Continuing Education Needs of Pediatricians Across Diverse Specialties Caring for Children With Medical Complexity

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Abstract

Objective. Care for children with medical complexity (CMC) relies on pediatricians who often are ill equipped, but striving to provide high quality care. We performed a needs assessment of pediatricians across diverse subspecialties at a tertiary academic US children’s hospital about their continuing education needs regarding the care of CMC.

Methods. Eighteen pediatricians from diverse subspecialties were asked to complete an online anonymous open-ended survey. Data were analyzed using modified grounded theory.

Results. The response rate was 89% (n = 16). Of participants, 31.2% (n = 5) were general pediatricians, 18.7% (n = 3) were hospitalists, and 50% (n = 8) were pediatric subspecialists. Pediatricians recognized the need for skills in care coordination, giving bad news, working in interprofessional teams, and setting goals of care with patients.

Conclusions. Practicing pediatricians need skills to improve care for CMC. Strategically incorporating basic palliative care education may fill an important training need across diverse pediatric specialties.

Keywords

continuing medical education, faculty development, chronic disease, children, pediatric, palliative care

Introduction

Children with medical complexity (CMC) have the most complicated chronic conditions and often require a significant number of medications, durable medical equipment, health care services, and family support to maintain a basic quality of life.¹⁻⁴ These children are markedly affected by the health care system. CMC make up <1% of the pediatric population but account for nearly one third of pediatric health care spending and more than one quarter of pediatric hospital readmissions.²⁻⁵ While CMC primarily receive care at academic medical centers, all pediatric providers are increasingly being called upon to provide care for this vulnerable population of children.⁶ In 2003, the Institute of Medicine recommended that all pediatric health care providers receive training in the care of medically complex patients to ensure care is safe, effective, patient-centered, timely, efficient, and equitable.⁷ Unfortunately, CMC continue to receive care that is fragmented and uncoordinated over a decade after the Institute of Medicine’s declaration.¹⁻⁸⁻¹¹

To circumvent these systemic issues, CMC and their families frequently rely on providers willing to take the extra step required to provide comprehensive care, manage patients’ complicated medical regimens and coordinate care across multiple specialists. Many pediatricians are motivated to deliver this care but are ill equipped, undertrained, and underresourced to provide the care needed for CMC to thrive.²⁻¹²⁻¹³ Lack of time, poor reimbursement, and system complexity are frequently cited

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as barriers. Within academic training institutions, educating pediatric trainees about care for CMC is an additional challenge for providers. The literature to date provides little guidance to pediatricians delivering this care or educating trainees about optimal approaches to care. To our knowledge, this study is the first to expand on the self-identified educational needs of practicing pediatric educators across a diverse range of specialties caring for CMC.

Methods

Participants

We conducted a qualitative study of practicing general and subspecialty pediatricians working at a single tertiary academic medical center in the United States. We used a purposive sampling technique to capture participants from a diverse range of specialties with direct experience caring for CMC. All participants were also faculty educators who served as resident mentors in a pediatric residency training program and had direct experience supervising residents about caring for medically complex patients. The program, Special Care Optimization for Patients and Education (SCOPE), pairs one faculty mentor and one resident over a 4- to 8-month period to follow, plan, and coordinate care for a medically complex patient and their family. Faculty mentors were selected for the SCOPE program by residents and residency program leadership based on their teaching performance evaluations and their reputation as highly effective teachers. We undertook this study to explore the educational needs of faculty caring for CMC and to identify opportunities to improve their training experiences.

Data Collection

All SCOPE program mentors were invited to participate in this study in June 2013. E-mail invitations were sent to each mentor describing the purpose and aims of the study. Those agreeing to participate were asked to complete an anonymous 10-item survey distributed online through Qualtrics (Qualtrics Research Suite, Copyright 2013 Qualtrics) after fulfilling their mentorship responsibilities for the SCOPE education program. Participant demographics and experiences in complex care were collected using multiple-choice and open-ended questions respectively. Three open-ended questions assessed participants’ perspectives regarding (1) qualities needed for pediatricians working with medically complex patients, (2) areas for their own continuing education, and (3) challenges to educating trainees about caring for CMC. Participants who did not immediately take the survey were sent one email reminder one week following their acceptance of participation. A full 2 weeks were provided to complete the survey. This study was evaluated by the institutional review board at Stanford University prior to its initiation and was exempt from formal review.

Data Analysis

Given the exploratory nature of this study, open-ended responses were analyzed in several stages using a modified grounded theory approach. Anonymous responses were taken from the online survey and grouped by question into a Microsoft Word document. Two content experts (JFB and CER) independently reviewed responses and manually coded the text to develop their own codebooks and a preliminary list of themes. They subsequently met to compare and discuss codes, emergent themes, and to develop a single codebook. The reviewers then individually re-read the responses to ensure accuracy of the codes and recode where necessary using the agreed on codebook. Any disagreements were discussed with a qualitative research expert (ALB) with reference to the data until consensus was reached.

Results

Participant Demographics

Eighty-nine percent (n = 16 out of 18) of those invited to participate completed the survey. Of the 16 total respondents, 31.2% (n = 5) were general pediatricians, 18.7% (n = 3) were pediatric hospitalists, and 50% (n = 8) were pediatric subspecialists. Pediatric subspecialties included representation from cardiology (n = 1), endocrinology (n = 1), genetics (n = 1), nephrology (n = 1), neurology (n = 1), pulmonology (n = 2), and rheumatology (n = 1). Nearly 44% (n = 7) of respondents were within their first 5 years of practice, 37.5% (n = 6) had been practicing between 6 and 15 years and 18.7% (n = 3) had been practicing over 15 years. Among all respondents, 81.2% (n = 13) reported that >25% of their patient caseloads were CMC, with 18.7% (n = 3) reporting that >75% of their patients were medically complex. Participants were also asked about their previous formal education on caring for medically complex pediatric patients; 62.5% (n = 10) reported no explicit training whatsoever during their medical school, internship, residency, and/or fellowship. Participants reported that what they learned about CMC was primarily self-taught through daily patient care.
**Participant Responses**

**Physician Qualities.** Participants identified several qualities necessary for pediatricians to successfully care for CMC. These fell into 2 general domains of (1) personal attributes and (2) professional abilities. Personal attributes were (1) patience, (2) compassion and empathy, (3) thoroughness, and (4) orderliness. These are reflected in the following quotes.

> It’s important to have patience, compassion and the desire to take care of the whole patient—not just the small medical “piece” that the subspecialist is responsible for.

Patience and compassion are important in any setting where you deal with sick human beings but are especially important with complex patients because their needs are so great and multifaceted.

> You have to be willing to listen and to see the issues from the family’s perspective . . . You also have to be willing to be observant because so much of what we learn about patients comes from non-verbal cues and interactions.

You have to have efficient time management skills, the ability to contact care providers who are involved in the child’s care, and the willingness to be contacted when off-duty. You also need to be detail-oriented and able to prioritize problems.

Participants also commented on the need to be active and purposeful in their demonstration of these qualities with their patients and colleagues. For example, participants recognized that a major challenge of working with CMC was coordinating care because it could be time intensive and emotionally frustrating. To successfully work through this challenge, participants actively sought to cultivate compassion and empathy toward patients and their families. In addition, thoroughness and orderliness were deemed particularly important for working with other members of the health care team and for integrating complex medical information into a complete understanding of the patient.

> Because there are relatively few tangible rewards in this setting, empathy goes a long way . . . it is probably the thing that motivates me the most consistently [in working with CMC] . . . but you have to be active about [demonstrating] it.

To have a complete understanding of the patient, you have to be thorough in terms of questions asked and care provided. You have to be patient working with other providers, which can be hard.

Professional abilities recognized as important in caring for CMC included the ability to (1) work in interprofessional teams, (2) practice patient-centered care, (3) master complicated clinical information, (4) maintain accessibility/continuity with patients, and (5) serve as patient advocates.

> It’s important to have an interest in and willingness to work cooperatively with other physicians, social workers, nurses, etc . . . to make things as clear and convenient as possible for the patient and his/her family.

> It’s important to have interest in seeing [your]self as part of a team of care and to be able to work well with other care providers and a number of health care ancillary personnel.

The ability to have continuity as a provider is essential. You have to have an ability and a desire to follow up on the impact of treatments to see how they’re working for the patient and family and to be able to work with other [providers] to regularly manage [your patient’s] care.

> Familiarity with the clinical issues and knowledge of available resources are especially important for these patients . . . you have to be a strong patient advocate to ensure patients receive all the care they need to maintain a good quality of life—[care] that often takes place outside of the medical setting.

**Continuing Medical Education Needs.** Participants’ continuing education needs fell into behavioral and cognitive domains. Skills in (1) care coordination, (2) giving bad news, (3) working in interprofessional teams, and (4) shared goal setting with patients were areas where additional training was needed.

> Goal-setting, defining roles to achieve these and clarifying treatment expectations are the most important. Discussing bad news with families and learning how to help families know what to ask [other providers] is also really critical because sometimes parents are just so overwhelmed they don’t know what to ask.

> I would love to know best practices for care coordination . . . [Also] presenting options to parents for difficult decisions and presenting new diagnoses are especially hard, so some education around those topics would be beneficial.

Notably, participants also commented that they would benefit from additional training in how to assess and respond to the psychosocial concerns of families. Office management skills (ie, leading an administrative staff and developing a system to complete paperwork) and strategies for self-care were also cited by participants as areas where additional training would be useful.
Training in dealing with patients’ psychosocial issues and related goals of care would be very useful. Also, self-care is critical and we need better strategies to address this to help us with [working with CMC] and in all our work.

Office management skills help tremendously [when working with CMC]. There’s a lot of paperwork we have to do for coordination, so it’s important to have those skills—which we need training in.

Deficits in clinical knowledge outside of participants’ areas of expertise (eg, gastrostomy tube care) and insufficient knowledge about community services were cited as areas where continuing education was needed. Participants recommended that educational efforts be directed toward improving knowledge in both of these areas.

Sometimes what patients need is outside our area of expertise. I think it would be helpful to have some guidance with that . . . maybe training in common medical problems so we can help. Also, knowing what some of the resources in the community are that we can refer people to [such as] transportation [and] support for families.

Despite general requests for more training to care for CMC, participants described strong commitments to patient care and to educating residents. They often were motivated to educate themselves to participate optimally in these responsibilities.

We need to do a much better job of providing comprehensive, consistent and coordinated care [for CMC] and I am eager to help nurture these skills in residents.

I was interested in [SCOPE] to work with residents to support them in their relationship with a family needing guidance through establishing goals of care and negotiating the [health care] system.

I enjoy working with patients with complex diseases and would like to share my experiences with residents so that they are able to recognize the positive aspects of care as well.

While participants readily identified the challenges of working with CMC, they also recognized the opportunities this care presented for their own growth as clinicians and educators. Participants commented on the joy of working closely with residents and CMC because the experience broadened their perspectives about their role as medical providers—namely, to be able to address the complex and diverse medical and psychosocial needs of patients. The challenges of working with CMC also encouraged them to embody and role model more patient-centered attributes such as compassion, empathy and partnership with patients and their families.

It helps us role model more patient-centered care—compassion and collaborating with families. The psychosocial issues too are important and we have to think about those. It stretches us in a good way.

Discussion

Until more coordinated systems of care are developed to meet the needs of medically complex children, these patients and their families will continue to rely on dedicated health care providers who take the extra steps needed to provide their care. Currently, few formal guidelines exist to support complex care and education during residency, fellowship, or for practicing physicians. While formal guidelines should be developed that align with each stage of training, this study reveals that continuing education in pediatric complex care is essential to ensure pediatric providers are confident in their abilities for patient care and have the knowledge and skills to build positive and meaningful patient interactions.

Despite their diverse subspecialties, pediatricians recognized the equal importance of personal and professional qualities required to care for CMC. This is not surprising given the emphasis nationally on patient-centered care and shared decision making, which requires providers to work collaboratively with patients and other health care professionals to achieve mutually agreed upon plans of care. While personal qualities may be difficult to teach, these elements often necessitate the compassion and empathy critical for patient care. Formally incorporating training on shared decision making in continuing medical education (CME) programs and maintenance of certification activities for pediatricians may be one way to build skills in these areas.

Initial assumptions about complex care also suggest that training requires significant increases in clinical information to take care of more complex patients. Instead, this study reveals that skills important for the care of all patients were also critically important in caring for CMC. Skills in effective care coordination, communication about sensitive or difficult topics with patients, working on interprofessional teams, and setting treatment goals were considered especially pertinent. Increasingly, physicians consider these skills to be an ethical imperative for all patient care and clearly direct education in these skills are still needed.

To this end, basic palliative care education may strategically serve as a model for CME and other training efforts for pediatricians learning about complex care.
Many of the skills described by participants are practiced in evidence-based palliative care programs, which aim to provide an interdisciplinary patient-centered approach to defining care given complex and often uncertain disease trajectories. Palliative care professionals are trained in establishing goals of care with patients, having difficult conversations and working on teams with nurses, social workers, and other health care providers. With basic competence in these skills, all health care providers could work more effectively with CMC to develop individual care plans around a particular family’s goals for their child. With evidence indicating that families of children with complex medical needs are comfortable partnering with providers and engaging in shared decision making, pediatricians working with CMC will increasingly be asked to practice these skills and to form close partnerships with patients and their families. Health care providers could continue to work in conjunction with palliative care teams if a child’s care became more complicated. Model programs that include palliative care for patients with complex chronic diseases and that promote care which incorporates the patient’s perspective should be further developed to support pediatricians caring for CMC.

Limitations

This study has several limitations. First, this study was conducted at one academic institution at a tertiary children’s hospital in the United States with a small sample size limiting the study’s generalizability. Second, participants were all volunteers in an education program to train residents about pediatric complex care and were therefore primed to recognize the limitations of their own education and the challenges in training others. While we purposely sought these perspectives, we recognize that such a sampling technique may have underrepresented the training needs of general and community pediatricians and those at other training institutions. Third, there are a variety of other health care providers who care for CMC who are not physicians. Clearly, their educational needs should be evaluated. Finally, responses to study questions were collected electronically for the convenience of participants, which may have limited the data available for analysis and our study outcomes.

Conclusion

Addressing the CME needs of pediatricians across diverse subspecialties is fundamental to improving care for CMC and their families. Current challenges for providers include fragmented, uncoordinated care and inadequate medical and psychosocial support for patients and their families. Training that specifically addresses skills in care coordination, interprofessional collaboration, and communication about sensitive and difficult topics are needed. These educational needs are not specific to one institution or to pediatrics. Rather, they are critical to the many other fields that focus on the care of medically complex and chronically ill patients. Formalizing basic palliative care education and broadening its scope to CME may address the educational needs of providers caring for CMC and improve their ability to teach pediatric trainees. This training may also foster the growth of personal attributes such as patience, empathy, and tolerance of uncertainty. Promoting competence in basic palliative care can enhance care delivery and guide education for the future pediatric workforce in this important area.

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References