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Prevalence and Reasons for Non-Follow-Up of Newborns with "Refer" Results on Initial Hearing Screening

ABSTRACT

Objective: To determine the prevalence rate of follow-up among infants who had a "refer" result on initial newborn hearing screening and to identify reasons for default by parents or guardians.

Methods:

Design:
Setting:
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Cross-Sectional Study
Tertiary National University Hospital

Participants: 79 parents or guardians whose newborns obtained a "refer" result on initial hearing screening were interviewed over the phone.

Results: Among those babies who had a "refer" result on initial hearing screening, 51% followed up for repeat testing. The most common reasons for non-follow up by parents or guardians include being busy, distance from the hospital and baby's health condition.

Conclusions: The follow-up rate in this study is higher compared to previous figures (27%), but is still below target. The reasons for non-follow-up obtained suggest problems may exist on all levels of the healthcare system. Appropriate solutions to address these problems should be explored.

Keywords: neonatal screening, hearing loss, infant, newborn, hearing tests, otoacoustic emissions

Republic Act 9709 also known as the Universal Newborn Hearing Screening and Intervention Act was signed into law in 2009 with the primary aim of ensuring that every newborn be given access to hearing screening examination and early intervention services.¹ Local published data documenting screening rates and follow-up rates in different Newborn Hearing Screening Centers in the Philippines have been limited. A 3-month screening of "995 babies or 75% of all (1,327) newborns at the Philippine General Hospital" in 2007 yielded a 10.6% 'refer' result, but "of 104 babies, only 27% followed up."² A similar study at the St. Luke's Medical Center in 2004 also revealed a follow up rate of 27.7% in patients who did not pass the initial OAE.³ These rates are dismal considering that in the Year 2000 Position Statement released by the Joint Committee of Infant Hearing, the ideal return-for-follow up rate of infants should at least be 70%.⁴

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Low follow-up rates pose a significant barrier to proper diagnosis and are lost opportunities for potential early intervention for patients confirmed to have hearing impairment. Implementation of any health program can only be considered effective if it involves a significant percentage of the population for which the program was intended.

This study aims to determine the prevalence rate of follow-up among infants who had a "refer" result in initial hearing screening and to identify the reasons for non-follow-up of hearing screening by parents or guardians whose newborn was found to have a "refer" result on initial OAE test at the Philippine General Hospital (PGH). Identifying these factors can help policymakers and stakeholders revisit existing protocols and guidelines to ensure better follow up for these patients in line with the overall aim of improving implementation of the Universal Newborn Hearing Screening Program.

METHODS

With Institutional Review Board approval, this cross-sectional study considered infants who had their hearing screening performed at the PGH Ear Unit between November 2014 and December 2016, but did not follow up for a repeat hearing screening within 3 months after a "refer" result on initial screening. Parents or guardians of the target infants were recruited and informed consent was obtained and those who did not consent to an interview, or who retracted consent anytime between the interview and writing of the manuscript were excluded.

The sample size was obtained using the formula $n= 1.96^2 p$ (1-p) DEFF/ d², where p was the expected proportion (27%^{2,3}), DEFF was the estimated design effect (1.0), and d was the desired level of absolute precision (0.1), computed at 95% confidence interval. A minimum number of 76 parents or guardians interviewed was needed (level of significance 0.05, prevalence of 50%). Convenience sampling was employed.

A review of records at the Ear Unit was performed. Those who did not follow up at the Ear Unit within 3 months from the time of the initial screen were considered "default." The contact numbers of their parents or guardians were obtained from their records at the Ear Unit.

Informed consent was obtained and recorded over the phone by the investigators prior to conducting interviews. The Total Recall call and voice note recorder version 2.0.42 (Killer Mobile^{*} Software LLC, Henderson, NV, USA), a phone application that allows users to record phone conversations was used with permission of interviewees to document consent. An open-ended questionnaire with a sample checklist of common reasons for not following up (based on our review of literature), was used as a coding guide to interview the parents or guardians. All interviews were conducted by one author (KMCO). All patient information was anonymized and kept confidential. Data was simultaneously encoded by two authors (KMCO and PERG) using Microsoft Excel v2013 (Microsoft Corp., Redmond, WA, USA), and analyzed by all three authors using frequencies, percentages, Chi Square and content analysis.

RESULTS

A total of 3,517 babies were screened at the Ear Unit using otoacoustic emissions between November 2014 and December 2016. These included both well-babies and those that required admission at the neonatal intensive care unit. Out of these, 384 (11%) babies obtained a "refer" result either unilaterally or bilaterally. Fifty one percent (195/384) of these babies followed up within 3 months from initial screening.

Of the 49% (189/384 babies) who defaulted, only 79 (42%) parents or guardians were successfully contacted. The rest of the given contacts were either "unavailable," "unattended or out of coverage area" or invalid. Six (7.6%) of the 79 had repeat screenings elsewhere while 13 (16.5%) had repeat screenings in our institution beyond 3 months from initial screening. The rest did not have a repeat screening at the time of interview. *Table 1* summarizes the demographic profile of these infants as well as information on their parents or guardians.

Respondents showed various levels of understanding regarding the reason for needing a repeat test. Some attributed the "refer" result to the baby's incessant crying and movement. Others were told that there might still be fluid in the ear that could be obstructing the ear canal or because the baby's ear is still not fully developed. Still others believed that a repeat hearing test was needed because the baby failed the initial screening, had hearing impairment, or there was a problem with the functioning of the machine.

Table 2 shows the reasons for failing to follow up. The most common reason given (35%) was that parents were busy or had other obligations. Many of the parents who gave this reason are part of the workforce and expressed an inability to follow up either because they could not take time off work or their free time did not coincide with Ear Unit opening hours. Under this busy cluster were parents who also had other children that needed their attention. Less common reasons under this cluster involved consecutive deaths in the family, and calamity in the locale.

The second most common reasons given were location and the baby's health condition. Fifteen of the 60 (25%) said that our institution was far from where they lived. Interestingly, however, there was no significant association between place of residence and citing location as a reason (Fisher's probability, 2-tailed, = 0.19), such that there was an almost equal number of respondents who lived within Metro Manila and who lived within the Luzon area (Cavite, Tarlac, Quezon) among those who cited this as reason. Only one respondent lived in Mindanao, who

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also cited distance as a reason. Fifteen of the 60 (25%) also mentioned their baby's health condition as a reason for not being able to follow up. Being "sick" ranged from the relatively simple upper respiratory tract infection to more serious medical conditions requiring prolonged hospitalization such as seizure disorder, pneumonia and sepsis. In fact, 5 of the babies had already expired at the time of interview due to various serious illnesses. On the other hand, we also interviewed one parent who opted to prioritize vaccination of his prematurely born baby. Fourteen (23%) of the respondents said that they were not aware of the results of their baby's hearing exam or were not told that they had to repeat the test.

Distance was the most commonly given reason for not having a repeat screening at our institution among those who opted to have them done elsewhere (5 of 6 respondents). On the other hand, late notification was the most commonly given reason for the delay in

Factor Category Frequency (n=79) Sex of Infant Male 40 (50.6%) Female 39 (49.3%) Laterality of Unilateral 45 (57%) **Affected Ear** Bilateral 34 (43%) 0 37 (46.8%) Number of Siblings 1 21 (26.6%) 11 (13.9%) 2 2 (2.5%) 3 or more Admission Public 41 (51.9%) Private 37 (46.8%) **Monthly Income** <15,000 24 (30.4%) (PhP) <30,000 12 (15.2%) <50,000 5 (6.3%) ≥50,000 7 (8.9%) 2 ≤ age 21 to 25 15 Age of Parent 26 to 30 16 31 to 35 21 36 to 40 10 ≥ 40 5 Metro Manila 38 (48.1%) Place of residence luzon 37 (46.8%) Outside Luzon 1 (1.3%) **High School** 13 (16.5%) Educational College Undergraduate 9 (11.4%) Attainment College graduate 33 (41.8%) Vocational 12 (15.2%)

ouncation was the most commonly given reason

Table 1. Summary of infants and parent/guardian profiles

repeat screening (6 of 13 respondents). According to these parents, they were notified of the need to repeat the hearing test more than 3 months after the initial screening was performed, via phone short message service (SMS).

Possible factors that could affect the decision to follow-up were analyzed using Chi Square test, comparing those that followed up within 3 months and those that did not, between November 2014 and September 2016. Laterality of "refer" result (unilateral or bilateral) and admission to private or public services (used as a surrogate marker for financial capacity) were the factors explored. Neither factor had a significant relationship with decision to follow up. (*Table 3*)

Table 2. Reasons for failure to follow up. Categories listed are not mutually exclusive

Reasons for Failure to Follow Up	% (n=60)	
Busy	35	
Distance	25	
Baby's health condition	25	
Unaware of results	23	
Patient is not deaf	18	
Lack of transportation	10	
Parents forgot	8	
Lack of companion	8	
Pediatrician said no	5	
Notified late	2	

Table 3. Relationship of laterality and admission type to status of follow- up

Factor	Categories	With Follow Up	No Follow Up	Chi Square	p value*
Laterality	Unilateral	101	103	0.14	.71
	Bilateral	65	72		
Admission	Public	72	91	2.54	.11
	Private	94	84		

* level of significance =0.05

DISCUSSION

The prevalence rate for follow up obtained in this study was 51%. The top three most common reasons for failing to follow up include: parents were busy or had other obligations, distance and baby's health condition. Distance was the most common reason for not having a repeat screening at our institution while late notification was the most common reason for delay in repeat screening. Laterality of result and financial capacity were not significantly associated with decision to follow up.

The 51% follow-up rate in this study is lower than the ideal return-

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for-follow up rate of infants set by the Joint Committee of Infant Hearing in 2000 which was set at a minimum of 70%.⁴ Nevertheless, this reflects a significant increase from 2007² where only 27% followed up ($X^2 = 18.77$, **a** = 0.05, p< .0001). Moreover, if we were to consider including the 6 respondents who followed up elsewhere and the 13 who had repeat screenings beyond three months, the actual follow-up rate improves to 56%.

A 2004 study at the St. Luke's Medical Center in Quezon City revealed that reasons for noncompliance with repeat testing included "the patient was seen responding well to sound," "the test was seen as an unnecessary expense," and "some patients were transferred to another pediatrician, to another city or to another province."³ Others were also "advised by pediatricians that repeat testing was not necessary."³ However, this study did not mention how many respondents identified each of these factors as their reasons for noncompliance.

Our results revealed themes similar to the aforementioned study. But in contrast, our study found other parental obligations to be the most common reason for default followed by distance and the baby's health.

The reasons for lack of follow-up may be categorized according to a four-level model of the healthcare system adapted from Reid *et al.*⁵ (*Figure 1*) The model may help us determine what level of action is required to address a problem. For example, problems at the patient or healthcare provider level might be deemed more manageable to address than problems at the environment level which require policy changes and involvement of regulatory agencies.



Figure 1. Four-level model of the health care system adapted and reproduced with permission from Building a Better Delivery System: A New Engineering/Health Care Partnership, 2005 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC. Reasons for default categorized according to levels.

The first two levels are self-explanatory-factors relating to the patient, his/her family and to healthcare providers. Reid et al. described organization, the third level, as the one that "provides infrastructure and other complementary resources to support the work and development of care teams and microsystems."5 It allows for the coordination of multiple care teams and the management of allocation of human, material and financial resources. It is at this level where referral systems between hearing screening units may be established and used to improve service, especially in our setting where distance between residence and hospital is a factor. Finally, the priorities of the Filipino family can be influenced significantly by the political and economic environment. These include "regulatory, financial and payment regimes and entities that influence the structure and performance of healthcare organizations directly and through them all other levels of the system".5 In our setting, this involves coverage and/or reimbursement schemes by the Philippine Health Insurance System (PhilHealth) and other insurance companies, as well as government policies on compensation and incentives for hearing screening.

Since this study delved into reasons for default as perceived by parents, it does not come as a surprise that most of the reasons elicited were more personal and may be categorized under the first two levels. However, it is also relevant to note that some factors go across levels of the healthcare system. The reason "busy" suggests that following up for repeat hearing tests would require certain sacrifices that parents or guardians were not willing to make-income, employment, time and the welfare of their other children. Hearing screening does not seem to be a priority for some Filipino families, and this must be addressed if follow up rates are to improve especially since this is the most commonly-cited reason for lack of follow-up-addressing this issue might require the efforts of the healthcare provider as well as higher levels of the healthcare system. Interviews with the respondents have shown that some lack understanding regarding the need for newborn hearing screening as well as the need to have it repeated. This might have contributed to down-prioritizing their baby's hearing screening. Healthcare providers such as physicians (otorhinolaryngologists, pediatricians and family physicians), audiologists and staff of the ear unit giving results to parents or guardians should emphasize the importance of a repeat OAE despite their busy schedule. However, there were respondents who showed adequate understanding of the need to repeat their baby's hearing screening yet made the decision not to follow up to prioritize other obligations. In such situations, higher levels of the healthcare system might play a role since it would be difficult to expect this subset of parents to stop working even for a day. Perhaps better incentives and appropriate compensation may

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ensure better compliance-- which is why we considered this reason under environment as well.

Parents and caregivers must have access to the necessary information they will need to make informed decisions regarding their baby's hearing screening. Healthcare providers must also be given access to updated information so they may be sufficiently equipped to educate patients. The reason "baby is not deaf" might not simply be an issue of parental perception but may also reflect a lack of information given by healthcare providers. In fact, some pediatricians actually advised that hearing screening was not necessary. Healthcare providers, especially physicians, are in the best position to encourage patient participation in the program as they are deemed the experts and should have developed trusting relationships with patients. Communication between healthcare providers and parents/ caregivers remains vital to overall improvement of the newborn hearing screening program.

Distance as a reason for non-follow up may not be just an issue of transportation for the family, but may also reflect a lack of referral systems and coordination among hearing screening centers. Taking into consideration that a good percentage of our participants live within and just outside Metro Manila, as well as the dismal traffic situation in the area, perhaps the true reason for lack of follow up might actually be the potential time wasted stuck in traffic, instead of actual distance. These issues should also be addressed, and we must recognize that for any program to be effective, it must be made convenient and efficient for the patient.

A major limitation in this study was its reliance on contacting potential participants using phone numbers they disclosed during initial testing. A significant percentage of these phone numbers were unreachable which proved to be a major hindrance both for conducting the interview as well as reminding them to follow up. Home visits may be done in future studies to aid in research delving on this topic and to encourage follow up. Nevertheless, results of this study will greatly impact follow up protocols at the Ear Unit. They may also have impact on policies that can improve implementation of the Universal Newborn Hearing Screening Program. Further research may be done comparing follow up rates, reasons for default and factors affecting decision to follow up across multiple hearing screening centers in the country. It might also be worthwhile to compare the profiles of those who defaulted against those who followed up.

Another limitation is that the reasons for non-follow up were not mutually exclusive, as each participant was allowed to enumerate all possible reasons they had. However, these reasons were only tallied and analyzed as individual frequencies and percentages without accounting for overlaps. Although certain trends and relationships between reasons were discussed, the data was not subjected to statistical treatment to determine presence of significant interaction between reasons. It would be interesting for future studies to examine the combinations of reasons given for default.

In conclusion, the reasons for poor follow-up given by our respondents suggest problems on all levels of the healthcare system. Improving implementation of the universal newborn hearing screening program will require efforts from families and healthcare providers as well as policy makers. We should explore appropriate solutions to address these problems.

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