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Factors Related to Not Following Up with Recommended Testing in the Diagnosis of Newborn Hearing Loss

Wendy Zeitlin, Charles Auerbach, Susan E. Mason, Lynn G. Spivak, and Bena Reiter

Children's hearing is a public health concern, and universal newborn hearing screenings are the first step in detecting and treating congenital hearing loss. Despite the high rate of participation in such programs, loss to follow-up (LTF) with additional recommended diagnosis and treatment has been a persistent problem. The current research seeks to expand the knowledge base at the point of diagnosis, where there is a large drop-off in parents following through with recommended care. This research was organized around the following question: What biopsychosocial factors are associated with LTF between screenings and diagnostic evaluations? A prospective quantitative longitudinal study tracked 203 families whose newborns were referred for additional testing at discharge from the hospital after birth. Binary logistic regression was used to determine what constellation of factors best predicted LTF. Psychosocial factors related to being lost to follow-up at diagnosis included race and ethnicity and access to health care professionals, with African American babies being most at risk for LTF; however, the impact of race and ethnicity declined when parents believed they had more health care professionals with whom to consult.

KEY WORDS: *diagnosis; hearing screenings; loss to follow-up; newborns*

Children's hearing is a public health concern, and universal newborn hearing screenings (UNHS) are justified by the high incidence of hearing impairment (eight per 1,000 screened) in relation to other congenital defects for which cure or treatment can be provided (Rai & Thakur, 2013). Poor hearing can result in long-term deficits in language and cognitive development, intelligibility, and behavioral and social adjustment (American Speech-Language-Hearing Association, 2008; Auerbach, Mason, Zeitlin, Schudrich, Spivak, & Sokol, 2013; Centers for Disease Control and Prevention [CDC], 2016; Joint Committee on Infant Hearing, 2007). The provision of hearing screenings to newborns results in early diagnosis and treatment of hearing loss, which has been found to maximize linguistic competence and literacy development for children with hearing loss (Rai & Thakur, 2013). As such, UNHS has become a vital public health population-prevention strategy using early detection and intervention to prevent disability (Finitzo & Grosse, 2003).

Since 2005, the CDC has been tracking and publishing national early hearing detection and intervention data, of which UNHS programs are the

first step. Since that time, between 94.2 percent and 97.9 percent of newborns participate in UNHS; however, during this time, between 32.2 percent and 64 percent of infants did not return for recommended follow-up diagnoses (CDC, 2010a, 2010b, 2012a, 2012b, 2013a, 2014, 2015, n.d.-a, n.d.-b). This means that, on average, 25,755 infants with possible hearing deficits are not receiving suggested care each year. Although this rate has declined slightly over the years, the national loss to follow-up (LTF) rate was still 32.2 percent in 2013, the year with the most recently available data (CDC, 2015).

Infants who do not receive recommended follow-up care are deemed either LTF or "lost to documentation" (LTD) (CDC, 2015). Those infants whose parents have been contacted but were unresponsive in some way are labeled LTF. Infants whose parents could not be contacted are labeled LTD. In the national figures, those classified as either LTF or LTD are grouped together, as these are all infants who require follow-up care but do not receive it (CDC, 2015).

On a state-by-state basis, there is great variability in LTF rates at diagnosis. In 2013, for example,

Rhode Island reported an LTF rate of only 4.1 percent, whereas New Mexico and Washington, DC, reported rates of 86.7 percent and 86.6 percent, respectively (CDC, 2013b).

From a public health perspective and to minimize disability in infants who have hearing loss, the CDC promotes a 1-3-6 Plan, which is supported by organizations such as the National Institutes of Health, the American Speech-Language-Hearing Association, and the American Academy of Pediatrics. This plan recommends that infants be screened for hearing loss by one month of age in UNHS programs. Those infants who do not pass the screening should receive a diagnostic evaluation by three months of age, and those infants diagnosed with hearing loss should receive treatment and begin early intervention services by six months of age (CDC, 2011). Despite a well-defined protocol, it has been found that follow-up is the most difficult part of an early intervention program, and this is the area in which many programs break down (Spivak & Sokol, 2005).

Overall, between two and three infants per 1,000 are born with congenital hearing loss (Vohr et al., 2008). Berg and colleagues (Berg, Prieve, Serpanos, & Wheaton, 2011) reported the prevalence of hearing loss in babies admitted to well-infant nurseries at birth is approximately 0.1 percent, whereas the prevalence in neonatal intensive care units is much higher, reported as ranging between 0.8 percent and 3.2 percent. Despite this, there is a relatively high rate of false positives in the hearing screening process that may contribute to parental stress (Vohr et al., 2008).

It has been reported that mothers of infants referred for additional testing after the neonatal screening experience increased stress at the time of the referral, and it has been proposed that false-positive results of neonatal hearing screenings may have a prolonged impact on families attributed to parental anxiety, distraction, disrupted family function, and unnecessary testing (Vohr et al., 2008). Furthermore, Vohr et al. (2008) found that families of infants diagnosed as having permanent hearing loss are likely to experience increased stress, particularly at the time of diagnosis.

Previous research has looked at factors related to being LTF for rescreening infants who have failed initial hospital screens or at the point of treating a diagnosed hearing loss. Spivak and Sokol (2005) found that the most common causes of loss to follow-up at rescreening included low socioeconomic status and social risk factors. Additional

factors related to loss to follow-up at this point include accessibility to follow-up facilities, financial burdens imposed by travel, unavailability of babysitters, needing time off from work, busy family schedules, and a lack of understanding about the importance of follow-up evaluation (Spivak & Sokol, 2005). Other researchers found that the reason most commonly given by caregivers for screening refusal was the failure of medical insurance to cover the costs. This was followed by the perception that such screening was unnecessary (Scheepers, Swanepoel, & Le Roux, 2014). Additional indicators of being LTF at the point of screening include the mother's level of education. Risk factors at the point of treatment include type of hearing loss, type of insurance, and laterality of loss (that is, loss in one ear compared with loss in both ears) at the point of treatment (Prince, Miyashiro, Weirather, & Heu, 2003; Spivak, Sokol, Auerbach, & Gershkovich, 2009).

To date, there has been no research examining factors that may contribute to being LTF at the point of diagnosis, the point in the 1-3-6 Plan with the greatest initial drop-off in care. Previous research, however, indicates that there are differential factors in loss to follow-up with regard to diagnosing other health conditions. For example, in a sample of women who needed additional diagnostic testing after abnormal screening mammography, those with higher levels of education were significantly more likely to return for diagnostic testing (Goldman, Walker, Hubbard, Kerlikowske, & Breast Cancer Surveillance Consortium, 2013). Similarly, differential rates of follow-up have been noted among African American women and those with lower levels of education in the screening, diagnosis, and treatment of breast cancer (Paskett et al., 2012).

Being able to predict who is at risk for being LTF allows for the design of targeted interventions to reduce the problem. The current research seeks to expand the knowledge base at the point of diagnosis, where there is a large drop-off in parents following through with recommended care. Our research was organized around the following question: What biopsychosocial factors are associated with being LTF between screening and diagnostic evaluation?

METHOD

Institutional review boards at the three hospitals included in the study and the Yeshiva University board approved this research.

Sampling

This prospective, longitudinal study included telephone interviews with 203 parents whose children were referred for additional testing after the newborn's initial failure of the hearing screening. Hearing and speech centers supplying data attracted patients from birth hospitals throughout the large metropolitan area.

Families were informed about the study after their children were referred for additional testing because they did not pass the hearing screening done in the hospital. Families were told that a member of the research team would contact them. Parents were contacted by telephone shortly after discharge of their infant from the birth hospital. The purpose of the study was explained, and parents were invited to participate. Those who agreed to participate in the study provided verbal consent. The structured interviews took approximately 20 minutes to complete, and parents were offered a \$25 gift card to compensate them for their time.

For those who agreed to participate in the study, data were obtained from the referring hearing and speech centers six to nine months after initial screening to determine follow-up status. Of the 203 parents interviewed initially, we were able to gather complete screening data on 166. These data included information about attendance and results of office visits, but also included information about laterality (that is, whether one or both ears were affected), gender of the baby, and severity of loss if that information was available. Eleven out of 41 infants ultimately referred for diagnosis were LTF.

Measurement

The survey instrument was designed to be comprehensive, tapping into a multitude of characteristics that could affect compliance with follow-up. The breadth of the survey reflected previous research that identified parental characteristics associated with being LTF with newborn hearing screening and noncompliance with other health programs. Measures included demographic information, an assessment of social supports for parents, parental depression around parenting a child with a health impairment or disability, locus of control, and state–trait anxiety.

The Inventory of Parent Experiences, a 54-item instrument, was used to measure satisfaction with parenting, social support, and general life satisfaction. Reported Cronbach's alphas for the subscales range from .52 to .94 (Crnic & Greenberg, 1983).

The Perinatal Grief Scale measures grief in three domains: active grief, difficulty coping, and despair (Potvin, Lasker, & Toedter, 1989). Reported reliability for each of the three subscales ranged from .86 to .92. The scale was modified to measure grief associated with learning that a newborn baby did not pass his or her initial hearing screening. A total of 21 self-reported items measured this on a five-point Likert scale ranging from 1 = strongly agree to 5 = strongly disagree.

The Parental Health Belief Scale (PBHS) consists of 20 items designed to measure parental locus of control concerning their child's health (Pachter, Sheehan, & Cloutier, 2000). Health locus of control is a measure of how much control individuals perceive they have over their health. Individuals who display an external locus of control believe that their health is determined by outside events. People with a strong internal locus of control feel that they have an important role in their health condition. We slightly modified this scale by removing two questions about dental care because these items were not applicable to newborns. All 18 items were measured on a five-point Likert scale ranging from 1 = strongly agree to 5 = strongly disagree. The PBHS has been found to be both reliable and valid.

Finally, the short form of the Spielberger State–Trait Anxiety Scale was used to measure state–trait anxiety (Marteau & Bekker, 1992). This scale has been used in other studies that focus on UNHS, particularly in the United Kingdom, and has a reported Cronbach's alpha of .82.

RESULTS

Characteristics of the Sample

Characteristics of the entire sample are displayed in Table 1. As shown, the sample represents diversity in terms of race and ethnicity and socioeconomic status. The families predominantly identified as Latino ($n = 91$; 46.7 percent), and the next largest group was African American ($n = 42$; 21.5 percent). More than half ($n = 115$; 58.4 percent) of the respondents were not married. The largest group of respondents had family incomes over \$50,000 ($n = 59$; 35.4 percent), whereas the next largest group ($n = 54$; 32.3 percent) had incomes under \$25,000. The remainder of respondents ($n = 54$; 32.3 percent) had incomes between \$25,000 and \$49,999. English was the most preferred language ($n = 141$; 71.9 percent) of the sample, with the next most common preference being a combination of English and Spanish

Table 1: Demographics of Total Sample

Measure	% (n)	M (SD)
Number of children		2 (1.3)
Only one child	43.1 (84)	
More than one child	56.9 (111)	
Race and ethnicity		
White	15.9 (31)	
Latino	46.7 (91)	
African American	21.5 (42)	
Other	15.9 (31)	
Marital status		
Married	41.6 (82)	
Not married	58.4 (115)	
Total household income		
Under \$25,000	32.3 (54)	
\$25,000–\$49,999	32.3 (54)	
Over \$50,000	35.4 (59)	
Language preference		
English	71.9 (141)	
English and Spanish	14.8 (29)	
Spanish	6.6 (13)	
Other	6.6 (13)	
Gender of child		
Female	46.8 (90)	
Male	52.6 (101)	
Age of interviewed parent (years)		27.5 (5.8)

($n = 29$; 14.8 percent). Over half the respondents had more than one child ($n = 111$; 56.9 percent). Finally, the mean age of the parent interviewed was 27.5 years ($SD = 5.8$).

Bivariate Analysis

Initially, bivariate analyses were conducted to determine what factors may be related to being LTF at the point of diagnosis. Because of the small number of cases, one-tailed significance tests were used to increase the likelihood that differences would be detected.

With regard to the relationship between grief and being LTF, the item “I feel I have adjusted well since I found out that my child needs a hearing re-screen” showed significant differences between the groups. Those not LTF had higher mean scores ($n = 30$, $M = 2.6$, $SD = 0.22$) than those LTF ($n = 11$, $M = 1.8$, $SD = 0.12$). For this question, higher scores indicated a higher degree of depression [$t(39) = -1.93$, $p = .03$]. For the item “I get angry with friends and family more than I should,” those not LTF had higher mean scores ($n = 30$, $M = 4.6$, $SD = 1.6$) than those LTF ($n = 11$, $M = 4.0$, $SD = 0.40$). For this issue, lower scores indicated a higher degree of depression [$t(39) = -1.66$, $p = .053$].

To acquire an understanding of the relationship of being LTF and social support, survey respondents were asked to rate a series of questions on this subject. In one question, survey respondents were asked, “How many professional persons (nurses, doctors, social workers, etc.) could you talk to if you have a problem with your child?” The possible responses were coded as follows: 1 = zero or one person, 2 = two people, 3 = three or four people, 4 = five to eight people, or 5 = more than eight people. Those not LTF had higher mean scores, indicating more access to health care professionals ($n = 30$, $M = 3.4$, $SD = 0.93$) than those LTF ($n = 11$, $M = 2.4$, $SD = 0.92$). The differences between groups were statistically significant [$t(39) = -3.1$, $p = .002$]. Respondents were also asked, “How helpful are family members to you (as babysitters, sources of information, sympathetic ears)?” For this item the possible responses were coded as 1 = not at all helpful, 2 = a little helpful, 3 = somewhat helpful, or 4 = very helpful. Those not LTF had higher mean scores, indicating that they found family members more helpful ($n = 30$, $M = 3.8$, $SD = 0.40$) than those LTF ($n = 11$, $M = 3.3$, $SD = 0.27$). The differences between groups were statistically significant [$t(39) = -1.97$, $p = .03$]. The final item found to be statistically significant was, “How involved are you with your coworkers?” For this item, the possible responses were coded as 1 = not at all, 2 = somewhat, and 3 = very involved. Those not LTF had higher mean scores, indicating that they found coworkers more helpful ($n = 15$, $M = 2.3$, $SD = 0.57$) than those LTF ($n = 3$, $M = 1.3$, $SD = 0.19$). The differences between groups were statistically significant [$t(16) = -1.75$, $p = .05$].

To acquire an understanding of the relationship of LTF and health locus of control, survey respondents were asked to rate a series of questions on this matter. For the item “I can do many things to fight illness in my child,” mean scores of those not LTF were lower ($n = 30$, $M = 2.0$, $SD = 0.55$) than those LTF ($n = 11$, $M = 2.6$, $SD = 0.31$). For this issue, lower scores (agreeing) indicated a higher degree of control [$t(39) = -1.93$, $p = .03$].

When looking at the relationship between race and ethnicity and being LTF, respondents were classified as either white, African American, Latino, or other. People who identified as “other” primarily indicated they were of mixed race or ethnicity.

As indicated in Table 2, none of the white respondents were LTF. On the other hand, 62.5 percent of African American, 25 percent of Latino, and 16.7 percent of other respondents were LTF [$\chi^2(3, N = 39) = 7.68, p = .053$].

Logistic Regression

Logistic regression was conducted to identify a constellation of risk factors related to LTF between screening and diagnosis. Those factors found to be significant predictors in the bivariate analysis were considered for inclusion in the final model.

To aid in interpretation, not being LTF was coded as 1 and being LTF was coded as 0. In terms of race and ethnicity, those indicating “other” as an ethnicity were the comparison group. The results are displayed in Table 3.

Post-estimation testing for collinearity and goodness-of-fit indicated a good fitting model. The results of a link test indicated that there were no specification errors in the model.

Statistically significant results indicated that, when holding race and ethnicity constant, for each unit increase on the measure of how many professional people parents can speak to, the odds of returning for diagnosis increased by 479 percent. When controlling for the number of health professionals parents can talk to, African American infants were 92 percent more likely to be LTF compared with infants from other ethnic groups.

Figure 1 shows that the predicted probability of not being LTF increases as access to health care professionals increases. Figure 1 illustrates that African American infants have a higher probability of being LTF compared with Latino infants and infants from the “other” category (primarily those of multiple racial or ethnic groups). The gap decreases as access to health care professionals increases. This model, with only two predictors, explained slightly more than one-third of the variance in returning for diagnosis.

DISCUSSION

Together, access to medical professionals and race or ethnicity were predictive of families being LTF or not LTF at the point of diagnosis, which has implications for the fields of public health, audiology, and social work. To some degree, this may explain the great variability of LTF/LTD rates reported state by state. For instance, in 2014, in the District of Columbia, the largest group of residents identified as black or African American, at 49 percent (U.S. Census Bureau, 2010). Perhaps it is not a coincidence that this locale had an LTF/LTD rate of 86.8 percent in 2013 (CDC, 2013b). Similarly, residents of New Mexico often live in sparsely populated areas and have less access to health care providers than residents of other states (New Mexico Nursing Education Consortium, 2013). The LTF/LTD rate in New Mexico was 86.7 percent in 2013 (CDC, 2013b).

Loss to follow-up is a difficult problem, and our research provides insight into contributing factors. This could, hopefully, lead to interventions designed to remediate the problem. For example, special attention should be paid to health care settings serving predominantly African American communities or those serving communities where access to pediatric health care is not readily available. In those contexts, it may be helpful to proactively engage families of infants most at risk for LTF during initial

Table 2: Relationship between Race and Ethnicity and Being LTF

Race or Ethnicity	Not LTF % (n)	LTF % (n)
White	100 (5)	0 (0)
Latino	75 (12)	25.0 (4)
African American	37.5 (3)	62.5 (5)
Other	83.33 (10)	16.67 (2)

$\chi^2(3, N = 39) = 7.68, p = .053$

Notes: LTF = lost to follow-up. Other = the respondent identified as more than one race or ethnicity.

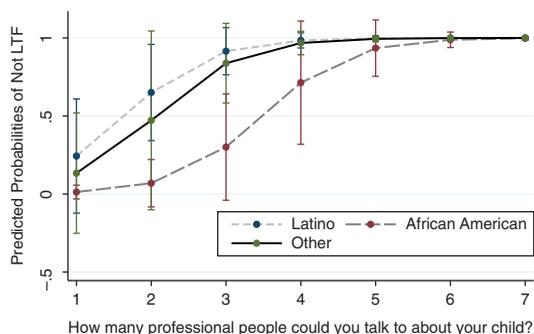
Table 3: Logistic Regression Predicting Being Not LTF

Factor	95% CI	z	p	OR
Number of health professionals parents can talk to	[1.40, 24.01]	2.42	.016	5.79
Race or ethnicity				
Latino	[0.15, 29.62]	0.54	.59	2.08
African American	[0.01, 1.01]	-1.95	.05	0.08

Pseudo $R^2 = .337, p = .000$

Notes: LTF = lost to follow-up; CI = confidence interval; OR = odds ratio.

Figure 1: Predicted Probability of Not Being Lost to Follow-Up (LTF) by Parents' Access to Health Care Professionals



screenings or follow-up rescreens, because there is relatively low attrition from care at that point. This could entail relying on medical social workers, who have historically worked at the intersection of health care practice and public health (Kerson & McCoyd, 2010).

From a health care perspective, interventions specifically designed to reduce racial and ethnic disparities have been supported by the literature. In their systematic review of reviews, Truong, Paradies, and Priest (2014) found that interventions designed to improve cultural competence in health care frequently focus on access to health care and health care utilization. Effective interventions include the use of patient navigators and community health workers (Truong et al., 2014). People in these roles typically act as liaisons to underserved cultural groups by connecting people to appropriate health care resources and by addressing barriers to care, including cultural beliefs that are not congruent with effective health care practices. These practitioners also provide health-related guidance and education (Chin et al., 2012; Fisher, Kelley, & Lomas, 2003; Natale-Pereira, Enard, Nevarez, & Jones, 2011; Patient Protection and Affordable Care Act [ACA] of 2010 [P.L. 111-148]; Truong et al., 2014).

Limitations

In this study, we interviewed 203 families of infants who were referred for additional testing during discharge from the birth hospital. Because most newborns referred for additional testing eventually pass additional screenings, only 41 were ultimately referred for diagnostic testing. This resulted in a small sample.

Although the findings of this research were interesting, there could be other factors that could help provide other, better or more nuanced explanations of being LTF.

In addition, this study was conducted in an area that was suburban and urban. The total LTF rate for the entire sample was 26.8 percent, which is lower than the national average. This may be reflective of the relative ease of access to health care available to people in the region.

It is interesting to note that the implementation of the ACA may naturally address the issue of access to health care professionals identified in this research, and attention should be paid to the relationship to changing insurance rates and LTF rates on a state-by-state basis. The ACA could trigger changes in LTF rates in two distinct ways. First, to date, 31 states have extended health care coverage through Medicaid expansion to low-income families, including both New Mexico and Washington, DC, jurisdictions with particularly high LTF rates (Families USA, 2015). In addition, Title V of the ACA provides for further development of the health care workforce through training for community health workers and social workers to increase access to care and better integrate care for patients. As of June 2015, the uninsured rate for all Americans has declined significantly, in general, and has declined by 9.2 percent for African Americans, in particular, increasing access to health care for 2.3 million previously uninsured African American adults (U.S. Department of Health and Human Services, 2015).

Finally, being LTF and LTD are often lumped together. There was no way for us to identify which families were LTF and which were LTD, and we, as others have done, grouped everyone who did not seek care at the center to which they were initially referred as LTF. In most cases, the center to which families were referred made multiple attempts to reach and make appointments for the infants; however, phone calls were often unreturned and scheduled appointments were missed. There was no way to tell, however, whether these attempts prompted parents to seek care elsewhere. Therefore, additional research should consider identifying which families are most at risk for being LTF as opposed to LTD given that those who are LTD may have sought care for their infants in other settings.

Because of these factors and the novel nature of this research, we recommend replicating this study with a larger sample in diverse settings.

Conclusion

From a social work practice perspective, we believe more research is needed to determine the degree to which race and ethnicity play a role in being LTF at this and other points in the newborn hearing screening-to-treatment process. The same holds true for access to health care professionals whom parents can talk to and trust. When the relationships between race and ethnicity and access to health care in being LTF are better understood, interventions to address this problem can be developed and piloted. **HSW**

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