

COMPLEX CARE ELECTIVE:

An Outpatient Learner-Directed Complex Care Elective for Pediatric Residents

Breann Butts^a, MD, Rebecca Steuart^a, MD, Jennifer Lail^b, MD

ABSTRACT

As the population of children with medical complexity (CMC) increases, the physician workforce needed to provide outpatient medical care for these children is also increasing. Currently, few published formal training opportunities exist to support pediatric residents with particular interest in pursuing careers caring for CMC. Here we report our experience creating and implementing a resident-designed, resident-directed elective in the emerging field of outpatient complex care pediatrics at our institution. With the assistance of an expert faculty advisor, we designed and completed a two-week outpatient complex care pediatrics elective as part of our pediatric residency training. The elective included supervised clinical experiences in our institution's Complex Care Center and subspecialty clinics, observation of specialized therapy visits, interactive lectures on funding mechanisms by financial advocates, and opportunities to learn from families of CMC during informal interviews. Two residents have completed the elective to date; during unstructured curricular assessments, residents reported the elective increased knowledge, skills, and comfort in caring for CMC, as well as offered networking opportunities and insight into career pathways within complex care pediatrics. Further development of formalized training opportunities in the emerging field of outpatient complex care pediatrics is crucial to the growth of a physician workforce passionate about and prepared to provide experienced, expert care for CMC.

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INTRODUCTION: Children with Medical Complexity and Resident Education

The field of complex care pediatrics has rapidly emerged as the framework for medical providers who care for children with medical complexity (CMC). CMC are a subset of children with special health care needs who have one or more serious chronic conditions, functional limitations frequently requiring medical technology, considerable family-identified health and other service needs, and high health care utilization.¹ The CMC population is growing substantially in number, in large part due to the advances in pediatric medicine that allow these children to survive much longer than in the past.¹ The proportion of children with a chronic condition that interferes with daily activities has increased >400% since the 1960s.² Although CMC comprise less than 1% of children, they consume up to one-third (> \$100 billion annually) of all child health expenditures.³ Furthermore, CMC have “high risk of hospital readmissions, total and preventable adverse events, and unnecessary variation in hospital care”.⁴ To address the ongoing needs of this diverse patient population and to potentially limit excessive medical costs associated with fractured and varied care, several outpatient care delivery models have been

conceptualized and implemented, including primary care-centered models, consultative or co-management models, and acute episode-based models.⁵

Pediatricians in many primary care settings have expressed concerns about their capacity to serve as a medical home for CMC due to time and cost restraints, among other challenges.⁶ Thus, at many large pediatric centers including our institution, complex care centers (CCC) based on the primary care-centered model are being established to address the preventive, acute, and chronic care needs of CMC specifically in the outpatient setting. Our institution’s CCC serves a patient-centered care medical home for CMC by providing team-based care and care coordination in partnership with families, subspecialists, and the child’s community.

Despite the growing need to provide outpatient primary care to the growing population of CMC, at the current time, there is not a well-defined career track for trainees to gain skills in this area of pediatrics. Although efforts addressing curricular priorities of resident education in caring for CMC are in process,⁷ there are currently no Accreditation Council for Graduate Medical Education (ACGME) clinical competencies that guide residents’

instruction in caring for this population. Thus, residency programs may have variability in learning opportunities (e.g. rotations, electives, or formal curricula) designed for interested residents; resident experiences that do exist are not often publicly shared or published. At our institution, residents who are interested in incorporating care of CMC into their future careers previously relied on their experiences caring for a variable number of CMC seen in general pediatrics clinics (e.g. continuity clinic), the inpatient setting (e.g. hospital medicine, intensive care units), or other closely related outpatient sub-specialties (e.g. physical medicine and rehabilitation, developmental behavioral pediatrics, palliative care) to guide their acquisition of skills. Here we report our experience creating and implementing a resident-designed and resident-directed elective in outpatient complex care pediatrics. Our goal was to gain critical, timely, and career-specific experience in caring for CMC in the outpatient setting.

PROGRAM DESCRIPTION: An Outpatient Complex Care Elective

Under the guidance of a CCC faculty advisor (J.L.), interested senior pediatric

residents (B.B. & R.S.) created a two-week, multidisciplinary elective at our free-standing, academic pediatric medical center (Table 1). Elective goals and objectives are outlined in Supplement 1. The elective included experiential learning in the hospital-associated multidisciplinary CCC, which operates as a primary care medical home for approximately 500 local CMC. While in the CCC, residents participated in pre-visit planning, observed clinic encounters, and provided supervised care to CMC during health maintenance and acute care visits.

Experience		Goals & Objectives
Day 1	Meet with financial advocates	<ul style="list-style-type: none"> Medical funding mechanisms (e.g. waivers, Medicaid, other insurance)
	Review articles and webinars	<ul style="list-style-type: none"> Chronic Care Model Family-centered and team-based models of care Ethical considerations Effective communication with patients with cognitive impairment
Day 2	Pulmonary Clinic	<ul style="list-style-type: none"> Medical technology: tracheostomies, ventilators, airway clearance
	Physical Medicine & Rehabilitation Clinic	<ul style="list-style-type: none"> Medical technology: Baclofen pumps
Day 3	Complex Care Center	<ul style="list-style-type: none"> Learn and perform basics of well care and ill care of children with medical complexity Work with multidisciplinary team Participate in provider-family shared decision making
Day 4	Shadow Respiratory Therapist	<ul style="list-style-type: none"> Medical technology: tracheostomies, ventilators, airway clearance
	Review articles and webinars	
Day 5	Complex Care Center	
	Resident Continuity Clinic	
Day 6	Physical Medicine & Rehabilitation Clinic	
	Complex Care Center	
Day 7	Gastroenterology Clinic	<ul style="list-style-type: none"> Medical technology: feeding tubes and nutrition
	Pulmonary Clinic	
Day 8	Complex Care Center	
Day 9	Home Care Visits	<ul style="list-style-type: none"> Experience alternate care setting
	Therapy Center	<ul style="list-style-type: none"> Medical technology: wheelchairs and other assistive technology
Day 10	Resident Continuity Clinic	
	Complex Care Center	
Day 11	Therapy Center	<ul style="list-style-type: none"> Observe Early Intervention and Early Childhood programming
	Complex Care Center	
	Elective Debriefing	<ul style="list-style-type: none"> Meet with faculty advisor to reflect on elective experience and advocacy opportunities

Table 1. Outpatient Complex Care Elective sample schedule of experiences with associated goals/objectives.

Given the pace and structure of our clinical setting, residents primarily provided care with faculty present in the exam room, then completed notes independently following the clinical encounter. Residents also observed clinical providers completing electronic and telephone communications such as phone triage, home nursing orders, and medical equipment orders. Residents were able to interact with and learn about the roles of the clinical nurse, nurse care manager, medical assistant, social worker, and registered dietician during clinic visits and through informal discussions between clinical responsibilities.

Given the subspecialty nature of caring for CMC, residents also spent time in various other relevant clinics, such as those for children with cerebral palsy in Physical Medicine and Rehabilitation, with ventilator-dependence in Pulmonology, and with feeding issues in Gastroenterology. Residents were able to observe speech, physical, and occupational therapy sessions during Early Intervention and Early Childhood programming at our on-campus multidisciplinary therapy and support center. One resident (R.S.) had the opportunity to attend scheduled home visits with a palliative care program home care nurse. To better understand the local, state, and national financial resources available to

Complex Care

Clinic	Notes
Complex Care Clinic	In addition to seeing complex care patients, you will spend time with RN, RN Care Manager, SW, and RD.

Subspecialties

Specialty	Clinic/Provider
Pulmonary	Ventilator clinic
	Neuromuscular Clinic
	Aerodigestive Clinic
Rehab	Transitional Care Center (ventilator-dependent unit), rounding and/or spending time with RT
	Cerebral Palsy and Spasticity Clinic
Perlman Center	Cerebral Palsy Clinic
	Early Intervention (EI) and Early Childhood (EC) Programs
GI	Equipment Evaluations & Speech Language Evaluation
	Feeding Team
Palliative Care & Hospice	StarShine Home Visits
Neurology	Various clinics may be applicable

Other Experiences

Group
Financial Advocates
Meeting with Complex Care Families
Complex Care Lectures
Ethics
Self-directed learning (see reference list)

Table 2. Potential Complex Care Outpatient Elective opportunities including subspecialties and other groups.

families of CMC, especially in light of the large proportion of health care costs experienced by these families, residents met with financial advocates at our institution. In order to introduce residents to concepts within the evolving national field of complex care pediatrics, residents were directed to read foundational publications by CMC experts (Supplement 2). Core reading topics included defining CMC and other related populations, care model

development, health systems of care, common symptom management, and healthcare spending. Residents met with the faculty advisor once during their elective to discuss one or more resident-selected article(s). A list of additional specialized topic readings were provided by the faculty advisor for resident self-directed learning during the elective time. Finally, residents had the opportunity to meet with families of CMC to discuss the joys and challenges of their journeys; these meetings were informal and held in a public hospital location such as the cafeteria. All experiences outside of time spent in the CCC were scheduled by each resident prior to the start of the elective time. Experiences of value were defined with the support of the CCC faculty advisor, who provided key contact information for scheduling. Table 2 includes a comprehensive list of opportunities available during this elective.

REFLECTIONS & DISCUSSION

This complex care elective is resident-coordinated, resident-implemented, and intentionally tailored to individual resident interests. Two senior residents (B.B. & R.S.) have completed this elective to date. While there was no formal learning assessment at the conclusion of the elective, both residents were able to

informally discuss their reflections surrounding the elective with the faculty advisor (J.L.) and felt this elective increased knowledge, skills, and comfort in caring for CMC in their current roles (B.B. is currently a 3rd year resident who will join the CCC after completing residency; R.S. is currently a 2nd year hospital medicine fellow with specific interest in clinical care and research surrounding CMC). Both residents also expressed that meeting with families of CMC was one of the most illuminating and meaningful aspects of the elective, as it provided direct insight into the day-to-day life and the incredible resiliency of these families. Importantly, the elective introduced various models of care and underscored the importance of a patient centered medical home for CMC. The elective allowed for residents to meet and network with a variety of colleagues within our institution who contribute to the care of CMC, including not only physicians, but also subject matter experts such as therapists, dietitians, nursing staff, financial experts, and families. Finally, residents were able to consider various career trajectories related to caring for this population.

Since training opportunities and models of care are evolving, we have created a guide to share with other residents interested in completing a pediatric complex care

elective and who seek learning opportunities around the care of CMC. Our elective was optimized by having a faculty champion in the setting of an established CCC, but could be adapted and replicated in other training settings and models of care (e.g. a community pediatrician who co-manages a CMC's medical issues with multiple sub-specialists in a medical center). In the future, it may be helpful to formalize an elective assessment process in order to continue developing and improving the experience for subsequent participating residents. Opportunities for expansion include integrating aspects of the elective into a residency-wide longitudinal curriculum on caring for CMC, as proposed by Homer, et al.⁸ We hope to further develop opportunities for mentorship between residents and CCC providers, as well as longitudinal clinical experiences (e.g. continuity clinic) in the CCC. Finally, we will continue promoting this elective to each class of residents and could consider monitoring the impact of the elective on their future career choices.

CALL TO ACTION

Various models of caring for CMC have been proposed,⁵ yet there is not a clear

consensus on the best locus of care for these patients. Furthermore, the population of CMC continues to grow, requiring prompt attention to the development of the provider workforce and examination of funding sources. Despite a need to develop a new generation of pediatricians prepared to care for CMC, clear training pathways do not currently exist. Here we have shared one educational model that may serve as an initial step for residents who are interested in caring for CMC, but have little exposure to these patients in outpatient settings. This elective represents one opportunity to increase provider exposure to CMC while in training. The ultimate goal would ideally be that this increased exposure increases the provider work force and access to care for CMC, whether in a dedicated Complex Care Clinic or translated to clinics more remotely located from an academic medical center. Interested pediatric residents must have formalized opportunities to explore and build skill sets in the ever-growing field of complex care pediatrics. Perhaps most importantly though, CMC and their families deserve providers who are well-trained, have a passion for caring for CMC, and are enthusiastic about future expansion of this field.

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Supplement 1. Goals and Objectives

Complex Care Outpatient Elective

Goals & Objectives

Summary

This make-your-own elective is designed for residents interested in caring for children with medical complexity and with career interests in outpatient complex care, primary care, or hospital medicine. While the elective is centered around time in the Complex Care Center (CCC), there are not enough clinic days or staffing availability to make up a full elective. Therefore, you must add in additional experiences; a list of suggested experiences is below.

Goals and Objectives

Knowledge

- Identify the basics of well care for children of medical complexity
- Identify the basics of ill care for children of medical complexity
- Describe and interact with various technological supports: GT, GJ tubes, trachs, central lines, ports, Baclofen pumps, Bipap, Vibratory vests and cough assists, etc.
- Review medical funding mechanisms (waivers, Medicaid and coordination of benefits with commercial insurers)
- Summarize the Chronic Care Model and its benefits to this population
- Understand the unique role of and work with various members of Complex Care Clinic team (e.g. Care Manager, SW, RD)
- Discover information regarding the Medical Home and Medical Neighborhood (school, camp, faith-based supports, funding, counseling, family/sib supports, respite care)
- Discover information regarding ethical concepts which might affect patient care
- Discover and participate in some of the various specialty clinics available to this population
- Review the basics of outpatient medical coding for this population

Clinical Skills

- Perform a complete well child physical exam of a child with medical complexity, with particular focus on commonly-observed pathology of this population
- Understand types of airway clearance and indications for their use
- Understand types of feeding regimens and interventions and indications for their use
- Utilize provider-family shared decision making
- Begin to advocate for children with medical complexity at the local, state, and/or national levels

Professionalism

- Review literature to optimize interactions with people with cognitive impairment
- Use family-centered and team-based models of care, especially around interacting with families and respecting their expertise about their child
- Express insight into the daily struggles a from family members of patients on a personal-social level

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Day 10	Resident Continuity Clinic	

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Table 2. Potential Complex Care Outpatient Elective opportunities including subspecialties and other groups.

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Palliative Care & Hospice	StarShine Home Visits
Neurology	Various clinics may be applicable

Other Experiences

Group
Financial Advocates
Meeting with Complex Care Families
Complex Care Lectures
Ethics
Self-directed learning (see reference list)

Supplement 2. Reading List

Reading List for Complex Care Elective

Core References

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 - [Research and Practice Perspectives—Coordinating Care for Children with Social Complexity](#)
 - [Care Planning for Children with Special Health Care Needs](#)
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