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Background

- In recent years, there has been a dramatic growth in the number of youth with chronic medical conditions surviving into adulthood
- Youth with chronic conditions transitioning to adult health care experience poor outcomes, including:
 - Poor clinical outcomes
- Increased health care costs
- Low patient and family satisfaction
- Recommendations have been made for more effective primary care provider involvement and broader policy which better integrates primary and specialized care

Objectives

The aim of this systematic review is to determine effective interventions to improve the role of primary care providers in the transition from paediatric to adult health care

Methods

- The search was conducted using Ovid MEDLINE, EMBASE, and Web of Science databases for articles and abstracts published in the past 50 years
- Selected articles were screened independently by two reviewers, and data were extracted into summary tables categorizing study details including: country, study subjects, primary care provider type, role/responsibility or intervention description, patient condition, and outcomes
- The search was not limited to individual conditions given that only youth with complex and/or chronic conditions would require transition to adult care
- Articles discussing opinion-based best practice or those defining family/caregivers as primary care providers were excluded

A systematic review of primary care interventions to improve transition of youth with chronic conditions from paediatric to adult healthcare



for high need populations

	Intervention	Study Design	Primary Care Engagement	Patient Condition	Results
•	Pilot program aimed at finding an adult medical home 3 components: tour, lunch discussion, scheduling 1 st visit	Controlled cross-sectional	Case manager facilitated 1 st appointment w/adult provider of patients' choice	Sickle Cell Disease	 74% (participants) vs. 33% (nonparticipants) completed 1st visit w/adult provider within 3 mo
•	Thriving After Cancer Treatment Is Complete (TACTIC): 1 ^e care clinic providing treatment summary & risk-based survivorship care plan	Descriptive pre-post	General internist assumed 1 ^e care responsibility in a multidisciplinary clinic setting	Survivors of childhood cancer	 Improvements in ability to identify resources & health risks (p= 0.03)
	LIFESPAN model 2 health science centers	Qualitative	Unclear	Cerebral palsy, acquired brain injury	 Lack of access to 1^e care identified as a barrier
	5 academic pediatric & adult health centre teams consisting of physician & transition care coordinator Assessed using the Health Transition Index	Time series comparative	Study setting in pediatric & adult 1 ^e care settings	Chronic physical, developmental, mental health conditions	 Improvements in transition quality indicators Transition policy & tracking process established
•	Pilot 1 ^e care-based transition program Groups: (1) Control (2) Education (3) Educational + in-person group support (4) Additional physician + social work consults Transition Readiness Assessment Questionnaire (TRAQ)	Randomized control trial	Conducted in pediatric & adult 1 ^e care settings.	Complex chronic conditions	 No significant differences in readiness at baseline & 6 mo Providers felt unable to provide assistance
•	Transition Nurse Coordinator led program components: health literacy training, skills for adult living, practical transition assistance	Retrospective descriptive	Transition coordinator attended 1 ^e care appointments	Sickle Cell Disease	 1^e care providers identified as a necessary point of contact throughout transition process
•	Maestro Project Community-based transition navigation service involving project coordinator	Uncontrolled cohort	Referrals connecting to family physicians	Type 1 Diabetes	 11% were referred to family physicians
	Secondary analysis of the 2005-2006 National Survey of Children with Special Health Care Needs Assessed transfer to adult providers, future health needs, health insurance & youth taking responsibility	Retrospective cohort	1 ^e care providers were the usual source of care for patients	Special health care needs	 Youth w/a usual source of care were more likely to receive counseling (47% vs. 34%; p<0.001) & take responsibility for their care (79% vs. 64%; p<0.001)

There are few innovative models of primary care interventions to improve transition outcomes for youth with chronic conditions, and even fewer rigorous evaluations to guide

Future research and policy should focus on developing and evaluating coordinated transition interventions in primary care settings to better integrate primary and specialized care

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