

Maternal Emotional Reactions towards Results of Newborn Hearing Screening: A Cross Sectional Survey

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ABSTRACT

Objectives. This study aims to determine the maternal reactions and emotions towards an initial “refer” result in the newborn hearing screening test and to determine the proportion of mothers who fully comprehended the test results of the newborn hearing screening test.

Methods. In this study, mothers of newborns with a “refer” result in the Universal Newborn Hearing Screening (UNHS) are given questionnaires which cover their understanding of the hearing screening test, the emotions they felt and attitude towards the results.

Results. Our findings showed that the UNHS program protocol was properly understood by almost all the respondent mothers. Of the emotions listed from the questionnaire, being “worried” was the most persistently felt emotion.

Conclusion. It is important that the results of the newborn hearing screening test be properly understood by the mothers. Mothers who experienced negative emotions brought about by the hearing screening test still believed that the newborn hearing screening test was important, were glad that their child underwent the newborn hearing screening test and will request it for their future offspring.

Key Words: *universal newborn hearing screening, maternal anxiety, otoacoustic emission*

Introduction

Worldwide, hearing loss occurs in one to three of 1000 live births annually.¹ In the Philippines, bilateral permanent congenital hearing loss occurs at 1.4 per 1000 livebirths.² Without early detection programs, hearing impairment is detected on the average at 2 ½ years of age.³ The critical period of speech and language development is between birth and 3 years of age.⁴ Infants with severe to profound

bilateral hearing loss are unable to develop normal speech and language without timely intervention. This is also the time wherein important infant-parent attachment develops.⁵ So that a “refer” or “fail” result may also be a source of frustration for the family, which in turn, may interfere with infant-parent attachment.

Early detection and intervention are the two key elements that will give the infant the best chance for normal speech and language development.⁶ Because of this, a number of countries have legislated universal newborn hearing screening programs for early detection of hearing loss and have provided early rehabilitative interventions.

The private tertiary hospital where this study was done has a universal newborn hearing screening (UNHS) program in place wherein all healthy newborns are screened. They use otoacoustic emissions (OAE) as a screening tool for the detection of hearing loss because the test is easy to perform and takes only a few minutes to finish. When choosing a screening tool, one must consider that it should be cost effective, easy to operate, fast and efficient. The gold standard today for detecting hearing loss is the diagnostic auditory brainstem response test (ABR). However, its cost, long testing time and need for a trained technician and interpreter make it unattractive as an initial screening tool.

Results of the hearing screening test would be either a “pass” or “refer”. A “pass” result would mean that the child has relatively normal hearing. A “refer” result however, does not immediately mean that hearing loss is present. It denotes that further testing and evaluation is required. There are factors such as vernix, collapsed ear canals and transient middle ear fluid which may lead to false positive results and thus false “refer” rates. In the U.S., the percentage of newborns who do not pass the hearing screening test prior to discharge range from 1-34%.⁷ In our institution, the average refer rate is 11.37%.⁸ In this study, we follow a protocol wherein the parent of the child with a “refer” result is asked to follow up with a pediatric otolaryngologist after 1 month for a rescreen. Those who still have a “refer” result after the rescreen are further tested with a diagnostic ABR.

UNHS programs have led to early detection and intervention for hearing loss. Because of this, the effects of hearing loss such as delayed development of speech and language, psychosocial issues and, later on, economic

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Table 1. Maternal Emotions after Disclosure of Newborn Hearing Screening Test

Emotions	Not felt at all		Minimally felt but dissipated		Persistently felt even during this consult		Strongly felt	
Angry	30	75.0%	6	15.0%	2	5.0%	2	5.0%
Confused	19	47.5%	13	32.5%	4	10.0%	4	10.0%
Worried/Anxious	9	22.5%	7	17.5%	10	25.0%	14	35.0%
Sad/Depressed	22	55.0%	7	17.5%	5	12.5%	6	15.0%
Powerless/ Helpless	27	67.5%	8	20.0%	3	7.5%	2	5.0%
Shocked	24	60.0%	10	25.0%	4	10.0%	2	5.0%
Upset	25	62.5%	7	17.5%	5	12.5%	3	7.5%
Stressed	30	75.0%	5	12.5%	4	10.0%	1	2.5%
Guilty	28	70.0%	6	15.0%	1	2.5%	5	12.5%

dependency may be prevented. As previously mentioned, the percentage of newborns who “refer” after the initial hearing screening test is quite high, requiring many of them to follow up after one month. When they are rescreened on an outpatient basis, only about <1% according to Spivak would require further audiologic evaluation. This has led the authors to raise the issue of the possible negative emotional impact of a “refer” result on mothers and/or primary caregivers. Does a “refer” result in the newborn hearing screening affect the mother-child relationship and will it be a cause of any anxiety on the part of the mother? Will these negative emotions lead mothers to adversely view newborn hearing screening? Studies have shown that in general, parents view the process of newborn hearing screening in a positive light, and that parents of children with confirmed hearing loss show more frustration and anger.^{9,10} However, parents of children who failed the screening 2 times and are in the end found to have normal hearing (false positives) may sometimes have lingering anxiety years after the tests.¹¹

The objective of this paper is to determine the maternal reactions and emotions of mothers towards an initial “refer” result in the newborn hearing screening in our institution’s outpatient setting using a self-administered questionnaire and focused discussion, to describe the proportion of mothers who fully comprehended the test results of the newborn hearing screening test and to determine the maternal feelings about their children upon disclosure of a “refer” result in the newborn hearing screening.

Materials and Methods

This was a cross-sectional analytic study done at the nursery of a tertiary private hospital which has adopted a UNHS Program for all newborns. Otoacoustic measurements were all done in the nursery using an automated machine (Echocheck manufactured by Otodynamics). The hearing screening test was done by a trained midwife. Included in the study were all mothers whose newborns had a “refer” result from initial OAE screening from August 15 to September 15, 2004. These newborns were otherwise healthy, full term with no risk factors for hearing loss. The mothers were given the questionnaire (Appendix A) after they were informed of the “refer” result and advised by the nurse prior to discharge. These are the major points advised by the nurse: 1) The baby “referred” on the newborn hearing screening test, 2) It

means that they need to have the test repeated after a month, 3) It may be just something temporary but it is better to have it rechecked, and 4) Many babies pass the rescreen. All the questionnaires were gathered and tabulated. All the mothers were college graduates who are fluent in English.

Informed consent was obtained for this study. The questionnaires did not include any names and other identifying personal information from the respondents.

The Research Questionnaire

The questionnaire consisted of three parts. The first part tested the knowledge of the mother on the hearing screening test. The second part consisted of listed emotions adopted from de Uzcatégui and Yoshiga-Itano’s study on emotions reported by parents after their baby failed the hearing screening test. The mothers were asked to rate each emotion from zero (0) to three (3). Zero being not felt at all and 3 being strongly felt. The third part of the questionnaire tested the mother’s attitude on future care of the baby and the hearing screening test itself.

Focused Interview

We determined the appropriateness of the questionnaire by using a focused discussion. Selected mothers were asked a set of questions regarding their comprehension of the emotions listed. Each mother from the seven selected was asked to define what each emotion in her own words. They were all each asked to give their own reactions in their own words. (Appendices A and B)

Results

1. Comprehension of the Newborn Hearing Screening Test

Focused Discussion Data

A total of forty (40) mothers aged 25-35 years old, were enrolled in this study. When the mothers were asked if the meaning of the results were fully understood, the following common themes were revealed:

- “I understood that a “refer” simply means re-testing to confirm the findings”
- “Only a fraction or percentage of the children with “refer” results are actually deaf”
- “I was reassured and made aware of what the results really meant by the technician”.

Majority of the mothers (37 out of 40) knew what the term “refer” meant while one did not and another one wasn’t sure. Thirty-six (36) respondents understood what the results meant while 2 did not and another 2 weren’t sure.

2. Maternal Emotions after the Disclosure of the Test Results

The table below shows the maternal emotions after the disclosure of the test results with feelings worried or anxious being most persistently felt by the respondent mothers.

To qualify these emotions our focus discussion data was subjected to content analysis.

Focused Discussion Data Content Analysis on Maternal Emotions

- *Confused* was defined as uncertainty of what will happen; not fully comprehending the results, and not knowing what to do.
- *Worried/anxious* meant apprehensions of the hearing test, anticipatory fear of the hearing disability, pervasive thinking about the possibility of having a deaf child.
- *Powerless or helpless* meant unable to help, “there is nothing that I could do”, “to wait is all that I can do”, “if there was something that I could do.”
- *Shocked* meant being surprised that my baby will be subjected again to another testing, “disbelief that there was something wrong with my child.”
- *Guilty* was defined as being accountable; in retrospect that there was pre-pregnancy event that could have led to this abnormal result.
- *Upset* meant being unhappy, disappointed but not depressed.
- *Stressed* in this study meant being “pressured”, “pervasive thinking” but not hassled.

Perceptions and actions taken by mothers upon disclosure of a “refer” result

Thirty-six mothers (36) felt that their children were “different” now that they knew that their child had to be brought back for rescreening, while four (4) felt otherwise. Majority (39) of our mothers informed us that they would probably treat their children differently. Most mothers intended to pay more attention to her child’s ability to hear. One suggested to do self-investigation whether her child could really react to sounds by repetitively “clapping”, and one mother intended to continuously observe her child’s reaction to various sound stimuli in the home.

Perceptions towards the newborn hearing screening

All mothers affirmed that they were glad to have their children tested for hearing. Furthermore, all of them wanted to have their future children tested. They all agreed that the newborn screening for hearing be recommended to other parents as well.

Discussion

The hearing screening test procedure and results, particularly what a “refer” result meant was understood by almost all respondents. Of the negative emotions felt by the mothers, being worried was the most persistently felt. It would be good to keep in mind that these emotions were felt even after the test procedure and what a “refer” means was explained to them.

Assessing the emotions felt by the mothers as objectively as possible was done using an appropriate questionnaire (Appendix A). The emotions listed in the questionnaire were adopted from one used by de Uzategui and Yoshiga-Itano.⁹ In the said study, the investigators gathered all emotions listed by mothers who failed in the newborn hearing screening. These emotions were then incorporated into the research questionnaire used in this study. Added to this, the authors included in the knowledge of the mothers about what the test was for and what the result meant and the attitudes taken after a “refer” result was disclosed to them.

The appropriateness of the questionnaire was determined using a focused interview of selected mothers who had a “refer” result. This interview was conducted using uniform questions as listed in Appendix B. From this focused discussion, the respondents were asked if they understood what a “refer” result meant, define in their own comprehension the emotions listed in the questionnaire and the change in practices after the result was disclosed. From this focused discussion, the authors decided that the questionnaire was appropriate and reflected a good comprehension of the mothers since all admitted that they understood the questions and could clearly define these emotions the way the investigators had in mind.

The impact of the hearing screening test to the mothers could be generally implicated as a cause of worry. However, the questionnaire was given shortly after the disclosure of the result of the hearing screening test. It would have been better if we found out if these emotions waned after discharge or shortly prior to the repeat hearing screening testing. By this time, the mother may have observed the baby and the appearance of a normal healthy baby may be reassuring, thus giving more security to the mother.

The understanding of the hearing screening test by a majority of the respondents was probably a factor why negative emotions were not overblown. Those who said that they did not understand the hearing screening test, all had persistent negative emotions as gathered from the questionnaire. Thus, communication between the examiner and mother is important for reassurance.

Another majority of mothers said that they would treat their child differently, meaning, they would pay more attention to their child and try to observe them if they have any response to sound, as suggested by the correspondents of the focused discussion.

All mothers felt that the hearing screening was a good idea, all were glad that their child was tested for hearing and would advocate it on future siblings. The impact of a “refer” result caused some of the mothers to worry, and yet all mothers agreed that newborn hearing screening is important. If ever there were some negative emotions or confusion involved after an initial “refer” result, it would be noteworthy that all mothers think that this test is necessary.

The authors believe that full comprehension of the test and making sure that a “refer” result does not equate that their child is deaf is an important factor to prevent unnecessary worry or anxiety. From the focused discussion, there was reassurance that only a fraction of those tested as “refer” would be truly deaf and that this would be confirmed on repeat testing. Nevertheless, the strongly felt negative emotion of anxiety should be further investigated and steps taken to make sure that the parents do not worry excessively because this may affect the success of the UNHS program.

We recommend that in similar studies that the questionnaire be re-administered after a few weeks to assess if the mothers’ feelings change over time.

Conclusions

The NBHS program was properly understood by almost all respondent mothers. Of the emotions listed from the questionnaire, worried was the most persistently felt emotion. There is a need to further investigate the reason for the strong emotion of anxiety in some of the mothers. However, despite some negative emotions felt by the mothers, all thought that the NBHS was a good idea, were

glad that their child underwent the screening and will request it for their future offspring.

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APPENDIX A

Newborn Hearing Screening Questionnaire

	Yes	No	Not fully/unsure
Was the meaning of “refer” explained to you when the newborn hearing screening test was done to your child?			
Did you understand the result of the newborn hearing screening?			

Upon knowing that your child had a “refer” result, which of the following emotions did you feel? Please rate from 0 to 3.

0 – emotion described below was not felt at all

1 – emotion described below was felt a little initially but subsided before this follow up

2 – emotion described below was felt and remained till this follow up

3- emotion described below being strongly felt.

	0	1	2	3
Angry				
Confused				
Worried/Anxious				
Sad/Depressed				
Powerless/ Helpless				
Shocked				
Upset				
Stressed				
Guilty				

	Yes	No
Did you feel that your child was different from other children?		
Did you give more care or attention to your child because he/she had a “refer” result, as compared to if he/she had a pass result?		
Were you glad that your child underwent the newborn hearing screening?		
Do you think the newborn hearing screening is a good idea?		
Would consent to a newborn hearing screening on your future siblings?		
Would you recommend the newborn hearing screening to other parents?		

APPENDIX B

I: Knowledge

Was the meaning of a refer result explained to you?

Was it explained to you that a refer result did not mean that her child truly had hearing loss and that only a small percentage of those with a refer result truly is hearing impaired?

II. Attitude

Can you define in your own words the meaning of the emotions in the questionnaire?

Did you have any concerns on the results of the hearing test?

III. Change in practice

Would you treat your child differently because of the result of the hearing test?

Can you give examples of change in the care if any?