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ARTICLE

Primary Care Physicians' Knowledge, Attitudes, and Practices Related to Newborn Hearing Screening

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ABSTRACT

OBJECTIVE. Universal newborn hearing screening focuses on providing the earliest possible diagnosis for infants with permanent hearing loss. The goal is to prevent or minimize the consequences of sensorineural hearing loss on speech and language development through timely and effective diagnosis and interventions. Pediatricians are in a key position to educate families about the importance of follow-up, if they are well informed. The objective of this study was to survey the attitudes, practices, and knowledge of primary care physicians in relation to newborn hearing screening and follow-up.

METHODS. A survey was created on the basis of input from focus groups with primary care physicians. Surveys (n = 12 211) were sent to primary care physicians in 21 states and 1 territory (Puerto Rico) regarding practices, knowledge, and attitudes related to universal newborn hearing screening. The response rate was 16.1% (n = 1968).

RESULTS. Physicians reported a high level of support for universal newborn hearing screening; 81.6% judged it to be very important to screen all newborns for hearing loss at birth. Although physicians reported confidence in talking with parents about screening results, they indicated a lack of confidence in discussing follow-up procedures and intervention needs. Several important gaps in knowledge were identified, and these represent priorities for education, as based on their relevance to medical management and parent support. Physicians expressed a strong preference for action-oriented resources.

CONCLUSION. Pediatricians and other primary care providers recognize the benefits of early detection and intervention for permanent hearing loss in infants. The current system of newborn hearing screening can be enhanced by strengthening the medical community's involvement in the process from screening to follow-up. Physician roles will be supported through the provision of action-oriented resources that educate parents about the importance of follow-up and that prepare professionals to incorporate appropriate surveillance procedures in daily practice.

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Key Words
newborn hearing screening, physician knowledge, childhood hearing loss, sensorineural hearing loss

Abbreviations
SNHL—sensorineural hearing loss
CME—continuing medical education
EHDI—early hearing detection and intervention
AAP—American Academy of Pediatrics

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UNIVERSAL NEWBORN HEARING screening has become the standard of care throughout the United States in an effort to provide early detection and intervention for infants with permanent hearing loss. In 1993, <5% of newborns were screened for hearing loss. Today, 93% of newborns are screened for hearing loss before hospital discharge, and 39 states have universal newborn hearing screening legislation.[1] The expansion of newborn hearing screening in the past decade has helped reduce the average age of identification of infants with permanent childhood hearing loss,[2] allowing families and professionals to prevent or minimize the negative impact of sensorineural hearing loss (SNHL) on speech and language learning.[3,4] The overall success of these efforts, however, depends on the provision of timely and effective diagnostic and intervention services.

Physicians are in a key position to educate families after hearing screening and, particularly for those infants who fail the newborn hearing screening, to ensure appropriate follow-up care and surveillance. Newborns and parents are seen regularly by their primary care physicians, and parents often seek input from their physician on the infant's medical and developmental needs. This provides an ideal opportunity to promote follow-up, make appropriate referrals, and support families. However, this requires that physicians be knowledgeable about the implications of hearing screening results as well as current best practices in the medical and educational treatment of infants with permanent hearing loss. Unfortunately, there is very little information about what pediatricians and other primary care providers currently know about this topic, what they need to know, and how they prefer to learn this information. Such findings are essential for creating effective partnerships with the medical home to meet the needs of families of infants with newly diagnosed permanent hearing loss.

In a previous study that was conducted in the United Kingdom, 520 general practitioners were surveyed to measure the effectiveness of an information dissemination campaign on newborn hearing screening that was targeted at the medical community.[5] The campaign involved distribution of leaflets and posters and the creation of a dedicated Web site. The results showed limited effectiveness of mailing unsolicited educational materials. Two thirds of the respondents indicated a desire for more information about newborn hearing screening but expressed concern about information overload. Researchers concluded that brief written information combined with tailored Internet resources (eg, relevant to physicians; downloadable fact sheets) were useful routes to pursue in future work. This study highlights the risk of creating an educational campaign before understanding the educational needs and preferences of the medical community.

In preparation for the present survey, 3 focus groups were conducted with pediatricians in Nebraska and Colorado in conjunction with continuing medical education (CME) events. In these focus groups, physicians discussed their current knowledge and their preferred strategies for learning about early hearing detection and intervention (EHDI). Broad themes that were identified included the need to (1) recognize the time constraints of daily practice for physicians and the limited frequency with which infants with SNHL are encountered, (2) avoid dense content that is designed to "make me an expert" because primary care physicians will refer to other specialists, (3) use terminology that communicates across disciplines, (4) provide evidence-based facts, and (5) use formats that are familiar to physicians (grand rounds, algorithms, patient education materials, CME seminars).

The input from focus groups was used to design a broader based survey of physicians. The specific aims of the survey were to (1) understand current practices of primary care pediatricians and other physicians related to newborn hearing screening and follow-up, (2) assess attitudes of physicians related to their general support of and concerns about universal newborn hearing screening programs (eg, cost/benefit, parental stress, etc), and (3) identify knowledge gaps and perceived knowledge needs of physicians, as well as preferred methods for learning about the management of SNHL in infants.

METHODS

Newborn hearing screening programs are managed on a statewide basis by EHDI program coordinators. These individuals in the 50 United States and territories were invited to collaborate with the researchers in surveying primary care physicians about newborn hearing screening and follow-up practices. EHDI coordinators from 21 states and Puerto Rico volunteered to send surveys to primary care physicians in their respective states. A random sample of at least 200 physicians was required for participation in the project, but some state EHDI coordinators chose to send surveys to more or even all physicians in the state who provided primary care for children. The researchers provided copies of the survey (in English or Spanish) along with postage paid return envelopes. Coordinators mailed the surveys to primary care physicians in their respective states. In total, 12 211 questionnaires were mailed. Two weeks after the original mailings, coordinators mailed a reminder postcard (provided by the researchers) to their list of physicians. Identification of nonrespondents was not possible because replies were anonymous.

The survey tool was developed on the basis of input from 3 focus groups that involved a total of 26 pediatricians from 9 states. The survey was pilot-tested for length and clarity at a medical society meeting of primary care physicians. Approval from the Boys Town National Research Hospital Institutional Review Board for the project and for waived written consent was ob-

tained before surveys were mailed to physicians. A copy of the survey is shown in the Appendix. Several questions on the survey allowed for handwritten comments about physicians' personal experiences and concerns with newborn hearing screening. These narrative comments are incorporated in this report, along with quantitative results.

RESULTS

Demographic Analysis

Of the 12 211 mailed questionnaires, 1968 (16.1%) useable surveys were returned within the established 4-mo timeline; these responses form the basis for analysis. The majority (79.1%) of responses came from the following 11 states: New York (259), California (258), Wisconsin (243), Minnesota (153) Nebraska (149) Utah (139), North Dakota (87), New Hampshire (81), Alaska (67), Hawaii (61), and Kentucky (61). Ten remaining states (Arkansas, Illinois, Indiana, Kansas, Massachusetts, Michigan, New Mexico, Virginia, West Virginia, and Wyoming) contributed an additional 346 responses, and Puerto Rico contributed 32 responses. Thirty-two (1.6%) survey respondents did not specify their states.

Demographic results are shown in Table 1. The sample was well distributed by gender and practice location.

TABLE 1 **Demographics of Sample**

Characteristics	*n* (%) (*N* = 1968)
Practice type	
Pediatricians	1153 (58.6)
Family practice	532 (27.0)
Otolaryngologists	58 (2.9)
Neonatologists	53 (2.7)
Residents	34 (1.7)
OB/GYN	9 (.5)
Other specialists	68 (3.8)
Unknown	56 (2.8)
Physician gender	
Male	972 (49.4)
Female	854 (43.4)
Unknown	142 (7.2)
Practice location	
Metropolitan area	1122 (57.0)
Small town	433 (22.0)
Rural community	239 (12.1)
Unknown	174 (8.8)
Practice setting	
Private/community clinic	1486 (75.6)
Hospital setting	205 (10.4)
Medical school/university	115 (5.8)
Other	70 (3.6)
Unknown	73 (3.7)
Experience with pediatric population, y	
0–10 (mean: 5.6; SD: 2.87)	699 (40.2)
11–20 (mean: 16.2; SD: 3.1)	496 (28.6)
21–30 (mean: 25.7; SD: 2.8)	391 (22.5)
31+ (mean: 37.4; SD: 5.7)	152 (8.7)
Unknown	230

OB/GYN indicates obstetrician/gynecologist.

Pediatricians (58.6%) and family physicians (27.0%) were the groups with the strongest representation in the sample; they serve as a basis for subgroup comparisons in this article. On average, respondents reported that 39.2% (median: 35%) of their practice was composed of children in the 0- to 5-year age range. However, statistically significant differences ($t = 38.04$, $P < .001$) were found on this measure when pediatricians (mean; 51.0%; SD: 21.1) were compared with family physicians (mean: 13.3%; SD: 12.3). Physicians were asked to report the approximate number of children whom they had seen with permanent hearing loss they in the past 3 years. Pediatricians reported seeing an average of 3.32 children (SD: 4.9), and family physicians reported an average of 1.25 (SD: 2.7); these differences also were statistically significant ($t = 8.82$, $P < .001$). We hypothesized that differences in experience, particularly with children with SNHL, may influence both physician attitudes and knowledge. However, as is discussed next, this factor did not differentiate among participant responses.

Attitudes About Universal Newborn Hearing Screening

There was a major increase in legislation and state participation in newborn hearing screening in the United States between 2000 and 2002, making this a relatively new practice. Before the widespread implementation of newborn hearing screening programs, physicians raised concerns about the cost, impact on parental anxiety, and potential for high false-positive rates of such programs.[6] The following section reports analysis of physicians' current attitudes about those issues now that most physicians have had more experience with universal newborn hearing screening.

When asked about the importance of screening all newborns for SNHL, a majority of physicians responded that it was very important (81.6%) or somewhat important (14%). Only 4.4% stated uncertainty or a belief that hearing screening was unimportant. There was a statistically significant difference in the number of pediatricians (3.0%) versus family physicians (6.0%) who expressed skepticism about the value of newborn hearing screening (Mann-Whitney *U*, 2-tailed significance of $P < .001$).

When asked whether newborn hearing screening causes undue parental anxiety or concern, the majority (84.7%) responded that it does not. However, 8.3% indicated the belief that screening does cause parental anxiety, and 7.0% of participants were unsure. There were no statistically significant differences in this belief by experience with children with SNHL ($P = .166$) or by years of experience in pediatrics ($P = .290$).

Although the approximate cost per infant for a newborn screening test in hospitals with at least 1000 births per year is $30 or less,[7,8] 35.6% of respondents estimated costs as high as more than $100. No statistically significant differences in cost estimates were expressed by

physicians from practices that were located in rural versus metropolitan areas ($P = .196$). Although 75.7% of respondents believed that newborn hearing screening is worth the cost, the remaining 24.3% were unsure or unconvinced of the relative costs versus benefits of the program. Our experience with focus groups suggested that understanding of the consequences of infant hearing loss on language development in addition to accurate understanding of costs played a role in attitudes about cost/benefit.

Physicians were asked an open-ended question about perceived barriers or concerns with newborn hearing screening. Of the 197 (10.0%) respondents who completed this question, a concern for high false-positive rates was mentioned most frequently ($n = 45$). High rates of loss to follow-up also were considered a barrier to program effectiveness ($n = 31$). Other responses included the need for physician training, uncertainty about the procedures, a perception of complexity of the procedures, and inconclusiveness of test results. A few respondents expressed a "lack of need" for the procedure. Others expressed the need for more parent education, for more funding, and for better equipment.

Current Practices Related to Newborn Hearing Screening

To promote appropriate follow-up care, state or local newborn hearing screening programs are encouraged to send screening results to the primary care physician. However, 12.0% of pediatricians and 17.0% of family physicians indicated that they receive newborn hearing screening results on <50% of their patients. These results were comparable across practice location (eg, rural versus metropolitan area). Physician awareness of the state EHDI program may facilitate communication with the medical home. Although the state EHDI program coordinators sent out the surveys for this study, 4.0% of respondents reported that their state did not have a newborn hearing screening program, and 10.0% were unsure. This provides additional documentation of the need for strengthening communication between newborn hearing screening programs and the medical home.

Respondents also were asked to list any specialists to whom they routinely would refer a family of a child with confirmed permanent hearing loss. Table 2 summarizes the frequency of their responses. Notably, although the majority refer to otolaryngology, which is an essential step before amplification can be fit on an infant, almost 25% did not. Furthermore, very few physicians reported that they refer to genetics or ophthalmology, which is recommended by the Joint Committee on Infant Hearing for children with congenital hearing loss.[9] As an example of why such referrals are so important, the American College of Medical Genetics points out that a genetic evaluation often can avoid unnecessary and costly clinical tests, allows one to anticipate potential/associated health problems and to offer appropriate therapeutic options, and often dispels misinformation and offers emotional support regarding the cause of the hearing loss.[10] However, physicians also should be aware of current challenges that exist for families in deciding whether to have genetic testing done (eg, cost issues, limited availability of geneticists with knowledge of hearing loss, discovery of unwanted information). Furthermore, genetic testing is not without controversy: some deaf community members fear that such testing can lead to devaluation of them as individuals. Regarding referrals for ophthalmology, vision problems are known to be more prevalent in children with permanent hearing loss than in the general population,[11] underscoring the need for this type of medical surveillance in children with SNHL. The results also suggest the need for greater awareness of appropriate options for referral to early intervention programs. For example, although occupational therapist was listed on 2.3% of surveys (see Table 2), it is rare for an occupational therapist to provide services for an infant with hearing loss unless there are secondary developmental issues. Speech pathology (27.9%) generally would be accessed through an early intervention program rather than through a direct referral from the primary health care provider.

TABLE 2 Specialists to Whom Doctors Refer Infants With Confirmed SNHL

Specialist Referral	% of Respondents
ENT/otolaryngologist	75.8
Audiologist	41.3
Speech pathologist	27.9
Child development specialist	11.4
Geneticist	8.9
Neurologist	7.1
Occupational therapist	2.3
Pediatrician	2.0
Other	2.1
Ophthalmologist	0.9

ENT indicates ears, nose, and throat.

Perceived Knowledge Needs

In focus group sessions, pediatricians reported that it would be unrealistic for them to become "experts" on the topic of permanent childhood hearing loss because they do not frequently encounter children with SNHL in their practice. However, they expressed strong interest in knowing how to access evidence-based practice guidelines and information that would provide appropriate guidance to families. These perceptions were supported by the survey results. Only 14.0% of the survey respondents believed that their training in medical school prepared them to meet the needs of infants with permanent hearing loss. They listed the following as their primary sources of information about EHDI: literature (38.0%), hospital program (15.9%), educational

meetings (12.9%), state EHDI program (10%), other physicians (5.7%), audiologists (4.9%), on-the-job training (4.4%), grand rounds (3.1%), and Internet (2.1%). Although the Internet was not accessed often for information about topics related to newborn hearing screening, 51.9% of respondents reported frequent access of the Internet and an additional 32.3% reported occasional access of the Internet for information on medical topics. This suggests the need to increase awareness of existing Internet-based resources on EHDI and to create additional resources that are tailored for physicians.

Most respondents were very confident (47.9%) or somewhat confident (41.1%) in explaining the newborn hearing screening process to parents who had questions about their infant's results. However, when specific content questions were asked, knowledge gaps were found related to the steps that follow identification of permanent hearing loss in infancy. Table 3 summarizes the range of responses that were obtained from questions about specific ages when follow-up steps should be initiated. In 2002, the American Academy of Pediatrics (AAP) and the National Center for Hearing Assessment and Management disseminated *Guidelines for Pediatric Medical Home Providers*, a flowchart that fosters 3 major action steps before 6 months of age.[12] The recommendations (often presented as the 1-3-6 guideline) are (1) completed newborn hearing screening before 1 month of age, (2) diagnosis of hearing loss and hearing aid fitting before 3 months, and (3) enrollment in early intervention before 6 months. The entries with a superscript "a" in Table 3 indicate the percentage of responses that are consistent with these AAP guidelines.

Knowledge of causative conditions was assessed with the multiple-choice question, "Which of the following conditions put a child at risk for permanent late-onset hearing loss?" The conditions listed in Table 4 include the correct answers (denoted by an asterisk) as well as several incorrect answers. The 3 columns represent the percentage of responses for pediatricians, family physicians, and all respondents. The vast majority of physicians knew that family history of SNHL was a risk indicator. However, almost half of the respondents were not well informed about the risk factors for late-onset hearing loss. In interpreting these results, it should be noted that 2 options for this question that were coded as being "incorrect" could be true in a small number of cases. Specifically, childhood hearing loss can co-occur with cardiac defects in multiple syndromes; however, the onset of hearing loss most often is congenital. Hearing loss (including auditory neuropathy) may be detected in a child with cerebral palsy secondary to hyperbilirubinemia or perinatal asphyxia. In general, however, the data identify knowledge gaps related to risk factors and causes of permanent childhood hearing loss. Pediatricians were somewhat better informed than family physicians in most categories. This content area has relevance for surveillance and identification of risk factors for late-onset permanent hearing loss in children.

The availability of cochlear implant surgery for deaf infants adds complexity to early medical management decisions. The technology is advancing rapidly, and candidacy criteria have shifted over time, making it challenging for primary care practitioners to be aware of current best practices. Families may consult pediatricians for advice regarding this surgical procedure after diagnosis of deafness. Nearly 70% of physicians who responded to this survey reported a lack of confidence in talking with families about this option. Survey results showed that physicians had difficulty determining the audiologic characteristics that qualify an infant for cochlear implantation. The correct response (bilateral profound) was selected by 74.3% of respondents, but an additional 48.5% of responses either were inaccurate (unilateral profound: 24.5%; bilateral mild to moderate: 15.5%; unilateral mild to moderate: 5.9%) or indicated uncertainty (27.1%).

Finally, physicians were asked to rate their confidence in talking with parents about 5 specific topic areas. Fewer than 10% of respondents were "very confident" on any of the topics. In order of less to more confident, the topic rankings were cochlear implants, communication approaches (sign, auditory/oral), causes of hearing loss, management of profound deafness, and management of unilateral or mild SNHL. It is interesting to note that physicians ranked themselves as most confident in addressing unilateral and mild hearing loss, when these 2 categories of hearing loss are more controversial among professionals in the field of audiology than other types and degrees of loss.[13]

TABLE 3 **Physicians' Estimates of Ages at Which Various Follow-up Procedures Should Be Conducted**

What Is Your Best Estimate of the Earliest Age at Which:	≤1 mo	1–3 mo	3–6 mo	6–9 mo	9–12 mo	>12 mo
Newborn who does not pass screen should receive additional testing	75.7[a]	11.8	7.0	4.2	0.1	1.2
Infant can receive a definitive diagnosis of SNHL	51.9[a]	10.8[a]	12.4	15.4	0.3	9.3
Child can begin wearing hearing aids	38.1[a]	9.1[a]	11.2	22.3	1.2	18.1
Child with SNHL should be referred to early intervention	61.6[a]	8.0[a]	9.8[a]	13.2	0.4	7.0

[a] Responses that are consistent with the AAP guidelines for pediatric medical home providers (www.medicalhomeinfo.org).

TABLE 4 **Percentage of Respondents Who Indicated That Specific Conditions Would Put a Child at Risk for Late-Onset SNHL**

Condition	% of Responses From Pediatricians	% of Responses From Family Practice	% of Responses From Total Group
Meningitis[a]	99.0[b]	97.0	98.6
>48-h NICU stay[a]	48.0	58.0[b]	51.5
History of CMV[a]	88.0[b]	78.0	84.7
Congenital syphilis[a]	64.0	71.0[b]	67.0
Family history of childhood hearing loss[a]	94.0	90.4	92.8
Mother >40 at delivery	13.5[b]	24.6	17.5
Congenital heart defects	20.0	23.0	22.2
Frequent colds	18.0[b]	33.0	23.0
Hypotonia	26.0	30.0	28.8

CMV indicates cytomegalovirus.

[a] Correct response.

[b] $P < .01$ for pair-wise comparisons of pediatricians and family practice.

Perceived Topic and Resource Needs

Table 5 summarizes pediatricians' perceived areas of need for training or resources related to the treatment of infants with SNHL. The pediatrician responses reported here also were similar to the responses of other physician subgroups and of the total group.

Finally, physicians were asked to judge the relative utility of specific types of materials or resources for learning about newborn hearing screening and follow-up. Resources that were judged as being most likely to be helpful (in order of percentage who responded "very helpful") included (1) laminated cards with clear protocol steps (63.8%), 2) brochures to use in patient education (63.1%), (3) a frequently updated Web site for physicians (55.4%), (4) on-line CME courses (46.6%), and (5) downloadable grand rounds materials (39.0%). Additional recommendations that were made in open-ended responses included conferences, educational seminars, and equipment demonstrations. Resources that were judged to be less helpful included DVDs, CDs, and videotapes to be used in patient education, but even these were selected by at least 29% of the respondents as being very helpful.

DISCUSSION

The present survey documented that the majority of physicians are in support of newborn hearing screening efforts; 81.6% believe that it is very important to screen all newborns for hearing loss at birth. This leaves 18.4% who are less sure about the importance, perhaps suggesting a need for clearer understanding of the consequences of hearing loss on early learning and speech and language development. Our data also suggest the need for newborn hearing screening and state-level EHDI programs to strengthen connections with the medical home by communicating all test results in a timely manner. Specific knowledge and practice gaps as well as attitudinal barriers should be addressed to maximize physicians' roles in the EHDI process.

In the early stages of implementing universal newborn hearing screening programs, some physicians raised concerns for the potential impact on parental anxiety.[6] Our data indicate that a majority of physician respondents currently do not see parental anxiety as a major concern or barrier. This belief has been supported by evidence in the literature.[14] It is difficult to predict an individual family's response to a failed screening result and/or after confirmation of permanent hearing loss, and individual differences exist.[15] Pediatricians reported the need for training to counsel parents better after diagnosis. One physician in the focus groups asked, "How worried should I tell parents they need to be about this?" Physicians expressed a need to understand better

TABLE 5 **Pediatrician's Perceptions About the Need for Training and/or Resources on Various Topics, Ordered by Level of Need**

Topic	Great Need, *n* (%)	Somewhat of a Need, *n* (%)	No Need, *n* (%)
Protocol steps for follow-up of screening	737 (66.0)	339 (30.4)	37 (3.0)
Early intervention options	687 (61.6)	390 (35.0)	37 (3.3)
Useful contacts for more information	678 (60.8)	422 (37.8)	15 (1.3)
Patient education resources	650 (58.2)	454 (40.6)	12 (1.0)
Impact of varying degrees of hearing loss on infant language	631 (56.7)	457 (41.0)	25 (2.2)
Guidelines for screening for late-onset hearing loss	630 (56.7)	445 (40.0)	34 (3.0)
Methods for screening children at well-child visits	568 (50.8)	495 (44.3)	54 (5.0)
Hearing aids and cochlear implants	567 (50.8)	529 (47.4)	18 (1.6)
Genetics and hearing loss	486 (45.2)	574 (53.4)	13 (1.2)
Guidelines for informing families about screening results	450 (40.0)	560 (50.3)	103 (9.2)

the consequences of varying degrees of hearing loss on infant development. A clear understanding that even minimal hearing loss has consequences for the development of speech and language[13,16,17] will put physicians in a better position to guide families.

Our data show that improved communication with the medical home could strengthen connections from screening to diagnosis and follow-up. A concerning number of pediatricians (12.0%) and family physicians (17.0%) reported receiving screening results on fewer than half of their patients. Previous research on newborn screening for inborn errors of metabolism and hemoglobinopathies demonstrated that 26.0% of physicians do not receive results of children who pass screening. Doctors in that study and in our focus groups reported a tendency in this situation to presume that "no news is good news"[18]; practitioners acknowledged that this may be a dangerous assumption. Several states have developed effective systems of communicating newborn hearing screening results with the infant's medical home. There should be continued efforts to share these effective models among states.

It has been estimated that pediatricians typically see a minimum of 12 children with severe or worse bilateral SNHL in the course of a practice lifetime.[19] Pediatricians who responded to this survey saw an average of 3.3 children in the previous 3 years, including children with mild through profound hearing losses. These results suggest that practitioners may encounter children with permanent hearing loss more often than previous estimates suggest. Nonetheless, given the many demands of daily practice, this remains a low-incidence condition, creating challenges for staying informed and current. This is even more the case for family physicians who reported seeing an average of 1.3 children with SNHL in the previous 3 years. Physicians in focus groups talked about the issue of hearing loss being "lower on their radar screen" than other health conditions that they deal with on a daily basis. This underscores the value of current AAP programs that focus on "just in time" resources related to EHDI.[20] "Just in time" resources are high-quality, evidence-based materials that can be accessed easily when patient needs present themselves. Our survey results also suggested differences in the educational needs of pediatricians and family physicians, which may be related to differences in their relative frequencies of encountering infants with permanent hearing loss.

In general, our data analysis revealed that, for this sample, neither years of experience nor number of patients with permanent childhood hearing loss affected the accuracy of responses. This suggests that experience alone is not adequate for responding to new technologies or changing management strategies. It supports the need for educational programs and resources that are tailored to address knowledge and practice gaps that are reported by physician groups. Data from this survey (see Table 3) demonstrate that many physicians did understand best practices related to the ages at which infants should be referred for follow-up. This may provide indirect support for the effectiveness of the AAP campaign directed at pediatrician education. Conversely, the results also indicate that more emphasis needs to be placed on appropriate referral ages for fitting of hearing aids and for enrollment in early intervention services. Our survey data on typical referral practices suggest that such training should be broadened to include information about the qualifications of professionals who can provide appropriate services to young infants as well as service access contacts in local communities.

Our results indicate some specific gaps in physician knowledge related to medical treatment of infants with newly diagnosed hearing loss. Many respondents reported a lack of understanding of causative and genetic issues. Given that at least 50% of infants who received a diagnosis of congenital hearing loss have a genetic cause,[21,22] it is essential that primary care physicians understand the need to collaborate with a medical genetics team in managing permanent hearing loss in infants. This testing is important not only in determining causal factors but also in identifying secondary medical needs or disabilities. The primary care physician also must stand ready to support families in interpreting the results of genetic testing. Primary care physicians who work with deaf parents must attend to cultural considerations, because some deaf adults may be opposed to surgical intervention, cochlear implants, and/or genetic testing.[23,24] Furthermore, the incidence of blindness and low vision is 3.9%, and visual acuity problems are 2 to 3 times more prevalent in children with SNHL than in typically developing children.[11] These facts underscore the need for ongoing developmental surveillance in these children and for regular ophthalmologic evaluations. In addition, knowledge of risk factors for late-onset hearing loss would support the surveillance process.

Other gaps that were identified by the survey relate to the physician's role in counseling and supporting families of infants who receive a diagnosis of permanent hearing loss. Physicians perceived 2 areas as particularly challenging: (1) cochlear implants and (2) communication methods. It is most relevant perhaps for physicians to know that not all children with hearing loss are candidates for cochlear implants and where to go to access current candidacy criteria. Furthermore, physicians should be aware of the complexity of the decision-making process for the parents, the value of parent-to-parent support, and that both the technologies and the evidence base in pediatric cochlear implantation are changing rapidly. The best approach in such circumstances may be knowledge of how to contact a skilled pediatric cochlear implant team that can respond to physician and patient questions. The topic of communication methods or ap-

proaches (eg, use of auditory/oral, auditory/verbal, signing, combined strategies) is complex and, at times, controversial.[25] The process of ensuring that families are well informed about all types of options should occur as soon as possible after the diagnosis of permanent hearing loss and ideally should happen as a part of the early intervention program in which the child is enrolled. Parent-to-parent contact also can be helpful for families who are working through this decision-making process. Families expect physicians to be sensitive to the complexity of decisions that they must make about their child's communication, device needs, and education.[26]

Physicians reported that they most often have accessed information about newborn hearing screening from fairly traditional sources, including the medical literature and CME meetings. Studies have not been conducted to determine whether these approaches bring about change in physician performance and patient outcomes in relation to management of infant hearing loss. However, several systematic reviews of CME research suggest that conferences, printed materials, and didactic lectures have only weak effects on medical practice.[27–29] Systematic reviews also indicate that CME programs with interactive elements and local opinion leaders within the medical community are effective in influencing physician practice.[27] It is interesting that physicians in the current study requested information resources other than didactic lectures on topics related to newborn hearing screening. Resources that were judged as most useful were action oriented; that is, they could be used to support immediate practice applications (ie, laminated protocol cards, patient education materials). They also requested Web-based materials and online CME courses. The advantage to these types of materials (similar to the existing AAP Pedialink course on newborn screening[30]) is the possibility of incorporating interactive and practice elements, consistent with the evidence on effective CME. In addition, AAP created a Chapter Champions program, which designates 1 pediatrician in each state as a leader for disseminating information and resources on newborn hearing screening. This program is consistent with the evidence on the effectiveness of local opinion leaders on physician practices.[27]

Our survey results show that Web-based resources about topics that are related to newborn hearing screening are underused by physicians. Although 51.7% of the group reported using the Internet to access medical topics, few physicians listed this as a source of information about issues related to newborn hearing screening. Numerous resources related to EHDI are on the Internet. It may be that physicians have not been informed about the availability of these resources, or perhaps they have not yet had the need for this information in their practices. Continued efforts to create and disseminate these types of materials, especially those with interactive media, seem to be warranted. Our findings are consistent with systematic reviews showing that multiple strategies are needed to address CME needs.[27]

A number of topics were identified by participants as priorities for education related to newborn hearing screening. These self-appraisal opinions, paired with an analysis of responses to knowledge questions, provide some priorities for CME. Although all of the topics listed in Table 5 were of interest to the respondents, priority needs included (1) protocol steps for follow-up, (2) information on early intervention, (3) contacts for more information, (4) patient education resources, and (5) impact of varying degrees of hearing loss on infant language. These requested topics and resources have direct application to working with families in the medical setting. We learned that it is imperative to understand the busy practice life, circumstances, and perspectives of physicians before attempting to create new resources.

The concern for high false-positive rates may be based in reality for some physicians, depending on the experience level of screening personnel in their community birthing hospitals. Physicians in such settings need to be aware of acceptable false-positive rates and methods for reducing high false-positive rates.[31] Persistently high false-positive rates add costs to the system and may create a complacent attitude with health care professionals that "infants always pass the second screen." This can influence information that is given to families, which in some cases may affect willingness to follow-up. Physicians appropriately raised concerns for the high rates of loss to follow-up that were reported by some states after newborn hearing screening. A working group of the National Institute on Deafness and other Communication Disorders explored factors that influence follow-up and concluded that return for these evaluations could be improved if (1) parents fully understood the child's screening results, (2) parents fully understood the importance of the diagnostic evaluation, and (3) parents were provided with necessary contact and resource information.[32] Well-informed physicians who understand the impact of permanent hearing loss among infants and young children can be part of the solution in reducing the rates of loss to follow-up. Repeat visits for well-infant checks and immunizations are ideal times to reinforce parental understanding of the need for follow-up.

There are several limitations to our study. Although we randomly sampled across 21 states and Puerto Rico and recruited a large number of participants (1968), our overall return rate was low (16.1%) compared with some published questionnaire studies.[33] This response rate may suggest some level of nonrespondent bias and the possibility that a propensity of responses were from physicians with greater interest in newborn hearing screening. If this is the case, then some of the findings about gaps in knowledge and misunderstandings are even more alarming because we would expect those

with more interest to be better informed. Although physicians from a variety of subspecialties participated, there was insufficient representation in all but 2 categories (pediatricians and family physicians) for making relevant comparisons. Physicians also may have become aware of their own knowledge gaps in the process of completing the survey. This may have biased their responses to questions about needed topic areas and resources. Furthermore, there was no attempt to measure directly the impact of knowledge or attitudes on physician treatment of infants with newly diagnosed SNHL. Future studies are needed to address this question.

CONCLUSIONS

On the basis of the results of this survey, we draw the following main conclusions and recommendations:

1. There is evidence that primary care physicians are becoming informed about universal newborn hearing screening, support the procedure, and feel confident in talking with parents about the screening results. However, important gaps in knowledge about follow-up stages of the process remain and need to be addressed.
2. Knowledge gaps centered on issues of medical management, such as knowing when and where to refer infants for follow-up procedures, understanding the genetics of hearing loss, implementing surveillance for late-onset hearing loss, and familiarity with cochlear implants and their candidacy criteria.
3. Knowledge gaps also were identified with regard to early intervention, including contacts for referral, appropriate communication options, and professional disciplines involved. Additional education of the medical community on these issues will put physicians in a better position to support families of newly identified infants with permanent hearing loss.
4. Primary care pediatricians perceived gaps in their knowledge about referrals and interventions that follow newborn hearing screening. They recommended that knowledge gaps be addressed through provision of (1) action-oriented resources (algorithms/protocol cards, parent education materials), (2) Web-based materials, and (3) online CME and materials for peer education.

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APPENDIX

Newborn & Infant Hearing Screening Survey

We need your help to improve newborn hearing screening programs. Please take ten minutes to tell us about your feelings and experiences. Your responses are completely confidential and will be used to improve services for infants and young children with hearing loss. Please return the survey in the enclosed envelope. Your participation is greatly appreciated.

- **Q1.** **Approximately what percentage of <u>your</u> practice is comprised of infants or children 0-5 years of age? _____**

- **Q2.** **Approximately how many children with permanent hearing loss (EXCLUDING otitis media) have you had in your practice during the past three years? _____**

- **Q3.** **How important do you think it is to screen all newborns for permanent hearing loss?**

  ❒ Very important
  ❒ Somewhat important
  ❒ Somewhat unimportant
  ❒ Very unimportant
  ❒ Unsure

- **Q4.** **For newborns in your practice during the past year, estimate the percentage for which you received newborn hearing screening results. _____%**

- **Q5.** **Do you think hearing screening causes parents excessive anxiety and/or concern?**

  ❒ Yes ❒ No ❒ Unsure

- **Q6.** **Estimate the approximate cost per baby for newborn hearing screening in your state: $ _____**

- **Q7.** **Do you believe that universal newborn hearing screening is worth what it costs?**

  ❒ Yes ❒ No ❒ Unsure

- **Q8.** **How confident are you that you could explain the newborn hearing screening process to parents who have questions about their infants' results?**

  ❒ Very confident ❒ Somewhat confident ❒ Not Confident ❒ Unsure

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- **Q9. What is your best estimate of the earliest age at which:** **Enter Age Estimate:**

  a. A newborn not passing the hearing screening should receive additional testing ..... _____

  b. A child can be definitively diagnosed as having a permanent hearing loss ..... _____

  c. A child can begin wearing hearing aids ..... _____

  d. A child with permanent hearing loss should be referred to early intervention services ..... _____

- **Q10. List any specialists to whom you would routinely refer the family of a child with a confirmed permanent hearing loss:**

  _____

  _____

- **Q11. Which of the following conditions put a child at risk for permanent late onset hearing loss? (check all that apply)**

  ❒ meningitis
  ❒ frequent colds
  ❒ hypotonia
  ❒ >48 hrs in NICU
  ❒ cleft palate
  ❒ mother over age 40
  ❒ congenital heart disease
  ❒ history of cytomegalovirus (CMV)
  ❒ congenital syphilis
  ❒ family history of childhood hearing loss

- **Q12. Which of the following infants may be a candidate for cochlear implants? (check all that apply)**

  ❒ infant with bilateral mild-moderate hearing loss
  ❒ infant with profound bilateral hearing loss
  ❒ infant with unilateral mild-moderate hearing loss
  ❒ infant with unilateral profound hearing loss
  ❒ unsure

- **Q13. Thinking about the physicians you know and work with, how informed do you think most of them are about issues related to permanent hearing loss?**

	Very Informed	Somewhat Informed	Somewhat Uninformed	Uninformed
a. The incidence of hearing loss among newborns/infants	❒	❒	❒	❒
b. Procedures for newborn/infant hearing screening	❒	❒	❒	❒
c. Consequences of unilateral or mild hearing loss	❒	❒	❒	❒
d. Consequences of bilateral severe or profound hearing loss	❒	❒	❒	❒
e. Medical interventions (e.g., cochlear implants)	❒	❒	❒	❒
f. Audiological interventions (e.g., hearing aids)	❒	❒	❒	❒
g. Educational interventions for hearing loss	❒	❒	❒	❒
h. Genetics of hearing loss	❒	❒	❒	❒

- **Q14. Did your training prepare you adequately to meet the needs of infants with permanent hearing loss?**

  ❒ Yes ❒ No ❒ Unsure

- **Q15. What has been your primary source of information about newborn hearing screening?**

  _____

- **Q16. For each item below, please indicate the level of need you believe physicians have for that type of information related to permanent hearing loss in children.**

	Great Need	Somewhat of a need	No need
a. Methods of screening	❒	❒	❒
b. Protocol for follow-up of screening	❒	❒	❒
c. Methods of screening children 0-5 during well-child visits	❒	❒	❒
d. Guidelines for informing families about screening results	❒	❒	❒
e. Impact of different degrees of hearing loss on infant language	❒	❒	❒
f. Early intervention options	❒	❒	❒
g. Guidelines for screening for late onset hearing loss	❒	❒	❒
h. Useful contacts for more information	❒	❒	❒
i. Patient education resources	❒	❒	❒
j. Hearing aids and cochlear implants	❒	❒	❒
k. Genetics and hearing loss	❒	❒	❒
l. Other (describe) _____			

- **Q17. How confident are you in talking to parents of a child with permanent hearing loss about….?**

	Very Confident	Somewhat Confident	Not Confident	Unsure
a. Causes of hearing loss	❒	❒	❒	❒
b. Use of sign language vs. auditory/oral communication	❒	❒	❒	❒
c. Consequences of unilateral or mild hearing loss	❒	❒	❒	❒
d. Consequences of bilateral hearing loss of moderate to profound degrees	❒	❒	❒	❒
e. Which infants may be candidates for cochlear implants	❒	❒	❒	❒

- **Q18. How helpful would the following types of materials be to you in your practice?**

	Very Helpful	Somewhat Helpful	Not Helpful
a. Grand rounds material that can be downloaded and personalized	❒	❒	❒
b. Laminated cards with clear protocol steps	❒	❒	❒
c. CDs or DVDs to use in patient education	❒	❒	❒
d. Web site that is frequently updated with information for physicians	❒	❒	❒
e. Brochures to use in patient education	❒	❒	❒
f. Videotapes to use in patient education	❒	❒	❒
g. On-line CME course dealing with newborn hearing screening and hearing loss	❒	❒	❒
h. Other (describe)_____			

- **Q19. How frequently do you use the internet to access information about medical topics?**

  ❒ Frequently ❒ Sometimes ❒ Rarely ❒ Never

- **Q20. Please list any professional medical organizations that have published policy statements about newborn hearing screening:**

  _____

  _____

- **Q21. Does your state have an Early Hearing Detection and Intervention program?**

  ❒ Yes ❒ No ❒ Unsure

- **Q22. Please list below any other concerns you have about newborn hearing screening, diagnosis, and intervention:**

  _____

  _____

  _____

  _____

  _____

Please tell us about yourself:

Type of practice:

- ❒ Pediatrician
- ❒ OB/GYN
- ❒ Family Practice Physician
- ❒ Neonatologist
- ❒ Otolaryngologist
- ❒ Internal Medicine Specialist
- ❒ Resident in _____
- ❒ Other (specify) _____

Practice setting:
(where you spend most of your time):

- ❒ Private practice or community clinic
- ❒ Hospital setting
- ❒ Medical school or parent university
- ❒ Other (specify) _____

Practice Location **State:** _____

- ❒ Metropolitan area
- ❒ Small town
- ❒ Rural area

Gender: ❒ M ❒ F

Year of birth: _____

Years of practice with pediatric population: _____

Thank You!

Primary Care Physicians' Knowledge, Attitudes, and Practices Related to Newborn Hearing Screening

Mary Pat Moeller, Karl R. White and Lenore Shisler

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