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Barriers to the Early Cochlear Implantation of Deaf Children

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Abstract

Objective—Identify social and healthcare system factors which prevent congenitally deaf children from receiving cochlear implants in a timely fashion.

Study Design—Retrospective chart review and parental interviews.

Setting—University medical center hospital in a state with mandatory newborn hearing screening (NBHS).

Patients—59 congenitally deaf children who received cochlear implant(s) between 1/1/2002 and 5/1/2009.

Interventions—Demographic and healthcare details were collected from the 59 patients.

Main Outcome Measure—Age at implantation.

Results—Thirty-four patients received implants at or before age 2 years (average age at implant surgery = 14 months) and 25 patients received implants after age 2 (average age = 65 months). The presence of NBHS ($p < 0.001$) and type of health insurance ($p = 0.05$) the child had at the time of CI surgery were significant predictors of age at implantation. The following factors were associated with increased risk of delayed implantation: no NBHS (RR=2.63), NBHS not identifying hearing loss (RR=1.63), Medicaid insurance alone (RR=1.21) or in combination with private insurance (RR=1.79), family physician as primary care provider (RR=1.50), audiologist (RR=1.30) or otolaryngologist (RR=1.31) as secondary care providers (vs. implant center RR=0.23). The main reasons for delay in CI surgery after age 2 were also identified and include slow referrals for care ($n=8$) and parental delays ($n=5$).

Conclusions—The data suggest placing special focus on children with associated risk factors, ensuring newborn hearing screening, and parent and primary care provider education on the

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importance of early intervention and referral to an implant center would likely limit delays in children receiving CIs.

Keywords

newborn hearing screen; health insurance

Introduction

Given the evidence of the safety of cochlear implant surgery in infants, children 12 months of age and younger are receiving implants^{1,2,3}. Early cochlear implantation leads to many benefits for deaf children including increased language ability, more integration into the hearing world, and an overall higher quality of life. In rate of language development and overall expressive and receptive language abilities, children implanted in infancy outperform their peers who receive implants later and approach the abilities of normal hearing children of the same age, with highest achievement seen in the children implanted before age one^{1,2,4,5,6}. Due to increased performance, children implanted earlier are also more likely to attend mainstream schools than their peers who receive implants later^{7,8}. Parent and child reports confirm that increased listening abilities are associated with a higher quality of life, and that children feel safer crossing the street, are more comfortable approaching people, and less often feel frustrated for not understanding^{9,10,11}.

In addition to the benefits to individual children, early cochlear implantation benefits society by lowering the cost of care of the congenitally deaf. The lifetime cost to society for a congenitally deaf child has been estimated at over one million dollars¹². This cost is due to the need for special education, social and support services, and the decreased work productivity and potential earnings of the deaf adult^{12,13}. Considering the cost of CI surgery, a lifetime of CI care, the decreased need for special education, the increased productivity and earning potential of the individual, and the added quality of life, early pediatric cochlear implantation is exceedingly cost effective for society^{12,13,14,15}.

Despite the fact that many states have mandatory newborn hearing screenings, congenitally deaf children often do not receive cochlear implants until age two or later. As discussed above, there are clear benefits to both deaf children and society in identifying and resolving the factors that delay cochlear implant surgery. We hypothesize that there are identifiable healthcare system and social characteristics which prevent some congenitally deaf children from receiving cochlear implants in a timely manner. By reviewing the cochlear implant process in a university medical center in a state with mandatory newborn hearing screenings, we aim to identify the factors that influence the age of implantation of congenitally deaf children. Our objective is to identify these factors so that delays in implantation may be overcome, both improving the lives of congenitally deaf children and lowering the cost of their care to society.

Materials & Methods

The study was approved by the internal review board of the University of Iowa. Fifty-nine pediatric patients who met the following criteria were identified from the database of 295 pediatric cochlear implant recipients maintained by the University of Iowa Department of Otolaryngology – Head and Neck Surgery: 1) received cochlear implant(s) between 1/1/2002 and 5/1/2009, 2) have congenital, severe to profound hearing loss, 3) were born in and received healthcare in Iowa. Chart reviews and parental telephone interviews were then conducted to collect information on the following factors: if the child had a newborn hearing screening and if it identified hearing loss; which local providers cared for the child from the

time of hearing loss diagnosis to referral to the cochlear implant team; if timely referrals for initial care were made after identifying hearing loss; if timely referrals were made for secondary care to an audiologist, otolaryngologist, and/or the implant team; if the cochlear implant team evaluated the child in a timely fashion; if parents delayed the process (through missed appointments, resistance to surgery, or in any other way); if there was a language barrier between the family and healthcare providers; what type of health insurance the child had at the time of surgery; if there were any delays due to lack of health insurance coverage at the time of surgery. Demographic information including if the child lived in an urban or rural community as defined by the United States Census Bureau, and in a single or two-parent household was also collected¹⁶. Whether or not the child received a NBHS was determined from audiological records which were obtained from a state registry for all patients except one. For this one child, the information was obtained by parental interview. Telephone interviews were conducted by the primary author using open ended, unscripted questions to address the factors listed above.

Using this information, the major cause of delay in CI surgery until after age two years was identified. While the preference of our center is to implant children at an earlier age, we chose the age of two as the upper age limit of what the implant team in our department feels is an acceptable time frame for cochlear implantation over the period of the study. Next, the relative risk of receiving an implant after age 2 was calculated for each categorical variable relative to the other levels of that variable. Specifically, the relative risk for each factor was calculated by generating the ratio of the probability of an event occurring in the given group (ie. probability of receiving an implant after age 24 months in the group of children whose HL was identified by NBHS) to the other groups (the probability of receiving an implant after age 24 months in the children who either did not have a NBHS or falsely passed the NBHS). One-way analysis of variance and multiple linear regression analysis with indicator variables were also performed to determine the significance of the differences in these variables as they related to age at implantation. Data were managed using Excel (Microsoft, Redmond, WA) and statistical analyses were performed with SPSS (Chicago, IL).

Results

In total, the 59 subjects had an average age at implantation of 35.8 months and a median age of implantation of 19.0 months. We evaluated the relationship of several variables with the age of implantation as well as the odds of receiving the implant before age 2.

Newborn hearing screening

To evaluate the relationship of NBHS with the age of implantation, the subjects were broken down into groups: those who had a NBHS that identified their hearing loss (n=44), those who had a NBHS that did not identify their hearing loss (n=6), and those who did not have a NBHS (n=5). Figure 1 presents the ages at implantation in months relative to these examined variables. For those whose NBHS identified a hearing loss, 15 received CIs after age 2, while 29 received them before age two, with the average age at implantation of 23.2 months and median age of 16.0 months. For those whose NBHS did not identify a loss, 4 received CIs after age 2 while 2 received CIs before age 2, with an average age at implantation of 26.7 months and median age of 29.5 months. For those who did not have a NBHS, all 5 received CIs after the age of 24 months, with the average age at implantation of 154.4 months and median age of 171.0 months. The relative risk of receiving a CI after age two for each of these groups is 0.42, 1.63, and 2.63 respectively (Table I). The ages at implantation between the newborn hearing screening groups were significantly different by ANOVA ($p<0.001$), and the category of newborn hearing screening was a significant ($p<0.001$) predictor of age of implantation by multiple linear regression analysis.

Health insurance status

To evaluate the relationship of health insurance status with the age of implantation, the subjects were broken down into the following groups: those with private health insurance (n=16), those with Medicaid (n=29), and those with private insurance and Medicaid supplementation (n=11). Figure 2 presents the ages at implantation in months relative to these examined variables. For those with private health insurance, 3 received CIs after age 2, while 13 received them before age two, with the average age at implantation of 25.9 months and median age of 14.0 months. For those with Medicaid, 13 received CIs after age 2 while 16 received them before age 2, with the average age of implantation of 37.0 months and median age of 19.0 months. For those with both private insurance and Medicaid, 7 received CIs after age 2 and 4 before age 2, with the average age of implantation 49.1 months and median age of 38.0 months. The relative risk of receiving a CI after age two for each of these groups is 0.38, 1.21, and 1.79 respectively (Table II). The ages at implantation between the health insurance groups was not significantly different by ANOVA, but the category of health insurance was a significant ($p=0.05$) predictor of age of implantation by multiple linear regression analysis.

Number of parents in the home

To examine the relationship of the number of parents in the patient's home with the age of implantation, the subjects were broken into two groups: those from a two parent household (n=48), and those from a single parent household (n=8). Figure 3 presents the ages at implantation in months relative to these examined variables. For those with two parents, 19 received CIs after age 2 while 29 received them before age two, with the average age of implantation of 29.8 months and median age of 16.0 months. For those with one parent, 5 received CIs after age 2 while 3 received them before age 2, with the average age of implantation of 75.0 months and median age of 31.5 months. The relative risk of receiving a CI after age two for each of these groups is 0.63 and 1.58 respectively (Table III). The age of implantation between these two groups was not significantly different by ANOVA, nor was parent status a significant predictor of age of implantation by multiple linear regression analysis.

Community size

To evaluate the relationship of the size of the patient's community with the age of implantation, the subjects were broken in the groups: those from an urban community (n=44), and those from a rural community (n=15). Figure 4 presents the ages at implantation in months relative to these examined variables. For those from an urban community, 17 received CIs after age 2 while 27 received them before age 2, with the average age of implantation of 35.5 months and median age of 17.5 months. For those from a rural community, 8 received CIs after age 2 while 7 received CIs before age 2, with an average age of implantation of 36.6 months and median age of 28.0 months. The relative risk of receiving a CI after age two for each of these groups is 0.72 and 1.38 respectively (Table III). The age of implantation between these two groups was not significantly different by ANOVA, nor was community type a significant predictor of age of implantation by multiple linear regression analysis.

Primary care providers

To examine the relationship of the primary care providers managing care of these patients with the age at implantation, the subjects were broken down into groups according to who managed their care after hearing loss was first identified: those who saw a local family physician (n=26), those who saw a local pediatrician (n=25), and those who were already being cared for at the same institution as the implant center (n=5). Figure 5 presents the ages

at implantation in months relative to these examined variables. For those who first saw a family physician, 13 received an implant after age 2 while 13 also received an implant before age 2, with the average age at implantation of 36.4 months and median age of 22.5 months. For those who saw a local pediatrician, 8 received an implant after age 2 while 17 received the before age 2, with the average age at implantation of 31.3 months and median age of 15.0 months. For those already being seen at the institution with the implant center, 2 received implants after age 2 while 3 received them before age 2, with the average age of implantation of 22.6 months and median age of 16.0 months. The relative risk of receiving a CI after age two for each of these groups is 1.50, 0.66, and 0.97 respectively (Table IV). The age of implantation between these two groups was not significantly different by ANOVA, nor was primary care provider a significant predictor of age of implantation by multiple linear regression analysis.

Secondary care providers

To evaluate the relationship of secondary care providers with the age at implantation, the subjects were broken down into three groups: those who were referred to the implant center after suggestion by a local audiologist (n=25) or a local otolaryngologist (n=18), and those who were referred directly from their primary care providers to the implant center (n=9). Figure 5 presents the ages at implantation in months relative to these examined variables. For those seen by a local audiologist, 12 received CIs after age 2, 13 received CIs before age 2, and the average of implantation was 47.7 months and median age of 20.0 months. For those seen by a local otolaryngologist, 9 received CIs after age 2, 9 received CIs before age 2, and the average age of implantation was 27.5 months and median age of 23.5 months. For those referred directly to the implant center, one received a CI after age 2 while 8 received them before age 2, and the average age of implantation of 24.1 months and median age of 13.0 months. The relative risk of receiving a CI after age two for each of these groups is 1.30, 1.31, and 0.23 respectively (Table IV). The age of implantation between these groups was not significantly different by ANOVA, nor was secondary provider a significant predictor of age of implantation by multiple linear regression analysis.

In all, an increased relative risk of implantation after age 2 years was associated with the child not having a newborn hearing screening (RR=2.63), the newborn hearing screening not identifying the hearing loss (RR=1.63), having Medicaid for insurance either alone (RR=1.21) or in conjunction with private insurance (RR=1.79), living in a single parent household (RR=1.58), living in a rural community (RR=1.38), having a family physician as the child's primary care provider (RR=1.50), and having an audiologist (RR=1.30) or otolaryngologist (RR=1.31) as the child's secondary provider. Conversely, more favorable risk ratios were seen with the newborn hearing screening identifying the hearing loss (RR=0.42), the child having private health insurance (RR=0.38), living in a two parent household (RR=0.63), living in an urban community (RR=0.72), having a pediatrician as a primary care provider (RR=0.66), and being referred directly to the implant center for secondary care (RR= 0.23). The presence of a newborn hearing screening and private health insurance were also strong predictors of earlier age of implantation.

For the group of children implanted after age 2 years, we sought to identify the major factors delaying CI surgery by reviewing medical records and interviewing parents. The reasons for delay varied (Fig. 6). A common reason was parents causing a delay (n=5). This category included three children who were in abusive and negligent homes who were later removed from their parents' custody, one child whose parents missed several appointments and delayed the process because of lack of understanding of the impact their child's hearing loss would have on development, and one child whose single mother could not afford the travel necessary to bring the child in for appointments. For 4 other children, their CI was delayed due to the newborn hearing screening not identify hearing loss. One of these children had

confirmed auditory neuropathy, and the other three had unknown reasons for the false positive test.

Another four children had other serious health issues which prevented surgery. One child born at 25 weeks had recurrent neutropenia which precluded surgery. Two children had heart defects at birth, one Tetralogy of Fallot and the other heart failure. Additionally, one child had Smith-Lemli-Opitz Syndrome and several congenital malformations of the head. Another four children's CIs were delayed due to a slow referral to an audiologist or otolaryngologist to confirm the hearing loss after it was first identified by parents in children who did not have a NBHS (n=3) or identified by a failed NHS (n=1). Four more children experienced slow referrals from local providers to the cochlear implant team.

Language barriers between the parents and healthcare providers which kept the parents from understanding the importance of early implantation delayed the CI surgery in two cases. This was deemed the main cause of delay for these two children, despite having interpreters present in both cases. Finally, for two children, the implant team was slow to evaluate the child. These two children were the earliest data taken from 2002, and no similar delays were present for children receiving care after that point.

Discussion

Identification and remediation of healthcare and/or societal deficiencies that contribute to delays in CI promise to help deaf children obtain the greatest possible benefit from the device. It would also benefit society by reducing overall rehabilitation costs. Here we sought to identify such deficiencies. We examined the reasons for delay in a state with mandatory newborn hearing screening, where the majority of implants are performed at a single center with a long-standing history of performing pediatric implants. In Iowa, a state funded agency, the Iowa Area Education Agencies, follows up on all children identified with hearing loss. Further, the majority of children in Iowa without health insurance receive healthcare coverage through Medicaid, and all have access to cochlear implants if referred to our institution. Thus, our population may represent a better case scenario compared with children in other states in terms of identification of hearing loss and access to care including cochlear implant centers. Despite these favorable healthcare system characteristics, 42% of children in our population failed to receive implants before age 2. This high percentage suggests that further measures need to be implemented to prevent delayed implantation.

In our population the reasons for delays in CI surgery varied and, in some cases, were likely interrelated reflecting the complex nature of this issue. Such complexities make it difficult to identify factors that are potential targets for intervention. Further, for some factors (e.g. parental delay), subjective judgment regarding their likely contribution to delays in CI was necessary. Nonetheless, the results of this study identify risk factors associated with delayed CI surgery and raise potential interventional targets.

Our data confirm the utility of mandatory newborn hearing screenings (NBHS). All children who did not receive a NBHS were born prior to 2004, the year the mandatory newborn hearing screenings took effect in Iowa. Children receiving a NBHS test which identified their hearing loss had a 68% risk reduction of receiving a CI after the age of 2 compared with the 163% increase in risk of implantation after age 2 in the children who did not receive a NBHS.

Similarly, having a high index of suspicion for children who passed their NBHS yet fail to reach normal auditory development milestones may help prevent some cases of delayed implantation. For the 4 subjects who had false-positive NBHS and received their implants after age 2, one of these children had confirmed auditory neuropathy and the other three had

unknown reasons. Children with documented progressive hearing loss were not included in the study. However, because we cannot absolutely rule out a very early progressive loss, a few of these children may represent that cause. Alternatively, the remaining three cases could also represent false-positive test results at local hospitals, again suggesting a need for close monitoring of children who passed NBHS yet fail to reach normal auditory development milestones.

Additionally, education for families and local care providers, particularly family physicians, on the importance of early direct referral to a cochlear implant center and the deleterious effects of unnecessarily delaying CI surgery could help prevent parental delays and delayed referrals for care. Placing special focus on children who live in a single parent household, live in a rural community, and whose parents don't speak English may also help to avoid implant delays.

Our data also suggest the need to closely monitor children with Medicaid insurance. Children with Medicaid alone had a 21% increased risk in delayed CI surgery, while the children with Medicaid and private insurance had a 79% increase in risk. These results are in contrast to what was recently demonstrated by Chang et al, who showed no significant difference in age of implantation between Medicaid and private insurance groups¹⁷. This difference could be due to our separation of those children with Medicaid from those with both private insurance and Medicaid, due to small sample sizes, or due to regional variation across the country. To the best of our knowledge, no additional work exists examining the effects of health insurance type or any of the other variables discussed above on age of implantation. Analysis of a larger sample of children from a variety of states, healthcare systems, and socioeconomic backgrounds will be needed to identify general trends.

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Figure 1.

Scatterplot of age at implantation (mo) by newborn hearing screening category. The bar represents the mean age for each population. The age of implantation between populations is significantly different ($p < 0.001$) by ANOVA. Newborn hearing screening is also a significant predictor of age at implantation ($p < 0.001$) by multiple linear regression analysis.

Figure 2.

Scatterplot of age at implantation (mo) by type of insurance child possessed at time of surgery. The bar represents the mean age for each population. The type of insurance the child had at the time of surgery is a significant predictor of age at implantation ($p=0.05$) by multiple linear regression analysis.

Figure 3.

Scatterplot of age at implantation (mo) by number of parents living with child. The bar represents the mean age for each population. The difference in age of implantation is not significant between groups.

Figure 4.

Scatterplot of age at implantation (mo) by category of child's residence, as defined by the United States Census Bureau. The bar represents the mean age for each population. The difference in age of implantation is not significant between groups.

Figure 5. Scatterplot of age at implantation (mo) by the primary providers (A) and secondary providers (B) managing a child's care. The bar represents the mean age for each population. The difference in age of implantation is not significant between groups.

Figure 6.

Bar graph of the main reason identified for CI delay in the 25 children implanted after age 2.

Table I

Relative risk of cochlear implantation after age 24 months based on newborn hearing screening.

		CI After 24 mos	CI Before 24 mos	Relative Risk
Hearing Screening	Newborn Hearing Screening Identified Hearing Loss	15	29	0.42
	Newborn Hearing Screening Did Not Identify Hearing Loss	4	2	1.63
	No Newborn Hearing Screening	5	0	2.63

Table II

Relative risk of cochlear implantation after age 24 months based on health insurance status.

		CI After 24 mos	CI Before 24 mos	Relative Risk
Health Insurance	Private Insurance	3	13	0.38
	Medicaid	13	16	1.21
	Both	7	4	1.79

Table III

Relative risk of cochlear implantation after age 24 months based on community size and parental status.

		CI After 24 mos	CI Before 24 mos	Relative Risk
Community	Urban	17	27	0.72
	Rural	8	7	1.38
Parent Status	Two Parents	19	29	0.63
	Single Parent	5	3	1.58

Table IV

Relative risk of cochlear implantation after age 24 months based on primary and secondary providers.

		CI After 24 mos	CI Before 24 mos	Relative Risk
Primary Care Provider	Family Physician	13	13	1.50
	Pediatrician	8	17	0.66
	Within Institution	2	3	0.97
Secondary Provider	Audiologist	12	13	1.30
	Otolaryngologist	9	9	1.31
	Implant Center	1	8	0.23