Access to and Uptake of Cochlear Implantation Among Children in North Carolina

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BACKGROUND Cochlear implantation (CI) is a highly effective intervention for children with advanced hearing loss who cannot benefit from amplification. Despite the established benefits of CI, it is likely that not all children who are potential candidates for CI receive this intervention. The purpose of this study was to determine the percentage of North Carolina children who are candidates for and end up undergoing CI, and to detect whether barriers exist that prevent access to care for unimplanted candidates.

METHODS This study was a retrospective analysis of 1,501 children whose families were served by BEGINNINGS from January 1, 2009 through December 31, 2013. All families of children identified as potential CI candidates who were able to participate in the study (n = 141) were contacted by BEGINNINGS parent educators who queried parents about their child’s use of technology and any reasons for lack of use of technology.

RESULTS Overall, 60.9% of children diagnosed with profound, severe-profound, severe, moderate-severe, or moderate-profound hearing loss received at least 1 cochlear implant. For children with profound hearing loss, 88.9% had at least 1 cochlear implant. Common reasons for the decision not to perform CI included parental preference and anatomical issues unfavorable to CI.

LIMITATIONS Some information was not included in the database, including socioeconomic status and the child’s age at the time of intervention.

CONCLUSION The rate of CI for North Carolina children who have advanced hearing loss is greater than 60% and significantly higher for children with greater degrees of impairment. No significant financial or geographic barriers to CI were identified. We hypothesize that the high rate of CI for appropriate candidates in North Carolina is due in part to parental access to counseling and education provided through BEGINNINGS.

Cochlear implantation (CI) is a highly effective intervention for children who meet candidacy criteria. Development of expressive and receptive language in implanted children parallels the trajectory for children with unimpaired hearing, with best performance noted for those implanted before the age of 18 months [1]. The majority of children treated with CI accompanied by appropriate aural rehabilitation may be educated in mainstream classrooms, at considerable cost savings compared to education in residential schools for deaf students [2]. A large national longitudinal study of children implanted between ages 6 months and 5 years demonstrated that health-related quality of life measured 6 years after CI, based on assessment by both the child and the parent, was comparable to that of normally-hearing peers [3].

Despite the established benefits of CI in children, it is likely that not all children who are potential candidates receive CI [4]. Potential barriers to CI include cost, either due to lack of insurance or inability to afford copayments and other related costs; lack of local services, resulting in geographic barriers to optimal care; ongoing general health issues that may preclude general anesthesia or consideration of CI; parental decision to not treat with CI; and lack of awareness of availability and benefits of CI.

Implantation at an early age is associated with the most favorable outcomes, and early identification of hearing loss is crucial for promoting early and effective access to appropriate hearing health care and optimal utilization of technology. A national strategy for early identification and rehabilitation of hearing loss in children is the 1-3-6 rule, in which children are screened for hearing loss by 1 month of age, provided with diagnostic audiological evaluation by 3 months of age, and have auditory rehabilitation intervention services implemented by 6 months of age if indicated [5]. In North Carolina, hearing screening for newborns was mandated by state law in 1999, and this law was fully implemented effective July 1, 2000. The state’s universal newborn hearing program is housed within the North Carolina Division of Public Health in the North Carolina Department of Health and Human Services (www.ncnewbornhearing.org).

For a child with advanced hearing impairment identified at birth, implant surgery would ideally be performed at age 12 months, following a hearing aid trial to demonstrate lack of benefit of amplification. Decisions regarding candidacy for CI in children are made by teams of experienced audiologists, otolaryngologists, and other professionals, depending on the child’s achievement of auditory develop-
mental skills while fit with optimal amplification. Criteria for CI candidacy are generally based on severity of hearing loss and depend on the exact audiometric configuration and the child’s ability to benefit from conventional amplification. For example, hearing loss in the low frequencies may be moderate, but if hearing loss slopes to profound in the middle to high frequencies, the child would likely not benefit significantly from amplification and would be a candidate for CI. One tool used to assess candidacy for CI among children fit with amplification is the LittleEARS Auditory Questionnaire, which is designed for use in the youngest children (up to age 2 in “hearing years”) [6]. Other factors, such as the child’s general health and the presence of other sensory deficits such as visual impairment, may also be factors when accessing candidacy for CI.

This study focused on children with severe, profound, severe-profound, moderate-severe, and moderate-profound bilateral sensorineural hearing loss who are potential candidates for CI. (See the American Speech-Language-Hearing Association website for definition of hearing loss [7]). Some of the children in this study received bilateral cochlear implants. Bilateral CI may be done during a single surgery or sequentially. Bilateral CI in either setting has been shown to be cost effective [8, 9]. Candidacy often depends on residual hearing and whether a child may be expected to gain significant benefit from a hearing aid worn in the better-hearing ear, or if both ears have sufficient hearing loss to warrant initial implantation. Bilateral auditory stimulation is the goal of treatment and, in an optimal situation, would be achieved by the most effective means possible.

Data Source
BEGINNINGS for Parents of Children Who Are Deaf or Hard of Hearing, Inc. is a North Carolina nonprofit organization that provides education and advocacy for parents of children with all types and degrees of hearing impairment. Through a network of parent educators, BEGINNINGS provides emotional support, comprehensive information, and technical assistance to families of hearing impaired children in all 100 counties within the state, from the time a child is diagnosed until he or she turns 22 years of age.

Since 1987, BEGINNINGS has served as a first point of contact for parents following a child’s diagnosis of hearing loss, with the goal of providing information and guidance to facilitate early initiation of auditory rehabilitation. Several mechanisms are in place to ensure that all North Carolina families who have a child with diagnosed hearing loss are served by BEGINNINGS (see Figure 1). First, the state tracks all children who fail newborn hearing screening to record both initial and follow-up screening results using a statewide database called Hearing Link. The state then requires that information about final diagnosis (degree of hearing loss) be entered for all children up to age 12 months. At the time of the initial diagnosis, families are informed about the services BEGINNINGS offers and give their permission for a referral. As soon as possible following the diagnosis, the Hearing Link data manager notifies BEGINNINGS via e-mail about each family who has requested a referral to BEGINNINGS. All parents are also informed at the time of diagnosis of the availability of the services offered by Part C Early Intervention provided by the North Carolina Department of Health and Human Services. Services from both agencies are provided at no cost to the family.

In addition to Hearing Link referrals, BEGINNINGS receives direct referrals from sources such as local education agencies, parents, family members, and physicians. This referral pathway unites the professional community with a collaborative network among the state’s stakehold-
ers including North Carolina Early Hearing Detection and Intervention, the Early Intervention Program for Children Who Are Deaf or Hard of Hearing, and health care provider diagnostic centers. These family and professional outreach initiatives ultimately ensure that parents are informed and supported as they make decisions for their children, and they align the technical and professional resources needed for successful auditory rehabilitation. While we are unable to track data that show the number of families who decline services from BEGINNINGS, we know from comparison between the Hearing Link database and the BEGINNINGS database that this number is very small.

BEGINNINGS reports that, historically, it is rare for a family to decline services and that they serve 90%-95% of all families whose children have been diagnosed. A comparison of the annual number of children younger than 3 months of age diagnosed with hearing loss in North Carolina (as reported to the Centers for Disease Control and Prevention [CDC] by the North Carolina Division of Public Health’s Early Hearing Detection and Intervention [EHDI] program) with the number of new families having children younger than 12 months of age who are referred to BEGINNINGS indicates the estimate to actually be closer to 100% [10]. For example, during the period January 2009 through December 2014, North Carolina reported to the CDC an average of 12 months of age who are referred to BEGINNINGS indicates the estimate to actually be closer to 100% [10]. For example, during the period January 2009 through December 2014, North Carolina reported to the CDC an average of 102 children younger than 3 months of age diagnosed with hearing loss annually, while BEGINNINGS reported serving an average of 137 children younger than 3 months for the same period. This rather significant discrepancy may be attributed to under-reporting on the part of the North Carolina EHDI program. Nonetheless, we have confidence that the subjects selected for this study are representative of the population of North Carolina as a whole.

BEGINNINGS maintains a database called FamilyTrac that contains information about all families served by the agency since July 2000—more than 5,000 families to date, with new families added each month. During the fiscal year that ended June 30, 2014, BEGINNINGS served a total of 916 families in North Carolina. Of these families, 414 were served for the first time by BEGINNINGS; among these families, 402 children had newly identified hearing loss. The other 502 families included in the 2014 database had previously been served by BEGINNINGS and were returning for additional support and services. Information maintained in FamilyTrac includes the age of the child at identification, the degree of hearing loss, the language used in the home, the chosen communication method used with the child, the child’s date of birth, contact information for the parents, and the number and types of services and information provided to each family. Although ethnic and economic data are not recorded for families served by BEGINNINGS, the county in which the family resides is recorded. During the time period for which we selected candidates for this study, participating families lived in 97 of North Carolina’s 100 counties; these represented urban, suburban, and rural settings and included the poorest and wealthiest regions of the state. Reports can be generated to provide aggregated data according to specified parameters.

The goal of this study was to determine the rate of technology use among North Carolina children and what, if any, barriers exist to CI for identified children. We hypothesize that the education and outreach provided by BEGINNINGS results in a high percentage of CI in appropriate candidates.

Methods

Subject Identification

Entry criteria for this study included advanced hearing loss potentially meeting candidacy criteria for CI (moderate-profound and greater) and no evidence of auditory neuropathy. Exclusion criteria are listed below. Using the BEGINNINGS FamilyTrac database, we identified 1,501 children whose families were served by BEGINNINGS between January 1, 2009 and December 31, 2013. From this pool of potential candidates, we had sufficient information to eliminate 911 children because they did not meet our minimum criteria for hearing loss. Subsequent review was performed on the remaining 590 children. More information was sought by reviewing narrative notes in the database and searching paper files for children and families for whom FamilyTrac data were incomplete. Further exclusions were based on failure to meet entry criteria noted above. If available information was insufficient to determine if children met our inclusion criteria, these children were excluded. Specific reasons for exclusion from this group of 590 included mild (57), mild-moderate (135), moderate (59), and no hearing loss (17); conductive hearing loss (19); unilateral hearing loss (79); medical fragility (2); and central auditory processing disorders (6). After applying these exclusion criteria, 216 families were identified for inclusion in this study (see Table 1).

Further investigation based on direct telephone contact (or lack of response to phone contact) resulted in the elimination of additional families for the following reasons: moved out of state (8); declined to participate in the study (2); child was deceased (3); families did not respond to phone calls, messages, e-mails, or letters and were considered lost to follow-up (39); hearing was found to be within normal limits (3); hearing loss was undetermined (9); child was medically fragile (3); hearing loss was unilateral (4); hearing loss was due to a central auditory processing disorder (2); child had conductive hearing loss (1); and child did not use any assistive hearing technology, such as hearing aids or assistive listening devices (1). Our sample of families who met hearing inclusion criteria but were considered lost to follow-up included 6 families for whom Spanish is the primary language; we were unable to reach any of these parents upon multiple attempts, and they were excluded from further study. Attempts to reach families occurred on different days at different times of the day. Families were considered lost to follow-up only after multiple attempts to contact them had failed, including contacting the last known audiologist.
and/or early intervention teacher to obtain the most current phone number, e-mail address, and/or mailing address. Additionally, families classified as “unknown” were placed into the appropriate category according to degree of hearing loss once this information about the child was obtained during data collection. After excluding those above, a total of 141 families comprised the final study pool.

Study Plan
A BEGINNINGS parent educator contacted each family in our study pool whose child, according to FamilyTrac data, did not have a cochlear implant. Phone calls were made to these parents by a single trained BEGINNINGS parent educator. The decision to use a parent educator to conduct the phone interviews was made because all of the families contacted had been served by BEGINNINGS, and the parent educator was able to easily establish rapport with them based on previous services provided. Additionally, the parent educator was familiar with FamilyTrac, which allowed her to update the family record at the time contact was made.

The parent educator followed an interview protocol developed for the interview (see Appendix 1; online version only). Additionally, a disclosure of data use statement (see Appendix 2; online version only) was read to all parents; this statement requested their verbal permission to ask questions about their child’s technology use. When contacting families, the BEGINNINGS parent educator explained the purpose of the call by reading a statement about the study, explaining the expected use of the data, and asking the parents’ permission to interview them about their child’s use of hearing technology. Interviews took place by telephone between February and May 2014. All data collected from each family were recorded in a Word document.

Results
Individual patients were aggregated (see Table 1) and analyzed according to the child’s level of hearing loss (see Table 2). Thirty-six children with profound hearing loss were identified, 32 of whom (88.9%) had a least 1 cochlear implant. Forty-four children with severe-profound hearing loss were identified; the rate of CI for this group was 77.3%. The presence of the BEGINNINGS program in North Carolina may be one factor driving the high rates of CI in this state.

When considered in aggregate, 60.9% of children diagnosed with profound, severe-profound, severe, moderate-severe, and moderate-profound hearing loss had received at least 1 cochlear implant. In the profound and severe-profound hearing loss subgroups, the percentage of children with at least 1 cochlear implant increased to 82.5%. In all children regardless of degree of hearing loss, the most common reason for parents deferring CI was that a parent was raised deaf and the parents preferred American Sign Language as the primary communication modality (see Table 3).

Discussion
We found that children in North Carolina who have been diagnosed with qualifying hearing loss have a high rate of uptake of CI. Among the 141 families included in this study, 60.9% of children diagnosed with profound, severe-profound, severe, moderate-severe, and moderate-profound hearing loss had received at least 1 cochlear implant. In the profound and severe-profound hearing loss subgroups, the percentage who had at least 1 cochlear implant increased to 82.5%. The presence of the BEGINNINGS program in North Carolina may be one factor driving the high rates of CI in this state.

In the United States, CI for children is covered by Medicaid if the child meets accepted indications for CI. Socioeconomic status alone has not been shown to affect access to CI program evaluations [11]. However, prior research has demonstrated that children with similar degrees of sensorineural hearing loss are inconsistently referred to CI programs in the United States [12]. We can only speculate at the reasons for this inconsistency, but single-parent families may be less likely to be referred for CI consideration. Family support and likelihood for successful compliance are components of the CI candidacy evaluation, and CI programs may consider single parenthood to be a compliance risk [12].

In our study, qualitative evidence suggested that children who did not receive CI were not impacted by cost or lack of access to care. The reasons cited by the parents in our study for forgoing CI included the parents’ preference for American Sign Language as a primary communication modality, deference to the child’s choice when emancipated, the parents’ religious beliefs, and a desire to not subject their child to a surgical procedure. There was one instance

| Degree of Hearing Loss | n (%) |
|------------------------|-------|
| Moderate-severe        | 67 (31.0) |
| Severe-profound        | 60 (27.8) |
| Profound               | 44 (20.4) |
| Severe                 | 23 (10.6) |
| Unknown                | 20 (9.3) |
| Moderate-profound      | 2 (0.9) |

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TABLE 2.
Auditory Rehabilitation Choice by Degree of Hearing Loss and Reasons Why Children Did Not Receive Cochlear Implantation (CI)

| Degree of hearing loss, n (%) | Profound | Severe-profound | Severe | Moderate-severe | Moderate-profound |
|------------------------------|----------|-----------------|--------|-----------------|-------------------|
| Hearing aids                 | 1 (2.8)  | 5 (11.9)        | 7 (41.2) | 28 (66.7)       | 1 (50.0)          |
| Unilateral CI                | 19 (52.8)| 23 (54.8)       | 5 (29.4) | 6 (14.3)        | —                 |
| Bilateral CI                 | 13 (36.1)| 11 (26.2)       | 3 (17.6) | 5 (11.9)        | 1 (50.0)          |

Reasons for no CI

| Reason for no CI | Profound | Severe-profound | Severe | Moderate-severe | Moderate-profound |
|------------------|----------|-----------------|--------|-----------------|-------------------|
| Deferred by family| —        | 5 (11.9)        | 1 (5.9) | 2 (4.8)         | —                 |
| Anatomical abnormalities| 3 (8.3)  | —               | 1 (5.9) | —               | —                 |
| Follow-up concerns| —        | —               | —      | 1 (2.4)         | —                 |
| Total            | 36       | 44              | 17     | 42              | 2                 |

where the CI team decided not to implant a child due to concerns that the parents would not follow through with necessary postoperative care. This follows previous evidence that lower socioeconomic status may be associated with a higher postoperative complication rate and difficulty with follow-up compliance [11]. We did not assess objective socioeconomic status of the families in our study, and we cannot comment on the effects of low socioeconomic status on referral patterns to the BEGINNINGS program.

Our study has a few limitations. First, we were unable to report the timeliness with which children were referred to the BEGINNINGS program, nor the age of intervention for hearing loss. On a national scale, a commonly cited goal for children is the 1-3-6 rule, which states that children should receive screening for hearing loss by 1 month of age, diagnostic audiologic evaluation by 3 months of age, and auditory rehabilitation intervention services by 6 months of age [5]. Future study will determine if our patient cohort is compliant with these benchmarks. Earlier age of CI is associated with favorable development of central auditory system plasticity as well as auditory development equivalent to children without hearing impairment [1, 13]. Other interesting avenues for further study include evaluating our patient cohort to determine how CI impacts language and literacy outcomes, as well as determining factors contributing to a child’s optimal use of cochlear implants, including the frequency and duration of early intervention service programs and the role of specialized instruction provided to school-aged children with cochlear implants.

The purpose of this study was to determine the percent-age of children who are CI candidates based on degree of hearing loss referred to the BEGINNINGS program in North Carolina and to identify potential barriers that prevent access to CI. We found that 60.9% of children diagnosed with profound, severe-profound, severe, moderate-severe, and moderate-profound hearing loss received at least 1 cochlear implant. In the profound and severe-profound hearing loss subgroup, the percentage of those receiving at least 1 cochlear implant increased to 82.5%. The most common barriers to CI emerged from parental sources and were not associated with cost or geographic barriers. The rate of CI in North Carolina may be significantly higher than the national average [4]. This is likely a result of the efforts of state agencies as well as BEGINNINGS to provide follow-up and education to parents to support their decisions regarding hearing health care for their children. NCMJ

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