

Caring for Children With Medical Complexity: Challenges and Educational Opportunities Identified by Pediatric Residents



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ABSTRACT

OBJECTIVE: High-quality care for children with medical complexity (CMC) is in its infancy. Residents have the opportunity to view care for CMC with a fresh perspective that is informed by their work across diverse health care settings and significant time spent at the bedside. This study aimed to identify the challenges and potential solutions for complex care delivery and education from their perspectives.

METHODS: We conducted three 60-minute focus groups with a purposeful sample of residents and recent graduates at a US tertiary-care medical center. Data were transcribed verbatim, and themes were identified using an iterative approach and modified grounded theory.

RESULTS: Sixteen participants identified 4 major challenges to caring for CMC: 1) lack of care coordination; 2) complex technology management; 3) patients' pervasive psychosocial needs; and 4) lack of effective health care provider training. Participants identified 3 solutions: 1) greater integration of primary care providers; 2) attention to psychosocial needs through

shared decision making; and 3) integration of longitudinal patient relationships into provider training. We found that residents who experienced longitudinal relationships with CMC felt more efficacious and better equipped to handle challenges of caring for CMC as a result of their broader understanding of patients' priorities and of their role as providers.

CONCLUSIONS: Residents recognize important challenges and offer thoughtful solutions to caring for CMC. Although multiple solutions exist, formal integration of longitudinal patient experiences into residency training may better prepare residents to understand patient priorities and identify when their own attitudinal changes can guide them into more efficacious roles as providers.

KEYWORDS: child; chronic illness; curriculum; graduate medical education; pediatric; resident

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WHAT'S NEW

Residents recognize the challenges inherent to caring for children with medical complexity (CMC). Longitudinal experiences with CMC may better equip residents to manage these challenges and to self-identify when their own attitudinal changes can constructively benefit patient care.

CHILDREN WITH MEDICAL complexity (CMC) account for <1% of the pediatric population but over a third of medical care for children.^{1,2} These children have diseases involving multiple organ systems and rely on medical technology to maintain a basic quality of life.³ CMC are frequently treated at tertiary-care hospitals within academic training institutions and are often cared for by pediatric residents.^{2,4,5} Residents and recent residency graduates have a fresh perspective to recognize the challenges of providing care for CMC and to identify potential solutions to these

challenges. Compared with senior providers, residents spend more hours at the bedside performing standard tasks required for hospitalization (eg, admission histories, medication reconciliation), interact with patients across hospital silos (eg, inpatient, outpatient, subspecialty care), and often witness the frustration of families navigating the health care system.

Residents currently learn about care for CMC in a haphazard and unstandardized fashion. This has led to inaccurate biases about CMC (eg, poor quality of life, burden to families) and lack of preparedness to meet CMC's needs.⁶ Although a small number of studies recommend that residents learn about CMC directly from the community and patients' families,^{7,8} no formal guidelines exist. Frameworks that standardize care delivery while simultaneously enabling learner assessment of competence according to milestones are also lacking. Integrating the growing patient care needs in complex care with education has the potential to improve care now and in the future.

We believe that understanding care challenges from the resident perspective is necessary to develop formative training experiences and is critical to bringing about positive changes in care delivery for CMC. We sought to identify the challenges and potential solutions to complex care delivery and education from residents' perspectives.

METHODS

PARTICIPANTS AND SETTING

Participants were pediatric residents and recent residency graduates from a moderate-size tertiary-care training institution in the United States where residents rotate at an academic hospital (regional referral center) and a county hospital. In addition to participating in core rotations standardized by the Accreditation Council for Graduate Medical Education (ACGME), residents can volunteer to participate in the Special Care Optimization for Patients and Education (SCOPE) program,⁹ a longitudinal elective training program that pairs a resident with a CMC and faculty mentor to develop and monitor the achievement of patient-centered goals.

PARTICIPANT SELECTION

All pediatric residents ($n = 83$) and residents graduating within 1 year of study recruitment ($n = 26$) were eligible to participate. We compiled a list with the names of all possible participants ($n = 109$), and each was assigned a number. A number generator was used to select study participants, who were then e-mailed invitations to participate. Individuals not responding after 2 e-mail invitations sent 1 week apart were removed from the list, and new participants were selected using the same process. We used these procedures to recruit 2 focus groups of 6 to 8 participants per group, an optimal size for focus groups.¹⁰ After holding 2 focus groups and analyzing data, we proceeded with further recruitment and analysis until saturation of themes was reached.¹⁰ All participants received a \$25 gift card. Study procedures were exempted by Stanford University's institutional review board before initiation.

DATA COLLECTION

We conducted three 60-minute focus groups from January to February 2014 using a semistructured interview guide. The interview guide was developed from our literature search, solicited perspectives about complex care, and was pilot tested for content and clarity in mock interviews with 2 residents. CMC were defined for participants as "children having diseases involving multiple organ systems and relying on medical technology to maintain a basic quality of life." Before beginning the focus groups, information about the purpose of the study was reviewed and questions were answered. Immediately after the focus group, participants completed a 4-item demographic survey. Audio recordings were transcribed verbatim by a professional transcription service and were reviewed for accuracy before analysis.

DATA ANALYSIS

Data were analyzed through an iterative multistage process using modified grounded theory^{10,11} by one content expert (JB) and one qualitative research expert (AB). First, the investigators individually read the transcripts line by line to descriptively label content areas with codes. The investigators met to discuss their codes and to combine them into a list of emerging themes. Next, the investigators reread each transcript, manually coding for the presence of each theme. In the third stage, the investigators met to discuss and refine their list of themes. During this stage, we determined that themes fell into 2 major domains of "challenges" and "solutions" for caring for CMC. In the fourth stage, we reread the transcripts with these domains in mind to further refine our themes and met to discuss any differences of opinion until consensus was reached. Validity of the final list of themes was established through participant review, whereby participants were asked to comment on whether the themes aligned with their experiences.^{10,11}

RESULTS

A total of 16 residents and recent residency graduates were interviewed after invitations were sent to 41 potential participants. Each focus group had representation from at least 1 graduate and resident from each postgraduate year (ie, PGY1, 2, 3). Of the residents who were invited but not interviewed, 17 (68%) were not available as a result of clinical or personal responsibilities during the designated focus group dates, and 8 (32%) did not respond to the study invitation. [Table 1](#) shows participant demographics. Of the 16 participants, 6 (37.5%) had participated in the SCOPE curriculum.

Participants identified 4 challenges and 3 solutions in caring for CMC. Representative quotations for each theme can be found in [Table 2](#).

CHALLENGES

Participants identified 4 challenges to caring for CMC: 1) lack of care coordination; 2) complex technology

Table 1. Participant Demographics

Characteristic	n (%)
Gender	
Female	12 (75)
Male	4 (25)
Level of training	
PGY 1	2 (13)
PGY 2	5 (31)
PGY 3	5 (31)
Recent residency graduate*	4 (25)
SCOPE experience	
Yes	6 (37.5)
No	10 (62.5)

PGY indicates postgraduate year; SCOPE, special care optimization for patients and education (longitudinal pediatric complex care elective).

*Residency graduate indicates graduated from residency within 1 year of recruitment.

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