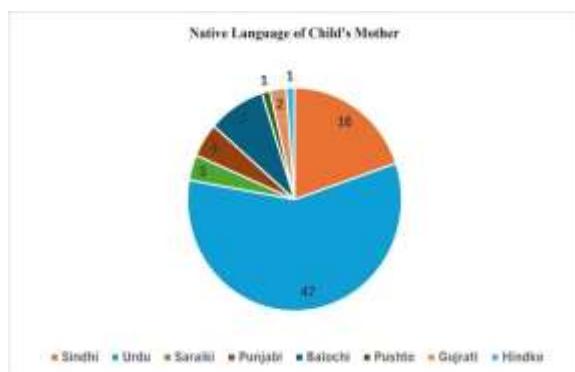


Figure-1 Pie chart showing the native language of the child's mother for the study

41 (50.62%) people responded that Urdu is the only language spoken as another language. 19 (23.46%) people responded that both Urdu and English are spoken, whereas 12 (14.81%) responded that only English is spoken as another language, and the same percentage responded for other local languages. The bar graph representation is shown in Figure-2.

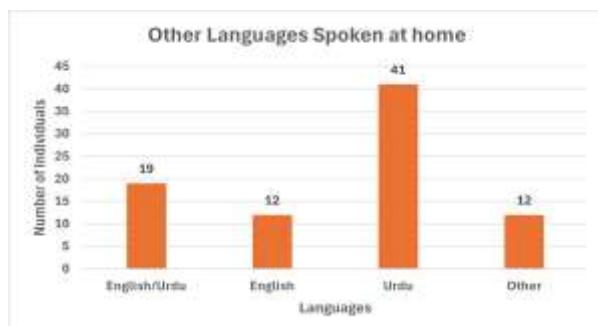


Figure-2 Other languages spoken at the home for the children included in the study

### Provision of Speech and Language Therapy

Following the cochlear implantation, providing speech and language therapy is crucial to developing verbal communication skills in children with hearing impairment. 73 (90.12%) of the participants responded that the child received speech and language therapy, whereas only 8 (9.88%) people responded negatively.

### Enrolment in School

Most children (49.38%) could attend the conventional mainstream schools. Only 4 (4.94%) participants responded that their children were enrolled in a special school. In contrast, a considerable proportion (38.27%) of the respondents declared that their children went to other kinds of schools, e.g., tuition centers, madrasahs, etc., whereas 6 (7.41%) of the participants did not respond (Figure-3).

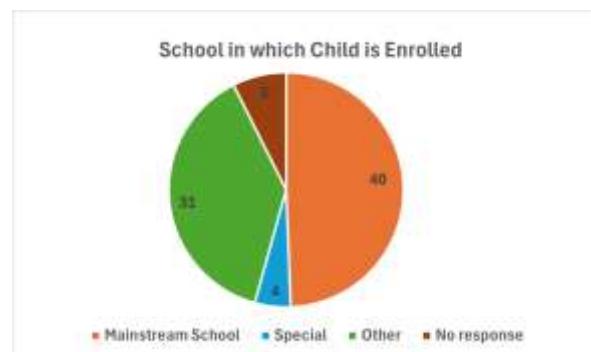


Figure-3 Pie chart representing the number of individuals enrolled in various kinds of schools

### Financial Cost of Cochlear Implant

Among the 81 parents, 35 (43.21%) responded that their child's CI was donated, whereas 44 (54.32%) responded that they had funded the expenses of cochlear implantation for their children. Only 2 (2.47%) participants did not disclose whether the financial cost of the implant was borne by the family or donor.

### Area of Residence

72.84% or 59 children from the collected data belonged to Karachi. Few other participants (3,3 and 1) belong to Lahore, Quetta, and Islamabad (respectively). 18.52% or 15 belonged to other regions, as shown in Figure-4.

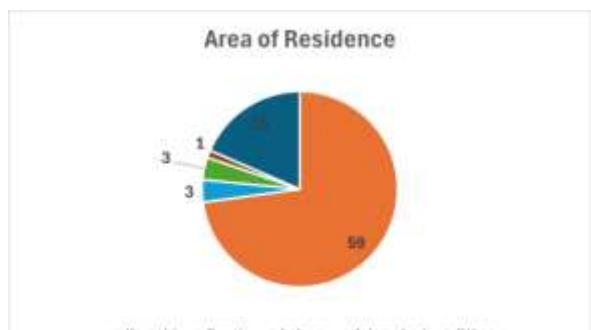


Figure-4 Area of residence for the participants

## DISCUSSION

The findings of this survey highlight a higher proportion of males (53.09%) compared to females with prelingual deafness who received CIs. Although this result aligns with other studies<sup>13</sup>, it may also indicate cultural trends or a gender bias, which requires further investigation. The most significant number of children who received their CI was between the ages of two and four years, which indicates a significantly important trend for cochlear implantation of congenitally deaf children in Pakistan. Although CI is given within the first year of life in the developed world, countries like Malaysia and India have capped their age of eligibility for CI among deaf children at 4 years of age chronologically<sup>17, 36-38</sup>. Since there is maximal development of speech and language skills during the first five years of a child's life, the period of 2-4 years for cochlear implantations holds significant value for acquiring academic success through school enrolment<sup>39-42</sup>. Although 90.12% of the parents enrolled their children for speech and language therapy post-implantation, indicating a high degree of cognizance of the aural rehabilitation process, only half (49.38%) of the parents enrolled their children in mainstream schools, whilst the remaining half of the children went to other institutions such as a madrasah, or they were home-schooled or received academic instruction individually through private tuitions. This indicates the need for more support for prelingually deaf children in mainstream schools.

Pakistan is a multilingual country. The CI children in this survey were most commonly exposed to Urdu through their mothers (58.02%), followed by Sindhi. It is important to have enhanced language support for children with CIs in local educational institutions. Having nearly half (43.21%) of the children receiving their CIs through donors in this survey underscores the importance of addressing financial barriers for optimal aural rehabilitation in Pakistan. This underscores the need for expanding public health initiatives and enhancing post-implantation support. These efforts are

crucial for improving outcomes for children with hearing impairments and ensuring more equitable access to hearing care services in Pakistan.

**Saudi Arabia and Kazakhstan Studies:** Similar studies in Saudi Arabia and Kazakhstan have shown that CIs can significantly improve the quality of life for children with hearing impairments. These studies highlight the importance of early detection and intervention and the role of family and geographic factors in accessing cochlear implant services.

The lack of government funding for CI on private or charitable funding sources in Pakistan exacerbates financial barriers. This context underscores the need for collaborative efforts between the government, private sector, and non-profits to enhance access to these life-changing technologies.

### Limitations

**Sample Size and Representation:** The study's sample size of 81 participants may not fully represent the diverse experiences of all cochlear implant recipients in Pakistan. This limitation could affect the generalizability of the results.

### Future Directions

Future research should focus on expanding sample sizes, reducing selection bias, and incorporating pre-implant assessments to provide a more comprehensive understanding of cochlear implant outcomes. Additionally, efforts to integrate hearing care into primary health programs and to increase public awareness about the importance of early intervention are essential for improving the lives of children with hearing impairments in Pakistan.

## CONCLUSION

This study provides insights into the progress and challenges of pediatric cochlear implantation in Pakistan. Early intervention and speech therapy can benefit children with CIs, facilitating integration into mainstream education. However, several limitations must be considered when interpreting these findings. The study's sample size of 81 participants may not fully capture the

diverse experiences of all CI recipients in Pakistan. Additionally, selection bias is inherent, as the study only included children who had already received CIs, excluding those who did not have access to this technology.

Furthermore, the lack of pre-implant assessments complicates the evaluation of true progress post-implantation. Despite these limitations, the study highlights the importance of addressing financial obstacles children with hearing impairments face. Collaborative efforts between government, private sectors, and non-profits are crucial for bridging gaps and ensuring more equitable access to hearing care services in Pakistan.

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None.

#### Author Contributions

**Amina Asif Siddiqui** and **Kehkashan Kanwal** jointly conceptualized the study and developed the methodology. **Amina Asif Siddiqui** conducted the formal analysis and data curation, while **Kehkashan Kanwal** was responsible for project administration and supervision. Both authors contributed equally to writing the original draft and reviewing and editing the manuscript.

#### Ethical Approval

This study received approval from the Ethical Review Committee (Reference No. 5330422ASSLT) Ziauddin University, Karachi, Pakistan.

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None.

#### Conflict of Interests

None.

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