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Community Health / Policy

Abstract Title

Health and Quality-of-Life Outcomes Important to Youth With Congenital Heart Disease and Caregivers
Transitioning to Adult Care: A Scoping Review

Authors

Name	Role	Profession
Sasha Kullman	Presenting Author	Graduate
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Will they participate in the poster presentation at CHRD?

No

Background

Background: People with congenital heart disease (CHD) need lifelong cardiac care, but over half

experience healthcare lapses in adulthood. To address this problem, clinical recommendations suggest that youth with CHD should receive information, education, and support as they transition from pediatric to adult cardiac care. We are co-designing a CHD transition care program in partnership with youth, caregivers, and healthcare providers.

Objective

Objective: To begin our co-design process, we conducted a scoping review exploring the health and quality-of-life outcomes that matter to youth with CHD and caregivers as they transition to adult care.

Methods

Methods: We searched OVID (MEDLINE and PsycInfo), Scopus and Google Scholar. Primary studies of any design examining this transition were included. We used Covidence for article screening and extraction. One author deductively coded all reported health and quality-of-life outcomes using a published taxonomy of outcomes in medical research.

Results

Initial Results: The review included 61 studies published between 1998 and 2025. Most were conducted in the United States (26%) and Canada (18%). Approximately 9,678 people with CHD and 2,536 caregivers were represented. We categorized 32 health and quality-of-life outcomes into 11 taxonomy domains: survival; physiological outcomes; physical, emotional, social, role, and cognitive functioning; global quality of life; perceived health status; care delivery; and personal circumstances.

Patient and Family Engagement: Our steering committee, comprising three young people with CHD and three caregivers, validated these findings and added one additional outcome: access to home and community care. The steering committee also designed a ranking activity to gather feedback on the review's findings from a larger group of youth and caregivers.

Conclusion

Future Directions: We will use the ranking activity to identify which health and quality-of-life outcomes identified through the scoping review youth with CHD and caregivers prioritize most. These outcomes will be targeted by our co-designed CHD transition care program.