

# The Critical Lens

## Care maps: De-medicalizing children with medical complexity

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### ABSTRACT

Children with medical complexity (CMC) have extremely high health care needs. Given their chronic complex diagnoses and involvement of multiple care providers, they are often over medicalized and seen as a list of diagnoses rather than as a child. Parents of CMC are extraordinary caregivers and advocates for their children. Parental values and perspectives are critical drivers of medical decision making, therefore highlighting the importance of collaboration between all members of the medical team. For health care providers (HCPs) to holistically guide and support families, an all encompassing, big picture understanding of CMC and their family is needed, and care maps are one such vehicle to provide this insight. Care maps are a parent-created tool that can be used to provide a holistic view of the child and demonstrate the complexity of life and interrelatedness of services for CMC. Previous research has shown that care maps have been used as a resource to promote parental reflection and identify parental priorities of care. Promotion of care maps by HCPs as a valuable tool in understanding the child and family's goals may help improve holistic understanding and promote collaborative care.

**Keywords:** Care coordination; Care map; Complex care

### CHILDREN WITH MEDICAL COMPLEXITY IN CANADA

Children with medical complexity (CMC) have complex chronic conditions, functional limitations, technology dependency, and high health care utilization (1). In Canada alone, CMC make up <1% of children and youth, yet they represent one-third of child health care spending and require more primary health care services, and hospital and emergency department care than the general paediatric population (2). CMC are often followed by numerous specialists, 35% are prescribed five or more classes of medications and are reliant on medical assistance technologies (1). This complexity of care contributes to the overmedicalization of CMC. The prevalence of CMC is increasing due to improved survival rates of pre-term infants, and children with chronic conditions and congenital anomalies. Due to these improved outcomes and increased survival rates for this population, a closer focus on clinical and research objectives that provide opportunities to improve care is warranted (2).

When interacting with CMC and their families, busy health care providers (HCPs) may not have time to focus on areas outside of the primary medical concerns. The overarching picture may be missed, namely that there is more to the child than just a list of diagnoses, problems, or complications (3). Knowing the broader context and having a holistic view of the child and family are needed to support their needs both medically and socially. It is important for HCPs to understand other areas such as their patients' preferences and goals of care. As CMC spend a significant amount of time in hospital, their lives outside of tertiary care may often not be acknowledged or appreciated by their well-meaning clinicians.

### WHAT IS A CARE MAP?

A care map is a visual representation of the people, places, or services involved in a patient's care (Figure 1). It is a family-driven, person-centred creation which highlights what is

Received: June 1, 2021; Accepted: May 3, 2022

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Figure 1. Sample care map.

important to the child and family. It communicates both the big picture and the small details of the resources needed to support the child and their family. A care map can provide a comprehensive snapshot of a child's medical and social

needs, as well as the family's support systems. It provides insight into a "day in the life" of a parent and child. It can help HCPs to appreciate how each of these aspects relates to each other.

## EVIDENCE-BASED USE

Previous research demonstrates the usefulness of care maps for both families of CMC and HCPs (4,5). Specifically, care maps demonstrate the complexity of life and interrelatedness of services for CMC. They have been used as a resource to promote parental reflection, and as a tool to identify parental priorities of care. Care maps have been seen as a resource and reminder for HCPs to appreciate all the different areas that families have to juggle in order to provide compassionate and holistic care (4,5). Additionally, integration of the care map into clinical care offers context about the family experience. The care map respects parents' experiential wisdom, by promoting an improved understanding and integration of the family experience into care-related decision making. Results from our most recent study involving the development of an online platform to support the parental creation of a web-based care map demonstrates that care maps are a valuable tool for parents and HCPs (6). The use of the care map allowed the HCP to see the bigger context surrounding the patient and their family, thus improving shared decision making and collaborative conversations appropriately (6).

## FUTURE RECOMMENDATIONS FOR CLINICAL USAGE

Partnership among HCPs and caregivers is crucial in order for HCPs to holistically guide and support families (4). An understanding of the bigger picture is needed, and care maps are one such vehicle to provide this insight (4,5). Understanding the patient and family's perspective through a care map can complement and inform traditional medical care, like routine clinic visits, by providing insight into areas outside of a child's medical concerns. In addition, care mapping provides caregivers of CMC the opportunity to demonstrate all aspects of their child's care and showcase areas that are most important to them. Having this visual representation demonstrating areas of value allows parents to be informed and active participants in the care of their child. This is in keeping with the underlying tenets of the chronic care model which include productive interactions between an informed active patient and family, and a prepared and proactive HCP team (6). HCPs who can view the care map prior to a patient visit, and discuss it during the visit, will be more prepared and proactive. Having both an active patient/family and HCPs who want to partner and share information has the potential to lead to improved outcomes in care.

However, not all parents may have the desire or capacity to create a care map. Therefore, the development of supportive tools are needed including incorporation of the care map into clinical workflow, the development of a user guide to encourage seamless usage, and parental support and education around creation.

Care maps can be placed in waiting rooms with templates to enable usage in primary care office settings. On a health systems level, organizations can continue to advocate for resources to increase the ability to provide patient- and family-centred care through new tools, such as incorporating the care map into the patient's electronic medical record. Looking to the broader context, care maps can also be used in teaching, training, and policy advocacy by effectively communicating the complexity involved in caring for a child with medical complexity (7).

## CONCLUSION

The ability of care maps to visually depict the intricate web of medical and non-medical care supporting a child with medical complexity in their daily life provides insight and value for parents and HCPs of CMC. Promotion of care maps by HCPs is a valuable tool in understanding the child and family's context and may help improve understanding and collaborative care. Methods to address overmedicalization in CMC are an important component of holistic care and care maps are one solution. Taking time in clinical appointments to understand and appreciate different components of a child, and involving the parents and family in collaborative decision making are ideally supported by the use of a care map.

*Funding:* There are no funders to report for this submission.

*Potential Conflicts of Interest:* All authors: No reported conflicts of interest. All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Conflicts that the editors consider relevant to the content of the manuscript have been disclosed.

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