

A Pediatric Resident Advocacy in Complex Care Curriculum

Ruchi Kaushik, MD, MEd, MPH*

*Corresponding author: complexcarepedi@gmail.com

Abstract

Introduction: Children and youth with special health care needs (CYSHCN) are a special, vulnerable population. Children with medical complexity (CMC) represent a smaller, medically fragile sliver (6%) of the US child population. Several professional pediatric entities direct (or require) pediatric educators to instruct residents in advocacy for all children, explicitly including CYSHCN/CMC populations. While many existing curricula address pediatric advocacy education, a gap remains in curricula specifically designed to aid learners in advocacy of CYSHCN/CMC. **Methods:** Using Kolb's experiential learning cycle as a framework, we designed and delivered a comprehensive outpatient complex care curriculum, including several didactic video lectures (total: 60:04 minutes, median: 6:25 minutes) and experiential site visits devoted to advocacy topics for CMC, as one portion of a 4-week elective complex care rotation. Residents completed pre- and posttests of knowledge and pre- and postsurveys to self-assess attitudes, comfort, and behavior; viewed didactic video lectures; and engaged in experiential site visits. Reflective statements captured attitudes regarding advocacy for CMC. **Results:** Between July 2016 and June 2020, 47 trainees completed the rotation; data were available for 30 trainees. Residents demonstrated a statistically significant improvement in knowledge ($p < .001$), as well as improved attitudes, diversity sensitivity, and comfort in advocating for CMC postrotation. Qualitative comments showed overwhelmingly positive learner reaction. **Discussion:** This curriculum, which can be offered as a stand-alone resource or a supplement to a comprehensive complex care curriculum, incorporates didactic and experiential teaching methods and addresses a significant competency in advocacy education.

Keywords

Complex Care, Resident Education, Advocacy, Pediatrics

Educational Objectives

Upon completion of this curriculum, learners will be able to:

1. Discuss social determinants of health and adverse childhood experiences and their impact on health outcomes.
2. Mindfully approach children with medical complexity (CMC) and their families by incorporating diversity sensitivity and person-first language.
3. Locate and describe community-based health care providers and nonmedical resources to advocate for medical, developmental, socioemotional, and behavioral health care of CMC.
4. Relate current health care and education policies that affect CMC to the daily experiences and outcomes

of these children and families and apply them when advocating for CMC.

Introduction

Children and youth with special health care needs (CYSHCN) are deemed a special, vulnerable population¹ and constitute 13%-18% of the children/youth in the US.² Children with medical complexity (CMC) represent an even smaller sliver (6%) of the US child population,³ have complex and chronic medical needs requiring extensive care coordination, and are considered to be medically fragile.⁴ Because CMC account for approximately 40% of pediatric health care spending,³ engaging in clinical, community, and systems/legislative advocacy is often vital to securing the services and resources they need to access and optimize care.⁵

The Accreditation Council for Graduate Medical Education core pediatric competencies,⁶ American Board of Pediatrics pediatric entrustable professional activities (EPAs),⁶ American Academy of Pediatrics Community Pediatrics Training Initiative Core Curricular Objectives in Community Health and Advocacy

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Training Milestones,¹ and recently published complex care EPAs⁷ direct pediatric residency programs to design and deliver high-quality and effective advocacy curricula. Advocacy curricula for CMC require not only a foundational discussion of the social determinants of health (SDOH) but also a depth of knowledge and skills in affording and treating families with respect and dignity (clinical level), supporting daily living through family engagement and collaboration within communities (community level), and applying health payor and education policy when advocating for CMC (systems/legislative level).⁷ Moreover, emerging pediatricians must have a strong grasp of the critical role of intersectionality in health outcomes.⁷

Although broad pediatric resident advocacy curricula are available in *MedEdPORTAL*,^{8,9} a gap remains in the design of curricula aimed at addressing advocacy specifically for the CMC population and their unique needs. With this gap in mind, we aimed to design a stand-alone and/or supplementary pediatric resident advocacy in complex care curriculum that would prepare residents to advocate for CMC at the clinical, community, and systems/legislative levels.

Methods

Setting

The Baylor College of Medicine–Children’s Hospital of San Antonio (BCM-CHofSA) Complex Care Clinic serves approximately 225 children and youth with medical complexity. Eligibility criteria include dependence upon at least one medical/technological device (including 75% with feeding tubes, 20% with a tracheostomy tube, and 26% dependent upon invasive or noninvasive mechanical ventilation) and the need for referrals to at least two pediatric subspecialists. Approximately two-thirds of patients are receiving private-duty nursing services.

Participants

The BCM-CHofSA Complex Care Clinic began delivering a comprehensive, 4-week, elective rotation to PGY 2-PGY 4 trainees (including pediatric hospital medicine fellows) in 2016 and PGY 1 trainees in 2019.

Curriculum Design and Implementation

We designed the comprehensive complex care curriculum utilizing an adaptation of Kolb’s experiential learning theory.¹⁰ We selected this conceptual framework as we believed pairing didactic instructional material with opportunities to observe and engage with CMC in their homes and communities when they were well and thriving would greatly enrich resident

education. Kolb’s learning cycle guides learners through concrete experience (feeling), reflective observation (watching), conceptualization (thinking), and active experimentation (doing).

Details of the curriculum design, including prerotation preparation, rotation components, and rotation evaluation, are already available in *MedEdPORTAL*.¹¹ Briefly, we originally divided the rotation into four weeklong blocks, with each week devoted to a theme or themes. Themes were selected to address published curricular priorities,¹² and educational objectives were devised for each theme. For each individual theme, we created or arranged pretests, didactic sessions, experiential site visits, and posttests. Primarily clinical complex care themes were presented in our previous publications,^{11,13} while this educational resource delivered instruction in advocacy themes for CMC.

The following processes represent the design and implementation of the advocacy for CMC portion of the rotation. Educators are encouraged to review the facilitator’s guide (Appendix A) for curriculum delivery details.

Rotation pretests and presurveys: We distributed the rotation syllabus and checklist (Appendix B) via email 1 week prior to rotation start date. Residents completed pretests of knowledge (Appendix C) and prerotation surveys of skills, attitudes, and behavior (Appendix D) prior to beginning the rotation.

Didactic lectures: We delivered didactic lectures either by narrated animated video lecture or face-to-face presentation (Appendix E: Education Policy, Appendix F: Medicare and Medicaid, Appendix G: Title V, Appendix H: SSI, Appendix I: Medicaid Waivers, Appendix J: ACEs and Today’s SDOH, and Appendix K: Diversity Sensitivity; total time: 60:04 minutes; range: 2:04-24:30 minutes; median: 6:25 minutes); learners subsequently completed posttests of knowledge (Appendix C). Posttest results and any questions were later discussed for clarification. The references for each didactic lecture were included on the final slide, and learners were encouraged to review this supplementary literature. We secured explicit permission from Powtoon to create and publish these video lectures.

Experiential site visits: Learners visited several community-based sites serving families of CYSHCN and CMC. The goal of these activities was to introduce pediatric trainees to community-based organizations with whom they could collaborate when advocating for CMC.

Learner Assessment and Evaluation

We assessed learner knowledge using pre- and posttests (Appendix C). Pre- and postrotation surveys (Appendix D) assessed learners' skills, attitudes, and behavior when caring and advocating for CMC. Following completion of the rotation and a subsequent inpatient rotation, learners were invited via email to complete the postrotation survey. Learners completed a postrotation evaluation of video lectures and site visits upon finishing the rotation.

Data Analysis

Descriptive statistics and frequencies were used to display learner differences in pre- and postrotation knowledge, self-assessed skills and behavior, and postrotation evaluation data. Pre- and posttest differences were compared using unpaired *t* tests.

A consent letter was attached to the orientation email, and pediatric trainees were given the opportunity to opt out of deidentified data collection (but not rotation procedures) at the beginning of the rotation. Evaluation of the curriculum was approved by the Baylor College of Medicine Institutional Review Board. No financial incentives were provided for participation.

Results

Forty-one pediatric residents and six pediatric hospital medicine fellows completed the elective rotation between July 2016 and June 2020. Data were available for 30 trainees; these 30 completed 105 pre- and 102 posttests, demonstrating a statistically significant gain in knowledge (37%, *SD* = 26%, vs. 85%, *SD* = 23%, *p* < .001). In total, 29 prerotation surveys and 15 postrotation surveys were available for analysis of self-assessed

skills, behaviors, and attitudes. Survey items, median Likert-scale scores, and percentage of trainees selecting Likert-scale scores of 4 or 5 are displayed in Table 1. We refer educators to our previous *MedEdPORTAL* publication for complete curriculum evaluation data.¹¹ A brief description of qualitative comments upon rotation completion regarding the advocacy portion of the curriculum is featured in Table 2; these comments are gleaned from written narrative reflections that have undergone thematic analysis in a separate publication.¹⁴

Discussion

Here, we present an advocacy supplement to a comprehensive complex care curriculum that incorporates didactic and experiential learning opportunities to effectively instruct residents in clinical, community, and systems/legislative advocacy for CMC. When delivered with previously published *MedEdPORTAL* educational resources,^{11,13} the combined curriculum addresses eight of 11 recently published complex care EPAs.⁷ Learners demonstrated significant improvement in knowledge (Kirkpatrick level 2) and self-assessed change in behavior (Kirkpatrick level 3) when advocating for CMC; qualitative comments regarding the advocacy portion of the curriculum demonstrate overwhelmingly positive learner reaction (Kirkpatrick level 1).¹⁵

While we opted to deliver these topics as part of a 4-week rotation curriculum, we encourage educators to adapt the videos and site visits to their own program structures. Because the Community Pediatrics Training Initiative's Core Curricular Objectives in Community Health and Advocacy Training¹ explicitly list care of special populations as a vital milestone, community health and advocacy rotation directors may choose to include this resource in their rotational or longitudinal instructional materials. Alternatively, for residency programs that

Table 1. Pre- and Postrotation Self-Assessment of Skills, Attitudes, and Behavior

Survey Item	Median Rating		% Residents Selecting 4 or 5	
	Prerotation (n = 29)	Postrotation (n = 15)	Prerotation (n = 29)	Postrotation (n = 15)
How comfortable are you using people-first language? ^a	3	5	41	67
How often do you use people-first language? ^b	4	4	59 ^c	100 ^d
How comfortable are you communicating/collaborating with the public education system (PPCD or K-12) about a child with special needs/disabilities? ^a	2	3	10	47
How often do you communicate/collaborate with the public education system (PPCD or K-12) about a child with special needs/disabilities? ^b	2	2	0	0
How important is advocacy when caring for children with medical complexity? ^e	5	5	100	100

Abbreviations: K-12, kindergarten through grade 12; PPCD, preschool program for children with disabilities.

^aRated on a 5-point Likert scale (1 = *not comfortable at all*, 5 = *extremely comfortable*).

^bRated on a 5-point Likert scale (1 = *never*, 5 = *always*).

^cTen trainees (34%) selected "I do not know what people-first language is."

^dZero trainees (0%) selected "I do not know what people-first language is."

^eRated on a 5-point Likert scale (1 = *not at all important*, 5 = *extremely important*).

Table 2. Qualitative Evaluation Comments of Advocacy for Children With Medical Complexity Curriculum

Reflection Topic	Quotes
Advocacy	“The lecture on insurance... was important as it has helped me to ask our social worker more targeted questions about why I am consulting her.” “I got to... see how much we can do to advocate for their care and all that goes into getting them what they need.... The most profound take away from this rotation was... an inspiration to be more involved in all patient’s lives.”
Communication	“People First Language reminds us that our patients... have interests and talents just like everyone else that make them unique.” “The last time I was on service, the resident compared a patient of yours to a ‘normal’ patient.”
Humanism	“Additionally, I had the pleasure of seeing complex children... while they were at school, at home, a playground, or at basketball practice.” “While I still don’t know where my career will take me, my core mission is to serve children that are in need. Whether they are poor, need advocacy or struggle with complex medical care I want to give them the best chance.”

have transitioned to an X+Y scheduling model, this resource may be incorporated alone into a Y week.

Delivering a curriculum that relies so heavily upon experiential site visits within the local community may prove challenging. We invite educators to review the Snowball ASSET Mapping guide detailed in our previous publication.¹¹ Moreover, state chapters of the American Academy of Pediatrics present excellent opportunities for learners to engage in legislative advocacy for CYSHCN. For example, this author volunteered as a Texas Pediatric Society Resident, Fellow, Medical Student Advocacy Day preceptor and accompanied learners to the capitol building in Austin, Texas, to advocate for funding for early childhood intervention services.

While our learners demonstrated statistically significant increases in knowledge scores, self-assessment of behavior was limited by low postsurvey response rates (50%). We suspect capturing postsurvey responses via email several weeks after completion of the rotation (and not during protected time as part of the rotation) resulted in fewer completed surveys. As a result, we were not objectively able to assess change in learner behavior. Future delivery of this curriculum may benefit from capturing self-assessed behavior data prior to completion of the rotation—allowing for protected time for the learner to complete the postsurvey—and use of a learner assessment tool while directly observing learners engaging in advocacy for CMC. Moreover, because we delivered our complex care curriculum within a community-based midsize residency program as a 4-week elective, our findings may be generalizable to similar programs and among learners similarly opting to engage in such a rotation. That said, residents who selected this rotation transitioned to a variety of career trajectories representative of numerous pediatric generalist and subspecialty fields (general pediatrics, pediatric hospital medicine, newborn hospital medicine, neonatal/perinatal critical care, critical care medicine, hematology/oncology, palliative medicine, emergency medicine, gastroenterology,

infectious disease, child abuse, child psychiatry, and pediatric dermatology).

In summary, this stand-alone advocacy for CMC curriculum or supplement to a comprehensive complex care curriculum addresses a significant competency in advocacy education and supports addressing the majority of recently published complex care EPAs. This educational resource incorporates didactic and experiential teaching methods and includes learning materials, assessment tools, and evaluation tools. The curriculum remains adaptable by other users to allow individual pediatric residency programs to incorporate it effectively within their own program structure.

Appendices

- A. Facilitators Guide.docx
- B. Rotation Syllabus and Checklist.docx
- C. Pre- and Posttests.docx
- D. Pre- and Postrotation Surveys.docx
- E. Education Policy.mp4
- F. Medicare and Medicaid.mp4
- G. Title V.mp4
- H. SSI.mp4
- I. Medicaid Waivers.mp4
- J. ACEs and Today’s SDOH.pptx
- K. Diversity Sensitivity.mp4

All appendices are peer reviewed as integral parts of the Original Publication.

Ruchi Kaushik, MD, MEd, MPH: Medical Director of Education and Research and Complex and Palliative Care Physician, Imagine Pediatrics; ORCID: <https://orcid.org/0000-0002-6769-2801>

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Ethical Approval

The Baylor College of Medicine Institutional Review Board approved this project.

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