

Pediatricians' Comfort Level in Caring for Children With Special Health Care Needs



Megumi J. Okumura, MD, MAS; Heather A. Knauer, PhD; Kris E. Calvin, BA; John I. Takayama, MD, MPH

From the Division of General Pediatrics (Drs Okumura, Takayama, and Knauer), Division of General Internal Medicine (Dr Okumura), Phillip R. Lee Institute for Health Policy Studies (Dr Okumura), University of California, San Francisco; School of Public Health (Dr Knauer), University of California, Berkeley; and American Academy of Pediatrics, California Foundation (Ms Calvin), American Academy of Pediatrics, California, Sacramento

The authors have no conflicts of interest to disclose.

Address correspondence to Megumi J. Okumura, MD, MAS, 3333 California St, STE 245, San Francisco, CA 94118 (e-mail: megumi.okumura@ucsf.edu).

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ABSTRACT

BACKGROUND: Few studies have investigated pediatrician attitudes about providing primary medical care for children with special health care needs. The objective of this study was to determine pediatrician perspectives on their comfort level in providing care and on where the medical home should be for children with chronic medical and developmental conditions.

METHODS: Survey of pediatricians in California in 2014. Pediatricians were randomized to receive surveys featuring either a case of a child with a chronic medical (neurofibromatosis) or a developmental condition (autism). They were then asked about their comfort level in providing primary care for the child. We developed logistic regression models to adjust for practice and provider factors, and availability of family social resources.

RESULTS: The survey response rate was 50.2%. Primary care pediatricians expressed more comfort than nonprimary care pediatricians in providing a medical home for a child with chronic medical or developmental condition (range, 84%–92% comfort-

able vs 58%–79% comfortable), respectively. All pediatricians expressed more comfort providing care for a child with autism than neurofibromatosis. Nearly all primary care pediatricians (90%) believed that the medical home should be in pediatric primary care practice. Pediatrician comfort in becoming a medical home was higher when the family had more social resources.

CONCLUSIONS: Most pediatricians endorse that the medical home for children with special health care needs be in the primary care setting. Improving access to subspecialty care and providing resources, such as case management, to address family social complexity might raise pediatrician comfort in providing primary care to children with medical and developmental conditions.

KEYWORDS: children with special health care needs; medical home; pediatrician; pediatrician comfort

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WHAT'S NEW

We describe the different comfort levels of pediatricians in caring for a child with a medical (neurofibromatosis) or behavioral (autism) condition. We also study practice and demographic factors associated with their comfort for treating each condition.

HIGH-QUALITY PRIMARY CARE for children with special health care needs (CSHCN) includes assuring access to a wide range of service providers and supports. These often vary depending on the medical and/or behavioral condition of the child; pediatric practices, therefore, must respond to the individual needs of each child and family. The American Academy of Pediatrics (AAP) proposes that primary care be coordinated by a family-centered, community-based “medical home.”^{1–3} Receiving care in a medical home might decrease hospitalization rates and improve health outcomes and family/patient satisfaction.⁴ With such potential benefits, the “medical home” is currently

being promoted by leading primary care organizations⁵ and has been emphasized in the Affordable Care Act.⁶

In California, 38% of families of CSHCN, lower than the national average of 43%, report receiving care in a medical home.⁷ To assure that all CSHCN have access to a medical home, it is critical to understand existing barriers to care. If pediatricians are not comfortable providing care for CSHCN in their practices, it would be difficult to assume that they would be a medical home for this population.⁸ To date, few studies have explored pediatricians' perspectives on their comfort level in caring for CSHCN in their practice or their willingness to be the medical home for CSHCN.^{9,10} Identifying barriers as well as facilitators to serve CSHCN can potentially guide policy and secure resources to improve access and quality of care for these children.

Previous studies suggest that provider-level factors, such as limited clinical resources and lack of time,^{8,9} affect the comfort level of pediatricians to care for CSHCN.¹⁰ Type of health condition and resources families bring to the caregiving process have not been

addressed in previous studies. We conducted a survey of practicing pediatricians in California: 1) to identify factors associated with being comfortable being the primary medical home provider for a child with either a medical or developmental health condition, and 2) to determine whether type of health condition and extent of provider and family resources are associated with pediatrician's level of comfort caring for CSHCN.

METHODS

STUDY SUBJECTS AND SURVEY ADMINISTRATION

Study subjects were identified through the AAP registry as active members of AAP California Chapters 1 through 4 as of December 30, 2013. Pediatricians were eligible for the study if their AAP membership designated them as "fellow members." Pediatricians who listed addresses outside of California, were not currently seeing patients, or were in training programs were excluded. The survey was conducted between May 2014 and October 2014, with closure of the study in January 2015. Initial e-mails encouraging completion of the online survey were sent to eligible pediatricians; these were followed by a mailed postcard introduction and 2 waves of paper surveys mailed 2 months apart. We sent 2 reminder e-mails after mailing the paper surveys. Participants initially received a \$5 gift card to complete the survey. To help increase response after the second survey wave, the incentive was increased to a \$10 gift card. Among 2646 eligible pediatricians, 77 were excluded because of inactive addresses, leaving a final eligible sample of 2569. The survey instruments are available from the authors upon request.

SURVEY DEVELOPMENT AND QUESTIONS

The survey was part of a larger initiative directed by the Lucile Packard Foundation for Children's Health with the AAP California Foundation (AAP-CA), in cooperation with the California Children's Specialty Care Coalition, to improve the care of CSHCN in California. To develop the survey, a literature review was conducted, followed by focus groups of key stakeholders identified by AAP-CA to explore domains related to the comfort level and capacity of pediatricians to care for CSHCN in their practices. Survey questions were developed on the basis of the domains, with some adapted from other surveys,¹¹⁻¹³ and appraised by a technical advisory panel; the resultant survey was then pretested with 15 practicing pediatricians.

DEFINING CSHCN, PRIMARY CARE, AND THE MEDICAL HOME

For the purposes of the survey and to decrease potential variations in interpretation of terms, we introduced pediatricians to standardized definitions of CSHCN, primary care, and the medical home. We used a modified Maternal Child Health Bureau definition of CSHCN,¹⁴ defined primary care using the Institute of Medicine definition of primary care,¹⁵ and used the AAP definition of the medical home¹⁶ (Supplementary Appendix 1).

DEFINING PRIMARY CARE PHYSICIAN VERSUS NONPRIMARY CARE PHYSICIAN

We defined and refer to pediatricians as "primary care pediatricians" if they indicated that they provided any type of primary care within their practice. Those providing a mix of primary and nonprimary care were classified as primary care pediatricians. Nonprimary care pediatricians were those who were 100% in subspecialty practice, hospitalists, urgent care providers, or "other."

PHYSICIAN AND PRACTICE CHARACTERISTICS

The survey asked respondents to indicate their sex, age, years in practice, practice type/setting, practice location, and proportion of patients with public health insurance in their practice.¹¹ In California, California Children's Services (CCS; California Title V) is a program that increases reimbursement and provides case management support to pediatricians who provide care for CSHCN. Therefore we asked if pediatricians were registered as CCS providers. The availability of various subspecialists and ancillary service providers was determined by responses to the question "Please indicate the availability of the following [subspecialty] providers for your patients and your practice." The complete list of subspecialists is included at the bottom of Table 1. A composite measure of accessibility to the 11 pediatric subspecialists was created using a 0 to 11 scale. The proportion of CSHCN was on the basis of pediatrician-reported proportion of practice that consisted of "Children who have a chronic physical, developmental, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."¹⁴ We describe the proportion of type of CSHCN in practice according to type/complexity.

CLINICAL VIGNETTES FOR CSHCN: ADDRESSING BEHAVIORAL AND MEDICAL CONDITION NEEDS

During survey instrument development, focus groups with experts and other stakeholders revealed that specific health care delivery processes differ between CSHCN with predominantly developmental/behavioral problems and CSHCN with medical conditions. Therefore, we designed the survey to include a case vignette that represented 1 of 2 different conditions. One (behavioral) featured a child with autism with developmental and behavioral needs; the other, a child with neurofibromatosis (medical) requiring coordination of care among a variety of subspecialists. Each of these cases was constructed to represent a child who was expected to be cared for by a primary care pediatrician, but would require significant consultation and care from pediatric subspecialists. Another key theme raised in focus groups was the availability of family social capacity, which included the ability of the family to accurately gauge the child's health and health care needs, to obtain necessary supports from within the family and community, and to navigate the complex network of services. To consider type of condition as well as family social capacity, we expanded the vignettes from 2 to 4 (Supplementary

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