Original Publication

OPEN ACCESS

Understanding the Needs of Children With Medical Complexity

Kathleen Huth, MD*, Sara Long-Gagne, MD, Jessica Mader, Anne Marie Sbrocchi, MD

*Corresponding author: kathleen.huth@childrens.harvard.edu

Citation: Huth K, Long-Gagne S, Mader J, Sbrocchi AM. Understanding the needs of children with medical complexity. *MedEdPORTAL*. 2018;14:10709.

https://doi.org/10.15766/mep_2374-8265.10709

Copyright: © 2018 Huth et al. This is an open-access publication distributed under the terms of the Creative Commons Attribution-NonCommercial-Share Alike license.

Abstract

Introduction: Children with medical complexity (CMC) are characterized by chronic conditions, functional limitations, technology dependence, and high health care utilization. There are limited formal training opportunities in the provision of complex care for pediatric residents. **Methods:** We developed a module to enable target learners to understand unique needs of CMC and the general pediatrician's role in creating a medical home. The module was piloted in a single pediatric residency program. The 60-minute session incorporated small-group activities and didactic instruction. Learners were given formative pre- and posttest questions to check understanding and completed a 1-minute paper to summarize anticipated changes in practice. Qualitative content analysis was used to identify themes in written responses.

Results: Fifteen pediatrics residents participated in the module at a single children's hospital. Most residents had not had a complex care clinical rotation. Themes in learner knowledge of CMC included recognizing functional limitations and recurrent health care utilization. Themes from anticipated changes in practice included having less fear/anxiety when approaching care for CMC and asking about diverse areas of need, including nonmedical. **Discussion:** This core module was developed as part of a national systematic approach to complex care curriculum development. It has the potential to be adapted to frame a broader complex care curriculum and to be implemented with other learners in the health professions who care for this vulnerable patient population. The pilot study informed implementation in multiple residency programs, with the goal of enabling future pediatricians to provide high-quality care within a medical home for CMC.

Keywords

Editor's Choice, Pediatrics, Complex Care, Medical Home

Appendices

- A. CMC Module - Tools of Instruction.docx
- B. CMC Module - Facilitator Guide.pdf
- C. CMC Module - Slides.pptx
- D. CMC Module - A Father's Letter.docx
- E. CMC Module - Formative Assessment Questions.docx

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

Educational Objectives

By the end of this activity, learners will be able to:

1. Identify children with medical complexity (CMC) by virtue of their medical fragility, functional limitations, service needs, and technological dependency.
2. Discuss the concept of the medical home as a model for providing optimal care for CMC.

Introduction

Children with medical complexity (CMC) are those with chronic conditions that cause severe functional limitations, often leading to technology dependence, with high health care utilization.¹ Although their medical diagnoses differ, CMC have similar high service needs with increased risk of care fragmentation, requiring care that is comprehensive, coordinated, and proactive. General pediatricians have a major role in coordinating care for CMC to meet their unique needs, both in hospital and in community practice.²

Currently, pediatric residency programs offer extremely variable educational opportunities in the provision of complex care. Pediatric residents may have different levels of expertise and comfort in the care of CMC depending on their own motivation to seek additional training. Multiple studies have highlighted the need for formal training opportunities during pediatric residency to support the delivery of safe, evidence-based care for CMC,³⁻⁵ as well as dedicated education in care coordination within a medical home.⁶

A review of relevant educational resources on *MedEdPORTAL* revealed that there were complex care curricular modules specific to supporting children with special health care needs in identifying community resources⁷ and on transition to adulthood and the medical home.⁸ However, there was no resource dedicated to the overall approach to caring for a child with complex needs as a general pediatrician—what does it mean for a child to be complex? How do you identify and meet needs for CMC and their families as a general pediatrician, within a medical home? Equipping members of the health care team with this core knowledge is essential for the delivery of comprehensive, proactive, and coordinated care for CMC in their community and is the goal of this module.

In order to address educational needs in complex care, members of the Canadian Paediatric Society's Complex Care Special Interest Group developed a module for pediatric residents to discuss the epidemiology, unique needs, and role of the medical home in supporting high-quality and holistic care for CMC. A systematic six-step approach to curriculum development was utilized to develop competency-based objectives and identify appropriate educational strategies.⁹ This module was reviewed by the Canadian Pediatric Program Directors (CPPD) for integration within pediatric residency programs in Canada, with pilot implementation of the module at a single site.

Methods

This module was targeted at pediatric residents of all levels of training. They may or may not have participated in a formal complex care rotation during training. There were no prerequisites for participation.

This stand-alone educational module could also be delivered in the context of a broader curriculum in complex care addressing aspects of clinical assessment, care planning, and medical technology care. The module takes 1 hour to complete and includes the following topic areas and allotted time:

- Pretest (5 minutes).
- Introduction (2 minutes).
- Who are CMC (5 minutes)?
- Why it matters (5 minutes).
- Improving quality of care for CMC (10 minutes).
- The medical home (20 minutes).
- A father's letter (3 minutes).
- Case example (10 minutes).
- Closing (3 minutes).

The module incorporates interactive group activities with didactic content (Appendix A). The materials consist of a facilitator's guide (Appendix B) with accompanying PowerPoint slide presentation (Appendix C) and supplemental information (Appendix D).

The facilitator's guide is an instructional resource including an overview of the module content, a description of resources needed, a step-by-step guide on how to facilitate the module, and other supporting information. The purpose of the facilitator's guide is to support instruction by providing clear road maps of the module. The guide is laid out to meet the module learning objectives while also providing the most effective and engaging learning environment for residents. The guide has been designed for health care professionals who may or may not have any experience in implementing curricula.

Facilitator Requirements

A facilitator for this module is someone who has experience and comfort in the care of children with complex medical needs and technological dependence. The facilitator may or may not have had formal

training in complex care medicine or medical education. The facilitator may be a subspecialist or general pediatrician or else a complex care nurse or nurse practitioner. The curriculum may be cofacilitated by an interdisciplinary team, including respiratory therapy, social work, and other allied health professionals with expertise in caring for this specialized population.

Facilitator preparation for delivering the module was as follows:

- Reading and printing the facilitator's guide.
- Reviewing the guide to familiarize themselves with the different instructional activities (i.e., think-pair-share).
- Making copies of the pre- and postassessments for learners.
- Gathering seven flip charts and markers or using the classroom whiteboard.
- Bringing index cards (one per learner).
- Uploading the slide presentation onto a USB key.
- Reviewing the PowerPoint presentation.
- Ensuring that the room where the presentation would be given could facilitate small- and large-group discussions, as well as flip charts/whiteboard use.

This module was piloted in the pediatric residency program at the Montreal Children's Hospital, a 4-year program at a tertiary care pediatric hospital in Montreal, Quebec. It was deemed exempt by the Research Ethics Board at the McGill University Health Centre.

There were formative assessments, including pre- and posttest questions for learners to check their understanding (Appendix E), as well as a 1-minute paper to assess the effectiveness of the module in enabling learners to achieve the educational objectives. The pretest was given in the first 5 minutes of the module. The posttest was given to the learners to complete following the session. The 1-minute paper was designed for residents to identify the key message that they had learned in the module and note what questions they still had (which may not have been addressed in the time allotted for discussion).

Qualitative content analysis was used to identify themes in written responses.

Results

Fifteen residents participated across all postgraduate years 1-4. Thirteen out of 15 (87%) had never had a clinical rotation in the Complex Care Service; however, 14 out of 15 (93%) described having had some informal teaching in complex care prior to the module. The curriculum was facilitated by two academic pediatricians in the Complex Care Service (Sara Long-Gagne, Anne Marie Sbrocchi) during an academic half-day, as part of a series of four modules.

Features of CMC

Similar ideas were suggested pre- and postimplementation in terms of chronic illness, technology dependence, and multiplicity of specialists involved, which may have been due to the fact that many residents had received informal teaching in complex care prior to participation in the module. Posttest responses (see the [Table](#)) included functional limitations and recurrent health care utilization of CMC that were not described in responses prior to the module.

Table. "List 3 Features That Characterize Children With Medical Complexity": Themes From Learner Responses

Pre	Post
Chronic illness	Chronic conditions
Multiple medical problems and medications	Requiring support for activities of daily living
Technology/devices that need to be managed at home	Technology-dependent
Need for regular/long-term follow-up	Frequent appointments/recurrent hospitalizations
Multiple specialists involved	Multiple specialists/teams involved

The Medical Home

There was no significant difference in learner responses to a multiple-choice question about the nature of the medical home ($p > .05$). The question was intended as a formative assessment to check understanding in a small sample of learners. The medical home concept emerged in themes from the 1-minute paper.

1-Minute Paper

The following themes emerged when learners were asked, “What is one thing that you learned from the session that will change how you care for CMC in your clinical practice?”: understanding the role of the pediatrician in CMC care, recognizing family perspective and challenges, prioritizing diverse needs in a medical home, and alleviating fear/anxiety about providing care for CMC. Exemplar quotations arranged by theme included the following:

- Understanding the role of the pediatrician in CMC care:
 - “As a primary medical provider we can be the face of continuity and accessibility.”
 - “I learned that there are multiple day to day needs that the MD can help with.”
 - “I learned that a general pediatrician can treat a complex patient.”
- Recognizing family perspective and challenges:
 - “The actual amount of time that parents need to spend coordinating.”
 - “What I have learned: 1) How hard it is having a child with complex medical problem 2) What is our role 3) What is the meaning of medical care.”
- Prioritizing diverse needs in a medical home:
 - “Things I learnt: To think about different aspects of care ‘not just medical’; To be in the parents’ shoes; that complex care delivery is possible.”
 - “Identify/address needs that are nonmedical (education, financial, psychosocial) as opposed to only focusing on medical needs.”
 - “Necessity of prioritization while maintaining a proactive focus.”
- Alleviating fear/anxiety about providing care for CMC:
 - “I learned not to be scared when we are referred a complex care child and to prioritize. I also learned what a medical home is.”
 - “I was introduced to the concept of the Medical Home. Change in Practice: Not to be afraid when treating CMC. And prioritize the medical need.”

Learners were also asked, “What is one question that you have after participating in the session?” Most responses were about how to provide care for CMC outside of a tertiary academic center. Exemplar quotations are provided below.

- “How do you coordinate care in hospital that is not multidisciplinary?”
- “What resources can I offer the family if they live really far from the hospital or tertiary care center?”
- “I want to know how it is feasible to do this in the community? What resources do you need? How to organize?”

Discussion

This module was developed with the ultimate goal of enabling future pediatricians to become competent in caring for CMC. Given the variability of clinical exposure and training opportunities in complex care, a module that introduces a standard approach to understanding and meeting the needs of CMC in a medical home provides a valuable educational experience for learners. It is notable that learners felt they had a new understanding of the role of a general pediatrician within a medical home, challenges faced by the family, and unique areas of need for CMC. The value of this module is its focus on broader systems of care and reflection on professional roles—areas of expertise that are often challenging to explore but are important to develop in order to enable learners to best serve their patients.¹⁰

The module has incorporated feedback from facilitators and pediatric resident participants as part of the dissemination strategy. Formative evaluation of the module informed revisions to its content for clarity and to ensure appropriate time for discussion. Formative evaluation also allowed us to capture new understandings endorsed by our learners and anticipated changes in practice as a result of participation in the module. Preliminary findings from the pilot evaluation have informed further study of the broader curriculum upon implementation in other pediatric residency programs. This includes evaluation of skills in approaching care of CMC in the context of an objective structured clinical examination, as well as qualitative study of changes in resident self-efficacy in the care of CMC.

This module was piloted with pediatric residents in the context of an academic-half day, yet it has the potential to be adapted to other settings and target learners. It can be facilitated as part of morning rounds within clinical teams, as a lunch-hour session, or as part of an academic retreat. In collaboration with the CPPD, members of the Canadian Paediatric Society's Complex Care Special Interest Group have facilitated implementation of this module in other pediatric residency programs in these different contexts. The module can also be adapted for other learners in the health professions who care for CMC, including nurses, nurse practitioners, physician assistants, social workers, and care coordinators. Thus far, it has been used for continuing education for nurses and members of interprofessional care teams.

Limitations of this resource include that it was piloted with a small sample of learners at a single site. Our formative evaluation did not allow us to capture a quantitative difference in knowledge or skills associated with participation in the session. The posttest questions and 1-minute paper were provided immediately after the session, without long-term follow-up, which did not allow us to assess knowledge retention.

Dedicated training about a growing vulnerable population is at the core of ensuring high-quality, family-centered care for children with complex medical needs. This module provides a high-level overview for learners of what it means for a child to be medically complex and how to approach care in collaboration with the family and interdisciplinary care team within a medical home—critical areas of understanding for future pediatricians.

Kathleen Huth, MD: Instructor, Pediatrics, Harvard Medical School

Sara Long-Gagne, MD: Assistant Professor, Pediatrics, McGill University Health Centre

Jessica Mader: Secondary School Teacher, Estes Park Middle School, Colorado

Anne Marie Sbrocchi, MD: Assistant Professor, Pediatrics, McGill University Health Centre

Acknowledgments

The Canadian Paediatric Society and the Canadian Pediatric Program Directors supported curriculum development as a national initiative. Hema Patel, Tammie Dewan, and the members of the Canadian Paediatric Society Complex Care Special Interest Group provided expert revisions to the curricular materials.

Disclosures

None to report.

Funding/Support

None to report.

Ethical Approval

The Research Ethics Board at the McGill University Health Centre approved this study.

References

1. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538. <https://doi.org/10.1542/peds.2010-0910>

2. Dewan T, Cohen E. Children with medical complexity in Canada. *Paediatr Child Health*. 2013;18(10):518-522. <https://doi.org/10.1093/pch/18.10.518>
 3. Bogetz JF, Bogetz AL, Rassbach CE, Gabhart JM, Blankenburg RL. Caring for children with medical complexity: challenges and educational opportunities identified by pediatric residents. *Acad Pediatr*. 2015;15(6):621-625. <https://doi.org/10.1016/j.acap.2015.08.004>
 4. Sbrocchi AM, Millar C, Henin C, Allard M, Patel H. Complex care core curriculum for pediatric post-graduate trainees: results of a North American needs assessment. *J Pediatr Rehabil Med*. 2015;8(2):141-146. <https://doi.org/10.3233/PRM-150327>
 5. Nazarian BL, Glader L, Choueiri R, Shipman DL, Sadof M. Identifying what pediatric residents are taught about children and youth with special health care needs and the medical home. *Pediatrics*. 2010;126(suppl 3):S183-S189. <https://doi.org/10.1542/peds.2010-1466O>
 6. Council on Children With Disabilities, Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5):e1451-e1460. <https://doi.org/10.1542/peds.2014-0318>
 7. Clark M, Hobson-Rohrer W, Benenson B, Stein R. EMPOWER curriculum: teaching effective use of community resources for children with special health care needs. *MedEdPORTAL*. 2015;11:9993. https://doi.org/10.15766/mep_2374-8265.9993
 8. Gooding H, O'Reilly C, Weitzman E, Burke P, Goncalves A, Pitts S. Transitioning Bryan: the transition to adulthood and the medical home. *MedEdPORTAL*. 2015;11:10226. https://doi.org/10.15766/mep_2374-8265.10226
 9. Kern DE, Thomas PA, Hughes MT, eds. *Curriculum Development for Medical Education : A Six-Step Approach*. 2nd ed. Baltimore, MD: Johns Hopkins University Press; 2009.
 10. Frank JR, Snell L, Sherbino J, eds. *The Draft CanMEDS 2015 Physician Competency Framework—Series IV*. Ottawa, Ontario, Canada: Royal College of Physicians and Surgeons of Canada; 2015.
-

Received: December 5, 2017 | **Accepted:** March 24, 2018 | **Published:** April 20, 2018