Caring for Children with Medical Complexity: Perspectives of Primary Care Providers

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Objective To describe typical care experiences and key barriers and facilitators to caring for children with medical complexity (CMC) from the perspective of community primary care providers (PCPs).

Study design PCPs participating in a randomized controlled trial of a care-coordination intervention for CMC were sent a 1-time cross-sectional survey that asked PCPs to (1) describe their experiences with caring for CMC; (2) identify key barriers affecting their ability to care for CMC; and (3) prioritize facilitators enhancing their ability to provide care coordination for CMC. PCP and practice demographics also were collected.

Results One hundred thirteen of 155 PCPs sent the survey responded fully (completion rate = 73%). PCPs endorsed that medical characteristics such as polypharmacy (88%), multiorgan system involvement (84%), and rare/unfamiliar diagnoses (83%) negatively affected care. Caregivers with high needs (88%), limited time with patients and caregivers (81%), and having a large number of specialists involved in care (79%) were also frequently cited. Most commonly endorsed strategies to improve care coordination included more time with patients/caregivers (84%), summative action plans (83%), and facilitated communication (eg, e-mail, phone meetings) with specialists (83%).

Conclusions Community PCPs prioritized more time with patients and their families, better communication with specialists, and summative action plans to improve care coordination for this vulnerable population. Although this study evaluated perceptions rather than actual performance, it provides insights to improve understanding of which barriers and facilitators ideally might be targeted first for care delivery redesign. *(J Pediatr 2017;182:275-82).*

Children with medical complexity (CMC) are a growing pediatric population defined by chronic conditions that require intensive resource utilization and/or technology assistance to achieve optimal health outcomes.[1] CMC report difficulty obtaining medical and social support services in the nonurgent setting and experience fragmented healthcare delivery because of higher rates of urgent care visits, hospitalizations, specialty care, and educational accommodations.[2-4]

To optimize care for all children including CMC, the American Academy of Pediatrics (AAP) has endorsed the medical home as the ideal model of care delivery.[5] AAP guidelines suggest primary care providers (PCPs) develop a plan of care, advocate for subspecialty care within health plans, and communicate subspecialists' reports to the family.[6] However, community PCPs and their practices may not have the time, resources, or training to address the multifaceted healthcare needs of CMC and may feel isolated from subspecialists.[7,8] Previous studies have evaluated provider performance with care-coordination tasks, communication strategies, barriers to care-coordination, preparedness for coordination tasks, and perceptions of the ideal medical home model for children with special health care needs.[9-15] However, which barriers or facilitators PCPs would prioritize for improvement remain unknown.

A wide range of organizational reform and communication strategies are possible; yet, institutional resources and provider time are limited. To facilitate optimal care for CMC and to inform targeted strategies for care delivery redesign, understanding the current experiences and preferences of practicing PCPs is essential. Therefore, the objective of this study was to describe the typical experiences of PCPs in caring for CMC in the outpatient primary care setting, identify the most challenging perceived barriers to care, and prioritize facilitators to care coordination.

Methods

We conducted a cross-sectional survey from February 6, 2012, through July 31, 2012, of PCPs who care for CMC. Recruitment of PCPs occurred within a larger, ongoing randomized control trial (RCT) of outpatient care coordination for CMC

AAP	American Academy of Pediatrics
ACOs	Accountable care organizations
CMC	Children with medical complexity
PCPs	Primary care providers
RCT	Randomized control trial
SCG	Seattle Children's Hospital

at Seattle Children's Hospital (SCH) (ClinicalTrials.gov: NCT01587105) that occurred from December 1, 2010, to September 29, 2014. PCPs were enrolled after CMC from their practice were identified as eligible. After all their eligible CMC were enrolled, the PCP and CMC were randomized together to either the control or intervention group. The control group provided usual care, and the intervention group received care coordination through a comprehensive care management service at SCH. CMC were eligible for the RCT if they met the definition for being medically complex and had ≥1 emergency department or inpatient stay at SCH between 2010 and 2011. Children were defined as medically complex if they had a dominant chronic condition using hospital discharge data and Clinical Risk Group (3M Health Information Systems, Salt Lake City, Utah) algorithm categories 5b, 6, 7, or 9.[16] PCPs were eligible if they cared for at least 1 eligible CMC who enrolled in the RCT. One hundred fifty-five PCPs were consented for the RCT at the time of this study and therefore were eligible to participate. CMC and their PCPs were ineligible for the RCT if the child had a subspecialty medical home at Seattle Children's Hospital that was providing coordination services, was aged ≤3 months or ≥18 years at the time of their index stay, was an out-of-state resident, or had parents who spoke a language other than English or Spanish.

All surveys were closed, anonymized, self-administered, web-based questionnaires completed 1 time only via an e-mail link to all enrolled PCPs in conjunction with surveys sent for the larger RCT at either the 0-, 6-, or 12-month postenrollment study time points (**Appendix;** available at www.jpeds.com). Survey reminders were sent via e-mail 3 times over a 2-week period or until the survey was completed. Participation in the survey was voluntary, and no incentive for this study was provided. Seattle Children's Research Institute granted Institutional Review Board approval for both studies. All participants underwent informed consent, and personal data was protected from unauthorized access.

Survey Design and Development

Survey content was based on the AAP policy statement on care coordination and a previously published survey on pediatric hospitalists' perspectives on care of CMC.[6,17] A pilot survey was conducted with 2 community pediatricians, 3 academic pediatricians, and 3 pediatricians with expertise in caring for CMC. Survey content was revised based on pilot feedback related to item understandability and topic relevance. The survey included 19 items, 8 of which had multiple response options; usability and technical functionality were tested before fielding occurred.

First, CMC were defined.[1] PCPs were asked about the perceived adequacy of care provided to CMC by themselves, their partners, and their clinic using a 5-point Likert scale. PCPs then were asked to recall the last 4 CMC who they cared for and answer the subsequent questions based on those experiences to understand PCPs' typical rather than ideal experience.

PCPs were questioned about whether patient characteristics and barriers to care affected their ability to provide care to CMC. Answer items were listed in 2 groups of patient characteristics (patient medical characteristics and patient non-medical characteristics) and 2 groups of barriers to care (practice barriers and institutional barriers). PCPs were also asked whether facilitators to care affected their ability to provide care coordination to CMC. Answer items were listed in 2 groups of potential facilitators (process and structure of care facilitators and information exchange facilitators). Within each group, PCPs were asked if a given item affected their ability to care for CMC (for patient characteristics and barriers) or affected their ability to provide care coordination (for facilitators). PCPs then were asked to prioritize which item was "most challenging" for patient characteristics and barriers or "most helpful" for facilitators. PCPs also were asked which outpatient practice setting would provide the most comprehensive medical home for CMC: a pediatric primary care practice; a pediatric primary care practice dedicated to CMC; a specialty practice related to a CMC's primary diagnosis; or an interdisciplinary clinic with pediatric PCPs and specialty physicians seeing CMC together. PCP demographics collected included age, years since medical school, sex, and race/ethnicity. PCPs were asked to estimate how their patient population was distributed across 6 payment models (any managed care, fully capitated managed care, discounted fee-for-service, fee-for-service Medicaid, Medicaid, or uninsured). Provider financial role in the practice and practice type were also collected. Provider zip codes were used to classify practice location using rural-urban commuting area codes.[18]

Analyses

Survey participation rate was calculated as the number of known PCPs who started the survey divided by the number of PCPs sent the survey. The survey completion rate was the number of PCPs who completed at least 25% of the items divided by the number of PCPs sent the survey. A descriptive statistical analysis was performed using Stata Statistics Data Analysis v 12.0 software (StataCorp, College Station, Texas). Univariate frequencies were calculated for all categorical variables, and means and ranges were calculated for continuous variables. For bivariate analyses, we constructed several dichotomous variables: years since medical school (<20 vs ≥20 years), race/ethnicity (white vs nonwhite), and practice location (urban vs nonurban). Years since medical school was dichotomized at 20 years based on the closest 5-year increment to the mean value for the population (21 years). Responses to 5-point Likert scale questions were trichotomized into affirmative (strongly agreed or agreed), neutral (neither agreed nor disagreed), or negative (disagreed or strongly disagreed) responses. The question asking PCPs to estimate their patient populations' payment model distribution (eg, percent insured by Medicaid fee-for-service) was excluded because of low response rates for this item (39%).

We calculated the proportion of PCPs choosing an item as affecting care for each patient characteristic or barrier and as affecting care coordination for each facilitator. The item within each of the 6 groups selected most frequently as "most challenging" or "most helpful" was considered the "prioritized" item for that group. The number of PCPs included in the denomi-