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Project:

Validation of a new needs-based stratification tool for attribution of health care services in children with medical complexity



Summary:

Known officially as children with medical complexity (CMC), these children are a vulnerable group of patients with a wide range of medical chronic conditions; from genetic neuro-developmental disorders, to being dependent on a tracheostomy tube, and everything in between. CMC and their families navigate a compartmentalized health system not suitable for patients with multiple chronic conditions. Beyond their medical fragility, these children have a legacy of prolonged hospital stays and frequent hospital readmissions, in part because of gaps in health care services and the fragmentation of their complex care needs.

Multiple coordination initiatives are in motion within the Complex Care Service (CCS) at the Montreal Children's Hospital (MCH) to encourage family-centered care, family empowerment, proactive care planning and collaborations across disciplines for families of CMC. However, CMC are a diverse group of children with a wide spectrum of medical complexity; all families may not need or want the same the same services. Matching health care services to the care needs of CMC seems like a sensible solution rather than adopting a "one-size-fits-all" care delivery philosophy.

To our knowledge there are no easy-to-use tools available to stratify CMC centered on their level of care needs. Therefore, based on extensive literature search, expert opinion and our own clinical experience, we created a scoring system questionnaire for assessment and stratification of the level of medical complexity of CMC; this short questionnaire filled by the parents measures key determinants of complexity, fragility and autonomy to determine a global score that corresponds to a complexity level (1=less complex and 4=most complex). Each complexity level is then matched with a care plan that promotes various care coordination strategies based on the care needs of the family at the time of assessment. The main goal of this stratification tool is to facilitate allocation of services based on the actual care needs of CMC.

The MCH MSSA Innovation fund supports the validation process of this unique needs-based stratification tool in CMC. The stratification tool is piloted with 80 MCH pediatric subjects with at least 1 complex chronic condition. The global score corresponding to a specific complexity level obtained with the stratification tool is correlated with the complexity level determined by a panel of clinical experts in the field of complex care (pediatricians and nurses) via chart review of each subject. Underlying components of the stratification tool is identified with principal factor analysis and internal consistency is checked with

Cronbach's Alpha. Finally, comments from parents on the practicality, user-friendliness and overall satisfaction with the stratification tool is transcribed and analyzed for tool revision. Once the stratification tool is revised, it will once again be pilot tested on 40 subjects with the same methodology as previously described.

This unique, innovative and easy-to-use needs-based stratification tool has the potential to: (1) improve patient and family satisfaction in meeting care needs for CMC, primarily through optimal coordinated care; (2) facilitate cost-effective and needs-based allocation of services for CMC; (3) position the MCH Department of Pediatrics as pioneers in reforming the care of CMC in Quebec, as well as promoting the MCH CCS as a centre of excellence in Canada via ongoing clinical innovations, research and education projects.