

Children with medical complexity in Canada

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The burden of chronic disease is placing pressure on the Canadian health care system. A small but important chronic disease population is children with medical complexity, defined as individuals with: high family-identified needs; complex chronic disease necessitating specialized care; functional disability; and high health care utilization. These patients present a challenge to community providers who are expected to provide holistic care and manage complex issues, often with a paucity of services and supports. Alternative models of care may address the complex needs of this population. In addition, strategies can be implemented in community practices that may assist with the care of children with medical complexity such as collaborative care, engagement of key workers, focus on goal-directed care and use of care plans. The paediatric community should engage in health care reform discussions focused on chronic disease to ensure that the complex needs of these children are met.

Key Words: *Canada; Children; Children with medical complexity; Complex disorders; Guidance; Health care reform*

Paediatric health care providers are caring for more patients with complex and chronic diseases, due, in part, to advances in intensive care and increased efficacy of treatments, which have resulted in improved survival rates. The term 'children with special health care needs' (CSHCN) describes a broad group of children who have medical, developmental or psychiatric conditions. CSHCN represent approximately 12% to 18% of the paediatric population in the United States (1) and include such varied conditions as type 1 diabetes, attention-deficit hyperactivity disorder and cerebral palsy. One common feature of CSHCN is the requirement for additional health care services compared with the general population; however, there is substantial variation in the depth and breadth of their needs.

CHILDREN WITH MEDICAL COMPLEXITY

The most complex CSHCN are described as 'children with medical complexity' (CMC) and share four characteristics (Figure 1). The first is the presence of one or more complex chronic conditions that are often multisystem and severe. The second criterion is functional limitation that is significant and often reliant on technology such as feeding tubes and tracheostomies. CMC have high health care utilization, requiring services from different providers in multiple settings. As an illustration, many CMC require the outpatient services of specialists, are hospitalized frequently, and are supported by nursing and allied health providers in their community. In addition, caregivers of CMC identify high health care service needs such as care provision in the home and care

Les enfants présentant des complexités médicales au Canada

Le fardeau des maladies chroniques accable le système de santé canadien. Les enfants présentant des complexités médicales constituent une population, petite mais importante, définie comme composée de personnes dont la famille a des besoins considérables, dont la maladie chronique complexe exige des soins spécialisés, qui souffrent d'une incapacité fonctionnelle et qui utilisent beaucoup les soins de santé. Ces patients représentent un défi pour les dispensateurs de soins communautaires, qui doivent fournir des soins globaux et prendre en charge des problèmes complexes, souvent malgré un manque de services et de soutien. D'autres modèles de soins peuvent répondre aux besoins complexes de cette population. En outre, des stratégies peuvent être mises en œuvre dans les pratiques communautaires afin de contribuer aux soins des enfants présentant des complexités médicales, telles que les soins coopératifs, la participation de travailleurs clés, une orientation vers des soins axés sur des objectifs et l'utilisation de plans de soins. Le milieu de la pédiatrie devrait entamer des discussions en vue d'une réforme de la santé qui répondra aux besoins complexes de ces enfants.

coordination; these can have a significant social and financial impact on the family (2).

CMC are perhaps best understood through discussion of a case. One example is the ex-preterm infant with cerebral palsy, bronchopulmonary dysplasia, gastroesophageal reflux disease and intellectual impairment. He requires multiple subspecialty teams, but does not fall within the scope of an existing comprehensive clinic. Therefore, his parents are primarily responsible for tracking and coordinating numerous appointments. Community-based providers are intricately involved in his day-to-day care and management of intercurrent illness, but often do not have access to timely information from specialists. The current system relies heavily on his parents to transmit information among health care providers (3). This sets the stage for potential inconsistencies and errors in management.

CMC are high utilizers of this health care system, which is not designed to meet their needs, with its focus on acute care and general lack of preventive health care services. Although very small in number (<1% of children), CMC account for approximately one-third of child health spending (4), 10% of hospital admissions and approximately one-quarter of hospital days. (5). However, costs are not only related to acute hospitalizations, but extend to the community setting. Approximately 36% of CMC in Ontario are receiving home care services, accounting for 11% of their total health care costs (4).

The present review article describes the population of CMC, including the challenges inherent in their care in Canada.

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Different models and principles will be discussed as they pertain to CMC. Finally, we will propose several practical strategies that may assist with the care of CMC in the community.

THE INHERENT CHALLENGES OF CARING FOR CMC

The clinical management of CMC presents additional challenges to health care providers and families. Their multiple conditions all must be taken into consideration when deciding on a new treatment. Implementing an intervention to target one symptom or condition could easily have deleterious effects on another condition. Practitioners often rely on anecdote and/or extrapolation from other patient populations to compensate for a lack of evidence in the literature to support clinical decision making. For instance, aspiration pneumonia is one of the most common reasons for hospitalization in this population, and few clinical trials exist to guide clinicians in its treatment. CMC are distinctly absent from most clinical trials, often excluded due to multiple comorbidities or the rarity of their specific underlying condition. Although their underlying conditions are diverse, they share many common consequences. In the future, studies could be designed to maximize on their similarities and enable increased evidence-based management.

CMC are at high risk of experiencing adverse outcomes, due to the complicated nature of their care and frequent interactions with the health care system. Almost one-quarter of CMC will experience readmission within 30 days of hospital discharge and 78% will be admitted again within two years (4). During these frequent hospitalizations, they are at higher risk for medical error. Indicators of medical complexity (eg, an underlying complex chronic condition, device dependency, etc) are independently associated with higher odds of experiencing an adverse event among hospitalized Canadian children (6).

Gaps in care and communication breakdowns are other potential complications. On average, CMC have 13 different physicians representing six subspecialties (4). Ensuring clear communication among members of this group is a formidable task. Often, health records are not shared between tertiary care and peripheral sites, despite increasing utilization of electronic health records. Although the majority of responsibility falls on community practitioners to care for CMC on a day-to-day basis, they may not have access to complete patient information. They are frequently charged with the Herculean tasks of providing routine preventive care, acute management of complex medical and social issues, and coordination of care (7), often with minimal financial incentives, resources and/or expertise. The need for this level of holistic care places enormous pressure on already strained primary care resources and, not surprisingly, it is often unachieved. Almost one-half of families of CMC identify an unmet medical service need, and one-third experienced difficulty in accessing nonmedical services (8).

This discrepancy between high health care needs and frequent lack of supports places a significant burden on families to 'pick up the slack'. Parents are expected to provide a level of medical care that formerly existed only in hospital intensive care units, and also assume a majority of the responsibility for care coordination (4). This burden of caregiving often leads to negative sequelae for caregivers and the family as a whole. In the United States, more than one-half of families of CMC had a family member stop working to care for the child. A similar number report that their child's health care causes significant financial problems (8). Parents of children with the highest levels of complexity score their own health lower than parents of healthy children or children with single chronic diseases (9). They are also at higher risk for depressive symptoms (8).

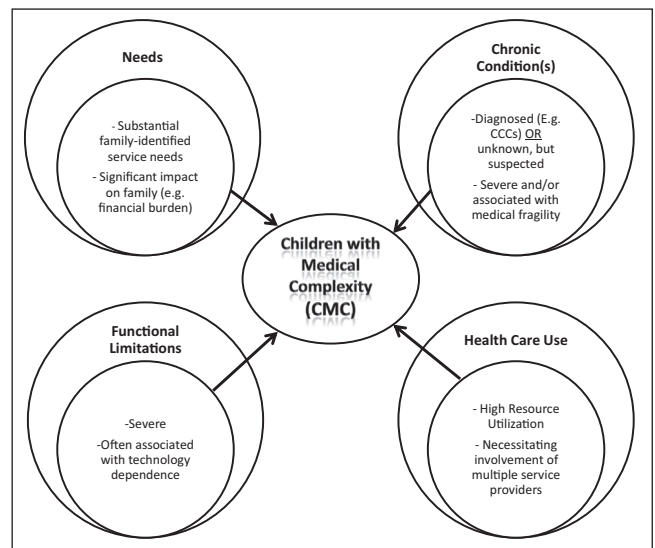


Figure 1) Definitional framework for children with medical complexity. Reproduced with permission from *Pediatrics* 127(3):529-38, ©2011, by the American Academy of Pediatrics. CCC Complex chronic conditions

MODELS OF CHRONIC CARE AND APPLICATION TO CMC

The optimal way to care for CMC may be best understood within models of chronic disease management, a number of which have emerged in the literature. Two examples include the chronic care model and the medical home model. The chronic care model (10) focuses on the interaction between the 'informed, activated patient' and the 'prepared, proactive practice team'. This model emphasizes concepts such as self-management, teamwork, expanded scope of practice and development of partnerships with community resources. Interventions that contain elements of this model improve clinical outcomes and quality of care in adult patients (11). However, this model fails to address the important social, developmental and psychological factors inherent in the care of children with chronic conditions.

The medical home is a model of primary care focused on care that is accessible, family-centred, continuous, comprehensive, coordinated, compassionate and culturally effective (12). The implementation of components of the medical home is associated with a variety of positive outcomes to CSHCN, including increased family-centredness and effectiveness of health care (13). Preliminary data also suggest that having a medical home could result in lower rates of health care utilization (14). However, implementation in primary care practices has proven difficult; in the United States, currently only approximately one-half of children have access to a medical home, and the children with the most severe functional limitations are less likely to have one (15,16). These are only two examples of models that could be considered in health system reform and program development for complex patients. Adaptation to the Canadian context may be required to address our unique challenges.

CHALLENGES IN THE CARE OF CMC IN CANADA

Chronic care models are difficult to operationalize in the Canadian health care system, especially with regard to provision of primary care. Although primary care reform strategies exist, they continue

to focus primarily on adult patients (17). Children with complex and chronic conditions pose many unique challenges to primary care, beginning with: "Who should be providing primary care services?" In many provinces, children with complex chronic conditions often receive primary care services from a paediatrician rather than a family physician (18). While this phenomenon may provide many CMC access to specialized paediatric knowledge, it also isolates them from family physicians and primary care reform efforts that focus on complex adult populations. Having paediatricians provide primary care may also lead to challenges in transitioning CMC to new primary care providers when the children become adults. An additional challenge to providing ongoing care to CMC is the centralization of paediatric care in tertiary or quaternary subspecialty institutions. Because many children live far from these centres, access to these specialized services can be limited and, therefore, most care is provided in the child's home community.

One suggestion for enhanced management of CMC and others with chronic conditions is the development of interdisciplinary teams, ideally those that are integrated with care delivery across organizations (eg, hospitals, home care organizations, primary care, etc). These teams benefit from the expertise of providers from multiple disciplines who work in a coordinated fashion toward shared goals and may be more effective in addressing the complex needs of CMC. However, provision of health care services in Canada still typically revolves around independently practicing physicians whose funding structures do not generally support engagement in interdisciplinary teams. Health care institutions are now implementing interprofessional training curricula, often with a specific focus on chronic disease management. More research is needed, but evaluation shows positive preliminary results in diverse outcomes, from patient satisfaction to improved rates of medical error (18).

Care in the community and, more specifically, in the home is considered to be ideal for patients with chronic disease. However, current health care policy in Canada does not adequately support its provision. There is increasing demand for home care services without a substantial increase of public health care spending (19) and children are at particular risk for receiving inadequate services. There is also significant geographical discrepancy in this provincially funded service. The provincial health authorities are not required to provide a minimum level of service. Even where policies exist, they do not adequately address the needs of children with complex medical conditions because they are based on the service provided (ie, nursing) rather than the population being served (20).

COMMUNITY CARE OF CMC

Clearly, system-wide policy changes are needed to support and optimize the care of CMC. In an attempt to address some of these challenges, many institutions, particularly in the United States, have developed comprehensive clinics targeting CMC in recent years. In Canada, the authors are aware of existing clinics at paediatric tertiary care hospitals in Nova Scotia, Quebec, Ontario, Alberta and British Columbia, and there are likely others. These clinics follow children with many different diagnoses who interface frequently with the health care system. Some act in a primary care capacity and others form partnerships between primary care and tertiary care settings (21). Although different designs exist, these comprehensive clinics for CMC have many commonalities including multidisciplinary practice, enhanced accessibility and care coordination functions.

Some of the principles inherent in the chronic care models and the design of comprehensive clinics can also be used by community

providers to guide individual and local practice in the care of CMC.

Interdisciplinary and collaborative practice

The classic model of the lone physician providing comprehensive care is neither feasible nor realistic in the care of CMC. Collaboration among health care sectors and providers should be an essential component. Using the expertise of other health professionals provides valuable ancillary information and allows an opportunity for collaborative problem solving. Through creation of these partnerships, the community paediatrician can better assist with coordination of care and information sharing, two areas in which families often request assistance (3).

Although challenging to enact in the community setting, there are simple ways to apply these principles. One useful exercise, especially when getting to know a family, is to create a 'care map', a schematic diagram of the child's health care team (Figure 2). Care mapping is a family-driven process that identifies the key practitioners and organizations involved in care of a particular complex child. The knowledge gained from this document could be used to aid communication with these other professionals through one-on-one communication, team meetings or joint appointments. Team meetings could be organized to discuss shared patients. Other health care providers could be invited to join routine appointments. Scheduling dedicated clinic days for complex patients could accommodate these extra activities and allow longer appointments times that are necessary to address complicated issues. Scheduling clinics for complex patients at the same time as visiting specialists would afford additional opportunity for collaboration.

Identification of a 'key worker'

The engagement of a 'key worker' has been shown to have considerable benefit in the management of patients with complex and chronic diseases. The key worker provides individualized support to a family and acts as a single point of contact. He or she can assist with coordination activities and help to bridge the gap between health and social services (22). The use of key workers in specific patient populations has been shown to result in high levels of satisfaction of families and health care providers (23). Although formal personnel may not exist, a key worker could be identified within the health care team, and their identity may change over time. A medically fragile child who frequently accesses services at the tertiary care hospital may benefit from a key worker based at that location. However, the same child may engage in more community-based care in the future, and the key worker would then be best situated in the community.

Goal-directed care

Many providers are, understandably, unsure how to make a difference to a child who is chronically ill and a family who is often overwhelmed. Asking the parents to identify their current goals and challenges may guide assessment and care. Although these goals may not have a significant impact on the underlying medical condition(s), addressing them could increase the parents' sense of partnership and potentially improve the child's quality of life. One tool that exists to evaluate patient or parent-identified goals is the Goal Attainment Scale. This technique involves setting shared goals, instituting timelines and evaluating outcomes. The Goal Attainment Scale can be used to assess diverse interventions targeting a variety of symptoms (24). This tool is used most frequently in the rehabilitation field and has undergone evaluation in the occupational and physical therapy literature (25). However, it has potential applications in many domains of care.

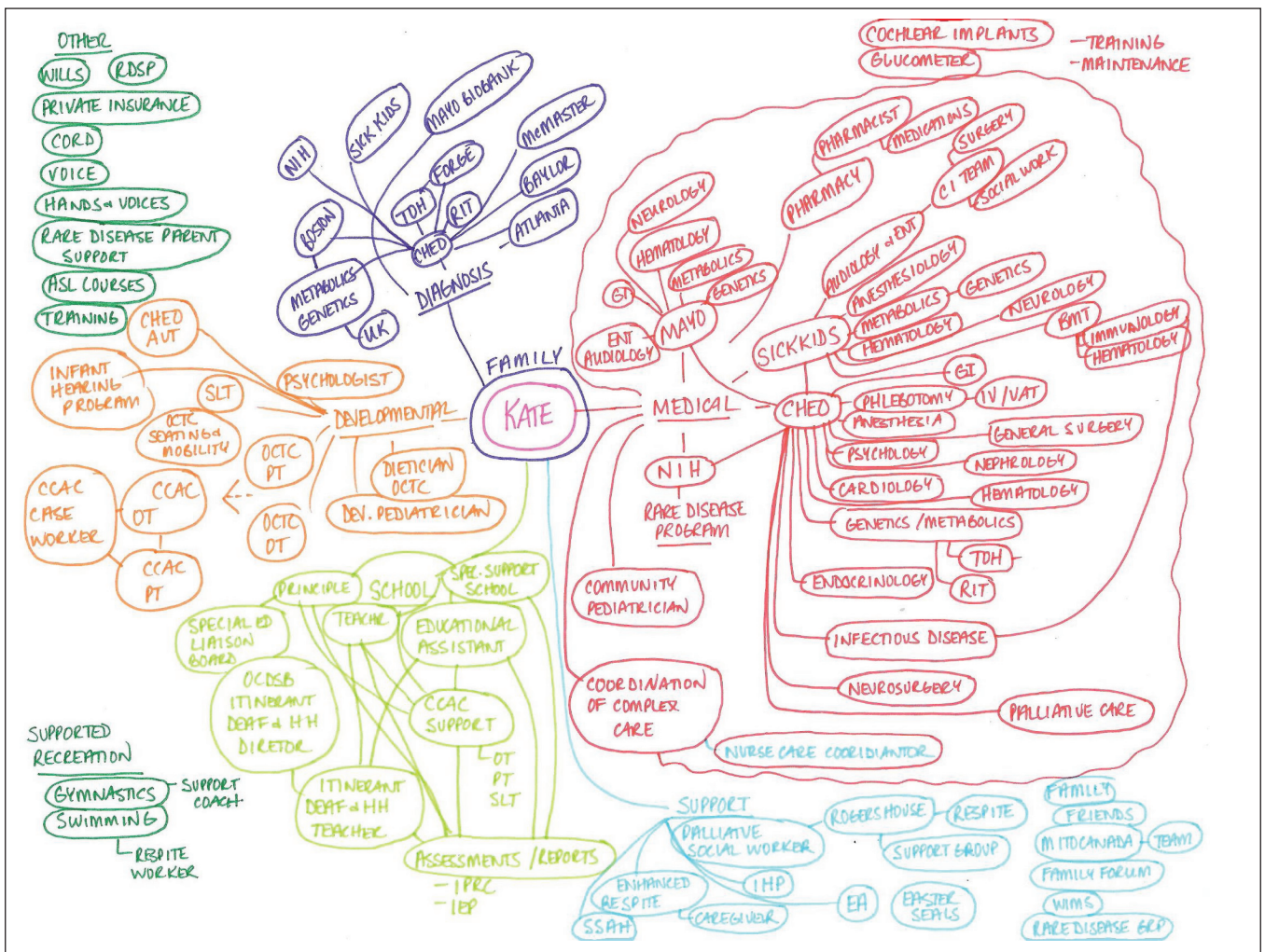


Figure 2) Example of a care map for a child with medical complexity

Care plans

Contemporary medical communication from one health care provider to another or from a provider to a family parallels the traditional organization of health care systems around episodic care. For instance, a specialist sees a patient and sends a letter to the patient's primary care provider with suggestions for alterations to a treatment plan. For CMC, this mode of communication can lead to voluminous medical records that are difficult to navigate, particularly for clinicians who are meeting the child for the first time. This leads to potential communication errors and frustrates patients and families who feel that they must 'tell their story' repeatedly. One potential solution is the creation of a care plan. A care plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the health care provider in collaboration with the family. The document can be modified to meet a variety of needs (eg, emergency care plans, advance directives and comprehensive care plans [26]). Resources, templates and toolkits have been developed in recent years for the creation of care plans (27,28). A concurrent challenge in the use of care plans is ensuring that the information contained within is up to date and accessible to all relevant parties. The increasingly widespread adoption of electronic medical records and further integration of information systems has the potential to address this issue.

CONCLUSION

Governments and health care policy makers are trying to address the epidemic of chronic disease in Canada through primary care service reform, emphasis on patient-centred care, continuity of care and increased attention to the broader dimensions of health (29). Future changes in the health care system in Canada must account for provision of integrated care at both specialty institutions and community practices. Technology, such as teleconferencing and remote monitoring, will provide an unprecedented opportunity to improve the ability to care for patients with complex and chronic diseases in their home communities.

Although smaller in number than their adult counterparts, CMC should be included in these reforms and the development of new models of care. Some models and services that are designed for adults with chronic conditions may be transferred to the paediatric population. Successful comprehensive care models already exist in paediatrics, such as in the cystic fibrosis population, and could be applied to other groups, including CMC (30). In addition to medical care, the models must address developmental and social needs, the health of caregivers and family members, and the need for a seamless future transition into adult care. The time is ripe for the paediatric community to collaborate in this health system transformation to ensure that children and youth are not left behind. A continued focus on integration across the continuum of care has the potential to enhance the

quality of care delivery and improve the support provided for the families of these vulnerable patients.

USEFUL LINKS

- National Center for Medical Home Implementation, Care Plans: www.medicalhomeinfo.org/how/care_delivery/#care
- Guide to Goal Attainment Scaling (Thames Valley Children's Centre, London, Ontario): www.tvcc.on.ca/measures-tools-and-resources-developed-from-projects.htm#gas

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