



The Use of an Online Health Communication Platform in the Care of Children with Medical Complexity: A Feasibility Study

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Background and Rationale

Children with medical complexity are often defined as having multiple chronic diseases, high rates of health care utilization and functional limitation. Their care is fragmented across specialties and geographic areas. In this context, communication can be challenging and inadequate. Families feel responsible for coordinating their child's care and ensuring continuity of information. Systemic changes must occur to provide these families with greater support and enhanced communication, both between families and health care providers and between the various members of a child's health care team.

Objectives

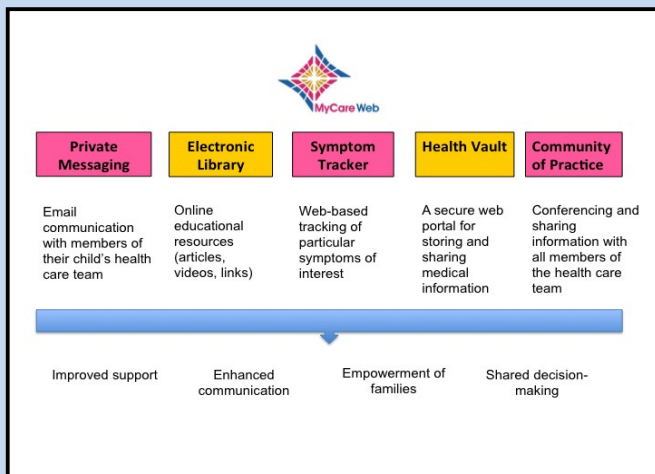
The objective of this feasibility study is to implement and evaluate the use of a comprehensive online health communication platform in the care of children with medical complexity. At this stage, the main purposes are:

- To establish the use, feasibility and acceptability of this type of intervention.
- To establish safety, privacy and confidentiality standards and policies.
- To propose a broad evaluation framework for use in larger future studies.

Method

Study Population: This will include 10-15 children followed by the Biochemical Diseases Clinic at BC Children's Hospital who fulfill the following criteria: (1) Developmental delay and/or Intellectual disability; (2) Multisystem disease requiring care by multiple subspecialists; (3) Identified need for care coordination. Each child's health care providers will also be consented for study participation.

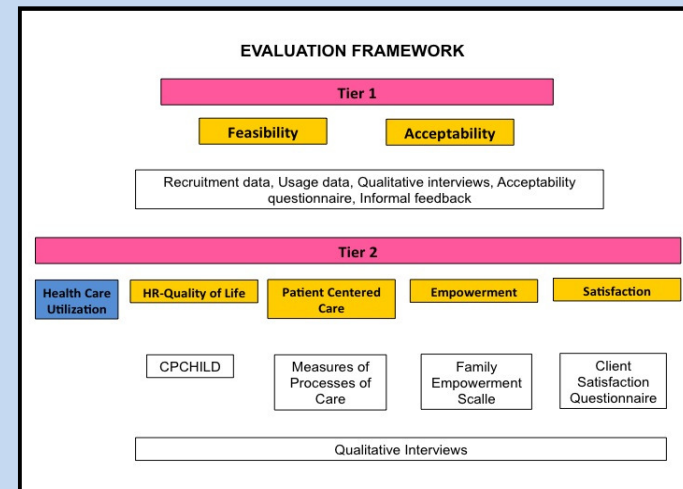
Intervention:



Evaluation

Data Collection: Participants will undergo semi-structured interview at baseline and every 6 months during the 2 year follow-up period. Content will focus on their opinions regarding the intervention itself, communication and health care delivery. They will also complete surveys addressing usage, acceptability, empowerment and quality of life.

Data Analysis: Repeated measures ANOVA will be used for quantitative survey data. Usage data will be summarized in a descriptive fashion. Interviews will be transcribed, coded and analyzed for recurrent themes.



Current Status and Future Directions

The research team is currently engaged in recruitment of participants so results are not yet available.

In terms of future directions, the intention is to modify and improve upon this intervention based on feedback from study participants, both families and health care providers. Depending on the results of this feasibility study, larger trials may be pursued to provide further evaluation of the intervention.

