EDUCATIONAL PROGRAM REPORT

Impact of a Multifaceted Complex Care Rotation on Pediatric Residents and Hospital Medicine Fellows

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ABSTRACT

BACKGROUND: Pediatric residents typically do not receive formal training in the care of children with medical complexity (CMC) in a medical home setting. Interest and momentum in the design of complex care curricula to achieve recently published complex care EPAs is building; however, an understanding of which facets of such a curriculum are effective is unknown.

OBJECTIVES: We aimed to conduct a qualitative evaluation of pediatric resident and hospital medicine fellow perceptions of a multifaceted complex care rotation. Utilizing Kolb's experiential learning cycle as a framework, we designed a complex care rotation that incorporated clinical, didactic, and experiential modalities. Upon completion of a complex care rotation, trainees wrote a one-page Reflection.

ELECTIVE OUTCOMES: Of 47 trainees who participated in the rotation, 34 (72%) completed Reflections from which we identified five themes: 1) Medical Home; 2) Communication; 3) Education; 4) Advocacy; and 5) Humanism. Furthermore, we describe lessons learned while delivering iterations of the curriculum over six years.

CONCLUSION: A multifaceted complex care rotation reveals insightful resident perceptions of its educational benefits. Facilitators and opportunities to support trainee learning inform complex care educators as they begin to design local institutional curricula.

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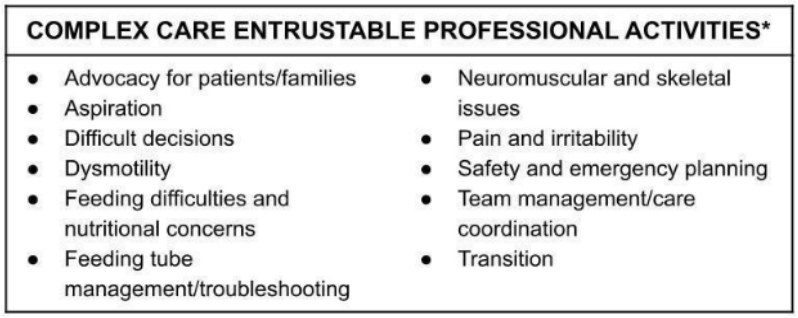
INTRODUCTION

Children with medical complexity (CMC) are an important subset of the children with special healthcare needs (CSHCN) population who have complex chronic health care needs and are considered to be medically fragile.[1] Their diverse conditions result in a need for extensive care coordination, collaboration with community-based services, and provision of compassionate, high-quality care within the medical home, perhaps best delivered in the setting of a Complex Care clinic.[2]

Pediatric residents often receive the training necessary to care for CMC when they are acutely ill;[3] however, residents typically do not receive the formal practical training necessary to care for these children in the outpatient, medical home setting. Clinician educators charged with delivering medical home curricula and concepts such as patient- and family-centered care, care coordination, health care transition, and care of CSHCN are challenged by lack of resident time, faculty time, funding, prioritization, and resident interest.[4] A failure to present these concepts to trainees, who will soon enter the pediatric workforce, will only compound the “fragmented, uncoordinated, and crisis-driven care” these children currently receive.[2]

The American Board of Pediatrics considers the “provi[sion] of a medical home for patients with chronic, complex, or special health care needs” an essential activity needed for practice.[5] In 2018 national experts in the care of CMC established a list of eleven curricular priorities in the care of this population.[6] More recently this expert panel garnered the support of competent members of the field to create and map eleven entrustable professional activities to all 21 pediatric competencies (Figure 1).[7,8] Interest and momentum are building in the institution of Complex Care rotations; however, at this time no educational resource that comprehensively trains, equips, and informs pediatric residents in the numerous aspects of the provision of a medical home for CMC is currently in place. The lived experiences of families of CMC have been described in the literature[9,10], and pediatric residents have identified several

Figure 1: Complex Care Entrustable Professional Activities



*Huth K, Henry D, Fabersunne CC, et al. A Multistakeholder Approach to the Development of Entrustable Professional Activities in Complex Care. *Acad Pediatr*. September 2021. doi:10.1016/j.acap.2021.09.014

challenges in caring for CMC, including lack of care coordination, complex technology management, patients' pervasive psychosocial needs, and lack of effective training.[11] To our knowledge, a qualitative understanding of pediatric resident perceptions of a comprehensive Complex Care curriculum that addresses resident-identified potential solutions–greater integration of primary care providers, attention to psychosocial needs through shared decision-making, and integration of longitudinal patient relationships into provider training[11]--through didactic and clinical instruction and an emphasis on these lived experiences has not yet been demonstrated.

ELECTIVE HISTORY: The Baylor College of Medicine-Children's Hospital of San Antonio (BCM-CHofSA) Complex Care clinic (CCC) first began serving patients in September 2014, ~ one year after this first free-standing children's hospital in San Antonio, Texas, opened its doors to this community. The BCM-CHofSA pediatric residency program's first residents began training in July 2015. Prior to designing this curriculum, no formal Complex Care training had been incorporated into the residency program's pediatric education.

EDUCATIONAL FRAMEWORK & OBJECTIVES: Using Kolb's experiential learning cycle as a conceptual framework, we designed a pediatric resident Complex Care curriculum, delivered via an elective four-week block rotation. Kolb posits that learning occurs via a cyclic process; learners first engage in an experience, which requires reflecting upon their current practice, resulting in thinking abstractly and drawing conclusions regarding the gaps in their current practice, and finally motivating them to act by experimenting with newly learned skills. This curriculum incorporates didactic, clinical, and experiential teaching methods and addresses eight of the eleven

recently published EPAs. The overarching goals of the curriculum were to prepare emerging pediatricians to deliver high-quality, effective, and well-coordinated primary care for CMC and their families in a medical home and to inculcate the values of empathy, humility, and humanism when residents interacted with families of CMC, in both the clinical and community-based settings. Our educational objectives are listed below. Devised prior to publication of Complex Care EPAs, these objectives are reflective of a consensus among complex care practitioners of the significance of not only training in clinical practice but also of knowledge and skills necessary to engage with community-based and policy-making partners to fully address the needs of families of CMC.

By the end of this four-week rotation, learners will be able to:

1) Identify children with medical complexity (CMC) and special health care needs (CSHCN). (Didactic)

2) Demonstrate improved competence in providing acute, follow-up, and preventive care services to CMC with an emphasis on the medical home setting (accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally effective). (Clinical)

3) Formulate care plans that take into consideration shared decision-making and the many socio-environmental factors that motivate families' choices. (Clinical)

4) Relate the current healthcare policies that affect CMC to the daily experiences and outcomes of these children and families. (Didactic)

5) Discuss social determinants of health and adverse childhood experiences and their impact on health outcomes. (Didactic, Experiential)

6) Locate and describe community-based health care providers and non-medical resources to advocate for medical, developmental, socio-emotional, and behavioral health care of CMC. (Experiential)

7) Relate current healthcare and education policies that affect CMC to the daily experiences and outcomes of these children and families and apply them when advocating for CMC. (Didactic, Clinical, Experiential)

CURRICULUM PUBLICATIONS: Our quantitative assessment of learner knowledge, skills, attitudes, and behavior

are presented under separate manuscripts. Our initial MedEdPORTAL submission was not considered as the content file sizes were too large for the MedEdPORTAL platform. Discussion with an associate editor led to division of this submission into two parts. The first half of the curriculum (Care Coordination, Non-oral Feeding and Feeding Tubes, Evaluation and Management of Aspiration, Sharing Unexpected News, and Health Care Transition) is currently under review with MedEdPORTAL; the second half of the curriculum manuscript (Education Policy; Medicare, Medicaid, SSI, Title V, and Medicaid Waivers, Adverse Childhood Experiences and Today's Social Determinants of Health, and Diversity Sensitivity) is in draft, awaiting decision of the first half. In this qualitative program evaluation, we aimed to better understand what aspects of this curriculum residents believed were most effective and inspired behavior change by conducting an evaluation of resident narrative reflection statements upon conclusion of the rotation.

ELECTIVE DESCRIPTION

EDUCATIONAL SETTING: The BCM-CHofSA Complex Care clinic (CCC) provides a medical home for CMC who require the use of technology (e.g., gastrostomy/gastrojejunostomy tubes, oxygen, tracheostomy tubes, invasive and non-invasive mechanical ventilation, central venous catheters, dialysis catheters, ventriculoperitoneal shunts, cardiac shunts, etc.). Patients typically qualify for private duty nursing services, habilitative and rehabilitative therapies, and durable medical equipment.

PARTICIPANTS: Study subjects included and the rotation was originally designed to be delivered to pediatric residents (PGY-1 to PGY-3) who elected to engage in the Complex Care rotation; however, after reviewing curriculum materials, an educational leader within our program who served as both associate residency program director and pediatric hospital medicine (PHM) fellowship program director added the rotation to the PHM fellows' first year schedule.

CURRICULUM: The CCC has offered a four-week elective rotation to 1-2 pediatric residents and/or pediatric hospital medicine (PHM) fellows per block since 2016. A complete description of the Curricular Elements is tabulated in Table 1. The curriculum incorporates clinical, didactic, and experiential components. The typical schedule includes 3.5 clinic sessions to complete ~ 15 well child, follow-up, and

acute patient encounters per week. When trainees are not engaging in patient encounters, they watch didactic videos and attend on-campus or community-based site visits. Although MedEdPORTAL houses several instructional complex care videos for pediatricians, we opted to independently create animated videos for pediatric residents for technical uniformity using Powtoon and to incorporate skills beyond clinical care that include the significance of effective communication and policy knowledge. Curricular outcomes are measured via learner assessment and rotation evaluation. Additionally, upon conclusion of the block, trainees are asked

Table 1: Complex Care Curriculum Elements

COMPLEX CARE CURRICULUM ELEMENTS	
Didactic Video Lectures	Topics (EPAs)[a] Care Coordination* (11) Non-oral Feeding and Feeding Tubes* (1,3,8) Evaluation and Management of Aspiration* (1,4) Sharing Unexpected News* (9) ACEs and Today's Social Determinants of Health** (10) Education Policy** (10,11) Titles XVIII, XIX, and V, SSI, and Medicaid Waivers** (10,11) Diversity Sensitivity** (10) Health Care Transition*** (7) *MedEdPORTAL manuscript under review **MedEdPORTAL manuscript in draft ***https://www.mededportal.org/doi/10.15766/mep_2374-8265.11239
Clinical Care	~ 15 well child, follow-up, or acute visits for CMC per week
Experiential	≥ 10 of 16 site visits of medical/community-based providers serving CMC **ON SITE** • Bronchopulmonary Dysplasia clinic • Craniofacial Anomalies clinic • Respiratory Therapist: tracheostomy tubes / ventilators • Pediatric Neurosurgery: ventriculoperitoneal shunts • Pediatric Nephrology: dialysis clinic • Wound Care Nurse **OFF SITE** • Public school designed specifically for CMC • Non-profit organization that provides physical and creative activities for CMC • Special needs amusement and water park • Residential support for children with special needs in the foster care system • Outpatient pediatric rehabilitation therapy center • Genetic diagnosis support group • State parent training and information center
Learner Assessment	Pre- and Post-Rotation Tests of Knowledge Pre- and Post-Rotation Surveys of Behavior Reflection

a. Mapping of Didactic Video Lectures to Complex Care Entrustable Professional Activities[1]
1. Evaluate and manage feeding difficulties and nutritional concerns for children with medical complexity
2. Evaluate and manage pain and irritability in children with medical complexity
3. Manage motility disorders in children with medical complexity
4. Evaluate and manage aspiration in children with medical complexity
5. Evaluate and manage common neuromuscular and skeletal issues in children with medical complexity
6. Develop and implement safety/emergency plans for children with medical complexity
7. Design and implement a developmentally appropriate transition process to adult care for children with medical complexity
8. Provide routine care for children with medical complexity with feeding tubes and troubleshoot common issues
9. Facilitate goals of care discussions and introduce the concepts of palliative and hospice care for children with medical complexity
10. Advocate for children with medical complexity and their families in the community setting
11. Facilitate team-based care coordination for children with medical complexity

to describe the following in a one-page Reflection:

a) Which of the lectures or articles you found most insightful and/or useful and why?

b) Which of the site visits you found most insightful and/or useful and why?

c) What new piece of information you learned during the rotation had the most impact on how you will approach care for CYSHCN and why?

d) What you will do differently in your career moving forward.

Initially these questions were designed to help the rotation director reflectively critique and improve upon the rotation. Because we utilized didactic and experiential methods in addition to instruction in clinical care, we hoped to understand which aspects of these methods would result in improvement in knowledge, skills, and behavior, with a goal to refine clinical practice.

ELECTIVE OUTCOMES

We aimed to conduct a qualitative evaluation of pediatric resident perceptions of a multifaceted Complex Care rotation. Upon completion of a Complex Care rotation, residents wrote a one-page Reflection. The study is more fully described in the Appendix.

Between July 2016 and June 2020, 47 trainees (41 pediatric residents and 6 PHM fellows) completed the Complex Care rotation, and 34 Reflections were available for review. For context, our program accepts 13 categorical pediatric residents per year and approximately 12-15 residents elect to complete this rotation annually. We identified five themes as strong contributors to the rotation experience: 1) Medical Home (Table 2); 2) Communication (Table 3); 3) Education (Table 4); 4) Advocacy (Table 5); and 5) Humanism (Table 6).

MEDICAL HOME: Trainees noted that caring for CMC requires a compassionate “village” mentality that positions the patient/family at the center of the “village,” or medical home, and that pediatricians serve as expert facilitators who ensure communication across all partners and through the life continuum. This statement was supported by four sub-themes.

Trainees commented on the significance of facilitating communication to the correct entity, other pediatric practitioners, school personnel, pharmacies, long term services and supports, insurance companies, and policymakers.

They also noted that the approach to caring for CMC must include particular and dedicated attention to family-centered care, often requiring pediatricians to engage in shared decision-making and refrain from inserting their own values into the discussion.

The role of community-based partnerships in the “village” allowed trainees to observe inclusivity, understand the process of developing partnerships themselves, and plan to refer families to relevant resources. One trainee expresses their surprise upon discovering a CMC in a school environment.

Finally, trainees describe the challenges of transitions (from neonatal intensive care nursery and/or repeated inpatient hospitalizations to home, from home to entry in the school system, from a pediatric to adult model of care) requiring pediatricians to coordinate comprehensive education, delineate discharge instructions explicitly, elicit families’ perspectives and needs, celebrate their joys, consider participating in home visits, and address families’ fears and concerns to achieve a successful out-of-hospital existence.

COMMUNICATION: Trainees expounded also on the quality of communication. Engaging in “clear and precise,” honest, empathetic, non-judgmental, person-first, two-way, values-driven communication with families of CMC is vital to developing trusting relationships; preventing medical errors; clarifying team roles; and eliciting families’ fears, concerns, and needs to ensure they are addressed.

Specifically, trainees expressed that words matter and that pediatricians should become competent in using person-first language, refraining from the use of terms that focus on a child’s disability.

Trainees affirm communication as necessary in effectively delivering the accessible care a CMC needs, preventing miscommunication and medical errors, and reducing family burden.

Moreover, they related that open-ended discussions during inpatient, outpatient, and at-home encounters helped them to improve communication skills and relationships with families of CMC, see the world through the eyes of the families, recognize the significance of families’ level of health literacy when caring for their children, and provide better care.

Lastly, trainees recounted that sharing unexpected news requires skill, preparedness, and compassion.

EDUCATION: Trainees found that the Complex Care rotation taught knowledge, skills, and attitudes from a unique outpatient, primary care perspective.

First trainees expressed that a Complex Care education should begin by defining CSHCN and those with medical complexity and include instruction in the provision of evidence-based medical care of CSHCN and CMC.

One trainee's observation, "I learned about the frustrations the advocate, schools, parents and patients face with the school system", supports the subtheme that families of CMC face great challenges that often remain hidden to trainees until the Complex Care rotation unveils them.

Trainees also voiced how the Complex Care rotation held the capacity to inspire reflective opportunities, reminding them why they chose pediatrics as a career path and fostering development of their personal and professional identities.

ADVOCACY: Residents recognized the essential component of advocacy when caring for CMC. Trainees find that advocacy for CMC requires collaborating across spheres and beyond the hospital/clinic room.

Trainees revealed that advocacy beyond the healthcare workspace entails collaboration with patients/families, schools, community-based resources, and decision-makers; this is essential for CMC's best quality of life in the homes and communities in which they live.

Moreover, trainees affirmed that pediatricians should empower families of CMC to become self-advocates.

Trainees comment on advocacy within the local clinical sphere as well. While adverse childhood experiences and the social determinants of health, including poverty, result in toxic stress, negatively affect a child's trajectory, and impact a child's long-term health and well-being, pediatricians can interject in this cycle by promoting nurturing caregiver relationships and resiliency.

At times, however, engaging in advocacy may first require trainees to examine their own individual values surrounding how health care dollars are spent.

HUMANISM: Finally, trainees expressed that all children's lives have meaning and purpose; bearing this in mind helps them reconnect with humanism and combat burnout. They note that the Complex Care

rotation helped them recognize the value and joy of families' hope, quality of life, and a focus on abilities, rather than disabilities. Furthermore, pediatrics is not an occupation solely for providing medical care to children, but rather a privilege and rewarding calling to serve, care, and advocate for all populations of children. The rotation helped them reconnect with humanism and with their decision to pursue medicine and pediatrics.

Nevertheless, they also found that varying competing responsibilities that steer them away from passion to provide care to children can exert toxicity and diminish empathy, resulting in burnout, moral injury, and compassion fatigue.

DISCUSSION

We conducted a qualitative program evaluation of pediatric resident and PHM fellow Reflections following completion of a multifaceted four-week Complex Care rotation. While quantitative outcomes of this rotation have been and hopefully will continue to be described elsewhere, we believe evaluation of these Reflections overwhelmingly demonstrate achievement of one of our overarching goals: to inculcate the values of empathy, humility, and humanism when residents interacted with families of CMC, in both the clinical and community-based settings. These Reflections defined which components of the rotation were most impactful and inspired trainee behavior change, and revealed themes demonstrating the influences of Medical Home, Communication, Education, Advocacy, and Humanism. We hope the description of our curriculum design and qualitative evaluation thereof will assist other clinician educators within the complex care community to develop similar rotational experiences in their home institutions.

Trainees endorsed the role of a Complex Care rotation to provide instruction in the concepts of a medical home, the definition of CSHCN and CMC, the approach to caring for children who use medical equipment, the various methods to advocate for families of CMC, and the development of interpersonal communication skills when addressing not only CMC and their families but also hospital- and community-based members of the comprehensive medical team.

Our trainees shared several quotes regarding the lived experiences of families of CMC. They noted families' numerous and diverse struggles including a desire to feel heard and supported by all members of the

healthcare team, reassured during transitions, empowered to advocate for their children, included in the community, granted dignity and respect in both clinical and community settings, and afforded empathy and compassion. These challenges represent trainees' reactions to their observation of families in clinical, community, and home environments and are similar to those of residents participating in a study conducted by Huth et al that examines learner reactions to completing a virtual home visit for a family of a CMC.[12]

Other qualitative studies aimed at directly eliciting families' perceptions illustrate comparable themes.[9] Boss et al interviewed families to better understand their experiences with home health care (HHC). As such, themes are primarily limited to the benefits of and potential threats resulting from gaps in HHC; nonetheless, the authors' conclusions align considerably with our trainees' quotes regarding open-ended discussions to understand families' needs and motivations in our study: "Families understand better than prescribers, providers, or policy makers what is working, and what is not".[9] Another analysis of focus group sessions held to identify end-of-life care themes emphasized honoring the parent, families' confidence in the care team, receiving gestures that represent compassion, and navigating the many challenges that present when caring for a child with terminal illness.[10] This study aimed to inform educational priorities in the design of pediatric end-of-life care curricula. Because families voiced having received support from all clinical and nonclinical hospital staff, Arora et al concluded the relevance of a multidisciplinary and interdisciplinary approach, similar to that of our multifaceted curriculum.

The presentation of our outcomes spans six years. Although the Reflection prompts have largely unchanged, we offer the following lessons learned in terms of curriculum delivery. First, we initially would present didactic lectures in person, beginning just prior to clinic start and attempting to discuss a few slides in between patients. As patient volume increased, this became quite challenging. As such, we opted to convert all didactic lectures to narrated videos and ensured protected time for learners to not only view the lectures but also ask questions and engage in discussion outside of clinic time. Next, following changes to billing and documentation guidelines in January 2021, we revisited clinic workflow. In lieu of learners independently conducting patient

encounters and staffing with Complex Care faculty following the visit, faculty entered the room with learners and proceeded to document while learners conducted the encounter. This allowed faculty to directly observe the learner, and faculty shared feedback with the learner in real time. Moreover, faculty only interjected when families asked questions the learner was not able to answer, allowing the learner to directly observe faculty when engaging in discussions about end-of-life care, long term services and supports, and insurance coverage. Finally, the faculty preceptor was able to bill for time spent as they were in the clinic room throughout the entire encounter.

Of 47 trainees who completed the rotation, 34 (72%) opted to write a Reflection, which may serve as a limitation of our study; however, during the coding process and following iterative review, we feel we conclusively achieved thematic saturation. This sample of trainees also represents a selection bias as they opted to engage in the rotation and further opted to write a Reflection, but we have no reason to believe that those who did not write a Reflection or did not engage in the rotation would not have purported similar experiences. Because we conducted our study in a free-standing, academic children's hospital that offers a Complex Care rotation, our findings are transferable to similar settings; however, because our conclusions substantially agree with studies that evoke families' perceptions, we believe they may apply to any pediatric resident educational environments in which CMC access care. Finally, our authors, and their biases, gleaned those qualitative findings salient to physicians who practice developmental behavioral pediatrics, obstetrics/gynecology (and a parent of a CMC), and complex care pediatrics; we cannot conclusively state that these are themes other specialties would necessarily extract from the Reflection data.

The qualitative impact of a multi-faceted Complex Care curriculum on pediatric trainees' knowledge, skills, attitudes, and behavior are best summarized within the topics of Medical Home, Communication, Education, Advocacy, and Humanism. These priorities align with those of families of CMC and with leaders in pediatric Complex Care and graduate medical education. These themes inform the content and process of frameworks for pediatric educators when designing and delivering Complex Care curricula.

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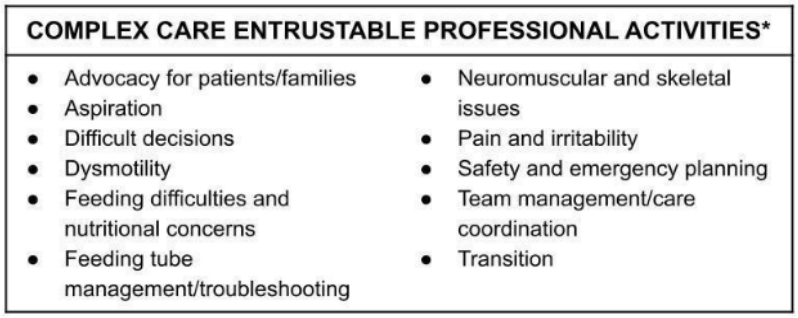
REFERENCES

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. doi:10.1542/peds.2010-0910
2. Berry J, Agrawal R. The landscape of medical care for children with medical complexity. *Child Hosp …*. 2013;(June):1-16. http://www.columbia.edu/itc/hs/medical/residency/peds/new_compeds_site/pdfs_new/PL3 new readings/Special_Report_The_Landscape_of_Medical_Care_for_Children_with_Medical_Complexity.pdf.
3. Rosenberg AA, Kamin C, Glicken AD, Jones MD. Training Gaps for Pediatric Residents Planning a Career in Primary Care: A Qualitative and Quantitative Study. *J Grad Med Educ*. 2011;3(3):309-314. doi:10.4300/jgme-d-10-00151.1
4. Turchi RM, Narayan A, Esquivel M, Serwint JR. Needs Assessment for a Medical Home Curriculum for Pediatric Residents. *Glob Pediatr Heal*. 2017;4:2333794X17740301. doi:10.1177/2333794X17740301
5. Entrustable Professional Activities for General Pediatrics. The American Board of Pediatrics.
6. Huth K, Newman L, Glader L. 17 Top Curricular Priorities for Pediatric Residents in the Care of Children with Medical Complexity: A National Delphi Study. *Paediatr Child Health*. 2019;24(Suppl 2):e7-8. doi:10.1093/pch/pxz066.016
7. Huth K, Henry D, Fabersunne CC, et al. A Multistakeholder Approach to the Development of Entrustable Professional Activities in Complex Care. *Acad Pediatr*. September 2021. doi:10.1016/j.acap.2021.09.014
8. Accreditation Council for Graduate Medical Education. Pediatric Milestones. Pediatrics Milestones.
9. Boss RD, Raisanen JC, Detwiler K, et al. Lived Experience of Pediatric Home Health Care Among Families of Children With Medical Complexity. *Clin Pediatr (Phila)*. 2020;59(2):178-187. doi:10.1177/0009922819894006
10. Arora G, Caliboso M, Baird J, et al. Educational Priorities for Providing End-of-Life Care: Parent Perspectives. *Pediatrics*. 2021;148(4). doi:10.1542/peds.2021-051379
11. 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. doi:10.1016/j.acap.2015.08.004
12. Huth K, Amar-Dolan L, Perez JM, et al. Visiting Jack: Mixed Methods Evaluation of a Virtual Home Visit Curriculum With a Child With Medical Complexity. *Acad Pediatr*. 2020;20(7):1020-1028. doi:10.1016/j.acap.2020.05.001

FIGURES & TABLES

Figure 1: Complex Care Entrustable Professional Activities



COMPLEX CARE ENTRUSTABLE PROFESSIONAL ACTIVITIES*	
• Advocacy for patients/families • Aspiration • Difficult decisions • Dysmotility • Feeding difficulties and nutritional concerns • Feeding tube management/troubleshooting	• Neuromuscular and skeletal issues • Pain and irritability • Safety and emergency planning • Team management/care coordination • Transition

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Table 1: Complex Care Curriculum Elements

COMPLEX CARE CURRICULUM ELEMENTS	
Didactic Video Lectures	Topics (EPAs)[a] Care Coordination* (11) Non-oral Feeding and Feeding Tubes* (1,3,8) Evaluation and Management of Aspiration* (1,4) Sharing Unexpected News* (9) ACEs and Today's Social Determinants of Health** (10) Education Policy** (10,11) Titles XVIII, XIX, and V, SSI, and Medicaid Waivers** (10,11) Diversity Sensitivity** (10) Health Care Transition*** (7) *MedEdPORTAL manuscript under review **MedEdPORTAL manuscript in draft ***https://www.mededportal.org/doi/10.15766/mep_2374-8265.11239
Clinical Care	~ 15 well child, follow-up, or acute visits for CMC per week
Experiential	≥ 10 of 16 site visits of medical/community-based providers serving CMC **ON SITE** • Bronchopulmonary Dysplasia clinic • Craniofacial Anomalies clinic • Respiratory Therapist: tracheostomy tubes / ventilators • Pediatric Neurosurgery: ventriculoperitoneal shunts • Pediatric Nephrology: dialysis clinic • Wound Care Nurse **OFF SITE** • Public school designed specifically for CMC • Non-profit organization that provides physical and creative activities for CMC • Special needs amusement and water park • Residential support for children with special needs in the foster care system • Outpatient pediatric rehabilitation therapy center • Genetic diagnosis support group • State parent training and information center
Learner Assessment	Pre- and Post-Rotation Tests of Knowledge Pre- and Post-Rotation Surveys of Behavior Reflection

a. Mapping of Didactic Video Lectures to Complex Care Entrustable Professional Activities[1]
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4. Evaluate and manage aspiration in children with medical complexity
5. Evaluate and manage common neuromuscular and skeletal issues in children with medical complexity
6. Develop and implement safety/emergency plans for children with medical complexity
7. Design and implement a developmentally appropriate transition process to adult care for children with medical complexity
8. Provide routine care for children with medical complexity with feeding tubes and troubleshoot common issues
9. Facilitate goals of care discussions and introduce the concepts of palliative and hospice care for children with medical complexity
10. Advocate for children with medical complexity and their families in the community setting
11. Facilitate team-based care coordination for children with medical complexity

Table 2: Theme – The Medical Home

THEME: The Medical Home: Caring for children with medical complexity (CMC) requires a compassionate "village" mentality that positions the patient/family at the center of the "village", or medical home, and pediatricians serve as expert facilitators who ensure communication across all partners and through the life continuum.	
SUBTHEMES	**RESIDENT QUOTES**
Pediatricians facilitate communication to the correct entity, other pediatric practitioners, school personnel, pharmacies, long term supports and services, insurance companies, and policymakers.	*"I realized how much a part of the proverbial village a pediatrician may be for a child with complex health care needs."* *"I have also witnessed firsthand the importance of building a strong network with pediatric specialists."* *"I was able to visit the home of a medically complex child and talk to his mother…the patient is in an ICU like room with every machine needed…[t]he shower is adapted with a lift…I learned about the tremendous obstacles this family has gone through to obtain the equipment."*
The approach to caring for CMC must include particular and dedicated attention to family-centered care, often requiring pediatricians to engage in shared decision-making and refrain from inserting their own values into the discussion.	*"I was told by one of the parents…they really appreciate…being asked what their objectives are at the beginning of the hospitalization."* *"Taking the time to discover the motivations behind a patient's or caregiver's decisions will assist in the decision making of what is the best next step for the patient."* *"The greatest lesson learned during this rotation is the importance of checking all personal values and feelings at the door and taking the time to truly listen to the patient and his family's perspective."*
Developing community-based partnerships allows pediatricians to observe inclusivity, refer families to relevant resources, and create a "village" for families of CMC. A Complex Care rotation highlights the vital role these partnerships play in the quality of life of CMC.	*"During the tour one of the site managers shared tear-jerking anecdotes about children who had laughed for the first time, walked for the first time, or even just swung on a swing for the first time."* *"[S]he was happy this garden was built because this is often the only chance that their students get to be outside…Similarly…Kinetic Kids...expressed that the athletic classes are pretty much the children's only chance to be physically active."*

	"Respite Care of San Antonio…is an incredible safety net for our most vulnerable populations." *"She provided valuable insight into the intimidating process of ARD meetings."* *"I was shown the process that needs to be completed in order to staff a patient's home with around the clock care."* *"[I]t helped me re-evaluate what the purpose of school was to kids with complex health care needs."*
Transitions (from neonatal intensive care nursery and/or repeated inpatient hospitalizations to home, from home to entry in the school system, from a pediatric to adult model of care) are challenging for families of CMC and require pediatricians to coordinate comprehensive education, delineate discharge instructions explicitly, elicit families' perspectives and needs, celebrate their joys, consider participating in home visits, and address families' fears and concerns to achieve a successful out-of-hospital existence.	*"One of the most impactful experiences…was arranged through the CHofSA Family Advisory Board…I have learned that transitions of care are especially scary times in the life of medically complex patients."* *"Perhaps education on the ages at which major transitions typically occur…and an easy-to-carry informational packet…would have helped to ease the anxiety this family experienced concerning the transition out of the …NICU."* *"[H]ow imperative it is, and how much more involved it is, to prepare a patient with complex medical needs for discharge."* *"Discussing with them the specific diagnosis their child has, going over all discharge instructions and making sure they know how to set up appointments with the sub-specialists their child needs is so important for the long term success of that family taking care of their child."*

Table 3: Theme - Communication

THEME: Communication: Engaging in "clear and precise," honest, empathetic, non-judgmental, person-first, two-way, values-driven communication with families of CMC is vital to developing trusting relationships; preventing medical errors; clarifying team roles; eliciting families' fears, concerns, and needs; and ensuring they are addressed.

SUBTHEMES	RESIDENT QUOTES
Words matter and pediatricians should become competent in using person-first language and refrain from using terms that focus on a child's disability.	*"The last time I was on service, the resident compared a patient of yours to a "normal" patient."* *"I remember…preparing a clinic note for a patient who was an ex-premie…requiring a trach/vent, and I formed an image in my head…[t]hen…I walked into the room to find the child had been decannulated and was eating entirely by mouth…I felt ignorant for having been so judgmental!"* *"[W]e always should take the extra second to think before we speak, especially with and about people with disabilities."* *"People First Language reminds us that our patients…have interests and talents just like everyone else that make them unique."*
"Clear and precise" communication is necessary to effectively deliver the accessible care a CMC needs, prevent miscommunication and medical errors, and lessen family burden.	*"I have learned the importance of clear and precise communication. I will ask appropriate questions…and save them the hassle of navigating…[t]his also allows everyone involved…to be on the same page and does not leave room for misinterpretation."* *"I plan on minimizing barriers to healthcare for my patient population."* *"[O]nce we stepped into the patient's room, we spent as much time as necessary to take [care] of the patient and family needs."* *"We must continue to encourage early inclusivity of case managers, social workers, home nursing, and other educators…when done correctly…it creates a great environment so that newly trached patients are well taken care at home."*
Open-ended discussions during inpatient, outpatient, and at-home encounters help pediatric trainees to improve communication skills and relationships with families of CMC, see the world	*"Not only does asking about these specific goals and desires improve our patient care, it improves our relationships with families and creates a trustworthy and empathetic environment."*

through the eyes of the families, recognize the significance of families' level of health literacy when caring for their children, and provide better care.	*"My new approach with children with complex needs will be to have the families do a teach-back with me. This way I can tell if they understand the diagnosis and any changes made prior to discharge."* *"I realized that by asking the question: "What are your objectives during this hospitalization?" I can get so many answers."*
Sharing unexpected news requires skill, preparedness, and compassion.	*"[W]hen having a difficult conversation with families, it is important to prepare as well as possible so that I can present the family with accurate information…At the same time, I have been reminded that it is better to say 'I don't know what will happen,' than to make predictions."* *"I will remember to never take away hope from parents of children with tragic starts in life."* *"Recently, I had to assess a newborn with hypoglycemia…I went into the room and introduced myself, saw the baby and then went to explain to the parents what was going on. Before I went to explain things, I realized that I had not yet congratulated them."*

Table 4: Theme - Education

THEME: Education: A Complex Care rotation teaches knowledge, skills, and attitudes from a unique outpatient, primary care perspective.	
SUBTHEMES	**RESIDENT QUOTES**
Complex Care education should begin by defining CSHCN and those with medical complexity and include instruction in the provision of evidence-based medical care of CSHCN and CMC.	*"[R]eading* Who Are Children with Special Health Care Needs? *…[w]hile I knew about the difficulties CYSHCN and their families face, I did not expect to see those high percentages listed in that national survey."* *"*Nonoral Feeding for Children and Youth With Developmental or Acquired Disabilities*…explained the process, coordination and commitment of the surgical and medical intervention…covered everything from gastrostomy care, to forms filled out by the pediatrician, to providing a list of medical homes and other resources."*

	"During my VPS teaching lesson…I reviewed multiple devices including cell phones, microwaves, and headphones that…can change the valve settings." *"[W]ith wound care, I was able to collaborate with the nurse coordinator to promote teaching to residents on pressure ulcers."* *"The knowledge gap I had for different government programs to assist children with special health care needs and low-income families has improved since watching these videos."* *"After being exposed to the concept of transition, I can honestly say that I realize the value of it more than ever."*
Families of CMC face great challenges that often remain hidden to trainees until the Complex Care rotation unveils them.	*"Getting a new piece of equipment often requires coordination with multiple parties including the DME company, Medicaid, therapists, physicians, and patient families."*
A Complex Care rotation also has the capacity to inspire reflective opportunities that remind residents why they chose pediatrics as a career path and foster development of personal and professional identity as a physician.	*"It was not at all about the medical education involved…It's about teaching the things that…I thought weren't teachable like compassion, empathy, and understanding."* *"It was a month for personal and professional growth. I learned the most from your daily orchestration of personal and professional life."* *"I am grateful for this rotation…grateful for being the best me I can be"* *"[A]s someone who hopes to be a fellowship or residency program director or head of a hospitalist rotation, I really enjoyed seeing how to set up a curriculum with multiple aspects."*

Table 5: Theme - Advocacy

THEME: Advocacy: Caring for CMC requires advocacy beyond the hospital/clinic room by collaborating across spheres.	
SUBTHEMES	**RESIDENT QUOTES**

Advocacy beyond the healthcare workspace entails collaboration with patients/families, schools, community-based resources, and decision-makers so that children may have the best quality of life in the homes and communities in which they live.	*"I realize that polices comprises at least half the battle in obtaining accessible, affordable, and available healthcare to all patients."* *"I particularly enjoyed the articles about healthcare policy…[O]ur health care system has become so broken and it affects so many of our patient's lives."* *"[T]he lecture on insurance…was important as it has helped me to ask our social worker more targeted questions about why I am consulting her."* *"One of my favorite articles…was…*Individuals with Disabilities Education Act (IDEA) for Children with Special Educational Needs*. It helped me to better understand the key elements of the law that ensures that every child requiring special education receives the services to which he or she is entitled."*
A pediatrician's role includes empowering patients/families to become self-advocates so they may serve as partners in overcoming barriers.	*"One thing I think is important to do…is to build up and encourage families that they will need to become an advocate for their child. [I]t seems that patients have better outcomes when their families are given the tools to be active participants in the health care system."*
Adverse childhood experiences and the social determinants of health, including poverty, result in toxic stress, negatively affect a child's trajectory, and impact a child's long-term health and well-being; pediatricians can interject in this cycle by promoting nurturing caregiver relationships and resiliency.	*"Although it is often overwhelming to think of the negative, trauma-inducing aspects of a child's life that can set them up for even more challenges in the future, it is inspiring to know that our role as pediatricians can positively impact that trajectory."* *"I think it's really cool that the medical community is beginning to realize the vast impact social experiences have on health."* *"It's so hard to imagine that our 1st world country still has the same federal poverty line…despite the fact that there's evidence to show that the chronic stress of poverty during childhood development affects their relational health."* *"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."*

Examining our own individual values surrounding how health care dollars are spent is essential to pediatric resident education.	*"When I look at patients that have complex medical needs, I have previously only see money and resources being used."* *"Many times I had an internal argument with myself during this rotation…As a direct result of…prior authorizations I continued to see more unnecessary admissions to the hospital. This is truly disappointing when you consider the wishes of…families…to manage as much as possible at home."*

Table 6: Theme - Humanism

THEME: Humanism: All children's lives have meaning and purpose; bearing this in mind helps residents reconnect with humanism.	
SUBTHEMES	**RESIDENT QUOTES**
A Complex Care rotation helps emerging pediatricians incorporate a "whole child" approach, recognize the value and joy of families' hope and quality of life, and emphasize a focus on function.	*"Not only did I gain invaluable experience in the world of primary care and patient management, but [e]very day, every patient…made me think beyond the medicine and the knowledge…made me remember what I love about this profession."* *"Additionally, I had the pleasure of seeing complex children…while they were at school, at home, a playground, or at basketball practice."* *"While I was there we celebrated a young man finding employment within the community and everyone was truly supportive of him and happy for his success."* *"Focus on the capabilities, not the disabilities."* *"I loved the re-emphasis on looking at the child and not their diagnosis."* *"I better understand the value of…being holistic."*
Pediatrics is not an occupation solely for providing medical care to children, but rather a privilege and rewarding calling to serve, care, and advocate for all populations of children.	*"Children can still have deep, meaningful lives no matter how short the life: a reiteration of my childhood lesson that every life has a purpose."* *"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." *"If I look back at my motivations to go into medicine…all of them needed someone to not only make them feel better, but most of all they needed someone to care about them and truly be in their service"* *"Being able to take care of kids for a living is such a unique and rewarding career. It is even more of a privilege to take care of those children with special needs and difficult challenges."*
A Complex Care rotation inspires pediatric trainees and helps them reconnect with humanism and with their decision to pursue medicine and pediatrics.	"*For me, the experience satisfied my initial desired goal when I opted to go into Pediatrics: to actually spend time with people and form bonds with patients and families."* *"All around, I left this rotation feeling inspired to better learn about my patient's beyond their diagnoses and to never lose sight of the passion that drove me to medicine in the first place."* *"It also made me feel a little proud about humankind…[I]t gave me hope that's there's a lot of people out there with…heart"* *"I have found that the pursuit of my own happiness and self-actualization is what shapes my passions and feeds my inner drive."* *"Personally, I was reminded of how lucky I am to be practicing medicine"*
Varying competing responsibilities that steer us away from our passion to provide care to children can exert toxicity and diminish our empathy, resulting in burnout, moral injury, and compassion fatigue.	*"Then when I came to residency my spirit and passion slowly went to the wayside and I was trying to keep my head up in a toxic environment…I questioned if this is what I was meant to do."* *"Having…just completed a PICU rotation…it…started to become a bit harder for me to not let the more pessimistic view-points that I've heard…creep into my own view of patients."* *"It's been a long time since then…I often fear that I would lose a piece of that little girl; I worried I would lose*

	her passion, her love for medicine, and her eagerness to serve others and heal." *"I had gone through periods throughout medical school where I saw others who appeared to have lost their passion and their ability to empathize."*

APPENDIX: Study Design and Procedures

Upon completion of the Complex Care rotation, residents wrote a one-page Reflection. We collected Reflections electronically and uploaded them to the Dedoose platform. Three co-authors individually reviewed Reflections and created and revised a codebook. Two co-authors individually identified themes and subthemes, met to resolve disagreement, and confirmed agreement with the third co-author through an iterative process.

Research Team: Our research team comprised a developmental-behavioral pediatrician, an obstetrician/gynecologist who is also the parent of a CMC, and a complex care pediatrician (medical director of the BCM-CHofSA CCC).

Data Collection: We collected Reflections electronically as either Word documents or as links to Google documents. All Reflections were de-identified prior to analysis.

Analysis: Co-authors conducted a qualitative content analysis by individually reviewing the Reflections for codes. Co-authors (TK, JB, RK) regularly met to discuss, review, and agree upon the coding process. Following discussion of individual co-author reviews of three Reflections, one author (RK) used these codes to develop a codebook, and the remaining co-authors (TK and JB) reviewed the codebook. Upon agreement on the codebook, we uploaded all Reflections to the Dedoose platform (Dedoose, LLC; © 2018), created a shared project, and added established codes to the project. At least two co-authors individually reviewed each of the remaining Reflections, added codes to the project when appropriate, and met to discuss added codes. A third co-author resolved disagreement when necessary. We continued to code Reflections until achieving thematic saturation. Using Dedoose exported data, two co-authors (TK and RK) individually combined related codes into categories, developed themes and subthemes, and met again to discuss this process and its outcomes. Once we reached theme and subtheme agreement, we shared with our third co-author who also appraised the data, codes, themes, and subthemes and shared suggestions until we reached unanimous agreement. This was an iterative process requiring numerous virtual and email communication encounters.

Ethics: This study was reviewed and approved by the Baylor College of Medicine (BCM) Institutional Review Board (IRB).

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Impact of a Multifaceted Complex Care Rotation on Pediatric Residents and Hospital Medicine Fellows

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