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Community Health / Policy

Abstract Title

Protocol: The healthcare preferences and valued outcomes of young people living with congenital heart disease and their care partners – a participatory co-design process (TRAILS-CHD)

Background

Congenital heart disease (CHD) is the most common birth defect in Canada, affecting ~4400 births annually. Youth with CHD (YCHD) aged 16-25 face particular challenges during the transition from pediatric to adult specialist care, as they must navigate new health systems and manage their condition more independently. Without structured support, 61% of YCHD may experience a care lapse in adulthood, increasing their risk for adverse health outcomes.

Objective

This protocol describes the development of a tailorable, patient-centered transition care program for YCHD. Our objectives are to (1) engage YCHD, their family and friends (care partners), health and social care providers (service providers), and decision makers in co-determining the transition care program's focus and components, and (2) co-develop the program's prototype.

Methods

This multi-method research project will be set at St. Boniface Hospital and Health Sciences Centre (HSC). Guided by a steering committee of ~10 YCHD, care partners, service providers and decision makers, we will apply the first three stages of the Intervention Mapping framework to co-design a theory- and evidence-based transition care program that optimizes the health and quality of life of YCHD. Data will be generated through a narrative review, participatory scoping review, focus groups, and prioritization exercises with ~10 YCHD, ~10 care partners, and ~12 service providers and decision maker participants. These activities will provide a comprehensive understanding of transition-related health and quality of life challenges and potential solutions.

Results

Expected outcome: This project will produce the prototype of a patient-centered transition care program co-designed by and for YCHD, care partners, service providers, and decision-makers.

Conclusion

Long-term goal: This work will establish the foundation for a future multi-site randomized controlled trial in Manitoba, with aspirations for scale-up across Canada.

Authors

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