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An Analysis of the Effect of Audiologic Management on a Newborn Hearing Screening Program's Refer and Loss to Follow-Up Rates

by

Megan M. Hornof

An Independent Study submitted in partial fulfillment of the requirements for the degree of:

Master of Science in Deaf Education

Washington University School of Medicine Program in Audiology and Communication Sciences

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Approved by: Lynda Berkowitz, M.S.S.H., Independent Study Advisor Kay Park, Au.D., Secondary Reader

Abstract: This study includes an exhaustive review of the literature related to universal newborn hearing screening and loss to follow-up. It examines refer and follow-up rates in Missouri and highlights three successful newborn hearing screening programs under the same audiologic management

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Abbreviations

ABR Auditory Brainstem Response

CDC Centers for Disease Control and Prevention

DHSS Department of Health and Senior Services

EDHI Early Hearing Detection and Intervention

JCIH Joint Committee on Infant Hearing

MNHSP The Missouri Department of Health and Senior Services' Newborn

Hearing Screening Program

NCHAM National Center for Hearing Assessment

NIH National Institutes of Health

OAE Otoacoustic Emissions

Introduction

The combination of early identification of hearing loss and appropriate early intervention has proven to be critical to the development of a child's speech, language, and cognitive skills. These three things serve as foundations for later-developing academic skills and occupational achievement, and they also contribute to a child's social skills, emotional development, and overall wellbeing. Evidence from a study conducted by Yoshinaga-Itano et al., (1998) shows that infants with hearing loss who receive early identification and intervention might acquire normal language by the time they are three years old. The study reports that language development has a stronger correlation with early identification than it does with a child's degree of hearing loss, socioeconomic status, communication mode, race, or gender. The study also notes that the first six months of age are a critical period for both early identification and normal language development (Yoshinaga-Itano et al., 1998).

Historically, a great number of babies were diagnosed with hearing loss after the critical six-month window. Prior to the implementation of universal newborn hearing screening, children with profound bilateral sensorineural hearing loss were typically not identified until reaching 17-24 months (Young et al., 2011). Because hearing loss is not observable, it was not uncommon for hearing loss to go undetected until parents and guardians recognized significant delays in speech and language development. By the time these children's hearing impairments were identified, it was incredibly challenging to close the language gap and "catch up" with their peers with typical hearing, despite quality intervention services.

History of Universal Newborn Hearing Screening

In 1965, the Advisory Committee on Education of the Deaf made the first federal recommendation for the development and implementation of "universally applied procedures for early identification and evaluation of hearing impairment" in the Babbidge Report (Babbidge, 1995). Two years later at the National Conference on Education of the Deaf, the U.S. Department of Health, Education, and Welfare recommended facilitating identification through a high-risk register and creating a public information campaign (Centers for Disease Control and Prevention, 2010).

The Joint Committee on Infant Hearing (JCIH) was formed in 1969 to attempt to reduce the average age of identification of hearing loss and make recommendations about hearing screenings. The initial Committee included representatives from the fields of audiology, nursing, otolaryngology, and pediatrics. Similarly, today's JCIH is made up of members of numerous professional organizations interested in children with hearing loss. These organizations include the American Academy of Pediatrics, the American Academy of Otolaryngology and Head and Neck Surgery, the American Speech Language Hearing Association, the American Academy of Audiology, and the Council on Education of the Deaf (Joint Committee on Infant Hearing, 2010).

One of JCIH's primary responsibilities is to issue position statements recommending preferred practice in early identification and intervention of newborns with hearing loss. The Committee issued its first position statement in 1970, stating that universal newborn hearing screening should not be implemented prior to the development of appropriate test procedures (Joint Committee on Infant Hearing, 1972). The National Center for Hearing Assessment and Management (NCHAM) defines universal screening

as screening at least 90% of all births or admissions prior to discharge from the hospital (National Center for Hearing Assessment and Management, 2010). In 1972, the Committee recommended that infants presenting with certain high-risk factors for hearing loss should be referred to audiologists for comprehensive assessment. At that time, risk factors included congenital prenatal infections (such as rubella, cytomegalovirus, and herpes), family history of childhood hearing impairment, craniofacial anomalies, low birth weight (less than 1500 grams), and hyperbilirubinemia (Joint Committee on Infant Hearing, 1972). Ten years later, JCIH added bacterial meningitis and severe asphyxia to the list (Joint Committee on Infant Hearing, 1982). In 1990, additional risk factors were added, including exposure to ototoxic medications, prolonged mechanical ventilation, and head trauma. Additionally, the Committee recommended a specific screening protocol (Joint Committee on Infant Hearing, 1994).

Although screening newborns from the high-risk registry provided many infants with documented diagnoses, the screening model was not optimal. A 1988 report from the Commission on Education of the Deaf reported that the average age that children were identified with profound hearing loss in the United States was 2 ½ years. Other reports showed that by screening only those infants with high-risk factors, 50% of congenital hearing losses were missed (Thompson, 2007). The issue was formally addressed when the U.S. Department of Health and Human Services released the *Healthy People 2000* initiative (1990). According to Objective 17.16, the goal was to "[r]educe the average age at which children with significant hearing impairment are identified to no more than 12 months" by the year 2000 (U.S. Department of Health and Human Services, 1990).

In 1993, the National Institutes of Health (NIH) Consensus Statement claimed that all infants – even those without risk factors – should have their hearing screened prior to discharge from their birthing facilities (National Institutes of Health Consensus Statement, 1993). Like NIH, The JCIH 1994 Position Statement endorsed universal newborn hearing screening for all babies. JCIH recommended the detection of all hearing losses before three months of age and the implementation of intervention services by six months. The American Academy of Pediatrics endorsed these suggestions in 1999, along with the implementation of universal newborn hearing screening. Another JCIH Position Statement was released in 2000, which issued detailed principles and guidelines for Early Hearing Detection and Intervention (EHDI) programs (Centers for Disease Control and Prevention, 2010). Recommended benchmarks included screening 95% of babies by one month of age, having less than 4% referral for audiologic and medical evaluations, having more than 70% of infants who do not pass the initial screening follow up for diagnostic evaluations, and implementing a method of documentation to obtain follow-up on more than 95% of infants who do not pass the initial screening (Joint Committee on Infant Hearing, 2000). That same year, the U.S. Department of Health and Human Services released the *Healthy People 2010* initiative, which aimed to increase the number of infants screened before one month of age, perform diagnostic assessments by three months of age, and begin intervention services by six months of age by the year 2010 (U.S. Department of Health and Human Services, 2000). These benchmarks are still in place today.

In an effort to maintain benchmarks, The Centers for Disease Control and Prevention (CDC) created objectives for EHDI programs to follow. According to the CDC, each state should have a computerized system to maintain its information. This information includes screening results of all babies, diagnostic results for babies who follow up with an audiologist after a screening referral, and details regarding intervention for those babies who are diagnosed with hearing loss. Additionally, the system must link with the state's birth certificate registry in order to ensure all live births are accounted for, and it must link with other state data systems that may provide information about risk factors for hearing loss. The CDC places strong emphasis on the development of written policies and procedures for tracking and surveillance and on the maintenance of privacy and confidentiality. EHDI programs are responsible for developing a mechanism for hospitals, audiologists, and health care providers to report information. A well-organized system should allow professionals to identify a child who needs an initial hearing screening, rescreening, diagnostic evaluation, or intervention (Centers for Disease Control and Prevention, 2003).

Newborn Hearing Screening and Referral Protocol

Multiple parties contribute to a child's intervention and the success of his or her language development. Family members, hospital administration, hospital-based screening programs, nurses, screening technicians, pediatricians, audiologists, diagnostic facilities, insurance companies, and the state and the federal government must develop a shared commitment to helping children receive early diagnoses and intervention services.

Today, every state has its own EHDI program aiming to reduce the average age of identification of childhood hearing loss. EHDI programs serve as tracking and surveillance systems that consist of three parts: the initial newborn hearing screening, the

follow-up diagnostic assessment, and intervention processes (Finitzo & Crumley, 1999). Each state's program follows JCIH recommendations and sets quality indicators for its newborn hearing screening programs to achieve. It is the responsibility of each state's Department of Health to manage the EHDI program in order to ensure the presence of a comprehensive statewide system (Park, 2001).

Although several variables differ among screening programs nationwide, all of today's screening programs rely on electro-physiological technology. There are two widely used types of objective electro-physiological hearing screening technologies: auditory brainstem response (ABR) and otoacoustic emissions (OAE) screening. Both tests are noninvasive, painless, and very easy to administer. Neither test measures an individual's perception of sound; rather, the results serve as indicators of whether or not an individual's inner ear and auditory brainstem system function properly. Since neither test requires cooperation from the patient, both are acceptable for screening infants (Park, 2001).

ABR testing, the "gold standard" of objective audiologic tests, measures the integrity of the auditory nerve. In order to assess an infant's auditory function, the administrator begins by applying three surface electrodes to the infant's scalp and inserting a small microphone probe into the ear canal. In order to avoid electrical signals that may interfere with the signals from the auditory system, the administrator must wait for the infant to be still or sleeping. Once the infant is still, the administrator sends an auditory stimulus from a computer to the microphone inside the ear canal. Typically, the stimulus is a short-duration, broad-spectrum, audible click. The acoustic stimulus travels through the auditory pathway to the auditory cortex, and the central and auditory nervous

systems generate an auditory evoked potential, or ABR, in response to the signal. Because the response is time-locked to the stimulus, computerized signal-averaging techniques can isolate and extract the ABR from the ongoing electroencephalogram (EEG) and obtain a distinguishable waveform. To determine whether or not an infant passes the hearing screening, the peaks of his or her ABR waveforms are compared to age-specific norms (Hays, 2003).

OAEs are sound waves emitted by the cochlea, either spontaneously or in response to sound stimulation. During OAE testing, an individual's cochlear energy is detected by a small microphone probe that is inserted into the ear canal. After verifying a secure probe fit, the administrator uses a computer to send an auditory signal through the microphone. Some screening programs use transient evoked OAE (TEOAE) technology, which involves sending a short duration click or tone burst into the ear canal. Other programs rely on distortion product OAE (DPOAE) technology, which uses two continuous pure tones at different frequencies. Both technologies detect the amplitudes of the echoes emitted from the outer hair cells. The amplitude of an infant's OAE serves as an indication of whether he or she passes the screening or needs to follow up with further testing to rule out a hearing loss (Hays, 2003).

Two programs using electro-physiological screening technologies may operate very differently from one another. For example, according to the state of Washington's protocol, the initial hearing screening should consist of a maximum of two attempts on each ear in order to avoid false positives (Washington State Department of Health, 2010), while the state of Iowa allows a total of six screens per ear (Iowa Department of Public Health, 2008). Even within the same state, one hospital may have only one of the

screening methods available, whereas a neighboring hospital may have the resources to utilize two. Many facilities determine suitable methods based on available screening personnel, hospital resources, cost per newborn, and the number of babies born at the facility annually (New Jersey Department of Health and Senior 2010b).

It is important to consider the screening method used because both technologies have significant advantages and disadvantages. For example, because OAE screening does not require electrode attachment, it takes less time to administer and is less expensive than ABR screening. However, OAE screening requires audiologic support and thorough knowledge of audiologic risk factors. It is possible to have profound hearing loss and pass an OAE screen: Because OAE measures inner ear function – not neural function – a child with auditory neuropathy and typically functioning inner ears who only receives OAE screening may not be identified. Additionally, debris or fluid in a typically functioning ear may prevent the occurrence of an echo, therefore preventing a baby from passing the screening. ABR screening, while costly and time consuming, is the most appropriate method for screening infants at risk for having hearing loss and neurological involvement. Unfortunately, many hospitals simply cannot afford to utilize ABR technology. OAE tends to be best for large birthing hospitals, while ABR is more ideal for small ones. (Park, 2001). Facilities fortunate enough to use both technologies are better equipped to make sure that infants receive appropriate screening methods.

As demonstrated by the effect of technology protocol, the anatomy of an infant is not the only thing that may determine the outcome of a hearing screening. Multiple other variables can influence screening results. Examples of influencing factors include the skill of the screener, quality of the equipment, level of background noise, state of the

baby, and age at which the infant is screened (Iowa's Early Hearing Detection & Intervention System, 2008).

Similarly, just as programs differ in screening protocol, there also lacks a uniform referral protocol among states. In fact, there is not even guaranteed uniformity among screening facilities within the same state. While screening programs are expected to notify parents, pediatricians, and the state Department of Health when an infant refers, the means by which parties are notified may vary. In Iowa, for example, the screener must report results to parents in written form. It is not mandatory to verbally tell parents when their child refers, but it is encouraged (Iowa's Early Hearing Detection & Intervention System, 2008). Even though it is not mandated by the state, some individual programs in Iowa might require screeners to explain results verbally.

There is also inconsistency concerning whose role it is to schedule a diagnostic evaluation. For example, the Minnesota Department of Health recommends that hearing screening program personnel explain to parents how they can schedule an appointment for a diagnostic evaluation (Minnesota Department of Health, 2011). The Washington State Department of Health gives the pediatrician responsibility for arranging follow-up screening (Washington State Department of Health, 2010). In Pennsylvania, hearing screening programs are responsible for scheduling the follow-up appointment with the parents prior to discharge (Pennsylvania Department of Health, 2009). These inconsistencies in protocol may affect the timelines and rate that infants receive diagnostic follow-up and intervention.

An Overview of Loss to Follow-Up

The U.S. Department of Health and Human Services and JCIH, among other organizations, have had a tremendous effect on the number of states mandating universal newborn hearing screening. In 1993, less than 5% of infants were screened for hearing loss (Moeller, 2006). By 2000, 38% of infants received hearing screenings at birth.

Today, an estimated 95% of infants are screened prior to discharge from their birthing facilities (Centers for Disease Control and Prevention, 2005). Although efforts toward increasing the percentage of infants screened by one month have proven successful, there is still great room for growth in improving the percentage of infants diagnosed by three months and receiving intervention by six months.

Since the purpose of any screening is to identify a population that needs more thorough testing, there would be little reason to implement universal newborn hearing screening without following up with appropriate diagnostic testing. After a baby who does not pass his or her initial hearing screening is discharged from the birthing facility, it is necessary for follow-up action to take place. Other populations who need follow-up include babies who did not receive an initial hearing screening, babies with a risk indicator for a delayed or progressive hearing loss, or babies whose initial hearing screening was incomplete (Finitzo & Crumley, 1999). Because JCIH set a benchmark for babies with hearing loss to be identified by the time they are three months old, it is best practice for follow-up appointments to take place within that initial three-month window. Follow-up involves electrophysiological testing – typically an ABR – to either rule out or confirm the presence of a hearing impairment. When a baby is too active or fussy during the follow-up appointment, preventing an audiologist from obtaining conclusive results,

another follow-up appointment is necessary. At an ideal follow-up appointment, an audiologist determines the degree of hearing loss, makes a diagnosis, and prepares to begin counseling the family about intervention options.

Unfortunately, although an estimated 92-95% of infants in the United States have their hearing screened at birth, nearly half of infants who do not pass the initial screening do not receive timely audiologic attention through a diagnostic evaluation (National Center for Hearing Assessment and Management, 2007; Centers for Disease Control and Prevention, 2008a). While several large programs meet or succeed the JCIH standard of 90% for follow-up testing, many programs do not. In many cases, of course, infants who do not follow up have typical hearing. At the time of the initial screening, infants in this false positive population may have had fluid in the ear canal, received a poor probe fit, or been influenced by other environmental factors that interfered with the screening results. However, some babies who do not receive a comprehensive diagnostic evaluation after referring on an initial screening do indeed have hearing impairments. Failure to follow up with an audiologist can result in an undiagnosed hearing impairment, thus hindering intervention and delaying language development.

The entire population of babies who do not pass the initial screening and do not receive a diagnostic evaluation is referred to as babies who are lost to follow-up. They are considered lost because a state's Department of Health loses track of the status of their hearing. Deceased babies and those discharged without an initial hearing screening (due to parents' refusal of consent or to a screening program's error) who do not receive testing after discharge are also considered lost to follow-up. Additionally, some babies may be lost due to poor documentation of diagnostic results. In order to decrease the

number of late diagnoses of hearing impairment, each state strives to have a low number of babies who are lost to follow-up. Just as they set quality indicators for total percentage of babies screened and total percentage of babies referred, states set benchmarks for percentage of babies who are lost to follow-up (Grbac, 2010).

Potential Causes of Loss to Follow-Up

Considering the many variables that set one screening program apart from another, isolating the factors contributing to follow-up rates has proven difficult. Among the most important factors potentially affecting follow-up statistics are the knowledge and attitude of the pediatrician or primary care provider, the shift of control from the birthing facility to the medical home, communication with caregivers, scheduling, the data management system, and both child and maternal demographics. Researchers have analyzed demographics and program characteristics that may contribute to the failure of an infant to follow-up with a timely diagnostic evaluation. While the solution to eliminating loss to follow-up has not been found, current research provides useful information for those making decisions about newborn hearing screening programs.

The 2000 JCIH position statement reports that within the context of the medical home, it is the pediatrician's responsibility to serve as an advocate for the whole child. "The pediatrician, as part of a well-functioning medical home, can be critical in insuring timely diagnosis, early intervention, family support, and ultimately, better long-term outcomes for infants identified with [hearing loss]" (Joint Committee on Infant Hearing, 2000). Unfortunately, many pediatricians do not understand the importance of newborn hearing screening and following up for early diagnostic evaluations. In a 2007 study,

Dorros et al. collected surveys from 107 Rhode Island pediatricians regarding their knowledge, beliefs, and practices relative to newborn hearing screening. Although 72% of pediatricians reported caring for children who have permanent hearing loss, and although the majority of the physicians considered themselves to be the medical home, only 43% percent reported feeling well-informed on hearing-related services. Similarly, 55% of the participating pediatricians reported feeling ill-informed about the steps necessary for follow-up (Dorros, 2007).

The implicit trust a family places in a pediatrician to take necessary steps for an infant's care, along with a pediatrician's ability to address parental concerns and questions, puts a physician in a crucial position to educate, support, and empower families. Physicians have a pivotal role in promoting timely follow-up and appropriate monitoring after an initial newborn hearing screening. Surely the extent to which a pediatrician is knowledgeable about technical aspects of the hearing screening, audiologic testing, diagnosis, amplification, and intervention affects the way he or she counsels families. Pediatricians must be knowledgeable about current best practice in both medical and educational intervention of children with hearing loss. Therefore, because a physician's role as a supporter and advocate is vital for the effectiveness and efficiency of a program, there is a strong need for pediatricians to be further educated about matters related to hearing screening, diagnosis of hearing loss, and the intervention process (Dorros, 2007).

Personnel involved in newborn hearing screening programs may also impact follow-up rates. While some hospitals – especially those with low birth rates – might require nurses to perform screenings, others can afford to hire trained technicians to

administer them. Because the administration of screening OAE and ABR technology does not require a strong audiologic background, some hospitals use volunteers as screeners. Audiologists contract with some hospitals to manage their screening programs and provide direct supervision and training of screening personnel. A study conducted by Thompson (2007) in Colorado analyzed data to determine the effect of program personnel on rate of follow-up for an outpatient rescreening. The study shows that newborns in hospitals that use technicians for hearing screenings are 52% more likely to receive further testing than those in hospitals who use nurses. Perhaps this is because screening is a hearing technician's only focus, while a nurse has a range of other responsibilities. A dedicated technician may be more likely to effectively communicate results to parents and stress the importance of obtaining an outpatient re-screen. The same study shows that infants born in a hospital with an audiologist are 27% more likely to receive an outpatient rescreen after referring on an initial screening than those infants born in a hospital without an audiologist. Audiologists often oversee scheduling of follow-up appointments. Perhaps the most alarming statistic in Thompson's study is that when a hospital does not schedule follow-up appointments prior to discharge, infants are 96% less likely to receive the outpatient rescreen. When parents are left to make the appointments themselves, follow-up rates plummet drastically. Poor rescreen rates also occur when hospital volunteers take responsibility for scheduling appointments, but the presence of an audiologist in a volunteer program improves the follow-up rate when volunteers schedule appointments (Thompson, 2007).

Communication between the screening program and parents is another factor that affects a family's decision about whether or not to follow up for diagnostic testing. Who

provides the information, what information is given, and how information is given all have a role in affecting a parent's response. A 2007 study conducted in Massachusetts surveyed approximately 1,000 families about their experiences with newborn hearing screening. Parents of children with hearing loss expressed that they received mixed messages when screening results were delivered (MacNeil et al., 2007). This is not surprising, considering the lack of universal referral protocol. A parent might respond differently to information delivered orally and in person than to written information left in a bassinette or even delivered by hand. Programs who do not require face-to-face delivery of results risk the possibility of having paper results overlooked or lost among the many forms and pamphlets given to parents before discharge. On the other hand, delivering information or ally has risks, too. The screener's knowledge and attitude may impact a parent's interpretation of the results. The screener must show sensitivity when delivering information and find a good balance between not causing unnecessary worry and panic while ensuring that parents know the importance of obtaining further timely testing.

Researchers have questioned whether parents' knowledge of the degree of a child's potential hearing loss would affect follow-up rate. While most parents do not receive any information about the potential degree of hearing loss after an initial hearing screening, *multilevel* ABR screening technology does indicate the degree of a potential hearing loss. Researchers from St. Louis Children's Hospital questioned if parents of children in the neonatal intensive care unit who were screened with a multilevel ABR would be more likely to follow up if they knew their children had potentially severe-to-profound hearing loss compared to parents who knew their children had potentially mild-

to-moderate hearing loss. However, their 2006 study showed no significant correlation between follow-up rate and potential degree of hearing loss (Lieu, 2006).

Even when communication is effective and families are provided with thorough explanations, other barriers may exist that make follow-up difficult. Parents from the MacNeil study expressed difficulties with making telephone calls for appointments, finding convenient appointment times, having long distances to travel for testing, and finding someone to care for other children during the appointment (MacNeil et al., 2007). These scheduling difficulties, in addition to transportation barriers, unfortunately delay follow-up testing and diagnoses.

According to Finitzo et al. (1998), the shift of control from the hospital to the medical home after discharge also has the potential to contribute to loss to follow-up. Possible medical homes include a pediatrician or family practitioner, health maintenance organization, or health clinic. Unfortunately, documentation and contact information can be lost during the transition. Changed names and incorrect or purposely misleading contact information make it especially difficult to keep in contact with families after discharge (Finitzo et al., 1998). Even when a follow-up location is determined prior to discharge, some parents change their minds and take children to different facilities. When this happens, primary care providers may be unaware of newborn hearing screening results. According to Shoup et al., "Keeping the coordination of follow-up services for [Universal Newborn Hearing Screening] at the birthing facility allows for improved continuity of care" (2005).

Interestingly, ten years after Finitzo et al. raised concern about documentation barriers, Mason et al. (2008) suggested that the phrase "lost to follow up" is often

inaccurate and that "lost to documentation" is sometimes more appropriate. According to the authors, very few children are truly "lost." Many children who receive the lost to follow-up label actually are known to follow-up programs, yet communication issues inhibit the state from maintaining follow-up results. Like so many aspects of universal newborn hearing screening, there is no universal protocol for reporting screening results to the states. Some newborns' diagnostic statuses are not reported to the state's EHDI program, even if they are receiving intervention services (Mason et al., 2008). While this may be true, there certainly are still newborns who truly are lost to follow-up.

Sass-Lehrer (2004) poses the suggestion that family and social issues play a bigger role in affecting follow up than screening technologies or data systems used. The author explains that cultural and language barriers may inhibit a family from understanding consequences in delaying identification and intervention, and illiteracy may be responsible for keeping some parents from following up. How cultures view disabilities might also influence parents' decision to obtain a diagnosis. Sass-Lehrer recommends the establishment of culturally sensitive relationships with families in order to reduce the negative effects of demographic and cultural factors on a family's likelihood to seek necessary audiologic attention (Sass-Lehrer, 2004).

A study by Chia-ling Liu et al., (2008) used data from Massachusetts to examine the potential demographic risk factors for becoming lost to follow-up. The researchers obtained demographic and medical information, hearing screening results, and diagnostic evaluation records for children born in Massachusetts in 2002 and 2003. The study found that 89% of infants born in Massachusetts who did not pass the initial hearing screening followed up for a timely diagnostic evaluation compared with the national average of

55%. Data was then analyzed to assess the predicting values of both child factors and maternal factors associated with follow-up. Child factors included birth weight and hearing screening results. Maternal factors included age, race, marital status, smoking status during pregnancy, educational attainment, health insurance, and region of residence. The results of the study showed that children of mothers who were nonwhite, had less than a high school education, were unmarried, were covered by public insurance, smoked during pregnancy, or lived in western, northeastern, or southeastern Massachusetts (compared to those who lived in the Boston region) were at higher risk of becoming lost to follow-up. Specifically, nonwhite infants were 1.5 times more at risk for becoming lost to follow-up than white infants, and infants whose mothers had public insurance were almost twice as likely to become lost to follow-up as those whose mothers had private insurance. After adjusting for covariates related to location, the study found that infants born outside of the Boston region were 2 to 4 times more likely to become lost to follow-up than those from Boston. This study suggests the relative impact of demographic factors on follow-up rate and allows newborn hearing screening programs in Massachusetts and elsewhere to pinpoint populations who may require more intensive attention to obtain follow-up (Liu, 2008).

Research shows that universal newborn hearing screening has become increasingly more effective in reducing the age of identification and intervention for children with hearing loss. However, potential benefits of newborn hearing screening are reduced if a family of a child who does not pass the screening does not obtain recommended follow-up testing to receive a diagnosis. There are multiple stakeholders who impact whether or not a child receives appropriate testing. While the list of potential

causes to loss to follow-up may be overwhelming, awareness of these factors might make stakeholders more conscientious of the ways they communicate with one another.

Purpose

The purpose of the present study is to narrow the focus of the review of newborn hearing screening and loss to follow-up to the state of Missouri. The goal is to provide a summary of recent statewide refer and follow-up rates and discuss factors that might contribute to these statistics. Finally, this study aims to highlight three newborn hearing screening programs under the same audiologic management and discuss the potential impact of the audiologist on follow-up rates.

Methods

The examiner investigated online state publications in order to gain knowledge of the Missouri Newborn Hearing Screening Program (MNHSP). Topics examined include legislation history, screening and referral protocol, benchmarks, and quality indicators.

Information regarding Missouri's newborn hearing screening refer and follow-up rates was provided at a presentation given at the 2010 Missouri Academy of Audiology Annual Scope of Practice Convention. The examiner attended the presentation and obtained a copy of the statistics discussed.

Three anonymous Missouri hospitals (Hospital A, Hospital B, and Hospital C) under the same audiologic management were identified. The examiner contacted the audiologist who contracts with the hospitals and manages their newborn hearing screening programs. The audiologist agreed to share information about the screening programs, including refer and follow-up statistics from the 2009 and 2010 annual reports. The examiner compared data from the three hospitals to data from the entire state of Missouri.

Results

Legislation enacted on January 1, 2002 mandates that all babies born in Missouri be screened for hearing impairment. Prior to discharge, hospitals are required to screen infants' hearing by the use of approved physiological technologies. If an infant is transferred for further acute care prior to completion of his or her hearing screening, he or she must be screened by the receiving facility. In addition to communicating screening results to parents or guardians and primary care physicians, hospitals and audiologists must report results to the Missouri Department of Health and Senior Services (DHSS) within one week of screening (Missouri Department of Health and Senior Services, 2010b). This is done by recording results on a multi-copy tear out blood spot card that is sent to the State. Screening programs are now being trained to use a web based data entry system, which will replace the use of blood spot forms (Centers for Disease Control and Prevention, 2008b).

If an infant is born outside of a hospital, it is the responsibility of the professional who undertakes his or her pediatric care to ensure that the screening is performed within the first three months of age and report results to parents or guardians and DHSS.

Exceptions to the legislation may be made if screening conflicts with a family's religious practices (Department of Health and Senior Services, 2003).

The law also requires those responsible for screening to provide parents or guardians of infants who fail the initial hearing screening with appropriate educational materials. Parents or guardians first must be made aware of the importance of scheduling and receiving for their child a full diagnostic audiologic evaluation to confirm or rule out hearing loss. Parents or guardians must then receive information about resources

available to provide rescreening and diagnostic audiologic assessment, along with other information as prescribed by DHSS (Harbison, 2008).

Missouri does not currently have written guidelines or protocols for performing hearing screenings, although DHSS will provide technical support to newborn hearing screening programs when needed. It is up to each screening program to determine who administers screenings and what refer protocol will be followed. Some hospitals operate two-tiered screening programs, in which infants who refer on initial screenings are rescreened prior to discharge. Other programs require families to return for outpatient rescreening. In these cases, it is the responsibility of the parents or guardians to schedule these re-screenings. Although Missouri's 44 diagnostic facilities follow uniform guidelines when performing follow-up testing, there is no uniform protocol for scheduling these diagnostic follow-up appointments (Centers for Disease Control, 2008a).

In order to guarantee that Missouri has quality newborn hearing screening programs, DHSS monitors programs' performance regularly. DHSS checks to see whether programs achieve the benchmarks and indicators recommended by the JCIH 2007 Position Statement and sends reports to hospitals to notify them whether or not they are in compliance with JCIH. It is recommended that hospitals utilize these benchmarks on at least a quarterly basis (Department of Health and Senior Services, 2010a).

In addition to monitoring program performance, DHSS works to identify the hearing status of children who either did not receive or did not pass initial hearing screenings. The Missouri Department of Health and Senior Services' Newborn Hearing Screening Program (MNHSP) staff takes responsibility for this. The MNHSP consultant

audiologist recently compiled and analyzed data revealing hospital-specific loss to follow-up rates in order to send report cards to Missouri pediatric audiologists (Centers for Disease Control and Prevention, 2008a). In 2010, the same audiologist presented EHDI data at the Missouri Academy of Audiology Annual Scope of Practice Convention held in St. Louis. The following information was obtained from the presentation:

Each year there are approximately 80,000 births in the approximately 70 Missouri hospitals that have labor and delivery units. These birthing hospitals vary in size, type of screening, screening personnel, and audiologic management. The majority of Missouri birthing hospitals (approximately 28%) have between 201 and 1,000 births annually, and only 2% of Missouri hospitals have greater than 3,000 annual births. 28% of Missouri hospitals utilize ABR screening technology, while 36% of programs only offer OAE screens. The remaining 36% of hospitals administer both OAE and ABR screenings. Only 10 Missouri hospitals utilize hearing technicians instead of nurses. 9 of these 10 programs are among the 35 hospitals who achieve the recommended referral rate of 4% or less of total screenings. 5 of the 13 hospitals that have an audiologist involved are among the hospitals with the lowest refer rates. (Grbac, 2010).

Because DHSS receives results daily, follow-up numbers tend to fluctuate. For this reason, the MNHSP audiologist primarily focused on follow-up statistics from 2007 instead of discussing numbers from more recent years. 44% of Missouri infants who referred on their initial newborn hearing screening in 2007 were lost to follow-up. The 11 hospitals with 20 or more infants lost annually contribute to 57% of total loss to follow-up. One small hospital had a 25% referral rate, and one hospital lost 97 of the 1,500 babies born, making the lost to follow-up rate 64%.

The MNHSP audiologist discussed potential causes to loss to follow-up consistent with factors suggested in the review of the literature regarding universal newborn hearing screening in the United States. Among these causes were language and literacy barriers, funding barriers, transportation issues, ineffective communication regarding the need for follow- up testing, and lack of concern from the pediatrician. The MNHSP audiologist then shared the results of a recent study conducted by Mei Lin (2010). Newborn hearing screening records were linked to Missouri birth certificate records from 2006 and 2007. Lin found that a total of 7,118 babies either did not pass or did not receive an initial newborn hearing screening during those years. Lin then used multivariate binomial regression analysis to estimate correlations between follow-up and various demographic factors related to the infant, mother, and screening facility. Several significant factors associated with loss to follow-up were identified. Those infants who referred on their initial hearing screening were estimated to be more likely to become lost to follow-up if their mothers were less than 20 years old, African-American, Hispanic, or enrolled in Medicaid, Women, Infants, and Children (WIC), or a food stamps program. Infants born to mothers without post-high school education, infants born to mothers who received late or no prenatal care, and infants born to mothers who smoked during pregnancy were also significantly associated with becoming lost to follow-up. Variables not proven to be significant included low birth weight, driving distance from the home and birthing hospital, and proximity to diagnostic facility. Whether or not the hospital was in an urban or rural setting and whether or not hospitals conduct outpatient rescreens also had no significance.

After addressing the potential correlations to loss to follow-up mentioned in Lin's

analysis, the MNHSP audiologist shared some of her own observations through her experiences and data analysis. According to the audiologist, loss to follow up is a hospital driven factor. Specifically, she has found poor communication with parents and poor organization of the system to make some of the most significant contributions to loss to follow-up. Additionally, she has observed the strong influence a pediatrician has on a family's decision to pursue outpatient re-screening and diagnostic evaluations: While some pediatricians take these appointments seriously, others tell families not to worry. The MNHSP audiologist also stressed that the hospitals who do best have "someone who cares." In some cases, this may be an audiologic manager, although it is not necessary that the dedicated professional be an audiologist. The hospitals with the best outcomes have staff members who are dedicated to managing screenings without having additional obligations (Grbac, 2010).

After attending the presentation, the examiner contacted an audiologist who manages the newborn hearing screening programs at three Missouri hospitals (Hospital A, Hospital B, and Hospital C). Among other things, the audiologist's job involves training screeners, ordering supplies, ensuring equipment is properly calibrated, monitoring results, and sending results to DHSS. The audiologist shared the following information with the examiner:

In 2001, the audiologist began managing the newborn hearing screening program at Hospital A, a large hospital in a metropolitan area. Hospital A has more than 6,000 births annually, and approximately 20% of patients have Medicaid (K. Park, personal communication, April 25, 2011). Hospital A is also a diagnostic facility, meaning that infants who refer on their initial hearing screenings can return to their birthing hospital

for follow-up diagnostic evaluations. During the early years of the audiologist's contract with Hospital A, nurses who were not very familiar with newborn hearing screening were responsible for administering hearing screenings. Now, the audiologist hires dedicated technicians to administer all screenings (K. Park, personal communication, April 20, 2011).

Infants born at Hospital A who have risk factors for hearing loss receive an ABR screen, and all other infants receive an OAE screen. Hospital A's program is a two-tiered screening program, meaning that a child who refers on an initial screening but is not yet going home receives a re-screen with the same technology the following day. Because of this, parents are not required to return to the birthing facility for outpatient re-screening. Ideally, infants are screened the day before discharge. A child who does not pass an OAE screen on the day of discharge receives an ABR screen, the more sensitive of the two technologies. If a child passes an ABR in both ears, he or she does not need to be referred for diagnostic follow-up.

One copy of the results is sent to the pediatrician, one is kept in the medical chart, and one is kept for the audiologist's records. The technician delivers a paper copy of screening results and recommendations to the parents and explains them carefully. When a baby refers on the final ABR screening attempt, the technician explains to the parents that 80-90% of infants who refer on the initial screening pass the follow-up diagnostic test. Parents are reassured that their child does not necessarily have hearing loss, but that it is very important to follow up with an audiologist for a more thorough examination. The technician confirms the family's contact information and helps the family schedule a follow-up appointment prior to discharge. Parents also receive a referral letter and the

audiologist's contact information. After leaving the family's hospital room, the technician notifies the audiologist that an infant referred. If the family has any questions, the audiologist calls them (Park, 2001).

In 2002, the audiologist began managing the newborn hearing screening program at Hospital B. Unlike Hospital A, Hospital B is located in a rural area and provides services to residents of five rural Missouri counties. Hospital B is much smaller and serves patients with lower socioeconomic status than Hospital A. Less than 1,000 babies are born at Hospital B annually, and approximately 55% of families have Medicaid (K. Park, personal communication, April 25, 2011). Because Hospital B does not have dedicated hearing technicians to administer hearing screenings, nurses are responsible for screening, explaining results, and helping families schedule follow-up appointments prior to discharge. The two nurses who do the majority of the screenings received direct training from the audiologist and trained a few others. Even though the audiologist is not located near Hospital B, she receives and reviews all paperwork, compiles data, contacts pediatricians when infants refer, and monitors follow-up. Babies who refer at Hospital B often receive follow-up testing at Hospital A, although they occasionally receive services from another metropolitan diagnostic facility (K. Park, personal communication, April 27, 2011).

The audiologist's contract with Hospital C began in 2007. Hospital C's demographics somewhat resemble those of Hospital A. Hospital C is located in a metropolitan area and has between 3,500 and 4,000 births annually. Only 12% of Hospital C's patients have Medicaid, which indicates that on average patients' socioeconomic status is higher than that of patients at Hospital A and Hospital B (K.

Park, personal communication, April 25, 2011). Hospital C utilizes dedicated hearing technicians and practices the same two-tiered screening and referral protocol as Hospital A, including scheduling follow-up appointments prior to discharge. One of the greatest differences between Hospital A and Hospital C is that Hospital C is not a diagnostic facility. Parents whose children refer on screenings at Hospital C must visit another facility – sometimes Hospital A – when attending follow-up appointments. Technicians give parents two choices of diagnostic facilities when scheduling the evaluations (Park, 2001).

Prior to the audiologist's contracts, the three hospitals did not monitor the follow-up status of babies who referred on hearing screenings. Instead of scheduling follow-up appointments prior to discharge, hospital staff provided parents with paper copies of screening results and told parents to talk to their pediatricians about follow-up testing. While the hospital tracked the total number of babies screened and the total number of babies who referred, the hospital did not know if or when follow-up was obtained. Furthermore, when babies did receive follow-up testing at a diagnostic facility, Hospital C was unaware of the testing results.

Now, even though the State monitors follow-up statistics for all birthing hospitals, the audiologist takes it upon herself to obtain follow-up data for each of the three hospitals she manages. When a baby refers on his or her hearing screening, a parent signs a release form granting the audiologist permission to send screening results to a diagnostic facility and receive the diagnostic results in return. If the audiologist does not receive diagnostic results within one week of the scheduled appointment, she contacts the diagnostic facility to determine whether testing took place, whether results were sent, and

whether a missed appointment was rescheduled. If necessary, the audiologist contacts pediatricians or the family directly to remind them of the importance of follow-up testing.

Although JCIH recommends that babies receive a diagnosis by three months, DHSS suggests obtaining follow-up testing by two months of age. The audiologist aims to schedule testing for two weeks after a referred screening. One reason for this is because it is more difficult for older babies to remain asleep during testing. In her years of practice, the audiologist has also found that testing must often be postponed or repeated due to sickness or sleep issues. By scheduling an early appointment, the audiologist feels she improves the chances of obtaining a timely diagnosis (K. Park, personal communication, April 20, 2011).

Statistics from the three hospitals' 2009 and 2010 annual reports confirm the audiologist's efforts to achieve timely follow-up. The reports list the recommendations of the Year 2000 Position Statement and Guidelines of the JCIH on infant hearing screening and demonstrate whether the hospitals achieve the recommended benchmarks. The following data was obtained from updates sent to the audiologist from DHSS and the annual reports:

According to the JCIH quality indicator, hospitals should screen a minimum of 95% of infants before one month of age. In 2009, approximately 88% of hospitals in Missouri achieved this benchmark (Missouri Department of Health and Senior Services, Benchmarks, 2010a). All three hospitals examined met this benchmark in 2009 and 2010. Prior to one month of age, Hospital A screened 99.9% of the 7,232 babies born in 2009 and 99.9% of the 6,906 babies born in 2010. The parents of one baby refused screening in 2010. Hospital B screened 100% of the 911 babies born in 2009 and 100% of the 892

babies born in 2010. Hospital C screened 100% of the 3,985 babies born in 2009 and 100% of the 3,974 babies born in 2010.

The quality indicator for percent of newborns referred is less than 4%. In 2009, approximately half of Missouri hospitals achieved this benchmark. 30% of the hospitals had refer rates between 5% and 9%, leaving about 20% of hospitals with refer rates greater than 9% (Missouri Department of Health and Senior Services, Benchmarks, 2010a). All three hospitals examined met this benchmark in 2009 and 2010. Hospital A's refer rates were 0.84% in 2009 and 0.64% in 2010. Hospital B's refer rates were 0.60% in 2009 and 0.67% in 2010. Hospital C's refer rates were 0.60% in 2009 and 0.75% in 2010.

The quality indicator for percent of newborns lost to follow-up is less than 10%. This benchmark comes from the JCIH recommended benchmark that 90% of infants who refer on an initial screening and subsequent screening should receive a diagnostic evaluation with an audiologist by three months of age (Missouri Department of Health and Senior Services, 2010a). In 2009, 58.3% of babies born in Missouri were lost to follow-up (Missouri Department of Health and Senior Services, 2009). 87% of Missouri hospitals have 20 or less newborns lost to follow-up each year. The other 13% of birthing hospitals have higher follow-up rates, making significant contributions to Missouri's total loss to follow-up rate (Grbac, 2010).

Hospital A had 100% follow-up in both 2009 and 2010. In 2009, 58 of the 61 babies who referred on their initial screening at Hospital A received follow-up testing by one month, and the remaining 3 babies received follow-up within three months. A total of 7 infants were identified with permanent hearing loss through follow-up testing. In 2010, 33 of the 44 babies who referred on their initial screening received follow-up testing by

one month, and the remaining 11 babies received follow-up testing by three months. A total of 12 babies were identified with permanent hearing loss through follow-up testing.

Hospital B had 80% follow-up in 2009 100% follow-up in 2010. In 2009, 4 of the 5 babies who referred on their initial screening at Hospital B received follow-up testing by one month. One baby did not receive follow-up testing. One baby was identified with permanent hearing loss through follow-up testing. In 2010, 4 of the 6 babies who referred on their initial screening at Hospital A received follow-up testing by one month, and the remaining 2 babies received follow-up within three months. One baby was identified with permanent hearing loss through follow-up testing.

Hospital C had 100% follow-up in both 2009 and 2010. In 2009, 20 of the 24 babies who referred on their initial screening at Hospital C received follow-up testing by one month, and four babies received follow-up testing within 3 months. 10 babies were identified with permanent hearing loss through follow-up testing. In 2010, 26 of the 30 babies who referred on the initial screening at Hospital C received a diagnostic evaluation within one month, and the remaining 4 received it by 3 months. 9 babies were identified with permanent hearing loss through follow-up testing.

Discussion

Despite evidence showing the benefits of early identification and intervention for children with permanent hearing loss (Yoshinaga-Itano et al., 1998), an alarming number of infants do not receive timely diagnosis following a referred newborn hearing screening. Even though 92-95% of infants receive newborn hearing screenings, nearly half of infants who refer do not obtain timely audiologic follow-up (National Center for Hearing Assessment and Management, 2007; Centers for Disease Control and Prevention, 2008a).

As demonstrated in the literature review, researchers have identified several potential causes to loss to follow-up after an infant's referred initial newborn hearing screening. While some studies identify infant characteristics and maternal characteristics significantly associated with loss to follow-up, others suggest hospital-driven factors that might contribute to follow-up rates. Examples of infant characteristics include low birth weight and gestation age. Some maternal characteristics include race, age, marital status, smoking status, education, and enrollment in Medicaid or food stamps programs. Hospital factors include funding, birth rate, equipment, screening personnel, refer protocol and follow-up scheduling. Additionally, multiple studies demonstrate the pivotal role of the pediatrician regarding follow-up.

It is also possible that parents who would otherwise be willing to attend follow-up appointments choose not to because they do not believe their children have hearing loss. Perhaps their babies appear to startle to sound or show evidence of hearing at home. This might be true for some children with mild or unilateral hearing losses. Unfortunately, when these children enter a noisy classroom, they might struggle to hear speech in the

presence of background noise. It is important for children to receive early audiologic diagnosis and attention in order to begin timely intervention.

The MNHS contracting audiologist's observation that the hospitals with the best outcomes have dedicated program management led the examiner to explore the potential impact of audiologic management on a newborn hearing screening program's refer and follow-up rates. Furthermore, a Colorado study revealed that infants born in hospitals without an audiologist were significantly less likely to receive outpatient re-screens (Thompson, 2007). While the examiner was more interested in follow-up for diagnostic evaluations than outpatient re-screens, Thompson's study confirmed the examiner's desire to explore the relationship between audiologic management and follow-up rates. It is important to recall the MNHS audiologist's explanation that it is not necessary for a program's dedicated individual to be an audiologist; however, because the program manager involved in this study is an audiologist, the following discussion will refer to the management role as audiologic management.

The examiner contacted the audiologist and explained the goals of the present study. The audiologist provided the examiner with refer and follow-up data for Hospital A, Hospital B, and Hospital C from 2009 and 2010. With the exception of one baby lost from Hospital B in 2009, all three hospitals had 100% follow-up rates in the last two years. Not only were these infants tested by the recommended three months, but also the majority of infants receiving further testing did so within one month of age. All three hospitals also succeeded the benchmark for screening more than 95% of infants and having a refer rate of 4% or less.

It should be noted that the present study is an analysis and reflection of existing

data, not a controlled experiment. The examiner learned by word-of-mouth that a Missouri audiologist managed newborn hearing screening programs that have follow-up rates well above the state and national statistics. Prior to obtaining the annual reports, the examiner knew that Hospital A, Hospital B, and Hospital C had excellent follow-up rates. The examiner aimed to gain information about the programs' audiologic management and identify any potential risk factors for poor follow-up that the hospitals might have been able to overcome with the help of a dedicated audiologist. Ideally, the examiner would have liked to obtain refer and follow-up data from all three hospitals prior to the implementation of audiologic management. This information could allow one to draw better conclusions about the effect of the audiologist on the screening programs. However, because the hospitals did not have someone dedicated to monitoring statistics prior to the beginning of the audiologist's contract, the audiologist was unable to provide this information to the examiner.

The examiner conducted an informal interview with the audiologist over the phone and communicated through electronic mail in order to gain information about audiologic management. When asked what sets her screening programs apart from some others, the audiologist stressed the importance of scheduling follow-up diagnostic evaluations for the families prior to hospital discharge and following up on whether or not scheduled appointments are attended. When the audiologist does not receive diagnostic results within one week of the scheduled appointment, she contacts the diagnostic facility to question whether testing took place, whether results were sent, and whether a missed appointment was rescheduled. When necessary, the audiologist contacts pediatricians or parents to remind them of the importance of follow-up testing.

There appears to be several advantages to scheduling follow-up appointments for the families before they leave the hospital. Even if a trained technician or nurse explains the importance of follow-up and provides parents with a written explanation to support this idea, there is no guarantee that a parent will follow through with the scheduling of the appointment. Some parents may deny that their children may have a hearing loss and therefore choose to disregard the referral recommendation. Even parents who intend to schedule appointments might forget or become too busy caring for their newborn – especially parents of children with other medical issues that need attention. Others may have limited resources or may not know how to schedule the evaluation. An additional benefit of scheduling an appointment for the family while they are still in the birthing facility is the fact that the appointment is scheduled before a pediatrician can tell parents if he or she thinks the appointment is unnecessary.

Studies demonstrating infant and maternal characteristics that contribute to follow-up rates could make hospital personnel consider the improvement of follow-up statistics to be out of their control. A screening program has no influence on the race, age, education, or socioeconomic status of mothers. This is also true for location in a rural or urban area and hospital birth rate. What the present study suggests, however, is that even though the literature shows some correlation between demographics and follow-up rates, action can be taken to overcome the potential risk for loss to follow-up due to demographic factors. A dedicated audiologist or program manager can take action to ensure appointments are made and kept.

Hospital B is located in a rural area with limited resources and without a nearby diagnostic facility, yet Hospital B still has follow-up rates well above the state and

national average. Furthermore, more than half of patients at Hospital B have Medicaid, which is an indication of low socioeconomic status. Despite this factor, parents of children born at Hospital B receive the recommended diagnostic evaluations for their children.

Hospital A serves many Spanish and Vietnamese patients who do not understand or speak English. For this reason, the audiologist utilizes the hospital's interpreter service to explain hearing screening results. Because the follow-up appointment is scheduled during the family's hospital stay, the interpreter can easily be involved in the scheduling of the appointment and can help parents understand the importance of timely follow-up (K. Park., personal communication, April 20, 2011).

Some communities are too small to support a pediatric audiologist or lack sufficient funds to hire an individual dedicated to the management of a newborn hearing screening program. Hospitals that already have pediatric audiology should consider following the example of the hospitals involved in this study and utilizing dedicated audiologic management of the newborn hearing screening program. An audiologist can troubleshoot equipment, train technicians and nurses, monitor benchmarks, and serve as a source of information for parents and pediatricians. Whether or not a program has an audiologist or dedicated manager, hospitals should consider scheduling appointments for the families prior to discharge.

The review of the literature and the present study suggest a strong need for future research on newborn hearing screening and loss to follow-up. Future research should compare refer and follow-up statistics from hospitals with similar demographics but different program management. Perhaps a better way to isolate the audiologic

management variable would be to identify hospitals with recently-implemented audiologic management and compare data from before and after the presence of the audiologist. Of course, it is understood that with the addition of audiologic management may come additional variable changes, such as new screening personnel or equipment. All of these variables should be considered when drawing conclusions about the effect of audiologic management on a newborn hearing screening program.

Conclusion

The goal of the present study was to examine the literature regarding potential causes of loss to follow-up after referred initial newborn hearing screenings.

Additionally, the examiner aimed to highlight three newborn hearing programs under the same audiologic management and compare referral and follow-up statistics to statewide data.

The literature suggests various maternal characteristics, infant characteristics, hospital-driven factors, and other variables that could contribute to poor follow-up. Of course, it is not possible to isolate a single cause to loss to follow-up. What may keep one family from attending diagnostic evaluations may be entirely different from what keeps another family from doing so. Some correlations, such as socioeconomic status or location in a rural area, may appear impossible to overcome. However, the present study suggests that having a dedicated individual who cares about monitoring a program's follow-up could help overcome potential risk factors for loss to follow-up. By scheduling appointments prior to birth facility discharge and taking action to ensure appointments are kept and diagnoses are received, programs can have follow-up rates that succeed recommended benchmarks. When benchmarks are met, a greater number of infants are able to receive early identification and intervention, thus providing them with greater opportunities for growth.

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