

Perceptions of the Medical Home by Parents of Children With Chronic Illnesses

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The medical home serves as a central source of a patient's medical care and records, which are vital for longitudinal care and care coordination.^{1,2} It provides care that is accessible, comprehensive, continuous, coordinated, family-centered, compassionate, and culturally effective.³ These principles informed medical professional organizations' collaborative definition of the patient-centered medical home (PCMH) and became the standards by which the National Committee for Quality Assurance (NCQA) now certifies primary care practices as PCMHs.⁴

Children with special healthcare needs (CSHCN) who are offered high-quality coordinated care have better health and fewer missed school days⁵⁻⁹; however, they are also more likely to utilize specialty care, sometimes relying on specialists as their principal sources of care. Thus, NCQA established a patient-centered specialty care certification for specialty practices.¹⁰ Nevertheless, little is known about parents' perceptions of medical home elements in specialty care or how they compare with those of primary care practices. Such knowledge might allow practices to provide more patient-centered care and tailor future efforts to improve care coordination. The purpose of this study was to describe the degree to which parents of children needing specialty care perceive PCMH elements in primary and specialty practices.

METHODS

Study Design

We conducted a cross-sectional survey study of caregivers (hereafter referred to simply as "parents" although this also includes other caregivers/guardians) of children presenting for specialty care to determine and compare their perceptions of PCMH elements in specialty and primary care. Parents of children presenting for a return appointment with one of 19 pediatric hospital-based specialty clinics at a tertiary care center were eligible. Parents were asked to complete the survey regardless of patient age; 6 surveys were completed by parents of dependents aged 19 to 21 years. We in-

ABSTRACT

OBJECTIVES: The patient-centered medical home (PCMH) strives to improve the quality of care in the primary care setting. Recently, certification programs for patient-centered coordinated care have expanded to subspecialty care. Children with chronic conditions are particularly in need of patient-centered and coordinated care. Our objective was to compare parent perceptions of PCMH elements at primary care and specialty practices for children receiving specialty care.

STUDY DESIGN: Cross-sectional survey study.

METHODS: We surveyed the parents of children returning for specialty care in a hospital-based pediatric subspecialty clinic on the presence of National Committee for Quality Assurance (NCQA) PCMH elements in their primary care practice and in their main specialty care practice.

RESULTS: More parents perceived good appointment access at primary care practices than they did at specialty practices (93% vs 87%, respectively; $P < .001$). They perceived good care coordination and referral follow-up both at primary care and specialty practices (89% vs 88% and 92% vs 92%, respectively). However, parents less frequently perceived the presence of 7 other PCMH elements at primary care practices compared with specialty practices; these included appointment and tests due reminders, distributing handouts, electronic prescribing, sharing test results, surveying experiences, and e-mail capability.

CONCLUSIONS: Despite an emphasis on PCMHs in primary care settings, parents of children seeking specialty care are more likely to perceive the presence of NCQA PCMH elements in specialty rather than primary care clinics. Future PCMH efforts should address parents' perceptions and interpretations of these services.

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cluded those attending a return appointment in order to exclude the parents of children not receiving ongoing specialty care and to ensure that parents had previous experience with specialty providers. From September to November 2012, front desk staff distributed English- or Spanish-language questionnaires to a convenience sample of parents at the time of check-in for a return specialty appointment. Parents completed questionnaires anonymously and returned them to a collection box.

A previous manuscript examined a correlation between specific components of the medical home and parents' preferences of from whom to seek care, but only this study compared all medical home elements in the primary care and specialty settings.¹¹

The University of North Carolina's Institutional Review Board approved this study (#11-1939).

Questionnaire Design

The questionnaire was derived from the Medical Home Family Index from the Center for Medical Home Improvement. This previously validated questionnaire was developed to measure whether practices contain elements that should be present in medical homes and has been widely used in primary care settings.¹²⁻¹⁴ We selected questions corresponding to PCMH elements based on 2010 NCQA certification (Figure).¹⁵ NCQA was chosen because of its widespread use in certifying primary care practices as medical homes.

The survey targeted each category of NCQA PCMH status with 1 to 2 items on a 10-item questionnaire; there are 9 NCQA PCMH elements. Eight of the 10 items assessed the extent to which PCMH elements were present using a 4-point Likert scale. For the 2 remaining—e-mail capability and care coordination—we asked if that element was present, not present, or if the parents were unsure. Parents rated both their primary and specialty practices on scales next to a single set of statements representing PCMH elements. If a child had more than 1 specialist, we instructed parents to complete the questionnaire with regard to their "main" specialist. Parents also provided information about their child's demographics, illness severity, and frequency of specialty and primary care clinic visits.

We pilot tested the abbreviated questionnaire with a convenience sample of 50 parents of children presenting for care in the same specialty clinics. We subsequently interviewed parents and used responses to refine the questionnaire for the larger study.

Data Analysis

We dichotomized questionnaire Likert responses as always/sometimes or occasionally/never. We regarded an element as present if parents responded that it was "always" or "sometimes" present on the Likert scale or if they responded "yes" to the dichotomous

TAKEAWAY POINTS

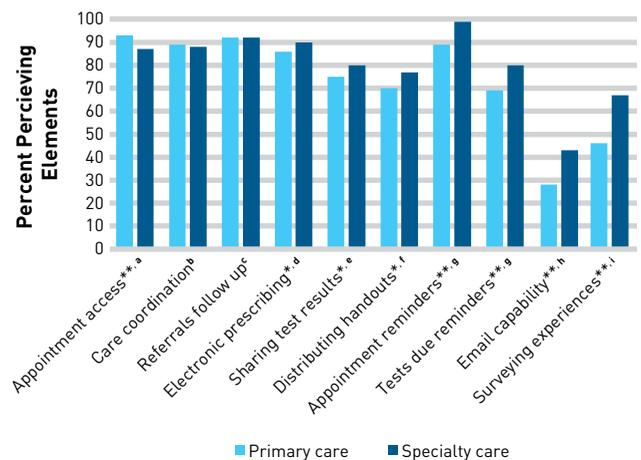
Parents of children seeking specialty care are more likely to perceive that there are more medical home elements promoted by the National Committee for Quality Assurance (NCQA) in specialty clinics than in primary care ones. This is despite the fact that primary care practices are frequently medical homes, and are incentivized to meet NCQA certification. This finding suggests that:

- ▶ Primary care practices should make their medical home elements more apparent to patients and families.
- ▶ Primary care practices should seek patient feedback on most meaningful medical home elements.
- ▶ For certain populations, specialty practices could consider serving as the medical home.

variables. We compared the proportion of parents who perceived PCMH elements at their primary care and specialty practices using χ^2 tests and paired *t* tests to compare participant-matched responses about primary versus specialty care.

We also examined whether several potential confounders—in-
surance status, type of primary care physician (pediatrician vs family physician), and child's health status—influenced parent reports. To assess for confounders, we first estimated logistic regression models predicting PCMH elements for both specialty and primary care. Using these, we tested differences in the effect sizes using adjusted Wald tests from seemingly unrelated estimation procedures. Seemingly unrelated estimation allows for the use of

FIGURE. Percentages of Parents Perceiving PCMH Elements in Primary and Specialty Care Practices (n = 685)



PCMH indicates patient-centered medical home.

** indicates *P* < .05; *** indicates *P* < .001.

^aPCMH standard: Access and communication.

^bPCMH standard: Care management.

^cPCMH standard: Referral tracking.

^dPCMH standard: Electronic prescribing.

^ePCMH standard: Test tracking.

^fPCMH standard: Patient self-management and support.

^gPCMH standard: Patient tracking and registry functions.

^hPCMH standard: Advanced electronic communication.

ⁱPCMH standard: Performance reporting and improvement.

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paired regression models: 1 with primary care and 1 with specialty care, with the parameters and covariance matrices combined into a simultaneous matrix. This permits comparison of the relative effect size of independent variables on reported PCMH components in primary and specialty care across the 2 models.

RESULTS

Subject Characteristics

Data from incomplete surveys were included; however, parents' perceptions of each PCMH element did not differ between complete and incomplete surveys. The greatest proportion of children were white (67%), had Medicaid (47%), and had a pediatrician as a primary care physician (77%). Children had a median of 1 (range = 0-12) chronic condition. Of the 685 parents surveyed, 680 parents (99%) indicated their child had at least 1 chronic condition and 96% had seen a specialist at least once in the 12 months preceding the appointment that day (Table).

Parents' Perceptions of PCMH Elements

Parents were more likely to perceive good availability of appointments at their child's primary care, rather than specialty care, practice (93% vs 87%; $P < .001$) (Figure 1). They perceived similar levels of care coordination in both settings (89% vs 88%; $P = .33$), and they perceived that primary care and specialty practices follow up on referrals at similar rates (92% vs 92%; $P = .78$). For all other PCMH elements, parents responded that primary care practices less frequently met PCMH criteria than did specialty ones, including for electronic prescribing (86% vs 90%; $P = .02$), sharing test results (75% vs 80%; $P = .03$), distributing handouts (70% vs 77%; $P = .01$), appointment reminders (89% vs 99%; $P < .001$), tests due reminders (69% vs 80%; $P < .001$), e-mail capability (28% vs 43%; $P < .001$), and surveying experiences (46% vs 67%; $P < .001$). Results were the same in sensitivity analyses, excluding those who reported that their child had no chronic condition.

Results of our confounder analysis show that parents whose children saw family physicians were less likely than those with pediatricians to report good primary care appointment access and test reminders, but there were no differences in specialist appointment access or test reminders. For all other PCMH elements, the comparison of parents' perceptions of primary and specialty care did not differ by type of primary care provider. We found no difference in perception of primary and specialty care practices based on a child's health or insurance status.

DISCUSSION

This study provides insight into how parents of children utilizing specialty care in a tertiary care center perceive medical home prop-

TABLE. Respondent and Patient Demographics

| Participant Characteristics (n = 685) | N (%) or Median (range) |
|---------------------------------------|-------------------------|
| Relationship to child | |
| Parent | 633 (94%) |
| Grandparent | 22 (3%) |
| Aunt or uncle | 5 (0.7%) |
| Sibling | 3 (0.5%) |
| Unrelated legal guardian | 5 (0.7%) |
| Other | 5 (0.7%) |
| Survey language | |
| English | 666 (97%) |
| Spanish | 19 (3%) |
| Child's age | 9 years (0.25-21 years) |
| Child's race | |
| Caucasian | 436 (67%) |
| African American | 122 (18%) |
| Other | 65 (10%) |
| Native American | 14 (2%) |
| Asian | 13 (2%) |
| Child's ethnicity | |
| Non-Hispanic/Latino | 500 (88%) |
| Hispanic/Latino | 70 (12%) |
| Child's insurance | |
| Medicaid | 307 (46%) |
| Private | 266 (40%) |
| Military | 86 (13%) |
| Self-pay | 7 (1%) |

(continued)

erties in specialty and primary care practices. Parents consistently perceive that there are more PCMH elements at their specialty practice than their primary care practice. In fact, the only category of PCMH criteria that was perceived to be more present at a primary care practice was appointment access. For parents of children receiving care in both primary and specialty practices, these findings raise important questions about their interaction with a primary care-based medical home.

Our study supports and builds on previous literature on perceptions of the medical home. Strickland et al found in 2004, and again in 2009, that many parents of CSHCN did not perceive elements of the medical home in their children's primary care facilities.^{8,16} Liem et al used the Medical Home Index to show that parents of children with sickle cell disease had overall higher rates of satisfaction with their sickle cell specialty clinic than with their primary care one.¹⁷ By using an NCQA-based questionnaire, our findings suggest that even when comparing specialty and primary care practices on

TABLE. Respondent and Patient Demographics (*continued*)

| Participant Characteristics (n = 685) | N (%) or Median (range) |
|--|----------------------------|
| Number of chronic conditions in past 12 months | 1 [0-12] |
| Number of specialists seen in past year | 2 [0-12] |
| Child's health in general | |
| Excellent/very good | 342 (51%) |
| Good | 243 (36%) |
| Fair/poor | 87 (13%) |
| Child's health compared with 12 months ago | |
| Better | 272 (41%) |
| Same | 329 (50%) |
| Worse | 61 (9%) |
| Primary care visits in preceding 12 months | |
| None | 25 (4%) |
| 1-2 times | 235 (37%) |
| 3-5 times | 228 (36%) |
| 6-12 times | 105 (16%) |
| >12 times | 45 (7%) |
| Specialty care visits in preceding 12 months | |
| None | 27 (4%) |
| 1-2 times | 180 (28%) |
| 3-5 times | 235 (37%) |
| 6-12 times | 118 (18%) |
| >12 times | 83 (13%) |
| Type of primary care practice | |
| Pediatrics | 522 (72%) |
| Family medicine | 138 (20%) |
| Don't know | 14 (2%) |

elements by which primary care practices are judged and incentivized, parents still perceived more elements were present in their children's specialty practices.

Parents of CSHCN who rate their primary care practices as having high levels of care coordination are less likely to note unmet specialty needs.¹⁸ The sample in this study reported overall high levels of care coordination—higher than in larger studies of CSHCN.^{8,16,18,19} As care coordination is most tightly linked with health outcomes, our sample may have been exposed to more medical home elements than the larger population of CSHCN, and the gap in PCMH elements between primary and specialty care may be even larger in other populations. Our findings also show that most elements are perceived as being present in both primary care and specialty settings. All clinics might serve as better medical homes by providing or advertising less well-perceived elements, such as e-mail capability, and surveying about experiences.

Limitations

Most importantly, parents were surveyed about their experiences in specialty clinics while they were waiting to see a specialist. This represents not only a potential sampling bias (parents actively engaged with a specialist), but also might have temporally inflated specialty perceptions given that they were actively waiting for that type of appointment. This may make the smaller differences in perception less meaningful; however, those elements demonstrating greater differences in perceptions—e-mail capability, surveying experiences, and appointment and test reminders—likely remain robust. Conversely, there may have been temporal aspects of the appointment day that lowered the perception of specialty care; for example, long wait times or logistical difficulties accessing specialty care at a large hospital-based clinic.

Second, we measured parental perception of PCMH practices, not actual services. This study does not address whether specialty practices actually offer more PCMH elements than do primary care practices, but it does demonstrate that parents perceive that to be the case, and healthcare-seeking behaviors may be shaped by parental perception.

Next, parents answered the survey considering their child's "main" specialist rather than a summary of specialty experiences, and so they may have considered the specialist they perceived as providing the most patient-centered care. Nevertheless, the wide variety of specialists included, and the large number of children only seeing 1 specialist, suggest these findings remain meaningful.

Furthermore, although modifying an existing questionnaire alters its validity, this pilot-tested, abbreviated, NCQA-based survey may be useful for clinics seeking to assess their own NCQA-based medical home properties. In addition, children in this study received their specialty care from a single tertiary hospital-based clinic, thereby potentially limiting generalizability to those receiving specialty care in other settings or geographic regions. Finally, only 3% of the surveys were completed in Spanish, despite a clinic population of approximately 10% Spanish speakers; this may indicate selection bias and limits generalizability to non-English speakers.

Implications

The presence of medical homes correlates with improved health outcomes for CSHCN.⁶ CSHCN with access to components of the medical home have improved access to care, with more efficient use of health services, fewer unmet health needs, better health status, and fewer emergency department visits.^{6,8,9,18} In addition, CSHCN have fewer missed school days, their caregivers miss fewer work days, and they contribute lower cost to the family overall.^{7,9,20,21} It appears that much of this effect is due to higher levels of care coordination in PCMH practices.^{18,19,22,23} Given the importance of the medical home in children with chronic illnesses, this study provides important insight into how parents view and compare medical home aspects of different care settings. This information

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is valuable to primary and specialty physicians caring for such populations, enabling them to better work together and with families to strengthen medical homes. This knowledge also can help NCQA and specialty practices further refine the concept of Patient-Centered Specialty Practice certification.

CONCLUSIONS

This study suggests that parents of children that seek specialty care at a tertiary care center perceive their main specialist as fulfilling more NCQA PCMH criteria than their primary care practice. This challenges the traditional paradigm in which a primary care practice is presumed to be the medical home. Future research into alternative care design should continue to focus on improving PCMH elements in primary care, but could also explore alternative models of engaging specialists and establishing their role in best meeting the needs of chronically ill children. ■

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