

Completed Research Projects With CDC-EHDI Funding

Family Interview and Family Perspectives - Rhode Island Department of Health, Women and Infants Hospital and the Rhode Island School for the Deaf, and consultants from Brown University

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Background: Universal newborn hearing screening has resulted in the earlier identification of hearing loss in infants and their subsequent participation in early intervention services. However, questions have been raised about the potential risk for stress and adverse effect on families whose infants receive a false-positive screening result, and the efficacy of intervention. Previous research has indicated that primary caregivers whose infants fail the initial screen report more stress than parents whose infants pass the screen. For a child who fails the initial screen and then passes a subsequent screen, is there stress or continued adverse impact? Additionally, it is known that the diagnosis of hearing loss in a child can be very stressful for a family and that adaptations of family members to a child's hearing loss varies.

Purpose: The purpose of this study was to study the psycho emotional effect of hearing screening results on families, including families with children with hearing loss, children who had a false-positive screen, and those who passed their initial screen.

Methods: This study enrolled families whose infants (1) passed the screen, (2) failed the screen and passed the rescreen, and (3) failed the screen and were identified with hearing loss. A one-hour assessment was conducted at three target age ranges, 6 – 10 months, 12 – 16 months, and, and 18 - 22 months. The purpose of these assessments was to collect data on primary caregivers' levels of stress, family support, family resources, receipt of early intervention, family empowerment, and child-parent communication skills. Caregivers were also asked about their perceptions of their child's language and behavior development. At each assessment, a videotape was taken of the caregiver and child playing, which was coded for the level and type of caregiver-infant interaction. Additionally, caregivers of children with hearing loss were invited to participate in a focus group to discuss their experiences with the screening and identification process, as well as with intervention services.

Summary of Results: The results indicated that, at 6 and 12 months of age, no differences were identified in maternal characteristics, infant characteristics, resources, or support across all three hearing screen groups. In addition, no differences were identified in the total parenting stress score and subscores or the total impact score among the three groups. Only financial effect was higher for primary caregivers of children with hearing loss (fail-fail group) than the controls (pass group) at the 12 month visit. In multivariate analysis, a neonatal intensive care unit stay predicted stress and impact, whereas older maternal age and greater family resources were protective. A false-positive screen was not independently associated with either stress or impact.

In subsequent analyses, all infants who passed the screen process (fail-pass and pass screen groups) were collapsed into one study group and the children with hearing loss were separated by degree of hearing loss into two groups: 1. unilateral/minimal or mild bilateral hearing loss and 2. bilateral moderate-to-profound hearing loss. While overall parent resources and support, stress scores and subscores, and impact scores were similar among the 3 study groups, significant differences were obtained. Some examples include primary caregivers of children with moderate-to-profound hearing loss reporting significantly more special professional and general professional support at 18 months, as well as significantly higher financial impact scores at 12 and 18 months. Differences were also seen in empowerment scores among the primary caregivers and Mac Arthur language assessments for children with moderate-to-profound versus minimal hearing loss.

Analysis of mother-child interactions for the hearing loss sample at 6 months showed older maternal age associated with increased verbal involvement. Additionally, primary caregivers of children with minimal hearing loss compared to those with moderate to profound hearing loss had higher verbal and play involvement. Subsequent play session and focus group analyses are currently being conducted.
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