

Reasons of Delay in the Referral for Cochlear Implantation of Pre-lingual Sensory-Neural Deaf Children

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Abstract

Background: Deafness is the most common congenital sensory disorder. Clearly, deafness has a lot of negative influence on a child's growth, learning, and social communications. More than 90% of deafness cases are sensory-neural, which can be cured with cochlear implantation. One of the most important factors, which can change the results of cochlear implantation, is the child's age at the time of implantation.

Purpose: In this work, we studied the reason of delay in referring sensory-neural deaf a child for cochlear implantation.

Methods: This study is a cross-sectional analytical study. A questionnaire was designed to investigate the reasons of delay in regards to deaf children referred of age 3 or more. Fifty-four children, 28 (51.9%) boys and 26 (48.1%) girls were studied. Variables such as age, sex, reason of delay, parents' level of education, etc. was considered. To compare data used t-test and chi-square at the 0.05 level of significance.

Results: Thirty-six (66.7%) cases were due to the unfortunate referrals by the ear, nose and throat specialists, among which 19 (35.2%) of them were reported this to be the only reason. Twenty (37%) cases reported improper services at the cochlear implantation centers as their reason. Three (5.6%) cases were due to the unfortunate referral by the pediatricians. Twenty-one cases reported the delay due to combined factors. In an additional study, 49 cases of children with deafness, which referred for a cochlear implantation before the age of 3 years, were questioned of how they were informed of this treatment. Twenty-seven (56.3%) cases reported that a physician referred them.

Conclusion: Many reasons can be concluded as the main reason for the delay in referring children with deafness for cochlear implantation. The most important factor can be inappropriate referral by the treatment-health system and the second reason can be considered improper services at cochlear implantation centers.

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INTRODUCTION

Neonatal hearing loss is the most frequent sensorial congenital defect in newborns (1, 2). About one to four children per 1,000 live births are born annually in developed countries with hearing impairment (3, 4) and this range may extend to six per 1,000 live births in developing countries (3). Due to consanguineous marriage, deafness might be more common in some countries such as Jordan with nine to eighteen children per 1,000 live birth prevalence (5). Unfortunately, no data is available on Iranian prevalence of congenital deafness. Clearly, deafness has a lot of negative influence on a child's growth, learning, and social communications:

1- Disability in language learning and speech: many researchers believe that during the first several years of life, human brains are open to original language learning. When this opportunity for learning is closed by deafness during this critical period, language learning does not follow its usual way (6).

2- A great deal of problems in social communication, job, and marriage.

3- A great deal of problems in social communication, job, and marriage. In addition, deafness might cause a huge economic burden. In one research on Italian population in 2007, the lifetime mean cost assessed for a subject affected by profound pre-lingual deafness turned out to be equal to 737,994 Euros for a male and 755,404 Euros for a female (7).

Sensorineural hearing loss (SNHL) accounts for about 90% of all hearing loss. Almost always the cause of SNHL is dysfunction of hair cells of organ of corti; which means auditory nerve and cortex are intact (8). Therefore, in 1972 an electrical prosthesis was made to bypass this defect. A study in Australia shows the cost of implantation per quality adjusted life years (QALY) ranges from \$5,070 to \$11,100 for each child (9). Obviously it is not comparable with “hearing” and its following effects on human growth.

The most important factors that influence a child’s speech ability after a cochlear implantation are the child’s age at the time of the implantation, the age at which the child lost his/her sense of hearing and the amount of time that the child was deprived of hearing prior to the implantation, and the condition of the child’s family in regards to the number of members in each family (8, 10, 11). The duration of implantation use during infancy and early childhood clearly affects the profoundly deaf children’s ability to speak (12).

The late detection of permanent congenital hearing loss often has severe effects on linguistic, speech, cognitive and educational development in affected children. Since newborn hearing screening (NHS) allows most of them to be detected early enough for optimal intervention. At the beginning of 1960s newborn hearing screening was suggested (13, 14).

Although in some developing countries SNHL is very common, there is no newborn hearing screening system and children’s hearing ability is first checked when they attend school. In addition to the lack of general screening, there are no screening facilities even for those who are at risk in these countries. Considering these issues, the issue of why sensory-neural deaf children are not diagnosed in time by any other sources e.g., their parents, their doctor, etc. and why they are referred so late for cochlear implantation, even when they are diagnosed, was studied in this work. Although, it is worth mentioning that recently neonatal hearing screening has begun in Iran.

PATIENTS and METHODS

This study is a cross-sectional analytical study. All subjects recognized as three years of age or more pre-lingual sensory neural deaf children who were referred for cochlear implantation during 2009-2010. Variables such as age, sex, reason of delay, parents’ level of education and number of family were recorded. Requirements included age of 3 years or more and pre-lingual sensory neural hearing loss.

At first a pilot study was completed on 11 children with 3 years of age or more, who had visited the Amiralam hospital in Tehran, Iran for a cochlear implantation. From that pilot study a sample volume of 53 children was estimated as described by Formula 1.

$$N = \frac{Z_{1-\alpha/2}^2 P(P-1)}{d^2}$$

Formula 1. Estimating the sample size: $\alpha=0.05$, $d=0.17$, $P=0.73$, $N=53$.

For data collection, due to lack of a questionnaire for such a study, a questionnaire was designed and then reviewed and approved by the ENT research committee of Amiralam hospital. The goal of the questionnaire was to collect these variables: patients’ age, sex, and reasons of delay in referral for cochlear.

Another study was completed at the same time. This one was designed to detect the referral way to cochlear implantation for younger than 3 years kids. There were two points we wanted to identify in this present study; first, the influence of factors such as; demographic factors, age and parents’ level of education on the reason of delay in proceeding for cochlear implantation, and second, the way they were informed of cochlear implantation and therefore, their on-time proceeding for their children’s deafness treatment.

Notice that the second study was a cross-sectional analytical study as well. We reviewed younger than 3 years old pre-lingual sensory neural deaf children who were referred for cochlear implantation during 2009-2010. The same variables as the first study were evaluated. After the importance and necessity of the research was explained to the parents, the

parents completed the questionnaires and the data was used for the research with their consent. According to the declaration of Helsinki all ethical rules were obeyed and data were kept confidential. Data was analyzed by SPSS 13 software using t-test and chi-square with significant level <0.05 .

RESULTS

a) Comparing the data collected from the first group (children age of 3 years and higher) and the second group (children under age of 3):

1- No significant difference was found in gender distribution (p -value = 0.618) or urban rural distribution (p -value = 0.323) between the two groups.

2- The educational level was not significantly different between the fathers of the two groups (p -value=0.579), but it was for mothers (p -value=0.017). In the second group nearly 80% of mothers had at least a high school degree, whereas about 60% in the first group had such a degree.

3- The mean age of parents in the first group was 38.47 ± 10.24 for fathers and 32.21 ± 7.32 for mothers, and in the second group it was 34.67 ± 6.91 for fathers and 29.57 ± 5.45 for mothers. Thus, the second group's parents (both fathers and mothers) were significantly younger than the first group with p -values of 0.032 and 0.043, respectively.

4- The mean age of the children when their parents first noticed their deafness, and their age at the time they first visited a hospital also showed a significant difference between the two groups (p -value <0.001). For the first group these numbers were 14.78 ± 9.85 and 88.22 ± 92.25 months and for the second group 8.17 ± 5.80 and 15.94 ± 8.53 month.

5- Another significant difference was the ratio of hearing aids usage and participation in speech therapy classes. Twenty-one people (3.7%) in the first group and 6 people (12.5%) in the second group had never used hearing aids (p -value=0.143). Six (16.7%) and 16 (34%) people in each group respectively had participated in speech therapy classes (p -value = 0.044).

6- However, the effectiveness of the hearing aids and the reactions of the children in the two

groups were similar according to the parents' judgments.

Therefore, comparison of these two groups showed significant differences in these variables: mothers' educational levels, both parents' ages, children's age when parents first became aware of their deafness and at the time they first visited the medical center.

b) Reasons of delay in referral in the first group:

To study the reasons of delay in referral for cochlear implantation, 8 questions were considered in the questionnaire and the ninth was an open question for more information if needed. Figure 1 shows the reasons of delay found by our study and the commonness of them. Thirty-six people (66.7%) reported unfortunate referrals by the ear, nose, and throat specialists to be the reason of delay. Although 19 people (35.2%) reported this reason to be the only reason of delay, but the rest (17 people) reported that aside from the unfortunate referral by the specialists, other reasons such as improper services at the cochlear implantation centers, unsuitable financial situation, and huge amount of distance were also effective. Twenty people (37%) reported improper services of the cochlear implantation centers and 3 people (5.6%) reported unfortunate referrals by the pediatrician to be the reason of delay. Twenty-one people reported the delay due to combined factors and only one family reported the reason of delay to not being aware of their child's deafness; this child was 55 months old. Children's heart disease and the denial of their families were other reasons parents reported.

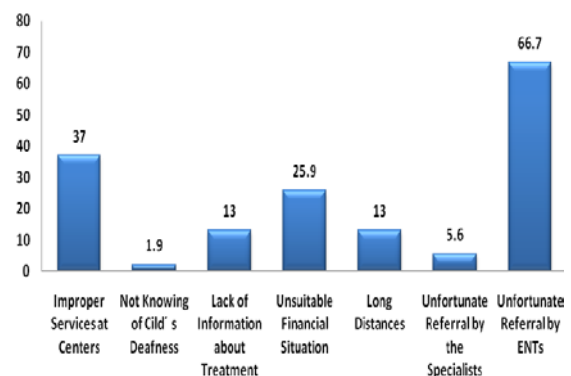


Figure 1. Frequency of the reasons of delay in referrals for cochlear implantation of pre-lingual sensory-neural deaf children 3 years old or more.

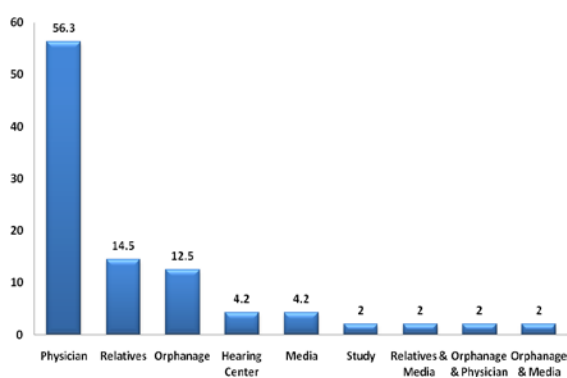


Figure 2. The distribution of frequency of “how to become familiar with cochlear implantation” of pre-lingual sensory-neural deaf children younger than 3.

c) Ways of becoming informed about cochlear implantation:

Parents of the second group were asked of how they became informed of this type of therapy (cochlear implantation) by an open question. Twenty-seven (56.3%) of the parents were informed by a physician, 7 (14.5%) by friends and relatives, and 6 (12.5%) by orphanage. Figure 2 shows how they became informed of cochlear implantation.

DISCUSSION:

In the results of our study we had personal information from 3 stages of the children’s lives:

1- The child’s age when their parents found out about their deafness: It had taken the second group about six months less time to notice their child’s deafness.

2- The child’s age at the time of their first referral to the cochlear implantation center: The second group’s first visit was done much earlier than the first group.

3- The child’s age at the time of the study considering the fact that none of the groups at the time had yet undergone surgery for cochlear implantation. The mean age in group 1 was 92.63 ± 85.24 months (around 8 years) and in group 2 was 22.56 ± 8.10 months (around 2 years).

The most common reason of the delay was reported to be unfortunate referral by the physicians.

In one study that was carried out in America in 2005 on 85 internal and family physicians

regarding their view towards deafness and the issues related to it like screening, referring patients, and curing possibilities. The results showed that the lack of time in physician-patient communication was the most important reason for not paying enough attention to diagnosing deafness. Seventy-six physicians (89.4%) had been aware of the cochlear implantation procedures, but only 22 of them (25.9%) referred the patients for this matter. Though, most of them were not certain to where they should refer the patient to and whether or not the patient would be considered as a candidate for cochlear implantation (15). Therefore, it is necessary for physicians to be updated in areas that are growing fast (16).

To be noted the most frequent source of becoming aware about cochlear implantation was physicians, according to 27 patients (56.3%). The second source was acquaintances (7 patients (14.5%)); especially someone mentioned that the parents of another deaf child in the same city/village informed them. Only 12.5% of the patients were informed by orphanages, 4.2% by hearing estimating centers, and 4.2% by mediums. Comparison of these data with the data of the first group and attention to the interval between the parents’ awareness of their child’s deafness and the time when the child was referred for cochlear implantation magnified the poor quality of referral systems. Considering this interval plus the time period between when the child was referred to the center and the time of our research, when no surgery had happened, we can conclude that the therapeutic centers are not so well, which was also reported by 20 families (37%). It may also be important to mention that 14 families (25.9%) indicated their poor financial situations as a reason and 7 families (5.6%) reported the huge amount of distance in addition to the conclusions made above. Armestrog, et al. in 2013 evaluated the barriers to early cochlear implantation in 57 patients; 52% were implanted more than 12 months after SNHL diagnosis. Parental barriers were reported to be the most common issue (17). Russell, et al. showed slow referral

process, parental delay and payer problems as the most serious reasons of delay in cochlear implantation (18).

Another important issue was the child's age at the time of our study. This time refers to the date when we knew everything, but did not do anything.⁺⁺ In many studies, the child's age at the time of the cochlear implantation was reported to be one of the most important factors in the surgery's outcome (8, 19, 20). Even Nicholas and Geers in a study in 2007 reported that children who had the cochlear implantation surgery before an obvious delay in their speech, between the ages of 12 to 16 months, had a higher rate of a better speech ability according to their age (21). In particular if a child's first language is an Asian language and syllable-based, their age during the implantation will have a greater effect on their speech ability in the future (20, 22). Also, it is worth to be mentioned that a delay in the cochlear implantation could cause a deficiency in the child's ethical, sight, and concentration skills development (23).

It should be noted that the data of our study was collected during 2009 and 2010 and changes in people's lifestyles and awareness may have affected the way they deal with SNHL.

Nicholas reports the best age for a cochlear implantation is before 24 months (8) and in the recent research, surgeons are attempting to perform the cochlear implantation before 12 months of age (24, 25). In contrary, even in the second group of our study, who supposedly referred at a good age, a mean age of 22.56 ± 8.10 months, no progress has been made.

CONCLUSION

Many factors are effective in this delay. The most common is inappropriate referrals by the health-treatment system and the second most common factor has reported to be inappropriate treatments in the specialized centers. To be mentioned this research only studied the reason from the children's parents' point of view, whereas, it seems that reasons such as the parents' low level of knowledge, late notice about their child's deafness and

deficiency of advice before the child refers to a health-treatment center could have roles in this delay. Not to mention that most parents with children under the age of 3 years were informed of the cochlear implantation by their physician.

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CONFLICT of INTEREST

The authors declare no conflict of interest

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