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Factors Influencing Access to Cochlear Implantation in Deaf and Hard-of-Hearing Children in Southern California

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Objective: To determine the epidemiologic relationship of family demographics and educational resources with parental knowledge of and willingness for their children to receive cochlear implantation (CI) for deaf and hard-of-hearing (DHH) children.

Methods: A total of 213 parents of DHH children were surveyed at local schools, specialized camps, and clinics in Southern California. Data on parents were solicited, including income, insurance status, education level, hearing status, primary language, and motivations towards CI.

Results: Sixty-six surveys were included in the analysis. Three of these patients had already undergone CI, thus of the 63 children without CI, 59% had been presented with the option of CI by a healthcare professional and 27% were willing to have their child undergo CI. Willingness for children to undergo CI was statistically higher in families

with an annual income less than \$15,000 or more than \$75,000 ($p=0.02$), and children enrolled in specialized schools for DHH ($p=0.02$). The leading reasons for unwillingness to undergo CI were risks of surgery (17%) and discouragement from others (14%).

Conclusion: A significant gap exists between the number of CI candidates and families and willingness to undergo CI. The difference could be related to socioeconomic status and the patient's school type. This underscores the importance of parental education through the use of a multi-disciplinary team to ensure all hearing rehabilitation options are explained. **Key Words:** Cochlear implantation—Congenital hearing loss—Deaf and hard-of-hearing.

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In the United States, the average incidence of neonatal hearing loss is 1.1 per 1,000 infants (1), with a 20-fold risk among infants in the neonatal intensive care unit (2). The universal neonatal hearing screening (UNHS) was introduced in the early 1990s and has since been mandated in 39 states (3–5). UNHS has been shown to improve long-term language outcomes at school age compared with those who were not screened (6,7). Nevertheless, ensuring appropriate audiologic follow-up upon identification of hearing loss with or without UNHS has been a persistent issue (4,5). In 2008, in the state of California alone, 511,830 (93%) of neonates were screened for hearing loss before hospital discharge (8). Of those screened, 832 (1.6 per 1,000 screened) were identified with hearing loss, but 3.6% of these infants

needing outpatient follow-up were lost (8). These regional statistics underscore the importance of early identification of children with congenital hearing loss and if desired timely referral to audiologic and otolaryngologic evaluation for potential hearing rehabilitation.

Cochlear implants (CI) are one option for hearing rehabilitation available to the deaf or hard-of-hearing (DHH) children. Early implantation for children born with bilateral severe to profound hearing loss has been shown to improve speech and language acquisition (9–12). Several studies have explored attitudes towards CI, with many of them focusing on parental values (13–17). Part of the impetus to this study was that the senior author continued to treat older pediatric patients who were CI candidates yet had not been implanted. On questioning the parents, they would often state that previous audiologists told them that CI would have not been helpful for their child. We sought to understand why children who were no longer CI candidates due to their age and would have been CI candidates when younger at the time of their diagnosis had not obtained a CI. We thus designed a simple regional survey study to determine the relationships between family demographics, parental knowledge, and willingness for their children to receive CI. Findings from this study may identify correctable factors that

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preclude parents of DHH children from receiving early CI for their children.

METHODS

Approval was obtained from our internal institutional review board. Candidate families were identified based on enrollment in specialized deaf education programs (e.g., special education at high school), participation in a specialized deaf camp, and medical evaluation at a tertiary otology clinical practice at an academic medical center. All patients had been assessed by an audiologist or neurotologist and determined to have been CI candidates had they presented earlier in life. A total of 213 parents of DHH children were anonymously surveyed in person or via mail. All survey respondents were residents of Southern California (Los Angeles, Orange, San Bernardino, San Diego, Riverside, Imperial, Ventura counties).

The survey instrument used contained multiple-choice questions with space to fill in customized responses (Supplemental Figure 1, <http://links.lww.com/MAO/A700>). Basic

family information, including the primary language used at home, use of sign language, child's current age and type of school attended, annual family income, ethnicity, type of insurance, and highest level of education by each parent was captured. Family history assessed was number of family members who have hearing loss and types of hearing remediation used—if any. The survey also contained specific questions gauging parents' knowledge of CIs and willingness to undergo CI. Specifically, questions determined if the possibility of CI was discussed at any point in their child's care. For those who were counseled, we determined if parents would have elected to have their child receive a CI and the reasons deterring parents from having their children receive CIs.

The majority of questions were completed in its entirety, with blank questionnaires excluded from data analysis. Chi-squared testing was used to determine relationships among the survey variables. Statistical analysis was performed using PASW Statistics 18.0 for Windows (SPSS Inc., Chicago, IL). An alpha of less than 0.05 was used for all tests.

TABLE 1. *Characteristics of children, families, and their association with knowledge and willingness to obtain cochlear implants*

	Frequency	Knowledge of CI	<i>p</i> Value	Willingness to get CI	<i>p</i> Value
Child's age			0.84		0.18
<12 years	27/66 (41%)	17/24 (71%)		4/22 (18%)	
≥12 years	39/66 (59%)	24/36 (67%)		10/27 (37%)	
Child's school type			0.51		0.02 ^a
Public school	30/58 (52%)	18/28 (64%)		2/22 (9%)	
School for deaf or hard of hearing	28/58 (48%)	19/26 (73%)		8/21 (38%)	
Family income			0.88		0.02 ^a
<\$15,000	8/62 (13%)	6/8 (75%)		5/8 (63%)	
\$15,000–\$29,999	13/62 (21%)	9/12 (75%)		3/10 (30%)	
\$30,000–\$49,999	19/62 (31%)	10/16 (63%)		1/14 (7%)	
\$50,000–\$74,999	8/62 (13%)	5/8 (63%)		1/6 (17%)	
≥\$75,000	14/62 (22%)	9/12 (75%)		4/7 (57%)	
Highest education in family			0.15		0.69
High school or lower	24/63 (38%)	14/24 (58%)		6/19 (32%)	
College or higher	40/65 (62%)	26/34 (76%)		7/28 (25%)	
Parents' hearing status			0.54		0.09
Both normal or one deaf	49/65 (75%)	30/43 (70%)		13/25 (52%)	
Both deaf	16/64 (25%)	10/16 (63%)		1/14 (7%)	
Family insurance			<0.001 ^a		0.002 ^a
Medi-Cal/Medicaid	3/66 (5%)	0/0 (0%)		0/0 (0%)	
PPO	6/66 (9%)	6/6 (100%)		1/2 (50%)	
HMO	12/66 (18%)	8/10 (80%)		4/9 (44%)	
California children's services	34/66 (51%)	25/34 (74%)		8/32 (25%)	
Other	11/66 (17%)	2/9 (22%)		1/7 (14%)	
Primary home language			0.33		0.06
ASL	7/65 (11%)	6/7 (86%)		0/7 (0%)	
English	44/65 (68%)	27/38 (71%)		8/27 (30%)	
Non-English	14/65 (21%)	7/13 (54%)		6/12 (50%)	
School curriculum			0.75		0.08
ASL	30/63 (48%)	20/29 (69%)		8/24 (33%)	
Mainstream	17/63 (27%)	13/17 (76%)		1/14 (7%)	
Oral/aural	11/63 (17%)	5/9 (56%)		4/7 (57%)	
Total communication	5/63 (8%)	2/3 (67%)		0/1 (0%)	

^aStatistical significance below 0.05.

ASL indicates American Sign Language; CI, cochlear implantation; HMO, health maintenance organization; PPO, preferred provider organization.

FIG. 1. Parental reasons for why cochlear implantation was not elected for their child.

RESULTS

Of the 213 participants surveyed, 66 (31% response rate) were returned. The mean and median age of all children was 12 years old (range, 2–20 yr). The demographics and characteristics of children included are presented in Table 1. Of the cohort, three children already had CI, thus were excluded from the analysis of willingness to undergo CI. Of the remaining patients without CI ($n = 63$), and at the time of hearing loss diagnosis, 37 (59%) had been presented with the option of CI and 17 (27%) were willing to have their child undergo CI. The leading reasons for an unwillingness to undergo CI were risks of surgery (17%) and negative feedback from others (14%) (Fig. 1). Sources of education about CI are shown in Figure 2. Willingness for children to have undergone CI was statistically higher in families with an annual income less than \$15,000 or more than or equal to \$75,000 ($p = 0.02$), and children enrolled in specialized schools for DHH ($p = 0.02$) (Table 1). No other association was observed between knowledge of or willingness to get CI and epidemiologic factors.

DISCUSSION

Early identification and intervention through audiologic remediation, such as with a CI, has a demonstrated benefit in language development for DHH children (18,19). Many studies have shown the long-term cost-effectiveness and improved quality-of-life associated with CI (20–22). A survey of parents who have DHH children and have undergone CI found that willingness to pay for CI was very high, with most seeing no other economic alternative for hearing rehabilitation (23). Several studies have reported on parental factors as a determinant for decision-making in having DHH children undergo CI (23–27). Parental factors should not be overlooked, as they have been found to be a major contributor to DHH children not undergoing CI (28). The current study expands on this topic and explores the relationships among demographic and family factors in DHH children who qualified for CI but elected not to undergo implantation.

By examining the list of reasons why the child had not undergone CI, we see that 17% of parents were

FIG. 2. Response to the question: If your child has severe hearing loss or is completely deaf, did anyone discuss the possibility of cochlear implant with you?—If yes, who?.

concerned about the risk of surgery. Given the low incidence of complication in CI surgery (29), proper education of parents by the surgeon may help increase the likelihood of implantation in potential candidates. For 83% of parents, the source of information for CI was from non-surgeon perspectives. Remarkably, 10% of patients obtained their information from a primary care physician. It has been reported that the general knowledge of primary care physicians regarding cochlear implantation is limited (30).

When compared to parents of public schooled children, parents of children who attended a specialized school for DHH children demonstrated greater willingness to have their children undergo CI. This is not unexpected, as families that have access to a DHH school are more informed in this regard and more willing to have their child try this therapy. Sach and Whynes (31), in surveying 216 normal hearing families of DHH children

who underwent CI, found that a major theme motivating their decision for implantation was to have their children “function in a hearing world,” possibly in an age-appropriate, non-specialized education setting. Naturally, narrowing the communication gap between parent and child, and the general population is beneficial. As a result, speech and language acquisition is perceived as a significant benefit for parents of DHH children.

The current study also found that annual familial income below \$15,000 or greater than \$75,000 was associated with willingness to have DHH children undergo CI. This is in contrast other studies, where socioeconomic factors, including household income, and Medicaid insured patients did not influence the decision for children to undergo CI (16,32). We hypothesize that low and high income groups are motivated by various different reasons. In the United States, low income patients may have less access to healthcare (33).

As pediatric CI is covered by Medicaid with the appropriate indications, many low-income patients are able to receive CI due to no additional cost burden to the patients (16). In this respect, families within the low income category have increased access to CI. Coupled with the potential benefits of CI they may be more likely to follow medical and audiologic recommendations. On the other hand, families in the high-income groups generally have increased resources and access to care, and previous research has found an association with implanted children living in higher income neighborhoods (34). In addition, high income families tend to, on average, have higher educational background. Yehudai et al. (35) found that parental education level was an independent predictor of mainstream education placement in DHH children who underwent CI. However, there is an uncertain relationship between educational background and willingness for children to undergo CI based on the current study's results and needs to be further investigated in the future.

A number of limitations need to be considered while interpreting the findings of the current study. First, the survey instrument was developed for descriptive statistical analysis and thus has not been formally validated. The self-reporting nature of the survey may also introduce limitations. In addition, the socioeconomic factors such as parental lost wage or single parent families and its role in obtaining CI was not assessed. Specifically, we could not assess financial and insurance status of the patient at time of diagnosis, which could have been an obstacle to CI. Given the nature of this study the true benefit of CI in these patients could not be assessed. Many had been told by the audiologist that CI could have no demonstrable changes in hearing or speech development. Finally, a relatively small proportion of DHH children in our samples had CI (4.5%), suggesting that most of the parents had little direct experience with CI. This may potentially create a selection bias against willingness to undergo CI. As such, continued education by pediatricians, primary care physicians, and the otolaryngologic and audiologic communities with clear explanation of the risks, benefits, and alternatives of hearing rehabilitation would be critical in elucidating a more accurate picture of actual willingness to undergo CI.

CONCLUSION

A significant gap exists between the number of children who are CI candidates and those who receive them. Factors contributing to non-implantation included risks of surgery, hearsay on non-efficacy or "bad experience," lack of knowledge, cost, as well as disagreement with the concept of CI. We found that the willingness to undergo CI was higher in families with <\$15,000 or ≥\$75,000 annual income, families with children attending specialized schools for DHH children, and those with certain insurance plans. Early, appropriate counseling for parents in addition to better education for DHH school staff, audiologists, and primary care physicians may help

close the gap between potential CI candidates and the number of recipients.

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