

## Enhanced Access and Parents' Preferred Contact for a Child's Chronic Condition

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**Objectives** To assess whether the perception of enhanced access by parents in their child's primary care and main specialty practices is associated with preference for contacting either practice when problems arise with a child's chronic condition.

**Study design** In this cross-sectional survey study of parents whose children use both primary and specialty practices, we assessed perceptions of 3 components of enhanced access: (1) appointment availability when needed, (2) electronic communication with practices, and (3) other staff that help manage a child's health care needs. Parents also indicated which practice they would contact for an exacerbation of the main chronic condition for which the child receives specialty care. We used logistic regression to examine relationships of enhanced access components in both practices with parents' indicated practice.

**Results** Among 609 parents, 244 (40%) would contact primary care and 365 (60%) the main specialty practice for a chronic condition exacerbation. Although parents perceived enhanced access components with similar frequency in both settings, enhanced access was associated only with preference for contacting the main specialty practice: e-mail communication (aOR for preferring the specialty practice 2.0 [1.3, 3.2]) and staff that coordinate a child's care needs (aOR 2.8 [1.4, 5.9]).

**Conclusions** Enhanced access is associated with preference for addressing chronic condition exacerbations in specialty but not primary care. Future study should further identify factors important to parents in deciding when and how to contact practices and should seek to develop family-centered communication within medical homes that integrate primary and specialty care. (*J Pediatr* 2016;■■■:■■■-■■■).

Between 5% and 10% of US children receive ongoing care from both primary care and specialty physicians for a chronic condition.<sup>1-3</sup> Physicians caring for these children should establish shared management plans and clear roles.<sup>4</sup> However, parents often lack this guidance and must decide whom to contact when they have concerns about a child's chronic condition.<sup>3,5-7</sup> Advance planning for communication is important to aid parents deciding who to contact and to improve family-centered outcomes. Lack of appropriate communication about children's care needs is associated with lower family satisfaction, inappropriate care, and unmet needs.<sup>8-11</sup>

Perceptions of access to physicians may influence parents' decisions about whom to contact. The concept of enhanced access is a feature of the medical home that includes "open scheduling, expanded hours, and new options for communication between patients, their personal physician, and practice staff."<sup>4,12,13</sup> Implementation of enhanced access has focused on primary care, though specialty practices can now receive recognition for providing medical home care.<sup>14-16</sup> Enhanced access to both primary and specialty practices may give parents multiple, efficient ways to receive advice and care, but may also complicate decisions about who to contact and lead to misdirected or redundant communication.

Many parents experience and value enhanced access at their child's primary care practice,<sup>17,18</sup> but little is known about enhanced access in specialty care, or about how it might relate to parents' preferences for where a child receives care for a chronic condition exacerbation. Better understanding of these aspects of enhanced access will inform conversations about role allocation and allow parents and physicians to develop shared management plans.

In this cross-sectional study, we assess how parents' perceptions of enhanced access in primary care and specialist practices relate to their practice preference when concerned about an exacerbation of a child's chronic medical condition. We hypothesized parents would perceive enhanced access more commonly in primary than in specialty practices and that enhanced access in either type of practice would be associated with preference to contact that practice.

### Methods

We conducted a cross-sectional survey of caregivers (hereafter "parents") of children up to 18 years of age returning to any of 30 subspecialty clinics (**Table I**; available at [www.jpeds.com](http://www.jpeds.com)) at a tertiary-care children's hospital in the southeastern

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US. The overall study assessed parents' general perceptions of the medical home as experienced in primary care and specialty practices. A separate manuscript currently under review reports the general findings, but only the present study addresses enhanced access and preferences for where to seek care.

We used convenience sampling to capture a large sample and to minimize cost and clinic flow interruptions. Eligible parents for this analysis were those who could complete a questionnaire in English and who reported at least 1 chronic condition for their child. Clinic registration staff gave questionnaires to all parents attending a return visit between September 1 and October 31, 2012. Participants were those who returned questionnaires at clinic check-out. To assure anonymity, the questionnaire contained no identifiable patient information. A unique survey identification number generated from, but not linked to, each child's name prevented duplicate submissions. The University of North Carolina-Chapel Hill Biomedical Institutional Review Board approved the study (Institutional Review Board #11-1939).

### Survey and Study Measures

The questionnaire assessed parents' perceptions of 3 components of enhanced access: appointment availability when needed; electronic communication with practices; and availability of nurses and other staff to help manage a child's condition (Figure; available at [www.jpeds.com](http://www.jpeds.com)). We also asked which practice (primary care or specialty) they would contact with acute concerns about a child's main chronic condition. We did not ask about telephone access because our main interest was the relationship between new modes of access to practices and parents' preference for which to contact. To focus on concern about chronic conditions, the questionnaire asked who parents would contact about a "typical childhood problem," such as sore throat or ear ache. We defined enhanced access using 3 prompts (below paragraph) derived from the Medical Home Index Survey and from the National Committee for Quality Assurance 2011 certification process.<sup>13,19</sup> We modified the questionnaire based on a pilot phase in which 50 parents completed questionnaires and follow-up interviews with an on-site research assistant to validate their responses.

The main outcome was parents' choice of a child's primary care or "main" specialty practice in response to the following question: "Who would you be most likely to contact for a problem with your child's primary medical condition?" The relationships between parents' choice of practice and their experience of enhanced access (first, at the child's primary care practice and, second, at that of the main specialist) were our main interests. Parents responded to the following prompts about both practices: (1) "It is easy to get an appointment with my child's provider when we need it"; (2) "I can communicate with the provider's office by e-mail"; and (3) "This provider's office has nurses/staff to help manage my child's care." For prompt (1), parents indicated one of "never," "occasionally," "usually," or "always," and for prompts (2) and (3), parents indicated "yes," "no," or "I don't know."

Parents rated their child's health on a 5-point Likert scale from "Poor" to "Excellent," and reported their child's age, race,

ethnicity, insurance, and 5-digit zip code. We estimated the distance from each child's home zip code to the specialty clinic using the directions feature on MapQuest (Map Data, 2012 MapQuest, Denver, Colorado). Parents also indicated the frequency of communication they perceived between a child's primary care and main specialist physicians.

### Statistical Analyses

To test the 2 relationships of interest, we considered the 3 components of enhanced access in primary and specialty care as separate, dichotomous variables, with "usually," "always," and "yes" representing affirmative responses and "never," "occasionally," and "no" representing negative responses. We organized parents' ratings of their children's general health into 3 categories to reflect health status: "excellent/very good," "good," and "fair/poor."

We used descriptive statistics to characterize children in the sample and conducted bivariate analyses of demographic and child health characteristics by parents' indicated practice preference using  $\chi^2$ , ANOVA, or *t* test, as appropriate. We used simple logistic regression to describe the relationship between each enhanced access component in primary and specialty care and parents' indicated practice preference. Then, we constructed a multivariable logistic regression model including each of the enhanced access components associated with parents' indicated practice preference from bivariate testing ( $P < .1$ ), adjusted for covariates. We chose covariates based on their relationship to health utilization using the Andersen Behavioral Model of Health Care Use.<sup>20</sup> Predisposing variables were age and race/ethnicity; enabling variables were private insurance, distance traveled from home to specialty care, and frequency of communication between physicians. The need variable was child health status. ORs and 95% CIs were estimated for variables in the model.

We performed 2 extreme-case sensitivity analyses to explore the effect on our study question of the higher rate of nonresponse to enhanced access prompts among parents of children with public insurance compared with those of children with private insurance. In the first, we treated each nonresponse as a negative response; in the second, as a positive response. All analyses were performed in Stata v 13.0 (StataCorp LP; College Station, Texas).

## Results

About 1900 questionnaires were available for distribution at clinic check-in during the study period. Parents of 667 children returned questionnaires, yielding an estimated total response rate of about 35%. Of these, 609 met inclusion criteria and responded to the outcome question: "Who would you be most likely to contact for a problem with your child's primary medical condition?" Those who did not report the main outcome were not different demographically or clinically from those who did. However, 29% of those with public insurance, compared with 15% of those with private insurance, incompletely responded to prompts on enhanced access. In the study sample ( $n = 609$ ) the average child was 8.6 years old, with

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