

Title: How Do Families of Youth with Medical Complexity Adapt to the Transition to Adulthood? Lessons Learned from a Parent-Engaged Qualitative Case Study

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ABSTRACT:

This presentation will: (1) describe an ongoing study on the transition to adulthood for youth with medical complexity (YMC) and their families, and (2) share lessons learned from engaging parent partners in doctoral research.

Background: Youth with medical complexity (YMC) have fragile health conditions and extensive caregiving needs that profoundly impact them and their families. Recent advances have extended the lifespan of many YMC, leading to a new generation who are surviving into adulthood. Now, their families are forced to navigate the transition from pediatric services to more fragmented and unfamiliar adult services. This transition often leaves families feeling abandoned, overwhelmed, and unsupported. In order to inform interventions tailored to the unique needs of this group, it is crucial to first understand how families of YMC currently manage transition, what supports they require, and how contextual factors influence the transition process.

Aim: The aim of this study is to understand how families of YMC adapt to the youth's transition to adulthood and transfer to adult services, and to explain how contextual factors interact to influence this process.

Methods: This study uses a qualitative case study design that is informed by the Life Course Health Development framework. The sample will include 10-15 families of YMC (aged 18-30) living in Ontario. Data sources will include semi-structured interviews and documents, tools, and resources that supported participants during transition. Interview data will be analyzed using reflexive thematic analysis and documentary evidence will be analyzed using directed content analysis. Two parent partners with lived experience will be involved in all research phases, from study design to dissemination.

Significance: This study will generate novel insights critical to the development of timely and tailored interventions that capitalize on family and community strengths and support families where they need it most.