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Follow-Up Services in Newborn Hearing Screening Programs

Claire A. Jacobson*
John T. Jacobson†

Abstract

Newborn hearing screening programs have gained wide acceptance as a means of identifying infants at risk for hearing loss. For the most part, the auditory brainstem response (ABR) technique has been the measurement tool universally adopted in the evaluation of high-risk infants. Over the years, the ABR has been used successfully with a negligible false-negative rate. Unfortunately, program follow-up services have not received similar attention, and there is a lack in program development. This article describes a series of follow-up measures that include the use of a questionnaire sent to the parents/caregivers of 401 infants who pass either the initial or retest ABR screen. A total of 262 (65%) response questionnaires were returned. The results of the questionnaire and recommendations regarding follow-up services are discussed.

Key Words: Auditory brainstem response, aural rehabilitation, follow-up services, hearing loss, high-risk criteria, newborn hearing screening

The implementation of newborn hearing screening programs has increased significantly over the past decade. Today, 14 states have created enabling legislation mandating newborn hearing screening (Blake and Hall, 1990). Another 12 states, while having no legislative mandate, are currently addressing the issue in some way at the state level. Of the 14 mandated programs, 10 have implemented state run programs, two programs are run privately, and the remaining two states are currently developing programs. Additionally, there are numerous excellent hospital-based screening programs throughout the country under private administration. This article describes one facet of a screening program, that of follow-up services for infants who both fail and pass newborn hearing screening.

*Department of Audiology, Geisinger Medical Center, Danville, Pennsylvania

†Department of Otolaryngology-Head and Neck Surgery, University of Texas Health Science Center, Houston, Texas

Reprint requests: John T. Jacobson, Department of Otolaryngology-Head and Neck Surgery, University of Texas-Health Science Center at Houston, MSB #6132, 6431 Fannin, Houston, TX 77030

RISK SELECTION

The ability to identify and diagnose infant hearing loss correctly has been significantly improved through the introduction of carefully designed screening protocol. For example, the use of the high-risk register (HRR) recommended by the Joint Committee on Infant Hearing (1982) has provided a means of selectively identifying those infants from the general population who are at greater risk for hearing loss. The HRR is a relatively precise (acknowledging the fact that recessive hearing loss in first born is undetectable) method of dividing the newborn population into two distinct groups: (1) those who show little predisposition to hearing loss and (2) those who are at greater risk. When implemented, the HRR will identify between 10 and 15 percent of newborns at risk for hearing loss (Downs, 1976; Feinmesser and Tell, 1976; Hosford-Dunn et al, 1987; Hyde et al, 1984; Jacobson and Morehouse, 1984; Mahoney and Eichwald, 1987). Many facilities also supplement the HRR with other risk criteria. For example, some hospitals consider admission to the neonatal intensive care unit (NICU) grounds for hearing screening.

EVALUATION PROCESS

Once infants are selected for testing, the next step in the identification process is the application of the hearing screening measure. The auditory brainstem response (ABR) is the electrophysiologic technique of choice in early newborn hearing screening (Durieux-Smith et al, 1985; Fria, 1985; Hall et al, 1988; Hyde et al, 1984; Jacobson and Jacobson, 1987; Schulman-Galambos and Galambos, 1979; Stein, 1984). Despite early concern (Downs, 1982; Murray et al, 1985), the ABR has proved to be a reliable and valid method of detecting hearing loss in the newborn population, particularly for those infants at risk for hearing loss (Cevette, 1984; Cox et al, 1982, 1984; Dennis et al, 1984; Galambos et al, 1984; Jacobson and Morehouse, 1984; Stein et al, 1983). Other, but less precise, methods include behavioral observation and automated behavioral techniques (Durieux-Smith and Jacobson, 1985; Durieux-Smith et al, 1985; Jacobson and Morehouse, 1984).

FOLLOW-UP PROCESS

Despite clinical advances in early identification, without adequate follow-up services, hearing screening programs fall short of their mission. That goal is to provide intervention and management strategies as early as possible once a hearing-impaired infant has been diagnostically confirmed. While the track record of follow-up services is improving, there still remains an alarming gap between identification and management (Elssmann et al, 1987). The reasons are several and complex; however, consider that as many as 50 percent of the congenitally deaf population do not present with any risk criteria. Unfortunately, these infants are not usually screened and are most often identified beyond 18 to 24 months of age after key developmental milestones have occurred.

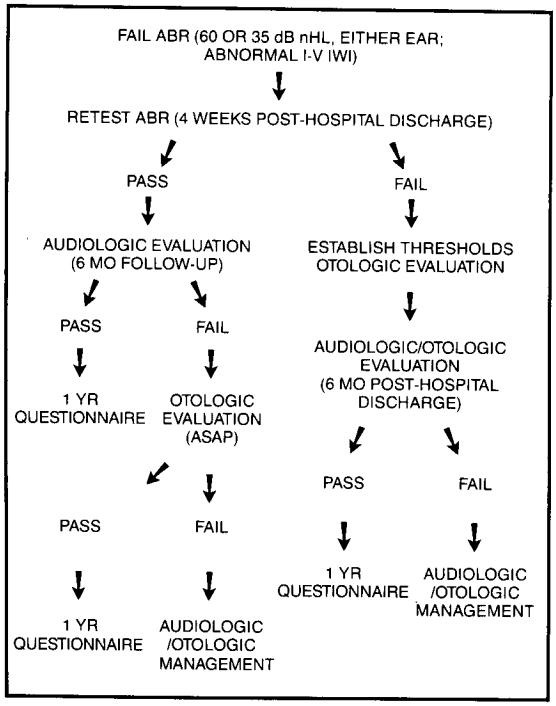

Figure 1 Neonatal hearing screening flow chart (initial ABR fail).

INITIAL FAILURE RESULTS

Most newborn screening programs that use the ABR measure as the pass/fail criterion report about 10 to 15 percent initial newborn failures with 3 to 5 percent permanent sensory hearing loss. For those initial failures, there are several possible channels to pursue. Usually protocol includes some form of retest assessment that may include repeat electrophysiologic or behavioral measures with or without medical intervention. Figure 1 presents a flow chart for *initial failures.* For example, any infant who *fails* the initial ABR screen is scheduled for repeat ABR testing within 4 weeks of original hospital discharge. If the infant *passes* the second ABR screen, an appointment is scheduled in 6 months to monitor auditory development. Additional rehabilitative measures are predicated on the 6-month evaluation. If the infant *fails* the retest ABR screen, thresholds are established within the same session, and otologic consultation is sought. If a conductive hearing loss is ruled out, the infant is scheduled for appropriate diagnostic testing at approximately 6 months when audiologic, rehabilitative, and otologic services are offered. The infant's physician is notified of the results and recommendations at every level of assessment.

Early diagnostic ABR testing is helpful in establishing peripheral auditory status (recognizing the limitations of the procedure) and alleviating parental anxiety. Further, test failure at low intensity levels ($\leq$35 dB nHL) may identify possible middle ear effusion requiring early medical intervention. Providing prompt follow-up testing also assists in securing services to diagnostic audiologic facilities for amplification and training, parent education/support and de-

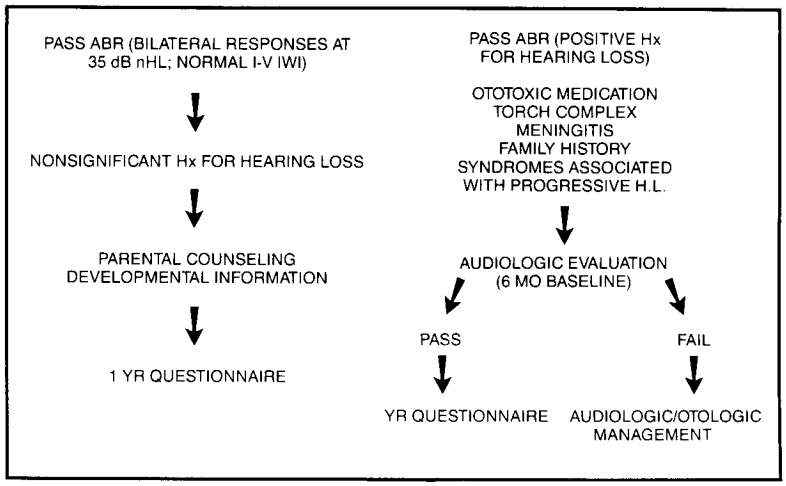

Figure 2 Neonatal hearing screening flow chart (initial ABR pass).

velopmental follow-up programs. These measures are available only with the cooperation of the parent/caregiver. Realistically, there will be some parents who, despite all efforts, will not comply, and the infant will eventually be lost to the program. Therefore, a primary concern of any follow-up service is to minimize the number of infants who do not return for retest evaluation.

INITIAL PASS RESULTS

Among the major criticisms of most screening programs has been the lack of longitudinal data regarding those patients who *pass* the initial ABR screen; that is, how many infants eventually present with hearing loss. In other words, what is the true false-negative rate? In reality, the only way to answer this question is to follow every infant regardless of initial screening status. From a practical point, this is a monumental task.

Figure 2 illustrates a suggested protocol for the following 2 groups of infants who *pass* the ABR screen: (1) those with no risk factors for potential hearing loss and (2) those infants who remain high-risk for latent emergent hearing loss. Decisions for classification and follow-up are made with consideration to ABR screening results, medical and family history. If a child *passes* the initial ABR screen and history is nonsignificant for hearing loss, the family is sent a questionnaire (to be described later) 1 year following hospital discharge inquiring about the auditory status of the child. If the child *passes* but history is significant for emergent or progressive hearing loss, the child is scheduled for reassessment at 6-month post-hospital discharge. A questionnaire is also sent at 1 year. Thus, questionnaires are sent to all infants who pass the ABR screen regardless of potential risks for emergent hearing loss.

FOLLOW-UP QUESTIONNAIRE

A questionnaire has been devised that asks parents/caregivers to provide input through observation. The questionnaire is sent to the families of those infants who pass either the initial or follow-up ABR screen, or who failed the initial screening but did not return for retest evaluation. All questions are brief and purposefully simple. A summary of data for a group of 401 infants discharged in 1988 is presented.

A seven-item questionnaire (Fig. 3) is mailed approximately 1 year following hospital discharge. Four items address developmental milestones, whereas the remaining three provide more descriptive information about current infant status. All results are entered on a spreadsheet (Microsoft Excel®) and stored on a personal computer (Apple Macintosh®). This report will focus on the three descriptive items.

During 1988, 432 infants were screened using ABR testing. Of those infants tested, 31 were excluded from the survey because of confirmed sensory hearing loss and, therefore, received audiologic and otologic management, or had expired. As a result, 401 questionnaires were mailed to the parents/caregivers of these infants along with a self-addressed stamped envelope. Of the 401 questionnaires mailed, 262 (65%) were returned. The three questions of interest were:

One-Year Follow-Up Questionnaire

Baby's name _____
Date of birth _____
Chart # _____

Your help is requested in completing the follow-up portion of our Newborn Hearing Screening program in which your child participated approximately 1 year ago.

Please answer the following questions and return them in the enclosed stamped, self-addressed envelope. Your assistance is appreciated.

How old is your baby now? _____ months

Has your baby had any ear infections? Yes _____ No _____
If "Yes" how many were medically determined? _____

Has your baby had ear infections that required tubes placed in the ear by an ENT doctor? Yes _____ No _____
If "Yes" how many sets of tubes were placed? _____

Does your baby stir or awaken when he/she is sleeping quietly and someone talks or makes a loud sound? Never _____ Seldom _____ Usually _____

Does your baby turn his/her head in the direction of an interesting sound? Never _____ Seldom _____ Usually _____

Does your baby turn his/her head when their name is called and when he/she cannot see you? Never _____ Seldom _____ Usually _____

Does your baby repeat some of the sounds you make? Never _____ Seldom _____ Usually _____

Do you feel that your baby has any hearing problems? Yes _____ No _____

If you are concerned about your baby's hearing

TELL THE BABY'S DOCTOR ABOUT IT.

If there are still some questions about the baby's hearing, you may contact the Audiology Department for a hearing check and evaluation.

PLEASE RETURN THIS QUESTIONNAIRE AS SOON AS POSSIBLE

Figure 3 Questionnaire sent to parents/caregivers of 401 infants who passed either the initial or retest ABR screen.

How old is your baby now?

The average age of the infants at the time of the survey was 12.8 months with a range from 11 to 20 months.

Has your baby had any ear infections? If yes, how many were medically confirmed?

The average number of ear infections reported was 1.9, the greatest number of infections reported was 25 (1 child), and the fewest reported was 0. Of the 262 infants, 162 (62%) reported at least one ear infection and of those 162 children, 84 (32%) reported two or more ear infections during their first year post hospital discharge. The remaining 100 (38%) reported no known ear infections.

Do you feel that your baby has any hearing problems?

A total of four (1.5%) parents/caregivers reported concern over their infant's hearing. Each of these infants were followed by direct contact through the child's attending physician and ultimately, with repeat testing. Of the 4, none were determined to have permanent sensory loss. Three (1.1%) additional families reported that their child had

ventilation tubes as a result of chronic otitis media with effusion. This information was given spontaneously from parents/caregivers and was not a question on the survey. It would be expected that the numbers would be greater if this question was specifically stated. It has now been added to the questionnaire.

COMMENT

The information retrieved from this survey has some interesting implications regarding the screening program and the type of test employed (ABR). Of those responding to the questionnaire, none of the children who passed the ABR screen at 35 dB bilateral were found to have a permanent hearing loss at the time of the survey. This finding suggests that in this surveyed population, there were no false-negative results attributed to the ABR screening, nor was there evidence of latent hearing loss. Obviously, this is not to say that the possibility does not exist that there may be sensory hearing loss in the group of 139 (35%) that did not respond to the survey. Further, the results of a 1-year survey does not eliminate the possibility of emerging auditory pathology. It is acknowledged that certain groups of high-risk infants, particularly those with a history of maternal or peri/postnatal viral infection (e.g., TORCH complex) and those exposed to ototoxic medication present a greater probability for sensory deficits later in life. However, the absence of parental concern regarding hearing loss has provided some indication that congenital hearing abnormalities were not overlooked during the initial screening process.

These results provide further justification of the screening process and the use of ABR. The sensitivity and specificity of ABR in the assessment of adult otoneurologic pathology has always been exceptional, exceeding 90 percent in most reported studies. Unfortunately, the ability to accurately monitor ABR testing in newborns has been frustrating given the negligible attempts to follow *all* infants evaluated. The use of a simple questionnaire may begin to shed some light on the true operating characteristics of the ABR test measure in the neonate.

We would be remiss to suggest that the questionnaire is inclusive or that there are not existing problems with its use. Obviously, data will always be lacking from those infants whose parents/caregivers do not respond to the questionnaire. Second, the questionnaire relies on the personal observations of the parents/caregivers who may not understand the subtleties of hearing loss or are biased to the degree that they are unwilling to correctly report their observations. Third, in the case of unilateral hearing loss, parents/caregivers may correctly observe patterns consistent with "normal" hearing yet miss asymmetrical hearing impairment. Obviously, under such circumstances, audiologic evaluation is the only method of confirming unilateral or asymmetric hearing loss. Despite the adversities, the questionnaire is a helpful means of closing the gap between newborn screening and auditory development. Finally, the use of a simple questionnaire also offers quality assurance to the hospital administration and staff neonatologies that the newborn screening program is effective by meeting goals and providing descriptive data for program accountability.

RECOMMENDATIONS

It must be understood that the institution (hospital, clinic, etc.) must take principal responsibility for initiating follow-up services. It is equally important that the primary care physician be involved and receptive when a hearing loss is identified. Parents and physicians must gain increasing awareness from the screening program of the significance of hearing loss. The efforts toward compensation and habilitation require a team approach.

A series of simple steps can be taken to ensure that the infant returns for follow-up. They include: (1) Coordinating appointments to occur on the same day and thereby facilitating an easier scheduling pattern for the parents; (2) Counselling the parents at the time of initial screening and sending a follow-up letter to the parents explaining the nature and importance of the test. Parents should not be needlessly alarmed, but may be more motivated to bring the child back if they understand the implications of possible hearing loss; (3) Sending a letter to the baby's physician explaining that follow-up hearing testing has been scheduled and request that he/she stress the importance to the family for recommended follow-up services; and (4) Notifying social workers and health care professionals who are directly involved with the infant.

Realistically, we need to accept the fact that there will always be infants who are at risk and will be lost to follow-up services despite our best efforts. Reasons may include a change of address, thus making contact difficult, poor parental response, and difficulty in obtaining adequate transportation. No program will be 100 percent successful. However, our experience has been that it is possible to reduce the number of follow-up losses due to administrative or coordination errors if these recommendations are pursued. Therefore, we encourage the use of a questionnaire to monitor newborn status on all infants who have *not* been identified with permanent hearing loss. Presumably, the *failure* infant group are routinely followed as part of an on-going aural rehabilitative service.

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