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Pediatrics 2007;120:288-294
DOI: 10.1542/peds.2006-2454

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Medical Home for Children With Hearing Loss: Physician Perspectives and Practices

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The authors have indicated they have no financial relationships relevant to this article to disclose.

ABSTRACT

OBJECTIVE. Our goal was to evaluate Rhode Island pediatricians’ view of themselves as the medical home for infants and young children with permanent hearing loss.

METHODS. An observational study was conducted between September 2001 and March 2002. A survey of knowledge, beliefs, and practices relative to newborn hearing screening was sent to Rhode Island pediatricians practicing primary care for children aged birth to 5 years. The data set consisted of 107 (52%) of the eligible physicians.

RESULTS. Seventy-two percent of the pediatricians reported caring for 1 to >5 patients with permanent hearing loss within the past 5 years. Sixty-three percent of the pediatricians reported that the professional who has primary responsibility for follow-up planning for these children is the primary care physician, and 59% agreed that they were the medical home for their patients with hearing loss. However, only 43% agreed that their practice was well informed of services for their patients, and only 45% felt well informed about paths of follow-up. Sixty-three percent of the pediatricians agreed that they should coordinate care, but only 41% reported that they do coordinate care most of the time or always. The pediatricians’ preferred methods for receiving educational information were resource guide (85%), grand rounds (75%), or journal articles (73%).

CONCLUSIONS. By contrasting pediatricians’ medical home beliefs with actual reported care-coordination practices, we show that there is a disconnect between beliefs and practice. The survey demonstrated that physician belief ratings were consistently higher than the practice ratings, which suggests that the motivation exists but that additional educational efforts and strategies for enhanced care coordination are needed to develop an effective, seamless medical home for children with permanent hearing loss.
EARLY DETECTION AND intervention for permanent hearing loss (HL) has been shown to improve language outcomes for children.\(^1,2\) Since 1993, there has been a Rhode Island state mandate (RI Pub L No. 23-23-13) that all newborns have their hearing screened before discharge from the hospital. Since implementation of this mandate, the Rhode Island Hearing Assessment Program has screened the hearing of 99% of newborns in Rhode Island.\(^3\) A hearing follow-up committee was formed in 1994 to address quality assurance for the Rhode Island Early Hearing Detection and Intervention (EHDI) system. This working group received repeated reports of the stress and distress that families experience with the EHDI process because of lack of accessible information and services, fragmentation of service provision, and poor coordination of services. It was noted that, historically, these issues were common for families of children with a variety of special health care needs (CSHCN),\(^4,5\) In efforts to improve patient care for CSHCN, the medical home concept was originally proposed in the 1960s, primarily as a single repository of medical information, and further refined and developed in Hawaii in the 1980s.\(^6\) In 1992, the American Academy of Pediatrics further developed the concept of a medical home for all CSHCN to be defined as an approach to providing health care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.\(^6\) In 2000, the Joint Commission on Infant Hearing described the role of the infant’s pediatrician as to “function as an advocate for the whole child within the context of the medical home.”\(^7\) Although >90% of infants in the United States currently have their hearing screened at birth, almost half of those referred for diagnostic evaluation do not receive it.\(^8\) The pediatrician, as part of a well-functioning medical home, can be critical in insuring timely diagnosis, early intervention, family support, and ultimately, better long-term outcomes for infants identified with HL. A review of the literature reveals limited information on physicians’ perceptions of themselves as the medical home for children with HL. One recent survey of primary care physicians in 21 states regarding newborn hearing screening indicated knowledge gaps of medical management and follow-up interventions for infants in EHDI systems.\(^9\) Our study examines this important area further by evaluating pediatric primary care physicians’ beliefs and practices relative to the medical home and EHDI systems in the state of Rhode Island.

The objectives of this study were to (1) determine whether pediatricians believe themselves to be the medical home for infants and young children with HL, (2) describe pediatricians’ reported office coordination practices, specialty service provider interactions, referral patterns, and knowledge of newborn hearing screening, follow-up, and intervention, (3) evaluate pediatricians’ beliefs about the psychological impact of HL on families, and (4) identify pediatricians’ preferred educational modalities for becoming better informed in these areas.

METHODS

An observational study was conducted between September 2001 and March 2002. Inclusion criteria for the study included Rhode Island pediatricians and family practitioners practicing primary care for patients aged birth to 5 years. Neonatologists were included because of their involvement with hearing screening of a high-risk population, and because during the newborn period, neonatologists often function as the infant’s primary care doctor and medical home.

We requested mailing labels from the office of the Rhode Island Board of Medical Licensure for all physicians (309) who identified themselves as pediatricians or family practitioners on their applications for licensure. A total of 102 practitioners were excluded because of one of the following: (1) practiced subspecialty medicine without primary care; (2) did not care for patients 0 to 5 years of age; (3) not actively in practice; (4) no longer in state; or (5) deceased.

A 39-question survey was developed by the multidisciplinary research team with input from providers and parents, and a review of the literature. The survey included the following areas: demographics of practice, coordination practices, medical home beliefs, psychological impact, general knowledge, and preferences for educational experiences. The majority of questions contained a 5-point Likert scale that allowed for varying degrees of agreement ranging from “strongly disagree” to “strongly agree,” or “never” to “always,” with a neutral option.

The survey was initially piloted with 5 pediatricians who were subsequently excluded from the final survey analysis group. These individuals were selected on the basis of their knowledge of medical home concepts and experience in working with families of children with HL. The survey was then revised to ensure clarity and ease of completion and approved by the institutional review board at Women and Infants’ Hospital before distribution. Informed consent was waived for this mail survey. The survey was then mailed to 207 eligible providers. A second mailing, reminder letters, and 1 telephone call were implemented over 6 months to nonresponders, resulting in 107 (52%) of 207 eligible physicians’ surveys included in the analysis.

The term “pediatrician” will be used throughout the remainder of the article to refer to all physicians included in the study.

All statistics were calculated by using the Statistical Package for the Social Sciences (SPSS, Chicago, IL). Frequencies were calculated for each item. Variable ratings ranged from 0 (never) or 1 (strongly disagree) to always (4) and strongly (5) agree. Because not all physicians
responded to all questions, the number (n) is listed in the text and tables.

RESULTS
The mean age of respondents was 45 years (range: 29–78 years), and 46.7% were women, as shown in Table 1. Ninety-eight respondents (91.6%) listed themselves as practicing strictly primary care, and 77.5% described their office setting as being a private office. Average years in practice was 14.6 years (range: 1–54 years). Seventy-two percent of pediatricians had >1 patient in their practice with permanent HL, and 9.3% reported ≥5 patients.

To identify pediatricians’ overall beliefs about professional responsibility for care coordination, the following question (not shown in a table) was asked, “Which professional has primary responsibility for follow-up planning (testing, parent support, referrals, intervention) for patients with HL birth to 5 years?” Although 66 (62.9%) stated it was the primary care provider, the remainder responded with the following: audiologist (13.3%), combination of professionals (9.5%), otolaryngologist (5.7%), early intervention (3.8%), and other (4.8%).

Table 2 shows whether pediatricians perceived themselves as the medical home for children with HL and how well informed they felt in areas important to coordinating care for these infants. Fifty-nine percent agreed or strongly agreed that their practice was the medical home for their patients with HL, and 62.6% that they should be coordinating services. Fifty-six percent agreed that it was their role to help parents create an intervention plan, and 72.7% agreed that pediatrician guidance is needed to meet a child’s educational needs. However, only 45.1% agreed that they are well informed about paths of follow-up care, and only 43.3% reported that their practices are well informed about the services needed for children with HL.

Table 3 shows the frequencies with which pediatricians reported that they were performing specific care-coordination practices. Forty-one percent stated that they coordinated the follow-up planning and care for their patients with HL always or most of the time, whereas 16.2% reported they never or rarely coordinated care. In addition, 37% stated that they never or rarely had ongoing communication with audiologists, 79.2% rarely or never participated in developing the individualized family service plan (IFSP), and 72.2% rarely or never participated in developing an individualized education program (IEP) for patients with HL.

Comparisons were made between specific beliefs (Table 2) and coordination practices (Table 3). Although 67 (62.6%) pediatricians believed that their practices should coordinate services for their patients with HL, only 41 (41.4%) reported that they actually did coordinate care most of the time or always. In addition, 58 (55.8%) believed they should help create an intervention plan, and 77 (72.7%) believed they should provide guidance in educational planning. However, only 8

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Characteristics of the Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
<td>Results</td>
</tr>
<tr>
<td>Age, mean (range), y</td>
<td>45 (29–78)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>57 (53.3)</td>
</tr>
<tr>
<td>Female</td>
<td>50 (46.7)</td>
</tr>
<tr>
<td>Practice type</td>
<td></td>
</tr>
<tr>
<td>Primary care alone</td>
<td>98 (91.6)</td>
</tr>
<tr>
<td>Primary care with subspecialty</td>
<td>4 (3.7)</td>
</tr>
<tr>
<td>Neonatology</td>
<td>5 (4.7)</td>
</tr>
<tr>
<td>Practice setting</td>
<td></td>
</tr>
<tr>
<td>Private office</td>
<td>79 (77.5)</td>
</tr>
<tr>
<td>University or hospital based</td>
<td>14 (13.7)</td>
</tr>
<tr>
<td>Community health center</td>
<td>9 (8.8)</td>
</tr>
<tr>
<td>Years in practice</td>
<td></td>
</tr>
<tr>
<td>0–5</td>
<td>25 (25.0)</td>
</tr>
<tr>
<td>6–13</td>
<td>28 (28.0)</td>
</tr>
<tr>
<td>14–20</td>
<td>27 (27.0)</td>
</tr>
<tr>
<td>&gt;20</td>
<td>20 (20.0)</td>
</tr>
<tr>
<td>Patients with HL</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>30 (28.0)</td>
</tr>
<tr>
<td>1–2</td>
<td>41 (38.3)</td>
</tr>
<tr>
<td>3–5</td>
<td>26 (24.3)</td>
</tr>
<tr>
<td>&gt;5</td>
<td>10 (9.3)</td>
</tr>
</tbody>
</table>

TABLE 2 | Medical Home Beliefs

<table>
<thead>
<tr>
<th>Specific Statements</th>
<th>n</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My practice is the medical home for my pediatric patients with HL.</td>
<td>105</td>
<td>4 (3.8)</td>
<td>5 (4.8)</td>
<td>34 (32.4)</td>
<td>43 (40.9)</td>
<td>19 (18.1)</td>
</tr>
<tr>
<td>My practice should coordinate services for my pediatric patients with HL.</td>
<td>107</td>
<td>0 (0.0)</td>
<td>12 (11.2)</td>
<td>28 (26.2)</td>
<td>55 (51.4)</td>
<td>12 (11.2)</td>
</tr>
<tr>
<td>It is the primary physician’s role to help parents create an intervention plan for a child with HL.</td>
<td>104</td>
<td>1 (1.0)</td>
<td>17 (16.3)</td>
<td>28 (26.9)</td>
<td>49 (47.1)</td>
<td>9 (8.7)</td>
</tr>
<tr>
<td>Parents need their primary care physician’s guidance to have their child’s educational needs met.</td>
<td>106</td>
<td>0 (0.0)</td>
<td>4 (3.8)</td>
<td>25 (23.6)</td>
<td>57 (53.8)</td>
<td>20 (18.9)</td>
</tr>
<tr>
<td>My practice is well informed about the paths of follow-up care for infants identified with HL.</td>
<td>104</td>
<td>3 (2.9)</td>
<td>26 (25.0)</td>
<td>28 (26.9)</td>
<td>43 (41.3)</td>
<td>4 (3.8)</td>
</tr>
<tr>
<td>My practice is well informed of the services my pediatric patients with HL receive.</td>
<td>104</td>
<td>3 (2.9)</td>
<td>28 (26.9)</td>
<td>28 (26.9)</td>
<td>40 (38.5)</td>
<td>5 (4.8)</td>
</tr>
</tbody>
</table>

The framing statement was: HL in children impacts family life and parenting. Consequently, parents may look to their physicians for opinions and advice. Based on your knowledge, beliefs and experience please respond to the following statements.
(8.8%) reported participating in development of IFSPs and 10 (10.3%) in the development of IEPs most of the time or always.

The percentage of respondents marking “unsure” to questions related to technical knowledge ranged from 10.6% to 37.4%. Only 21 (19.6%) respondents knew that the initial in-hospital failure rate for Rhode Island newborn hearing screening was 2%. Of the tests that are used in the screening and diagnosis of HL, 28% of physicians correctly identified otoacoustic emissions as a test of cochlear function, 70% reported that automated auditory brainstem response screening tests neural integrity, and 35% knew that visual reinforcement audiometry can be used to obtain responses to specific sounds in typical children as young as 6 months of age.

In an open-ended question physicians were asked, “In your practice, which factors would cause you to refer a child for a hearing test?” Ninety-nine of 107 physicians responded, providing, on average, 3 answers (range: 1–5). Pediatricians would refer for the following reasons: 77 (77%) would refer if a parent expressed concern regarding speech, language, or developmental delay; 45 (45%) if there was recurrent or persistent otitis media; 38 (38%) for a “failed hearing test” either in the newborn hearing screen, office, or school; 18 (18%) for a family history of HL; 14 (14%) for syndromes known to include HL; 6 (6%) for a history of extracorporeal membrane oxygenation; 4 (4%) for prolonged mechanical ventilation; 4 (4%) for postnatal infections; for example, bacterial meningitis; 4 (4%) for reasons related to antibiotic use; 4 (4%) for behavioral or attention issues; 3 (3%) for hyperbilirubinemia; 2 (2%) for head trauma; 2 (2%) for very ill newborns; and 1 (1%) for excessive noise exposure. Intrauterine infections were not included as a reason for referral.

Table 4 includes beliefs about the psychological impact of childhood HL on the family and knowledge regarding frequently used assessment and intervention tools. Ninety-eight (91.6%) pediatricians agreed that parents whose children are diagnosed with HL experience a grief response, and 87% of physicians agreed that addressing the emotional needs of parents was integral to the primary care of children with HL.

Sixteen (14.9%) agreed that hearing aids can correct hearing to normal in the way glasses correct vision. Ten percent agreed, and 35 (34.3%) were unsure whether cochlear implants restore hearing to normal. Six (5.6%) respondents believed that sign language interferes with the development of speech.

Physicians reported that they would be likely or highly likely to use educational information about HL in children in the following formats: (1) a resource guide on care in Rhode Island (90 [85%]), (2) grand rounds (78 [75%]), and (3) professional journal articles (75 [73%]). Just over half of pediatricians (62 [59%]) reported they would be likely to attend a meeting about state resources, and 60 (57%) would access the Web. Pediatricians reported that they were less likely to attend seminars on improving communication skills with families (31 [30%]), counseling skills (29 [28%]), (3) parents’ emotional response to the diagnosis (32 [33%]), and (4) medical home for children with HL (38 [37%]).
Finally, through an open-ended question, physicians were asked what recommendations they had to improve Rhode Island’s newborn hearing screening program and follow-up care. Thirty (28%) responded. The individual recommendations focused on issues in 2 areas: (1) improved care coordination (25 [83.3%]) and (2) education about HL, newborn hearing screening, and follow-up (24 [80%]). Specific recommendations for improving care coordination were as follows: (1) all hearing screen results should be in the newborn chart or sent to the pediatrician; (2) improve communication among professionals; (3) develop an algorithm for physicians listing specific tests and referral specialists; (4) a letter indicating a failed screen should be followed by a call to further coordinate diagnosis and treatment; (5) create a team for consultation and delivery of a care plan; and (6) create a “hearing center of excellence.” Recommendations related to education included the following: (1) provide more training in residency programs; (2) develop physician guidelines for care of children with HL; (3) create a succinct resource guide for physicians; and (4) develop resource materials for families explaining stages of the screening process.

DISCUSSION
More than half (52%) of the pediatricians in Rhode Island providing primary care for children aged 0 to 5 years responded to the survey. This rate of return is consistent with mean response rates for surveys mailed to physicians. It was reassuring that the majority of pediatricians felt they were the medical home for infants and children with HL, supporting our primary hypothesis. However, the findings point to significant gaps in knowledge of the specifics of newborn hearing screening, diagnosis, and interventions, supporting our second hypothesis. Although the majority of pediatricians believed themselves the medical home, they felt ill informed on paths of follow-up and needed services. Our findings are consistent with Moeller et al., who recently reported important gaps in knowledge of physicians caring for children with HL that relate to medical management and parent support.

Physicians answering the survey represented approximately equal numbers of men and women, and a wide range of age, years in practice, as well as practice setting. The survey population approximates Rhode Island and national data for pediatrician gender, age, and practice setting (R. Burke, MD, MPH, and M. Spoerri, PT, MPH, written communication, 2006). The data provide information on pediatricians in Rhode Island who are both experienced and less experienced with managing permanent HL in infants and young children. The majority (72%) reported some to moderate experience (range: 1 to >5 patients with HL within 5 years). The low number of patients per physician reflects the incidence of childhood HL. In a pediatrician’s lifetime in practice, he/she is likely to encounter ~12 patients with severe HL.

It is of interest that about two thirds of pediatricians felt they have primary responsibility for follow-up planning for patients with HL, whereas one tenth listed a team of professionals. The success of EHDI programs along with the medical home model depends on pediatricians, other professionals, and families working in partnership as a well-coordinated team. Development of successful medical homes for children with HL must include strategies that support team collaboration and communication.

By contrasting pediatricians’ medical home beliefs with actual reported care-coordination practices, we demonstrate a disconnect between beliefs and practice. Sixty-three percent of pediatricians agreed that they should coordinate care, but only 41% reported that they actually do coordinate care most of the time or always. Although 55.8% agreed that the pediatrician should help create an intervention plan, and 72.7% agreed that they should provide guidance in educational planning, only 9% reported participating most of the time or always in the development of IEPs and only 10% in development of IEPs. We speculate that the discrepancy between care-coordination beliefs and practices may be related to factors such as lack of communication among professionals, time constraints, and the costs of care coordination. It is important to note that pediatrician involvement often includes informal counseling and guidance, and our questionnaire may not have tapped into the ways pediatricians are commonly involved in intervention and educational planning.

Pediatricians are in a key position to educate families after newborn hearing screening and to help ensure expedient follow-up and appropriate surveillance. Our survey questions attempted to assess pediatricians’ knowledge of common tests used in infant hearing screening and diagnosis and intervention technologies that might affect how physicians counsel families. Survey results indicated pediatricians continue to need education about technical aspects of hearing screening, audiologic testing, amplification, and the EHDI system. Although the majority of physicians reported that their practices were not well informed of the services their patients with HL received, it was not clear whether physicians would most need education about the types of services children need; for example, options for communication interventions, hearing aid fitting, cochlear implants, and so on, or how actually to obtain these services.

Audiologists play a pivotal role in the diagnosis and management of HL, but physicians may not appreciate that audiologists and state EHDI coordinators may have the most current information and skills to provide coordinated care. The majority of pediatricians in Rhode Island reported limited communication with the pa-
tient’s audiologist. Although approximately half of the physicians felt that the written reports from audiologists helped them to understand the developmental implications for their patients, more than one third found the reports helpful only sometimes, rarely, or never. To provide the most effective medical home for families, mechanisms for increasing meaningful communication between pediatricians and audiologists need to be explored.

It was reassuring that 77% of physicians reported that parent concern would prompt them to refer for hearing evaluation. Before universal newborn hearing screening, there were reports of late diagnosis of HL, even after parents expressed concern much earlier. Our study results suggest that pediatricians are recognizing the value of parent observation. Only 44% of physicians reported that they would refer for persistent otitis media. Other risk factors associated with “delayed-onset” HL were listed rarely or not at all. It is important that pediatricians be updated in an effective and regular manner on risk factors for HL to prevent delays in the diagnosis. The American Academy of Pediatrics, in partnership with the National Center for Hearing Assessment and Management and the Centers for Disease Control and Prevention, have focused educational efforts on EHDI systems. An algorithm developed to inform physicians of the EHDI process contains a clear list of risk factors.

One element of a successful medical home is that it is compassionate, and resolution of parental grief was found to be associated with better language outcomes in children with HL. For this reason, the study queried the perspectives of pediatricians regarding the psychological impact of HL on families. It was encouraging to find that pediatricians recognized the grief response experienced by families when their infant is diagnosed with HL.

To optimize educational opportunities and create comprehensive medical homes, it is important to identify physicians’ desired formats for receiving information. Pediatricians in our survey stated they would be most likely to use a state-specific resource guide, grand rounds, and professional journal articles; approximately half of the pediatricians would use the Internet. Studies indicate that the Internet is frequently underused by physicians for information about newborn hearing screening. In addition, although physicians identified didactic sessions and written materials as their preferred modes of education, research demonstrates that these techniques alone may have little effect on changing physician practices or health care outcomes. Interactive and sequenced (learn-work-learn) methods were shown to result in larger affected change.

One third of the respondents chose to answer an open-ended question that requested their recommendations to improve Rhode Island’s EHDI system. The suggestions to improve documentation, communication, education, and training, if shared with the state EHDI team, can help direct changes in care and coordination practices that will better support the development of effective and more satisfying medical homes for children with HL.

We believe this study provides a valuable window into issues affecting medical homes for children with HL in Rhode Island. The study has limitations: (1) although the sample represented a geographic area, the sample size was small; (2) it is possible that nonresponders were less motivated, which could have biased the results; however, previous studies of mailed physician surveys reveal only modest response bias in nonresponders; (3) improvements have occurred in EHDI systems since the data were collected; and (4) the data were based on self-report and may vary from actual practices if measured objectively.

CONCLUSIONS

A total of 72% of responding pediatricians in Rhode Island reported caring for children <5 years of age with HL. The majority felt they were the medical home for children with HL. However, this was not reflected in their reported care-coordination practices, and they felt ill informed about the paths of follow-up and needed services. Although progress is being made in the development of effective medical homes for children with HL, the fact that physician belief ratings were consistently higher than the practice ratings suggests that the motivation exists, but that additional educational efforts and strategies for enhanced care coordination are needed. Additional research is needed to evaluate whether interventions developed from physician input lead to better outcomes and more seamless EHDI experiences for infants and families.

ACKNOWLEDGMENTS

This work was supported in part by project 1 H61 MC 00009 from the Maternal and Child Health Program (Title V, Social Security Act), Health Services Administration, Department of Health and Human Services.

We gratefully acknowledge the contributions of Ellen Amore, MS, Robert Burke, MD, MPH, Ellen Gurney, MD, David Robinson, EdD, Boris Skurkovich, MD, Christina Zarcadoolas, PhD, and all the Rhode Island physicians who participated in this study.

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