

How Families Adapt as Their Youth with Medical Complexity Transitions from Child- to Adult-Oriented Systems of Care: A Qualitative Case Study

Background:

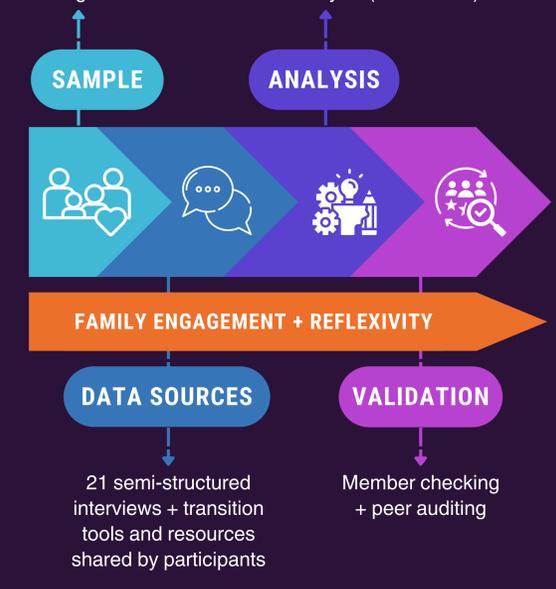
A growing population of youth with medical complexity (YMC) are entering adult systems (health, social, education) that are unprepared to meet their needs. To better support these families, a deeper understanding of how they manage the challenges associated with transition is needed.

Objectives:

1. Understand how families of YMC adapt to the youth's transition to adulthood and transfer to adult services
2. Identify ways in which transitions can be better supported

Methods:

17 participants from 11 families of YMC living in Ontario
 Reflexive thematic analysis (interviews) + directed content analysis (documents)



Presenter: Lin Li

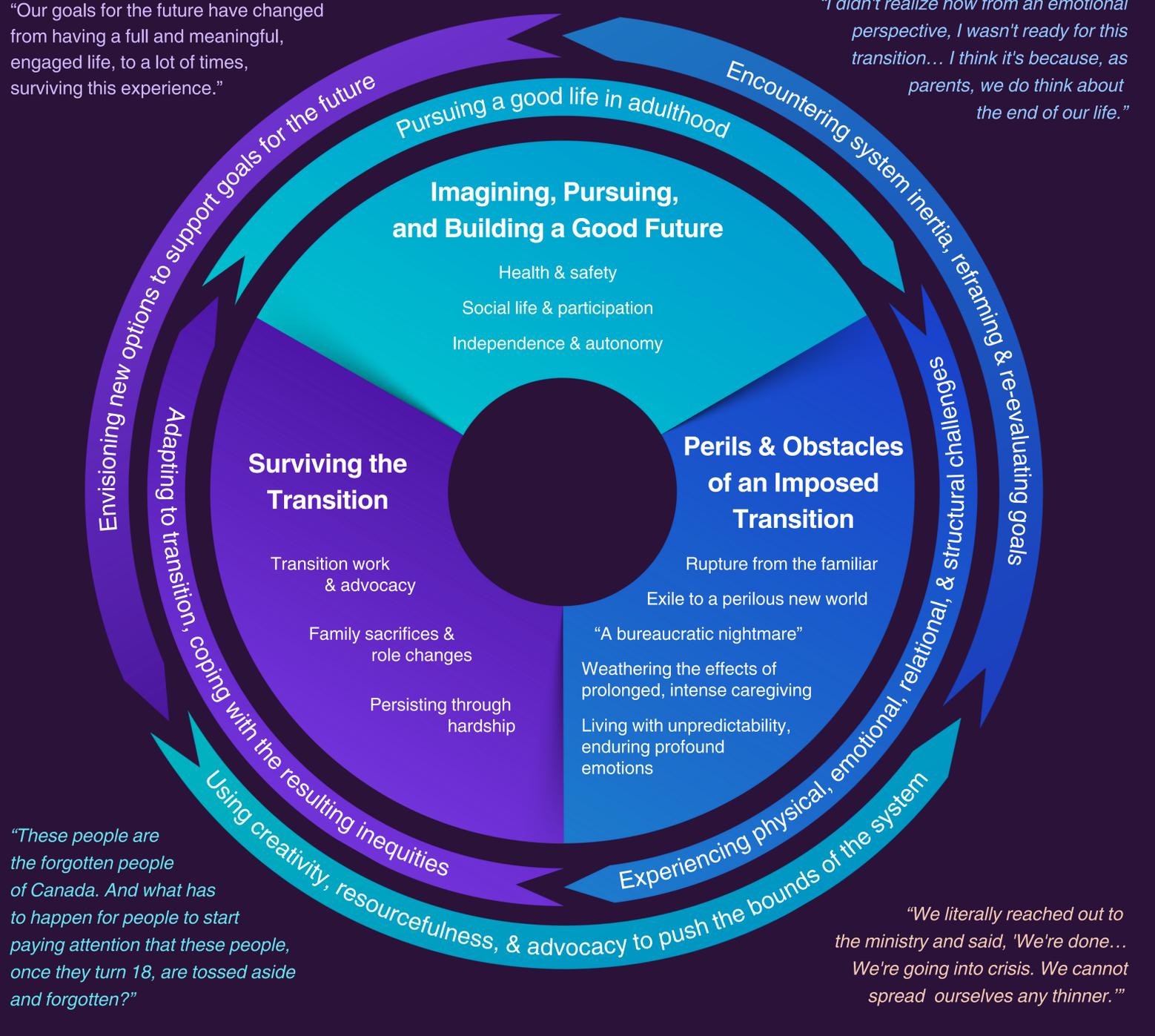
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Families of YMC shoulder tremendous work to navigate transition and advocate for services. They adapt to imposed service transitions through a process of survival, sacrifice, persistence, and reframing.

“Our goals for the future have changed from having a full and meaningful, engaged life, to a lot of times, surviving this experience.”

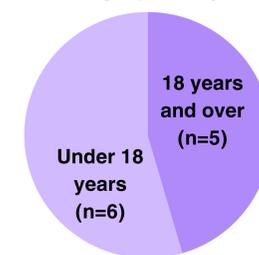
“I didn't realize how from an emotional perspective, I wasn't ready for this transition... I think it's because, as parents, we do think about the end of our life.”



“These people are the forgotten people of Canada. And what has to happen for people to start paying attention that these people, once they turn 18, are tossed aside and forgotten?”

“We literally reached out to the ministry and said, 'We're done... We're going into crisis. We cannot spread ourselves any thinner.'”

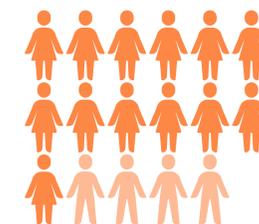
YMC Age (16-28 years)



YMC Gender



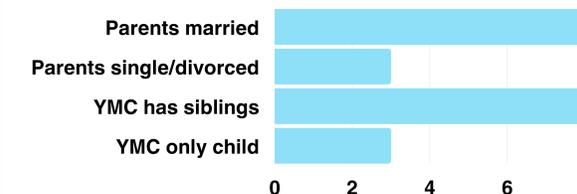
Participant Gender



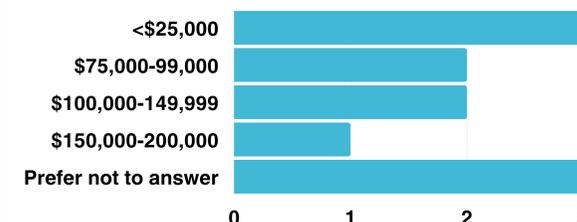
Residential Area



Family Structure



Annual Household Income in Canadian Dollars



Implications

Pediatric providers should:

- Offer families anticipatory guidance and psychological support
- Advocate for the YMC and family
- Not relinquish responsibility for care until YMC is securely attached to safe adult care

Education for adult and primary care providers should focus on:

- Developing competencies in YMC care
- Building capacity through clinical exposure to YMC
- Fostering culturally safe environments

At the policy level:

- YMC require holistic, lifelong service models that provide comprehensive, multidisciplinary care management

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CanChild SickKids

