Care coordination for children with medical complexity

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Abstract: Children with medical complexity have complex health management and care coordination needs. Care models that address these needs rely on interprofessional teams that include NPs. Understanding these care models allows NPs from all disciplines to support the care of this growing patient population in pediatric and adult settings.

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Children with medical complexity (CMC) are a small but growing patient population, attracting interest from policy makers, insurers, health systems, researchers, and clinicians.[1] CMC are a subset of children and youth with special healthcare needs (CYSHCN) and represent less than 1% of children in the US and Canada.[2,3] This population is defined as having multiple chronic conditions, such as brain and spinal cord malfunction, muscular dystrophies, multisystem congenital anomalies, malignant neoplasms, heart and great vessel malformations, cystic fibrosis, and cerebral palsy, requiring care from multiple

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specialists and service providers, is frequently dependent on life-sustaining technology, and/or has severe neurologic and functional impairment.[1,4] Although CMC account for a small percentage of children in the US and Canada, they require disproportionately higher rates of service to optimize their function and health status, accounting for up to one-third of spending on all childhood healthcare.[3-5]

The pediatric medical home is the recommended model for pediatric primary care delivery.[6,7] Serving as a child's central point of care and directed by the primary care provider, a foundational component of the pediatric medical home model is a team-based model of care.[8] For CMC, additional care team members often include physician specialists and subspecialists, NPs, teachers, child life specialists, and home-care services. As the team expands, partnering with families to reduce care fragmentation through integrated care coordination is essential.[9]

The purpose of care coordination is to provide comprehensive coordination across all medical, nonmedical, and service providers, with an emphasis on primary care collaboration and coordination to help the child stay in their home and community.[10] For families of CMC, care coordination is central to maintain their child's well-being and meet health and lifestyle goals.[11] Care coordination is a reimbursable service for physicians and nonphysician practitioners, including NPs, and defined by the Centers for Medicare and Medicaid Services (CMS) with corresponding Current Procedural Terminology (CPT) codes.[12]

Successful comanagement requires effective information exchange between primary care, specialty care, and patients/families.

Although primary care practices have embraced the medical home model, they may experience difficulty coordinating and managing the multifaceted needs of CMC due to time, knowledge, and resource constraints.[13] The involvement of the many specialists needed to care for CMC can lead to fragmented communication and care between specialty and primary providers.[9,14,15] This article describes care models that address the needs of a growing CMC population, using interprofessional teams that include NPs as providers, care coordinators, and clinical nurse leaders.

Components of complex care

Over the past 20 years, models of comprehensive care for CMC have emerged. Grounded in medical home principles and typically referred to as complex care programs, components of these programs include medical comanagement, care coordination, and family/caregiver support.[16,17] The complex and often rare conditions of CMC require specialty and subspecialty care, necessitating medical comanagement between specialty and primary care providers.[14] Successful comanagement requires effective information exchange between primary care, specialty care, and patients/families.[18] While medical comanagement has typically been advocated as a physician role, complex care programs are embracing NPs in the comanagement provider role because of their holistic preparation, advanced assessment skills, and, in many states, autonomous scope of practice.[11,14,19]

The impact of care coordination for CMC and their families is well documented.[10] Initially described over 20 years ago with the CYSHCN population, care coordination has been embraced by the medical home model.[20,21] Care coordination is family-centered, with a planned, proactive, and comprehensive focus that promotes self-management, and supports cross-organizational communication and relationships.[10] (See *Essential characteristics of care coordination.*)[22]

In the medical home, the care coordinator role is typically filled by an RN or social worker.[21] While complex care programs use similar licensed personnel, NPs are ideally prepared to meet the high-intensity care coordination needs of high-acuity CMC.[23,24] A pediatric medical home center using pediatric nurse practitioners (PNPs) to provide telephone-based care coordination for CMC showed significant reduction in unplanned hospitalizations.[25,26] A randomized controlled trial of PNP telehealth (telephone and video) care coordination versus the medical home model of provider-directed care coordination in an established pediatric medical home showed a significant decrease in unmet care coordination needs in the telehealth groups.[27] Both examples illustrate how NPs' advanced skills support autonomous assessment, diagnosis, and treatment, and attention to holistic care, key elements necessary for high-quality, proactive care coordination of CMC.[28]

Support for families/caregivers of CMC is essential to family well-being. Families of CMC often report their greatest challenge is disconnect and lack of communication between services and providers.[29] Parents frequently assume the role of care coordinator because their child lacks a designated one.[29] Complex care programs fill this gap by designating a single point of contact for families of CMC, typically the child's care coordinator.

Models of complex care

Models of complex care that incorporate medical comanagement, care coordination, and family/caregiver support were initially developed in tertiary academic settings, but primary care-based programs focusing specifically on CMC have grown.[25,30,31] Labeled as primary care-centered (PCC) models, these embrace pediatric medical home principles and can be found in both primary and tertiary care settings.[6,7,17] The fundamental advantage of a PCC model housed in a child's community-based primary care setting is the primary care provider (including NPs) serving as the comprehensive single point of care. Evidence regarding the impact of this model on cost, and patient and family outcomes has been demonstrated.[27,31,32] Conversely, and as noted earlier, the primary care provider may lack the time, resources, and knowledge to care for these complex children.[13] A PCC model housed in a tertiary setting can address these disadvantages, but requires increased diligence to ensure communication and collaboration with community-based providers and services.[11,33]

The second model of care for CMC is described as consultative- or comanagement-centered (CC) and typically resides in tertiary or specialty care settings with clinical expertise caring for CMC.[17] In this model, the CC provider, which includes NPs, partners and comanages a child's care with the primary care provider to provide the essential components of complex care and care coordination.[11,34] The main disadvantage of the CC model is its location in tertiary and specialty settings. These settings are found in urban areas, making access difficult for rural families and potentially leading to fragmented care across health systems.[9,15,35]

The evolving role of clinical nurse leader is ideally suited to advance models of complex care.[36] The master's degree-prepared clinical nurse leader combines quality improvement, outcome measurement, care coordination, communication, and leadership skills to facilitate implementation and evaluation of evidence-based practice models of care delivery within a health system.[37] Identifying models of care delivery that will improve outcomes while lowering costs is a key metric of success for the clinical nurse leader. These nurse leaders are well positioned to develop effective care delivery models that support CMC and their families.

Essential characteristics of care coordination[22]

- Family-centered, team-based function with defined tasks and supporting infrastructure
- Health and psychosocial assessment determines level of care coordination services
- Health and psychosocial assessment and family-defined goals contribute to a jointly developed plan of care
- Plan of care goals monitored and modified as needed
- "Single point of contact" that communicates and coordinates with patients, families, clinicians, and services
- "Between clinic visit" communication conducted by telephone, email, or telehealth to enhance care coordination relationship and partnership
- Patient and family given tools to develop self-management competencies
- Care coordination "neighborhood" includes all clinicians and services that support patient
- Method of sharing relevant health information, ideally electronic, between patient/family and care coordination neighborhood
- Monitors and facilitates transitions of care (for example, hospital discharge, pediatric to adult care)

Implementing a complex care program

A small specialty health system located in the upper Midwest provides specialty-only care to children, youth, and adults with child-onset disabling conditions. In 2016, the health system implemented a complex care clinic (CCC) using the comanagement model of complex care described above. Although the CCC is housed within a specialty health system and does not provide primary care, the program is grounded in the medical home model and received medical home certification from the state accrediting body in spring 2019.[38]

The CCC serves as a hub for CMC where their chronic, multisystem healthcare needs are addressed. A team of six CCC providers (four NPs and two physicians), supported by social workers, dietitians, pharmacists, and nurse care coordinators, uses a model of provider-directed care coordination. CCC providers work with a patient/family to understand access gaps and care needs and develop a detailed medical plan of care and roadmap that integrates the patient's current and future treatment plans into a single document. This occurs during the initial 2-hour CCC visit and is reviewed and updated during subsequent 1-hour follow-up visits.

Chart review prior to a clinic visit is a standard practice among providers in specialty settings. For CCC NPs and physicians, comprehensive chart review is time and labor intensive but essential. The review identifies specialists and services involved in the child's care, prior imaging, labs, surgeries, immunizations, and growth charts, and allows the provider to identify potential gaps in care needs prior to the child's visit.

The CCC NP works with the primary care provider to coordinate follow-up needs locally, a vital component of the comanagement process.

The NP or physician has the primary role during the CCC visit and establishes the child and family's care goals. A head-to-toe review of systems is performed and includes body systems, medications, birth history, hospitalizations, surgeries/procedures, immunizations, and diet/feeding regimen. Family and social history, and equipment and services such as home nursing and rehabilitation therapies and benefits are assessed. Following this review, a thorough physical exam is conducted, focusing on areas of concern during the review of systems. The NP relies on members of the CCC team to assess and identify additional gaps and concerns. Pharmacists perform a comprehensive medication reconciliation of the often extensive list of medications, noting recent changes, and evaluating for interactions and caregiver concerns. Social workers perform a detailed review of service and community support needs and connect families to eligible county and state benefits and resources. Many of the clinic patients rely on feeding tubes for nutrition, and dietitians conduct nutritional assessments and make recommendations for changes.

The NP summarizes the assessments of the CCC team; formulates a list of needs, gaps, and concerns; and works with the family to finalize and prioritize the list. A panel of labs, which often includes nutritional markers, blood counts, iron studies, and vitamin D, is frequently recommended. The goal of the CCC visit is a detailed medical plan of care and roadmap that integrates the patient's current and future treatment plans into a single document that lists referrals, recommendations, medication prescriptions, and future appointment needs. The nurse care coordinator works with caregivers after a CCC visit to coordinate the provider-driven medical plan of care.

A fundamental goal of the CCC is collaboration, coordination, and direct communication with primary care providers to help a child continue to live at home and in their community. After the CCC visit, the NP contacts the child's primary care provider and gives a detailed report of the visit assessment, recommendations, and referrals. The CCC NP works with the primary care provider to coordinate follow-up needs locally, a vital component of the comanagement process. This collaborative relationship is emphasized with families, so they can feel comfortable seeing their primary care provider for ill and health maintenance visits. The CCC NP also connects with and updates the child's specialty care providers as needed.

The following illustrates how the CCC NPs comanage and coordinate care for their CMC patients. A 5-year-old who lives in a rural area 3 hours from the CCC is scheduled for her 2-hour initial CCC visit. Chart review reveals a congenital chromosomal disease, epilepsy, and dysphagia, all lost to follow-up, and no weight gain over the last 2 years. Anticipating the need for a swallow study to evaluate for dysphagia, risk for aspiration, and potential gastrostomy tube placement, the NP coordinates with a dietitian to evaluate the child during the CCC visit. The NP directs nursing staff to provide education on indications for feeding tubes, and the NP discusses surgical interventions with the child's caregivers during the CCC visit.

Evaluating complex care models

Developing evidence-based models of complex care requires evaluation of model effectiveness. Primarily due to the high cost of care for the CMC population and easy access to claims and medical record data, model effectiveness has largely been evaluated in terms of cost.[26,30,39] These studies showed significant cost reduction, often through care coordination efforts that reduced ED visits and subsequent inpatient admission. Sustainability of cost reductions for CMC is directly tied to sustainability of health for the child and an increase in the cost of health maintenance (increased outpatient and community-based services). Additionally, family support can reduce the cost of inpatient hospitalizations.[16] Complicating the evaluation of complex care model effectiveness is the lack of standardized noncost outcomes for the CMC population. A scoping review of recent CMC literature (n = 63) categorized study outcomes as economic, humanistic/patient-reported and clinical, and approximately a third of these publications reported multiple outcomes.[40] The published outcomes showed 65% of CMC research relied on economic outcomes (cost, inpatient days, readmissions, outpatient visits), 43% on humanistic outcomes (child or family quality of life, family-centered care, satisfaction, unmet need), and 32% on clinical outcomes (death, complications).[40]

Developing evidence-based models of complex care requires evaluation of model effectiveness.

A 4-year award from the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (UJ6MC32737: Health Care Delivery System Innovations for Children with Medical Complexity) is addressing the gap in humanistic and clinical outcome evidence for the CMC population. Referred to as the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity (CMC CoIIN), this award uses CoIIN methodology to test and spread care delivery strategies for CMC.[41] CoIIN is an evidence-based methodology successfully applied to complex pediatric populations, including a National Institute for Children's Health Quality Infant Mortality CoIIN with significant reduction in newborn deaths.[42] The CoIIN methodology engages participants from multiple settings around a common aim using virtual "cyberteams." Quality improvement methods are applied to implement process change, and findings are shared to spread successes and scale policy and program innovation.[41]

Participants in the CMC CoIIN include a National Advisory Committee of experts, the American Academy of Pediatrics/National Resource Center for Patient/Family-Centered Medical Home, Population Health Improvement Partners, the Association of Maternal and Child Health Programs, Family Voices, Health Management Associates, and clinical partners from 10 states (AL, CO, IN, KY, MA, MN, OR, TX, WA, WI). The clinical partners include hospital or outpatient complex care programs and are composed of Title V Maternal and Child Health Program leaders, families raising CMC, providers, nurses, and other clinical staff. The collaborative has three primary goals: improve the quality of life for children with medical complexities; improve the well-being of their families; and improve the cost-effectiveness of their care. Over the 4-year project, each state clinical partner will enroll 150-300 CMC using the definitional framework of CMC described earlier. Families complete a standardized survey, compiled from previously validated outcome tools, to measure achievement of collaborative goals.

A fundamental philosophy of the CMC CoIIN is partnership with parent advisors in all aspects of process design, implementation, and evaluation. This partnership is based on evidence from the Coordinating All Resources Effectively (CARE) Award (1C1CMS331335, Children's Hospital Association) that showed the impact of including parent advisors in all aspects of quality improvement process redesign.[43]

The complex care program at the authors' institution was invited to join the CMC CoIIN collaborative in 2017. Our process improvement team consists of CCC NPs, physicians, nurse care coordinators, a social worker, parent advisors, and quality improvement facilitators. The group meets monthly to identify, design, and evaluate process changes to the complex care program that focus on collaborative goals.

Conclusion

CMC are a small but important pediatric population. Advances in technology and care have increased life expectancy of these children into adulthood.[44,45] Although formal complex care NP training programs do not exist, the comprehensive education of NPs supports their integral role in caring for the CMC population from childhood through adulthood. As primary care, complex care, and specialty care providers, NPs provide holistic comprehensive healthcare services to patients and families. As a care coordinator/care manager, an NP's advanced scope of practice supports the complex coordination and comanagement needs of the CMC population.

NPs working in specialty or primary care can apply principles implemented in the CCC described above to their practice, identifying both medical and social needs of their medically complex patient population. Acknowledging the challenges of having a CMC in their clinical practice, NPs have an opportunity to improve the care of this unique population of patients through care management and care coordination.

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