International Journal of Pediatric Otorhinolaryngology 95 (2017) 34–38

Contents lists available at ScienceDirect

International Journal of Pediatric Otorhinolaryngology

journal homepage: http://www.ijporlonline.com/

Parent educational materials regarding the newborn hearing screening process

Lata A. Krishnan*, Breanne Lawler, Shannon Van Hyfte

Department of Speech, Language, and Hearing Sciences, Purdue University, USA

ARTICLE INFO

Article history:
Received 17 November 2016
Received in revised form
17 January 2017
Accepted 21 January 2017
Available online 29 January 2017

Keywords:
Infants
Screening
Hearing

ABSTRACT

Purpose: Newborn hearing screening (NHS) procedures and implementation vary from state to state in the US. The purpose of this study was to evaluate the content and nature of information provided to parents about their infant's NHS across states to answer two questions: 1) what information is included in each state's parent information brochure? and 2) do the brochures include educational information requested by parents that may help reduce parental anxiety, improve satisfaction, and decrease the potential for misunderstandings?
Method: Each state's parent brochures and educational resources provided to parents were accessed via the National Center for Hearing Assessment and Management (NCHAM) website, categorized, and reviewed for content.
Results: Results indicate that the information provided to parents varies considerably across states and many brochures do not contain important information that is desired by parents.
Conclusions: NHS procedures may be improved by providing standardized information regarding the process to parents in all states.

1. Introduction

Newborn hearing screening (NHS) procedures and protocols have evolved over the past two decades since the Joint Committee on Infant Hearing [45] endorsed the implementation of universal newborn hearing screening (UNHS) in 1994. Currently, every state and territory in the US has an Early Hearing Detection and Intervention (EHDI) program that focuses on hearing screening at birth, diagnosis before the age of three months and enrollment in appropriate early intervention services before the age of six months [26]. EHDI systems are managed by each state and annual data regarding screenings, diagnoses, enrollment in early intervention programs and loss to follow-up for each state are reported to the Centers for Disease Control and Prevention (CDC) so that nationwide data are available.

With the advent of UNHS, many studies focused on various aspects of NHS programs such as their feasibility (e.g. Refs. [32,36], optimal screening procedures (e.g. Refs. [24,30] and methods to ensure that false positives were kept to a minimum (e.g. Ref. [13]. Fewer studies have examined the more subjective aspects such as parental understanding of, satisfaction with, and anxiety related to the NHS process.

1.1. Parental understanding of and satisfaction with the NHS process

A recent nationwide survey revealed that only 62.9% of parents recalled their infant having a NHS, and that parent recall of follow-up recommendations was not always consistent with guidelines, suggesting low awareness about the NHS process [28]. Various stakeholders including parents, primary care providers, and professionals involved with NHS have indicated that communication to parents about NHS is limited and happens primarily at the hospital [2]. Parents of children identified as hard-of-hearing (HOH) subsequent to NHS recall the message provided to them after the screening as being inconclusive and 48% of families expressed that it caused concern, with 22% reporting that the process was highly unsatisfactory and indicating that they linked the concern to the screening process [44]. Parents of infants who did not pass the initial screening have also reported feeling insecure and uncomfortable after the screening because they felt they were not getting clear answers. [16], but appreciated the reassuring manner of the

* Corresponding author. Department of Speech, Language, and Hearing Sciences, 715 Clinic Drive, West Lafayette, IN 47907, USA.
E-mail address: krishnal@purdue.edu (L.A. Krishnan).

http://dx.doi.org/10.1016/j.ijporl.2017.01.025
0165-5876/

screener [44].

In general, 87–95% of parents report high satisfaction with the NHS process when their infant passes the screening [12,14,18,20] but lower satisfaction, greater anxiety, and need for additional support if their infant is referred for additional testing [12,18].

One factor that has been investigated as possibly related to low parental understanding of the NHS process is lack of knowledge regarding NHS amongst professionals involved in prenatal care. A large majority (82–89%) of pediatricians and family physicians believe NHS to be very important. However, only 14–21% said that their medical training prepared them to meet the needs of children with hearing loss. Only 58–79% of physicians had accurate knowledge of the JCIH 1-3-6 guidelines, and expressed a need for knowledge regarding evidence-based practice guidelines, basic information they should provide to parents, and who parents could contact with questions [6,23]. In a nationwide survey, although 98.4% of pediatric otolaryngologists said that they diagnose and treat children referred from EHDI programs, more than a third (34%) were not familiar with the JCIH [46] guidelines, 17% said their role in NHS was unimportant, and a majority (78%) wanted additional information about the NHS process, protocols, and recommendations [10].

1.2. Attempts to improve parental understanding

A few studies have attempted to find ways to improve parental understanding of the NHS process. During interviews in the maternity ward, a significantly higher proportion of mothers who advocated for NHS were well-informed about the screening, were present at the screening, or knew the result of the screening, suggesting that providing information about the screening process positively affects parental attitudes towards NHS [41]. Parents and professionals involved in NHS all agree that communication about the NHS process should begin before birth, with prenatal caregivers providing simple, to-the-point information on NHS and a parent brochure to take home [2]. Strategies that have been identified as helpful when providing information regarding NHS to families include: (1) explaining the reason for the ambiguity of screening results, (2) avoiding selective information, (3) providing information both verbally and in writing, (4) providing information about the process, (5) having both parents present, (6) providing easy access to professionals, and (7) enabling families to seek information independently [16]. Other strategies that help parents include providing clear and concise reasons as to why their infant needed additional testing [44], better information about the journey from screening through diagnosis and intervention in a single document, and using a standard scripted message to decrease potential misunderstandings from the spoken message [29]. Increasing the knowledge regarding NHS amongst primary care physicians may also help provide parents with additional information on NHS prior to delivery and additional involvement amongst prenatal care providers may help prevent misunderstandings regarding the results of NHS and help ensure infants complete the recommended diagnostic assessment [23].

1.3. Parental anxiety and NHS

Early studies related to parental anxiety during the NHS process suggested that the process was associated with excessive anxiety, which affected the parent-infant bonding process and therefore questioned the wisdom of implementing NHS programs [3,5,7,21,25]. However, many subsequent studies have shown that NHS does not affect the parent-infant bonding process [4,14,17,19,32,39,41]. Several studies addressing false-positive screening results have shown that up to 15% of parents experience short-term mild anxiety levels during the NHS process, and up to 25% of parents report moderate or severe anxiety following a referral from NHS [8,15,38,40]. However, overall, parents do not appear to experience severe levels of anxiety (e.g. Ref. [39], including parents of infants in the Neonatal Intensive Care Unit (NICU) [33] and parents of infants who had false-positive outcomes [34,35,37]. A recent comprehensive assessment of maternal anxiety related to hearing compared with maternal anxiety related to other aspects of infant development indicated that 14.6% of mothers were moderately worried or very worried about their infant's hearing immediately after the screening, although NHS does not appear to be associated with any more anxiety than other aspects of infant development [34].

1.4. Factors contributing to parental anxiety

Factors that have been investigated as contributors to the mild to moderate parental anxiety during the NHS process include the outcome of the screening, parental level of education, socioeconomic status, family structure, and race. Parents of infants who need multiple hearing screenings [9,14,19,38], whose infant is referred for a diagnostic hearing evaluation [14,19], and whose infant had a bilateral referral [9] report higher levels of anxiety. Some parents thought that a referral from the hearing screening indicated that their infant was Deaf [44]. The misunderstanding regarding the intent of screening caused parents to feel that information was being withheld, increasing anxiety [16].

Increased levels of anxiety have also been reported in first time parents, single parents, parents of non-white ethnicity, bilingual parents, families on Medicaid insurance and families with a low level of maternal education [38]; high level of maternal education [8]; and low level of knowledge or a lack of familiarity regarding the NHS process [9,44]. Learning about NHS during hospitalization was associated with greater levels of anxiety than the anxiety experienced by parents who were aware of NHS prior to delivery [38].

Improving parental education regarding NHS [44] and increasing knowledge regarding the prevalence of childhood hearing loss [9] helps decrease parental anxiety and increase overall parental satisfaction.

1.5. Educational information regarding NHS

Interviews with parents and health-care providers [2] have indicated that all stakeholders agree that information regarding NHS provided to parents should include the following items: 1) that all infants should have a hearing screening, 2) hearing is important for developing speech and language and for learning, 3) the screening does not hurt the child, 4) a few infants will need additional testing, 5) many things can be done to help a child if a hearing loss is identified, and 6) completing the diagnostic testing quickly is important. Parents also request a concise, easy to read brochure with additional contact information in addition to the verbal results, while none of the parents requested details regarding how the hearing screening equipment or the ear works, or what is included in a diagnostic appointment, unless their child is referred for additional testing. Of parents asked to provide feedback on a general brochure regarding NHS, 84–90% of mothers of infants who passed the NHS reported that the brochure was helpful; while only 15–21% of mothers whose child was referred for a diagnostic evaluation felt that it was helpful [38]. Parents of children referred for a diagnostic assessment request additional information such as the prevalence of childhood hearing loss, options available to help a child with hearing loss, reasons their child may have referred, what they can expect at their child's diagnostic appointment, and why the appointment is necessary [2,44].