

Information Given to Parents of Neonatal-Intensive Care Unit Graduates on Hearing

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Abstract

Preterm infants and neonatal intensive care unit (NICU) graduates are more likely to have risk factors associated with hearing loss than their full-term, healthy peers, making them more prone to experience hearing loss (Behrman & Butler, 2007). This study examined information presented to parents during and after the newborn hearing screening (NBHS). A 22-question survey was posted on NICU and premie support websites for parents to access and participate in anonymously. Results of the survey were analyzed for respondents indicating that their child was born in the year 2007 to the present. Thirty-nine percent of responding parents were unaware their child had a risk factor for hearing loss. Parents reported that nurses most often delivered NBHS results, although all medical professionals listed in the survey were equally likely to educate parents on risk factors pertaining to their child. Data indicated a gap between medical professionals and parents concerning NBHS follow-up information. Written follow-up procedures after NBHS test results are given to the parents should be included in a discharge packet as well as information relating to the normal development of auditory, speech, and language milestones.

Key Words: Prematurity, NICU, Universal Newborn Hearing Screening

Acronyms: JCIH = Joint Committee on Infant Hearing; NBHS = newborn hearing screening; NICU = neonatal intensive care unit

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Introduction

Preterm infants and NICU graduates are more likely to have risk factors for hearing loss than their full-term, healthy peers, making them more prone to experience hearing loss (Behrman & Butler, 2007). Preterm birth, according to the World Health Organization, is defined as an infant born before 37 weeks gestation. In 2010, the United States of America had the sixth highest preterm birth rate in the world, representing 3.5% of all preterm births worldwide (Blencowe et al., 2012). The present study was conducted to learn more about the information related to hearing loss presented to parents who have had children in the NICU and to examine their level of perception of preparedness to manage health concerns, specifically in regard to hearing, upon discharge.

The most common birth defect in the United States is congenital hearing loss, with an incidence of about 3 in 1000 births (White, Forsman, Eichwald, & Muñoz, 2010). The Joint Committee on Infant Hearing (JCIH) has historically suggested the need for a universal newborn hearing screening since this is a common birth defect. In 1994, a position statement was released recommending a hearing screening before infants are discharged from the hospital, in an effort to promote intervention before

6 months of age for those identified (American-Speech-Language-Hearing Association, 1994). Studies have shown that unidentified hearing loss can negatively impact a child's language abilities if the hearing loss is not diagnosed early in the child's critical language learning time period (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

In 2007, JCIH released a position statement defining risk indicators for childhood hearing loss, whether congenital, delayed-onset, or progressive. The risk indicators are listed in Table 1. Seewald and Tharpe (2010) found the prevalence of bilateral congenital deafness to be 10 times higher in NICU graduates than well babies. Well babies are defined as babies born requiring normal care following birth ("Well Child Care Law," n.d.). For this reason, separate protocols were recommended by JCIH (2007) for screening the NICU nursery versus the well-baby nursery (Xoinis, Weirather, Mavoori, Shaha, & Iwamoto, 2007).

Table 1
Risk Factors for Hearing Loss

Family History of Permanent Hearing Loss in Childhood
Toxoplasmosis
Syphilis
HIV
Hepatitis B
Rubella
Herpes Simplex
Cytomegalovirus (CMV)
Physical Problems of the head, face, ears, or neck (cleft lip/palate, ear pits/tags, atresia, and others)
Ototoxic Medications given in the neonatal period
Syndrome associated with hearing loss (Pendred, Usher, Waardenburg, Neurofibromatosis)
Admission to NICU greater than 5 days
Prematurity (<37 weeks)
Low Birth Weight
Jaundice

Note. Risk factors listed in “Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs,” by Joint Committee on Infant Hearing, 2007, *Pediatrics*, 120, 898-921.

In the midst of serious or life threatening health concerns, other health concerns, such as monitoring hearing, can be overlooked. Many of these at-risk children are lost to follow up with audiology after leaving the hospital and the reason could be due to the lack of education and/or information given to parents at the time of hospital discharge from the NICU (Clemens, Davis, & Bailey, 2000). One study found that 31% of parents reported not having the opportunity to ask questions once they were notified their child did not pass the initial screening, and 55% said the purpose and meaning of the screening was not well defined (Clemens et al., 2000). There is a lack of research regarding the information presented to parents about the newborn hearing screening (NBHS) and the support they receive after receiving the NBHS results from the hospital (Clemens et al., 2000). This study sought to examine the knowledge base of parents of NICU graduates with regards to risk factors for hearing loss, education about hearing loss, and information presented to the parents regarding NBHS results.

Method

A 22-question survey was created in Qualtrics by the authors (see Appendix) and presented to parents of preterm infants that graduated from the NICU via multiple preemie support websites and preemie social media support groups (i.e., What to Expect When Expecting Moms of Premies Group and Preemie Moms Facebook Group). Internet distribution provided worldwide exposure. Data was collected over a period of three months from January through March of 2016. Question skip logic was used within the Qualtrics software to prevent displaying questions to some participants that did not apply to them based on their previous answers. For example, participants indicating their child was born in the United States had a follow-up question regarding the city and state of birth and those indicating child birth occurred outside the United States

were asked the country of birth only. Questions that were set to be displayed based on skip logic are marked with an asterisk in Appendix. See Table 2 for survey question content.

Table 2
Content of Survey Questions

Length of NICU stay
NBHS prior to hospital discharge
Results of the NBHS
Format the results of the NBHS were given
Who conveyed the results of the NBHS
Told to monitor the child's hearing
Select risk factors from a list
Notified by medical personnel that their child had risk factors
Notified by their state of the need to follow-up
Educated and informed on hearing loss.

Note. NICU= Neonatal Intensive Care Unit; NBHS = Newborn Hearing Screening

Although voluntary response sampling carries inherent bias, detailed demographic information was collected in order to individually weigh responses based on geographical or age-related differences. Demographic information of U.S. respondents was compared with population data from the 2010 U.S. census. Parents from the state of Alabama had increased exposure to the survey compared with others due to social media distribution that primarily targeted those geographically near the study authors. However, the resulting increase in response rate was taken into account during subsequent analysis. Geographical-related differences were evaluated by calculating Pearson Product-Moment Correlation coefficients between respondents' state of residence and state populations using 2010 census data.

Because data was weighted, the Taylor series linearization method was employed for variance estimation of proportional data using PROC SURVEYFREQ of Statistical Analysis System (SAS). Comparison of proportions was conducted using Pearson's χ^2 test for independence and continuous data was evaluated using Student's t -test in Base SAS. Significance was determined at $\alpha < 0.05$. Descriptive statistics including means and proportions were calculated.

Results

Parents of NICU graduates completed 272 surveys. Respondents that indicated their child was born before 2007 ($n = 44$) were eliminated from data analysis. Respondents were primarily from the United States (92.5%) with 70.5% of international responses coming from Canada. All respondents from the United States included their state of residence. Table 3 lists the states represented. Seventeen international residents responded to the survey. Table 4 lists the countries represented. A sampling bias was found that resulted in a disproportionate number of responses from the state of Alabama. However, the response rate was still correlated with state population ($r = 0.48$, $p = 0.0012$). Removal of Alabama from the analysis resulted in a correlation of 0.76 ($p < 0.001$). Thus, the response rate was indicative of overall non-biased survey exposure. Participant demographics were analyzed by the authors to review the information provided by respondents. The mean of the mother's age at the time of birth was 29.0 years, with a range of 18 to 42 years. Gestational age reported for these infants ranged from 22 weeks to full term, with a mean gestational age of 31.2 weeks. Mean NICU stay was 50.6 days, with a range of 2 to 254 days. Data was collected from birth years 1997 through 2016, but only data from birth years 2007 to 2016 was analyzed. Respondents were asked many questions regarding their child's NICU stay. Answers to several of those questions are listed in Table 5.

Table 3
States Represented by Survey Respondents. (N = 211)

Alabama	31	Missouri	5
Alaska	1	Montana	2
Arizona	1	Nevada	1
Arkansas	1	New Hampshire	1
California	13	New Jersey	2
Colorado	2	New Mexico	2
Connecticut	2	New York	6
Delaware	2	North Carolina	8
Florida	13	North Dakota	1
Georgia	12	Ohio	9
Idaho	1	Oklahoma	5
Illinois	7	Pennsylvania	16
Indiana	5	Rhode Island	2
Iowa	3	Tennessee	5
Kentucky	4	Texas	10
Louisiana	1	Utah	1
Maryland	6	Virginia	5
Massachusetts	5	Washington	3
Michigan	5	West Virginia	1
Minnesota	3	Wisconsin	5
Mississippi	2	Wyoming	1

Table 4
Nations Represented by Survey Respondents Outside the United States (N = 17)

Australia	1
Canada	12
France	1
New Zealand	1
United Kingdom	2

Table 5
Respondent Survey Results

Survey Question	Percentage
Child has a NBHS prior to hospital discharge	98.6%
Child passed NBHS	91.9%
Child spent 5 or more days in the NICU	91.7%
Child spent less than 5 days in the NICU and had at least one other risk factor for hearing loss	8.3%
Was not told to monitor their child's hearing upon NICU discharge	79.5%
Was not told they would receive a letter from their state regarding follow-up on their child's hearing **	84.2%
Was not told by professionals that their child had positive risk factors for hearing loss	74.5%

Note. NBHS = Newborn Hearing Screening; NICU = Neonatal Intensive Care Unit
**Varies state by state

Variables of participants, including both U.S. and international respondents, were evaluated regarding the method in which parents were notified of the results of the NBHS, whether written or verbal. Sixty-one percent of respondents were told the results of the NBHS in verbal format. Twenty-one percent of respondents were told the results of the NBHS in written format. Eighteen percent of respondents were told the results of the NBHS in both formats. Personnel responsible for delivering the results of the NBHS and recommendations regarding follow-up upon hospital discharge were evaluated as well (see Table 6). Respondents indicated that nurses (54.0%) were the most common health professional who delivered results and that the NBHS results were relayed to the parents primarily verbally (60.8%). Analysis of personnel (i.e., nurses, technicians, audiologists, nurse practitioners, speech-language pathologists, doctors, physician's assistants, and social workers) that delivered results and follow-up recommendations did not indicate a certain medical professional was more likely or more effective in educating parents about risk factors for hearing loss that apply to their child ($p > 0.05$).

Table 6
Personnel Giving Results and Follow-Up Recommendations

Personnel	Percentage
Nurse	54%
Audiologist	17%
Doctor	11%
Technician	5%
Nurse Practitioner	3.5%
Other	3.5%
Not Sure	2.5%
Speech Language Pathologist	1.5%
Physician's Assistant	1%
Social Worker	1%

This study examined parent's perspectives and opinions on the NBHS protocol explicitly in the NICU population throughout many different states and several countries. Most survey respondents indicated that their child passed the NBHS. Of survey participants whose child was born in the United States and passed his/her NBHS (193 respondents), 94.4% indicated that at least one of the risk factors for hearing loss published by the JCIH (2007) applied to their child. Of those respondents, 76 did not indicate they were previously aware of any of the JCIH (2007) risk factors for hearing loss. Further analysis of specific risk factors indicated that the two most prevalent risk factors for hearing loss in this population were prematurity (< 37 weeks) and a NICU stay greater than 5 days (Table 7). Parents' awareness of these conditions as risk factors for hearing loss was measured at 41.7% and

12.7% respectively (Table 8). These data indicated that the majority of parents were unaware of the risk factors for hearing loss even after their child graduated from the NICU. Survey respondents were given the opportunity to include suggestions for improvement of the NBHS and discharge process at the end of the survey. Many comments targeted the need for additional education. One respondent stated, "I feel I could have been more educated on prematurity and hearing loss." Another suggestion requested "education regarding speech delays in preemies and what to look for and do." Some respondents expressed feelings of stress created by an overload of information encompassing multiple health concerns. Two respondents in particular gave insight into these emotions stating that "so much information [is] being given to a mom with a critically ill child in the NICU" and "[p]arents are already overwhelmed with information... that you [don't want] to give parents too much to handle at once." Some respondents' comments gave suggestions that of what they believed may be beneficial to include in discharge papers. These suggestions are listed in Table 9.

Discussion

Even though the majority of respondents indicated that their infants passed the NBHS, their lack of risk factor awareness is concerning because hearing loss can manifest months or years later. Also, the timeline of identification can profoundly impact speech and language development. A study conducted by Barreira-Nielsen et al. (2016) found that more than one-third of infants diagnosed with a progressive hearing loss had passed an initial screening, and 28.5% developed a hearing loss after 6 months of age. Parents of NICU graduates need to be made aware of their child's risk factors for hearing loss in order to monitor their child's auditory milestones. If parents are educated on those facts, they can seek help earlier to prevent the negative effects of unidentified hearing loss (Tomblin et al, 2015).

Considering the results of this study, education within the fields of medical professionals working with this high risk population may need to specifically address the manner in which NBHS results and recommendations are provided to parents. Increased training for professional staff and regulation of protocols for the delivery of results and follow up procedures may be helpful in dissolving the information barrier between parents and health care professionals. Guidelines published by JCIH (2007) suggest at least one diagnostic audiologic evaluation by 24 to 30 months of age for all infants who passed the NBHS and have at least one risk factor for hearing loss. The statement also directed responsibilities to medical care providers to monitor appropriate development of milestones, auditory skills, and middle ear health and to educate parents on auditory and speech and language development. Parental concern should be heavily considered within the medical community during follow up.

Table 7*Percentages of Risk Factors Respondents Indicated Applied to Their Child (N = 228)*

RISK FACTORS	Percentage
Toxoplasmosis	0%
Syphilis	0%
HIV	0%
Hepatitis B	0%
Rubella	0%
Herpes Simplex	0%
Cytomegalovirus (CMV)	0%
Syndrome associated with hearing loss (Pendred, Usher, Waardenburg, Neurofibromatosis)	0.9%
Physical problems of the head, face, ears or neck (cleft lip/palate, ear pits/tags, atresia, and others)	1.8%
Family history of permanent hearing loss in childhood	3.1%
Ototoxic medications given in the neonatal period	4.8%
Low birth weight	69.3%
Jaundice	70.6%
Admission to NICU greater than 5 days	75.4%
Prematurity (< 37 weeks)	86.4%

Note. Risk factors listed in “Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs,” by Joint Committee on Infant Hearing, 2007, *Pediatrics*, 120, 898-921.

Table 8*U.S. Parental Awareness of Risk Factors for Hearing Loss (N = 228)*

RISK FACTORS	Percentage
Toxoplasmosis	5.3%
Syphilis	6.1%
HIV	1.7%
Hepatitis B	1.3%
Rubella	5.3%
Herpes Simplex	3.1%
Cytomegalovirus (CMV)	4.8%
Syndrome associated with hearing loss (Pendred, Usher, Waardenburg, Neurofibromatosis)	13.6%
Physical problems of the head, face, ears or neck (cleft lip/palate, ear pits/tags, atresia, and others)	17.5%
Family history of permanent hearing loss in childhood	38.6%
Ototoxic medications given in the neonatal period	10.5%
Low birth weight	19.7%
Jaundice	6.6%
Admission to NICU greater than 5 days	12.7%
Prematurity (< 37 weeks)	41.7%

Note. Risk factors listed in “Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs,” by Joint Committee on Infant Hearing, 2007, *Pediatrics*, 120, 898-921.

Table 9

Parent's Suggestions for Discharge

<p>Written information requests</p>	<p>"[Giving] pamphlet[s] on hearing loss and signs to look for in infants"</p> <p>"I was never given anything written and feel like EVERYTHING should be [written] so parents can deal with it at their own rate."</p> <p>"I think it would be greatly beneficial for NICU parents to be provided pamphlets or educational material over the tests ran and information about their special circumstances having a NICU baby. I know I personally was overwhelmed and going through a lot so even if something was told to me, it would be a lot more helpful to be able to have the information on paper for me to read and understand during a quiet time instead of the limited few minutes we had with the doctor."</p>
<p>Education</p>	<p>"...more information as prematurity as a cause for hearing loss and a follow up appointment for hearing testing."</p> <p>"Education regarding speech delays in preemies and what to look for..."</p> <p>"I feel I could have been more educated on prematurity and hearing loss and warning signs—that there could be warning signs."</p> <p>"Educate the parents!"</p> <p>"...more explanation of potential problems would have been great"</p> <p>"Talk to parents [to] let them know the risk and possibilities."</p> <p>"To this day I am unaware of the long term effects of prematurity on hearing loss following an infant passing the newborn hearing screen before discharge"</p>
<p>Scheduling referrals and follow up</p>	<p>"Perhaps a follow-up hearing check should be scheduled with the child's pediatrician or local audiologist just before discharge at an appropriate time interval in the future. Or if it's not needed for a year or more, perhaps the baby could be placed on the "call list" for when appointment calendars are open."</p> <p>"Schedule follow up hearing test(s) prior to discharge"</p> <p>"Add the follow up plan for hearing to the discharge plan. It is overwhelming to face all the follow ups; we had five different doctors without hearing [and] vision! If they added the milestone time to check hearing, we would have done so through a referral from his pediatrician."</p>

Based on the results of the survey, screening results should be included in discharge paperwork, as well as information indicating the risk factors that apply to the child, specifically for the population that passes the screening with risk factors. As indicated previously, many parents reported that they were unaware their child had risk factors for hearing loss. Verbal and written instructions may be more effective in combination. Parents could have the opportunity to converse with a medical professional while in the hospital, but also be able to reference pertinent material later. Additionally, information regarding speech and language milestones would be a valuable resource to include in paperwork sent home with parents. This would allow parents to engage as active members following their child's developmental process and ensuring that a child with late onset or progressive hearing loss is not overlooked. Information gathered from this survey adds a parent perspective to the newborn screening process, specifically in the high risk population (NICU). Information obtained from this survey indicates the need to ensure parents are not missing information related to the health and development of their children or follow up procedures.

Limitations of this study include the range of birth years sampled, non-representative sampling, and web-based surveying. Future research should sample a smaller range of birth years and mail out the surveys to include respondents who may not have access to the internet. Future directions of this research should explore how information is currently given to parents regarding hearing loss in the NICU and then explore the implementation of the suggestions based on the results of the survey. A longitudinal study could then be implemented to follow the infants in both scenarios to examine the influence of the suggestions on the lost to follow-up rate.

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Appendix

Survey

Q1 Was your infant admitted to the neonatal intensive care unit (NICU)?

- Yes
- No

Q2 At how many weeks gestation was your child born?

_____ Gestational Age in Weeks

Q3 What was the mother's age at the time of child's birth?

Q4 Was your child born in the United States?

- Yes
- No

*Q5 What city and state was your child born in?

*Q6 In what country was your child born?

Q7 What year was your child born?

Q8 How many days or weeks did your child spend in the NICU?

*Q9 Did your child have a newborn hearing screening in the NICU prior to discharge?

- Yes
- No
- Not Sure

*Q10 Did your child pass his/her newborn hearing screening?

- Yes
- No
- Not Sure

Q11 How were you told the results of your child's hearing screening?

- Verbal
- Written
- Other: _____

Q12 Who told you the results of the hearing screening?

- Nurse
- Nurse Practitioner
- Physician's Assistant
- Doctor
- Audiologist
- Speech Language Pathologist
- Social Worker
- Technician
- Not Sure
- Other: _____

*Q13 If your child did not pass the hearing screening, who was responsible for making a hearing evaluation appointment after discharge?

- Nurse
- Nurse Practitioner
- Physician's Assistant
- Doctor
- Audiologist
- Speech Language Pathologist
- Social Worker
- Technician
- Not Sure
- Other: _____

Q14 Has your child been identified with a hearing loss?

- Yes
- No

Q15 Were you told to monitor your child's hearing?

- Yes
- No

Q16 Were you told your child has risk factors for hearing loss?

- Yes
- No

Q17 Please check any that apply to your child.

- Family history of permanent hearing loss in childhood
- Toxoplasmosis
- Syphilis
- HIV
- Hepatitis B
- Rubella
- Herpes Simplex
- Cytomegalovirus (CMV)
- Physical problems of the head, face, ears, or neck (cleft lip/palate, ear pits/tags, atresia, and others)
- Ototoxic medications given in the neonatal period
- Syndrome associated with hearing loss (Pendred, Usher, Waardenburg, neurofibromatosis)
- Admission to a neonatal intensive care unit greater than 5 days
- Prematurity (< 37 weeks)
- Low birth weight
- Jaundice

Q18 Please check any factors that you were aware were risk factors for hearing loss.

- Family history of permanent hearing loss in childhood
- Toxoplasmosis
- Syphilis
- HIV
- Hepatitis B
- Rubella
- Herpes Simplex
- Cytomegalovirus (CMV)
- Physical problems of the head, face, ears, or neck (cleft lip/palate, ear pits/tags, atresia, and others)
- Ototoxic medications given in the neonatal period
- Syndrome associated with hearing loss (Pendred, Usher, Waardenburg, Neurofibromatosis)
- Admission to a neonatal intensive care unit greater than 5 days
- Prematurity (< 37 weeks)
- Low birth weight
- Jaundice

Q19 Were you told you would receive a letter from your state regarding follow up testing for your child's hearing?

- Yes
- No

Q20 Did you receive a letter from your state to follow up on your child's hearing?

- Yes
- No

Q21 Did you feel that your hospital staff properly educated and informed you about hearing loss?

- Yes
- No

Q22 Do you have any suggestions for improvement?