

BMJ Open Improving the transition from paediatric to adult healthcare: a scoping review on the recommendations of young adults with lived experience

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ABSTRACT

Objective The goal of this review was to identify recommendations within the literature on how to improve the transition from paediatric to adult healthcare from the perspective of young adults (YAs) living with chronic conditions who have gone through the process.

Design This review was conducted in accordance with JBI methodology for scoping reviews.

Search strategy We searched MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (EBSCO) and EMBASE (Elsevier) databases, and conducted a grey literature search for relevant material. The databases were searched in December 2019, and re-searched June 2020 and September 2020, while the grey literature was searched in April 2020. This scoping review focused on the recommendations of YAs with chronic conditions who have transitioned from paediatric to adult healthcare, in any setting (eg, hospital, clinic or community), and across all sectors (eg, health, education and social services).

Results Eighteen studies met inclusion criteria for this review. These studies included YAs with 14 different chronic conditions, receiving primary health services in North America (67%) and Europe (33%). YAs' recommendations for improving the transition from paediatric to adult healthcare (n=number of studies reported) included: improving continuity of care (n=12); facilitating patient-centred care (n=9); building strong support networks (n=11) and implementing transition education preparedness training (n=7).

Conclusion Review findings can benefit service delivery by addressing important barriers to health, education, and social services for youth transitioning to adult healthcare.

BACKGROUND

In the past, living beyond their 20th birthday was an unattainable goal for many children and youth with chronic conditions; however, the survival rate has increased to over 90% in recent decades.^{1–3} These survival trends extend to multiple childhood-onset conditions, such as congenital heart disease and cystic fibrosis.^{4–7} Many of these children and youth with chronic conditions have complex care needs that require more medical, social,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first scoping review to focus on capturing the improvement recommendations of patients who have chronic conditions through the lens of young adults (YAs) who have transitioned from paediatric to adult healthcare.
- ⇒ The search strategy included robust databases with peer-reviewed literature, with no restrictions to the condition, sex, ethnicity, or other demographic variables of the YA.
- ⇒ Non-English studies were excluded; thus, eligible studies may have been missed.
- ⇒ Given the nature of scoping reviews and as per scoping review guidelines, the quality of included studies was not assessed.

and/or educational support.^{8–12} As a result, there is a new generation of patients entering adulthood with chronic conditions, which gives rise to unprecedented health system impacts.^{8–11}

Despite growing interest in improving health outcomes for young adults (YAs) aged 18–30 with chronic conditions transitioning from paediatric to adult healthcare, difficulties continue to be reported due to inadequate transition services and a lack in programming.^{13–15} For example, the 2019–2020 National Children's Health survey indicated that 81% of youth in the USA failed to receive services to facilitate this transition process.¹⁶ Furthermore, many YAs lack a plan for continued assistance beyond paediatrics and the skills to self-manage their varied care needs.^{17–20} For YAs, this lack of transition preparedness, coupled with the loss of long-term services and supports provided by paediatric care providers, can lead to gaps in care and disengagement with adult services.^{21–24} Indeed, poor transitions to adult healthcare have been associated with increased morbidity and mortality in several childhood-onset

chronic conditions.²⁵ For example, patients with spina bifida report experiencing an increase in serious complications during transfer to adult services, and mortality for youth with sickle cell disease was found highest in the emerging adult age category.^{26–27} Moreover, decreased adherence to medications during this transition can lead to declining health status and quality of life for many YAs living with chronic conditions.^{28–32} These complications are not only detrimental to the individuals' health, but also costly for both the patient and the healthcare system.

Two recent scoping reviews have examined transitions from paediatric to adult care, but have focused on the lack of healthcare access for youth with intellectual and developmental disabilities and on the availability of transitional care services for youth with arthritis and epilepsy.^{33–34} Currently, limited evidence exists on how transitional-care programmes can impact outcomes for the larger population of YAs living with chronic conditions (ie, improving experiences); yet this information is urgently needed to inform service delivery.^{34–35} Compiling the service delivery preferences of these YAs could be extremely useful for designing practical service improvement initiatives for this population (eg, Institute for Healthcare Improvement's 'Model for Improvement').^{35–39} As such, gathering findings as a scoping review is a key first step in identifying important service delivery priorities in the areas of health, education and social services for youth transitioning from paediatric to adult healthcare. Mapping the current literature on recommendations for transitions from paediatric to adult healthcare, as voiced by YAs, will help identify service delivery gaps (eg, transition planning and transfer) and create direction for future systematic reviews and research.

Objective

The primary objective of this scoping review was to comprehensively search the literature for recommendations to improve the transition from paediatric to adult healthcare, based on the transition experiences of YAs' (aged 18–30) with chronic conditions and/or complex care needs.

Review question

What recommendations have been reported in the literature on how to improve the transition experience from paediatric to adult healthcare from the perspective of YAs living with chronic conditions and/or complex care needs aged 18–30, who have transitioned to adult healthcare services?

METHODS

Study design

This review was conducted in accordance with the JBI methodology for scoping reviews.^{40–41} Data were analysed using qualitative content analysis.⁴² For additional information on the review methods, refer to the published protocol.⁴³ A preliminary search of CINAHL, PubMed,

and the JBI Database of Systematic Reviews and Implementation Reports found no current or ongoing reviews with the same objective.

Patient and public involvement statement

Patient opinions from a local advisory group will be consulted to design a collaborative strategy for disseminating finding results.

Search strategy

The systematic search process, as outlined in [table 1](#), aimed to locate both published and unpublished studies. An initial limited search was conducted in MEDLINE (Ovid) and CINAHL (EBSCO) to identify text words from titles and abstracts, as well as index terms from relevant articles. During this process, a librarian (AG) developed full search strategies (online supplemental appendix 1) and searched all databases listed in [table 1](#). A grey literature search was conducted and is fully described in online supplemental appendix 1. Database searching occurred on 20 December 2019, with searches rerun on 2 June 2020 and again on 23 September 2020; grey literature was searched on 21–24 April 2020.

Inclusion criteria

Participants

This scoping review focused on the recommendations of YAs living with chronic conditions and/or complex care needs who have transitioned from paediatric to adult healthcare. Specific inclusion criteria are shown in [table 1](#).

Concept

The main study concept was recommendations to improve the transition experience from paediatric to adult healthcare. Transition to adult healthcare from the paediatric system was defined as the planned process of moving YAs from paediatric care through to the transfer and integration into adult healthcare, and encompasses physical, mental, and behavioural health.^{44–45}

Context

This review considered recommendations to improve the transition experience of YAs living with chronic conditions and/or complex care needs in all settings (eg, hospital, clinic or community), and across all sectors (eg, health, education, and social services). Studies were included only if they captured YA verbatims using open-ended language (eg, via qualitative or mixed methods studies). Studies were excluded if they focused solely on intrainstitutional transfer (eg, intrahospital) or if recommendations were not identified as a primary outcome.

Study selection

Search results were first collated and uploaded into the citation manager, Endnote V.X8.2 (Clarivate Analytics, Philadelphia, Pennsylvania, USA) and then uploaded to Covidence (Veritas Health Innovation Ltd, Melbourne, Australia), a screening and extraction tool for systematic

Table 1 Search strategy and inclusion and exclusion criteria

Search strategy	
Sampling strategy	▶ Externally peer-reviewed by a second librarian using PRESS guidelines. Databases were searched 20 December 2019, 2 June, with final update 23 September 2020
Types of studies	▶ English language academic journals. No date limits used
Databases searched	▶ MEDLINE (Ovid), CINAHL Full-Text (EBSCO), PsycINFO (EBSCO) and EMBASE (Elsevier)
Additional sources and search methods	▶ Grey literature; Google; Google Scholar; Conference proceedings EMBASE (Elsevier); Dissertations and Theses (Proquest); hand searching of select youth health journals; hand searching the reference lists of included studies; ‘Cited by’ feature through Scopus (Elsevier) and Google Scholar to locate more recent publications citing studies in this review
Inclusion criteria	<ul style="list-style-type: none"> ▶ All primary research studies using a qualitative design. Mixed method designs were included only if accompanying a qualitative design ▶ All categories of chronic health conditions and complex care needs (CCN) were included. CCN were defined as health and social care needs in the presence of a recognised condition, with or without a diagnosis¹² ▶ YAs were defined as young adults aged 18–30. We accepted various terms used in the literature referring to young adults (eg, emerging adult, adolescent, young man or young woman)
Exclusion criteria	<ul style="list-style-type: none"> ▶ Systematic reviews. ▶ If descriptions included young adults’ experiences above the age of 30, given that many young adult transition programmes worldwide are completed by the age of 25. ▶ According to JBI methods, the team excluded quantitative studies given the research aim was to capture YA recommendations in their own descriptive words.

YA, young adults.

reviews. Both tools were used to remove duplicates. Two independent reviewers (MC and AG) then screened titles and abstracts for assessment against the inclusion criteria. The full texts of selected citations were retrieved and assessed in detail against the inclusion criteria by two independent reviewers. This data extraction tool was developed by the reviewers (see [table 2](#)). Any disagreements between reviewers were resolved through discussion. When full text was not available (eg, conference abstracts), a decision was made to contact authors for further information (eg, if text met majority of predefined inclusion criteria and was missing one key piece of evidence).

RESULTS

The initial search strategy identified a total of 5749 records. After title and abstract screening, 120 remained for full-text review. A total of 18 studies met the final inclusion criteria for this review. [Figure 1](#) presents a modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram that presents the number of records identified, included and excluded, as well as the reasons for exclusions (see [figure 1](#)).⁴⁶ Included studies were published between 2011 and 2019. Two-thirds of articles were from North America, with 44% from the USA (n=8) and 33% from Canada (n=4). The remaining articles were from Europe (n=6). Over 83% of the articles (n=15) involved transitions from paediatric tertiary care settings. Studies describing adult services included healthcare (n=17) and educational settings (n=1). These studies took place within healthcare settings that varied with regards to organisational structure, policies, and

funding models. Therefore, it was not possible to conduct direct comparisons of service provider responsibilities and resources, or compare transitions between different levels of care across countries and settings. All studies included YAs with chronic conditions (eg, T1 diabetes, HIV, neuromuscular, organ transplant, mental health, cardiac, spina bifida); however, the complexity of conditions and care needs were not consistently described and could not be accurately captured. Therefore, for the remainder of the results and discussion we will refer to the population as YAs with chronic conditions, rather than YAs with chronic conditions and/or complex care needs.

Our review included all primary research studies using a qualitative design. Mixed method designs were included only if accompanying a qualitative design (qualitative methods=13; mixed methods=5). A total of 18 articles reported recommendations on how to improve the transition from paediatric to adult healthcare as voiced by YAs living with chronic conditions who have completed the transition process themselves. Content analysis was used to gather YA recommendations for transition improvements across the included studies. YA recommendations were synthesised into four major areas: improving continuity of care (n=12); facilitating patient-centred care (n=9); building strong support networks (n=11) and implementing transition education preparedness training (n=7). A table summarising the studies’ major areas of recommendations is presented in [table 3](#) with full citations presented in online supplemental appendix 2.^{47–64}

Table 2 Data extraction

Author	Country	Sample (age/sex)	Health conditions	Transition setting	Study design: method/aim or purpose
Ådnanes and Steihaug ⁴⁷	Norway	N=9; ages 18–30; F(8) M(1)	n=5: severe mental illness (eg, PTSD); n=4: personality disorder	Pretransfer paediatric care: primary care Post-transfer adult care: health clinics/facilities (mental health)	(Qualitative: Interviews) Capture experiences and views about treatment and care, with focus on (dis)continuities and episodes
Bryant <i>et al</i> ⁴⁸	USA	N=14; ages 19–25; F(8) M(6)	Chronically ill youth with haemoglobinopathy	Pretransfer paediatric care: hospital centre/clinic Post-transfer adult care: health clinics/facilities	(Qualitative- descriptive phenomenology: Interviews) Describe the transition experience, expectations and concerns of chronically ill youth with haemoglobinopathy who transitioned to adult care
Chandra <i>et al</i> ⁴⁹	USA	N=12; ages 18–23; F(8) M(4)	Chronic liver disease and/or liver transplant	Pretransfer paediatric care: hospital centre/clinic Post-transfer adult care: health clinics/facilities	(Mixed Methods: Survey) Assess patient/parent perspectives after their transfer process to adult care to develop a more effective transition programme; and acquire improvement suggestions for facilities and paediatric caregivers
Grivetta <i>et al</i> ⁵⁰	Italy	N=7; ages 19–27; F(4) M(3)	HIV+youth	Pretransfer paediatric care: infectious disease department Post-transfer adult care: health clinics/facilities	(Qualitative: Interviews) Identify obstacles and areas of improvement in HIV patients' healthcare transition and nursing process implications
Huang <i>et al</i> ⁵¹	USA	N=10; ages 18–25; F(6) M(4)	n=4: T1D; n=3: IBD; n=3: CF	Pretransfer paediatric care: none provided Post-transfer adult care: health clinics/facilities	(Qualitative: Focus groups) Examine the transition process from paediatric to adult care services from perspectives of YAs with chronic disease and paediatric and adult care providers
Kakkar <i>et al</i> ⁵²	Canada	N=25; ages 19–25; F(15) M(10)	HIV perinatally infected youth	Pretransfer paediatric care: none provided Post-transfer adult care: health clinics/facilities	(Mixed Methods: Questionnaire) Determine outcomes after transition to adult care among HIV+youth; and to document transition process experiences, identify barriers to successful transition and process improvements
Kerr <i>et al</i> ⁵³	Ireland	N=7; ages 18–24; F(3) M(4)	Neuromuscular conditions	Pretransfer paediatric care: none provided Post-transfer adult care: health clinics/facilities	(Mixed Methods- realist evaluation: Interviews) Develop theory about interventions, and organisational and human factors that help/hinder successful child to adult services transition, drawing on experiences and knowledge of YAs with life-limiting conditions, their parents/carers and service providers
Kola <i>et al</i> ⁵⁴	UK	N=6; ages 19–25; F(2) M(4)	n=3: dyslexia; n=1: epilepsy; n=1: Epilepsy and CP; n=1: quadriplegic CP	Pretransfer paediatric care: medical services Post-transfer adult care: educational centre	(Qualitative- interpretive phenomenology: Interviews) Explore the lived experiences, perceptions, and challenges of chronic neurological condition YAs, undergoing transition from adolescence to adulthood

Continued

Table 2 Continued

Author	Country	Sample (age/sex)	Health conditions	Transition setting	Study design: method/aim or purpose
Lindsay <i>et al</i> ⁵⁵	Canada	N=12; ages 19–25; F(8) M(4)	Spina bifida	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: none provided	(Qualitative- descriptive: Interviews) Explore youth and parent experiences of a new transition model for youth with spina bifida, compared young adults with spina bifida who did not participate
Lindsay <i>et al</i> ⁵⁶	Canada	N=4; ages 20–28; M(4)	Duchenne muscular dystrophy	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Qualitative- interpretive: Interview) Explore enablers and barriers of clinicians, young men and parents in transition from an adult DMD clinic within a paediatric hospital to an adult health facility
Margolis <i>et al</i> ⁵⁷	USA	N=33; ages 19–27; F(4) M(29)	Chronic granulomatous disease	Pretransfer paediatric care: none provided Post-transfer adult care: health clinics/facilities	(Mixed Methods: Survey) Identify strengths and barriers to transition from paediatric to adult care; and determine strategies to enhance the transition process
Plevinsky <i>et al</i> ⁵⁸	USA	N=29; ages 18–30	Chron's disease or ulcerative colitis	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Mixed Methods- qualitative phenomenology: Survey) Understand transition of YAs with (IBD), the impact of the paediatric patient–provider relationship; and what determines the adult patient–provider relationship
Asp <i>et al</i> ⁵⁹	Sweden	N=16; ages 19–24; F(11) M(5)	Congenital heart disease	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Qualitative- descriptive: Interviews) Explore the experiences of YAs with congenital heart disease after transfer from the paediatric cardiac clinic to adult congenital heart disease clinic
Dimitropoulos <i>et al</i> ⁶⁰	Canada	N=15; ages 18–21; F(15)	Eating disorders	Pretransfer paediatric care: specialised tertiary programme Post-transfer adult care: therapy/group programmes	(Qualitative- grounded theory: Interviews) Identify systemic facilitators and barriers of transferring YAs with eating disorders from paediatric to adult and mental health services
Valenzuela <i>et al</i> ⁶¹	USA	N=10; ages 24–29; F(7) M(3)	Behaviourally acquired HIV	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: providers in multi-settings	(Qualitative: Interviews) Describe experiences of youth with HIV transitioned to adult care, to identify difficulties encountered and to explore improvement areas
Garvey <i>et al</i> ⁶²	USA	N=26; ages 23–29; F(16) M(10)	T1D	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Qualitative: Focus groups) Explore transition experience from paediatric to adult diabetes care reported by post-transition (T1D) emerging adults, with focus on care transfer preparation

Continued

Table 2 Continued

Author	Country	Sample (age/sex)	Health conditions	Transition setting	Study design: method/aim or purpose
Iversen <i>et al</i> ⁶³	Norway	N=11; ages 19–23; F(5) M(6)	T1D	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Qualitative- explorative: Interviews) Explore how YAs with (T1D) experienced the transition from paediatric to adult care services
Ritholz <i>et al</i> ⁶⁴	USA	N=26; ages 23–29; F(16) M(10)	T1D	Pretransfer paediatric care: hospital centre/ clinic Post-transfer adult care: health clinics/facilities	(Qualitative: Focus groups) Explore perceptions that (T1D) emerging adults have of their patient–provider relationships across transition from paediatric to adult care

CF, cystic fibrosis; IBD, inflammatory bowel disease; PTSD, post-traumatic stress disorder; T1D, type 1 diabetes; YAs, young adults.

Improving continuity of care

Several studies reported that YAs recommended improving the transition from paediatric to adult services by receiving organised and coordinated care throughout the transition from paediatric to adult healthcare.^{50–53 55 57 59–64} This continuity in care should include professionals across all settings, and this cohesive process must begin far in advance of final transfer to adult services.^{51 53 57 61} Specifically, YAs recommended: (1) improving communication and collaboration; (2) participating in a warm handoff and (3) implementing a point-person.

Improving communication and collaboration

Improving communication and collaboration refers to the way information is exchanged between care providers and youth to improve the transition experience. YAs report

that care should be seamless in nature and is improved with the implementation of communication tools (eg, integrated health records). It was recommended that this communication and collaboration occur among inter-agency health professionals, their staff, as well as YAs and their families. This improved communication would help foster understanding of shared goals and roles.^{51 53 57} Specifically, YAs wanted to be more engaged in this communication process while under paediatric care, such as by having opportunities to practice asking more questions to understand decisions about their care.⁵⁷ YAs overwhelmingly expressed preferences to begin early transition discussions (eg, at age 15) with their providers and families.^{53 57 61} One YA said, ‘... Start at a young age, just to let them know that it’s [children’s services] going to come to an end’ (p130).⁵³ Another participant said, ‘Have the doctor tell parents to talk to their kids at age 15 or 16 [about beginning the transition process communications]’ (p719).⁵⁷

Participating in a warm handoff

A ‘warm handoff’ is an in-person interaction with providers, the youth, and their family that occurs during the transfer process from paediatric to adult healthcare. This process is intended to be positive and friendly in nature and can occur in different settings as a bridging technique between paediatric and adult healthcare.^{55 59} YAs experienced discomfort and ‘insecurity’ during this transition due to a lack of familiarity with their future adult care environment.⁵⁹ During the pretransfer period, YAs wanted to meet their new providers and staff, visit the physical location(s) of their new provider(s) (eg, by means of a tour), and begin any onboarding processes (eg, scheduling a first appointment).^{50 53 55 57 59–62 64} As one YA suggested, ‘... having somebody say ‘OK, this is [...] where things are [...] This is where the waiting room is’. Instead of that first appointment where you’re meeting your doctor’ (p195).⁶² Of note, YAs provided numerous ways this in-person meeting could occur, such as connecting together at the last paediatric appointment

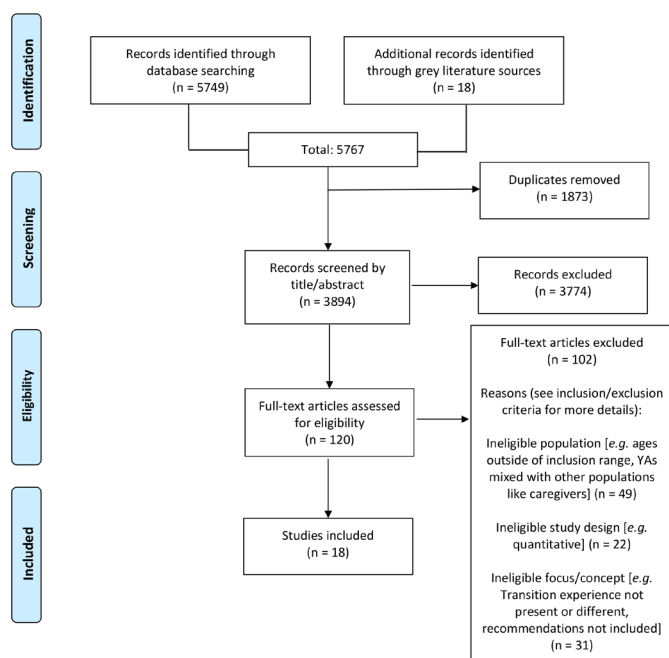


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of study selection and inclusion process.⁴⁶

Table 3 Included studies major areas of recommendations

Improving continuity of care	Improving communication and collaboration	Huang <i>et al</i> ⁵¹ Kerr <i>et al</i> ⁵³ Margolis <i>et al</i> ⁵⁷ Valenzuela <i>et al</i> ⁶¹
	Participating in a warm handoff	Asp <i>et al</i> ⁵⁹ Dimitropoulos <i>et al</i> ⁶⁰ Garvey <i>et al</i> ⁶² Grivetta <i>et al</i> ⁵⁰ Iversen <i>et al</i> ⁶³ Kakkar <i>et al</i> ⁵² Kerr <i>et al</i> ⁵³ Lindsay <i>et al</i> ⁵⁵ Margolis <i>et al</i> ⁵⁷ Ritholz <i>et al</i> ⁶⁴ Valenzuela <i>et al</i> ⁶¹
	Implementing a point person	Asp <i>et al</i> ⁵⁹ Garvey <i>et al</i> ⁶² Grivetta <i>et al</i> ⁵⁰ Iversen <i>et al</i> ⁶³ Kerr <i>et al</i> ⁵³ Lindsay <i>et al</i> ⁵⁵ Valenzuela <i>et al</i> ⁶¹
Facilitating patient-centred care	Listening	Ådnanes and Steihaug ⁴⁷
	Providing developmentally appropriate information	Ådnanes and Steihaug ⁴⁷ Asp <i>et al</i> ⁵⁹ Garvey <i>et al</i> ⁶²
	Including YAs in care decisions	Ådnanes and Steihaug ⁴⁷ Kerr <i>et al</i> ⁵³ Dimitropoulos <i>et al</i> ⁶⁰ Valenzuela <i>et al</i> ⁶¹
	Shifting to 'patient-first' care	Asp <i>et al</i> ⁵⁹ Ådnanes and Steihaug ⁴⁷ Iversen <i>et al</i> ⁶³ Lindsay <i>et al</i> ⁵⁵ Ritholz <i>et al</i> ⁶⁴
	Building strong support networks	Nurturing relationships with care providers Asp <i>et al</i> ⁵⁹ Ådnanes and Steihaug ⁴⁷ Grivetta <i>et al</i> ⁵⁰ Iversen <i>et al</i> ⁶³ Kerr <i>et al</i> ⁵³ Lindsay <i>et al</i> ⁵⁵ Margolis <i>et al</i> ⁵⁷
	Increasing family/caregiver involvement	Chandra <i>et al</i> ⁴⁹ Kerr <i>et al</i> ⁵³ Plevinsky <i>et al</i> ⁵⁸
	Improving access to peer support	Bryant <i>et al</i> ⁴⁸ Huang <i>et al</i> ⁵¹ Margolis <i>et al</i> ⁵⁷
Implementing transition educational preparedness training	Increasing education for youth	Asp <i>et al</i> ⁵⁹ Chandra <i>et al</i> ⁴⁹ Dimitropoulos <i>et al</i> ⁶⁰ Garvey <i>et al</i> ⁶² Lindsay <i>et al</i> ⁵⁵ Margolis <i>et al</i> ⁵⁷
	Increasing training for care providers	Lindsay <i>et al</i> ⁵⁶ Garvey <i>et al</i> ⁶²
YAs, young adults.		

or having the paediatrician attend the first visit in adult healthcare.^{50 52 59 63} As stated by participants, ‘The adult provider should participate in the last visit at the pediatric outpatient clinic’ (p726)⁶³ or ‘... an opportunity to visit the adult outpatient clinic before the transition’ (p726).⁶³

Implementing a point person

The importance of identifying a key person to facilitate the transition process and serve as a bridge between paediatric and adult healthcare frequently emerged as a recommendation from YAs.^{50 52 53 59 61 63} Youth often felt disoriented about where and how to access the information they required to participate in adult services.^{53 62} As such, a transition coordinator role was identified as a potential solution to address unmet needs and to facilitate guidance and plan care coordination across sectors from health, education, and employment.^{50 53 55 61 63} As suggested by one YA, ‘How about one of the nurses, like every Monday night call all the incoming young adults?’ (p195).⁶² Registered nurses were most often suggested for this position as transition coordinators.^{50 62 63} Physicians were also suggested as care professionals who could help youth as they transition from paediatric to adult services.⁵⁰ One YA reaffirmed the benefits of a designated role stating, ‘if there was one person that could find it all out for you and then give all the information to you at once, that would be helpful’ (p131).⁵³

Facilitating patient-centered care

Numerous studies reported that YAs prefer care providers to be focused on individualised patient needs and preferences.^{47 53 55 59–64} YAs want this care to be delivered in a respectful and emotionally intelligent manner. By providing care through these methods, patient–provider relations were strengthened.^{47 53} These dynamic interactions between providers and youth produced the following specific recommendations: (1) listening to YAs; (2) providing developmentally appropriate information; (3) including YAs in care decisions; and (4) shifting from parent-focused care to patient-focused care.

Listening to YAs

Listening, according to YAs, refers to being heard and responded to with understanding.⁴⁷ YAs expressed that their concerns were not taken seriously, or actively listened to, which made them feel their needs were not being addressed by their provider.⁴⁷ As a point of emphasis for improving healthcare transitions, one YA advised that doctors should prioritise ‘listen[ing] to the patient’ (p100).⁵⁰ Another YA participant highlighted the impact of ineffective listening in stating, ‘[...] I was not understood, because they are 100 percent certain that I have a [borderline personality] disorder. They took this as a starting point in their treatment; what I said had no importance, and I wasn’t believed either’ (p4).⁴⁷ Participants also reinforced the importance of, ‘being understood, respected, and taken seriously’ (p4).⁴⁷

Providing developmentally appropriate information

This recommendation reflects that youth wanted to understand information about their clinical condition.⁵⁹ This goal was hindered when YAs felt communication was not tailored to their health literacy level.⁵⁹ YAs preferred providers to listen actively and use lay terms that were ‘developmentally appropriate’.^{47 62} One participant stated, ‘I don’t really know and definitely can’t describe my condition in medical terms [...] I would like, so to speak, some kind of summary of my medical record that a layman can understand, especially since I have become an adult’ (p17).⁵⁹ When this type of communication occurred, YAs suggested, ‘directness from the therapist [provider] was also very much appreciated’ (p4).⁴⁷

Including YAs in care decisions

This recommendation refers to the inclusion of YAs in care decisions and activities, with the goal of youth becoming empowered and prepared for adult healthcare prior to transition.^{60 61} YAs perceived this active participation as necessary in developing their skills of autonomy, which are required for adult healthcare, but also help during their transition.⁵³ As such, YAs concurred, ‘[...] that throughout the transition process the development of the YA autonomy could be focused on more by service providers’ (p132).⁵³ Ideas for improving care included provider and youth collaboratively setting expectations (eg, sharing treatment goals), and creating a space where informed health decisions can take place.^{47 60 61} According to one YA participant, prior to transfer to adult services, youth care inclusion could ‘take the form of sharing information with patients, (eg, test results, treatment rationale, and goals)’ (p151).⁶⁰

Shifting from parent-focused care to patient-focused care

The final recommendation related to patient-centred care emphasises how YAs wanted to receive care that was focused around their holistic, individualised needs (eg, include emotional and social aspects), and not their needs as perceived by their parents.^{47 55 63 64} Regarding the types of services received, YAs, ‘desired a treatment program that would take a holistic approach to their various diagnoses and difficulties’ (p3).⁴⁷ Overall, YAs’ suggestions were in response to feeling that the healthcare they received in paediatrics was overly ‘parent-centred’ (p44) in its approach, with minimal conversations and expectations of responsibility directed towards the youth.^{59 64} Indeed, YAs desired a balanced integration of individual and family-oriented care on both sides of the paediatric and adult transition spectrum.^{59 64} For example, YA participants living with diabetes, ‘discussed the importance of pediatric providers shifting from a ‘parent-centric’ approach and encouraged speaking directly with emerging adult patients while maintaining parental involvement’ (p44).⁶⁴

Building strong support networks

As reported in several studies, YAs wanted to build and establish strong relationships and support networks throughout the transition to adult healthcare.^{47–51 53–55 57–59 63} Specific recommendations in this area included: (1) nurturing relationships with care providers; (2) increasing family/caregiver involvement and (3) improving access to peer support. These individuals and groups are in a position to provide both motivational and informational support, resulting in the development of trusting relationships.^{57–59}

Nurturing relationships with care providers

YAs mainly rely on their primary care providers (eg, nurses or physicians) for information and support throughout the transition process.^{58 63} Once youth made a connection with an adult care provider, they wished to continue seeing that same provider, to establish a trusting relationship.^{47 59 63} YAs wanted to see this adult care provider more than once a year to enhance feelings of security and establish positive therapeutic relations.^{47 50 59 63} Participants stated, ‘The transfer was facilitated by meeting the same doctor who thereby became familiar with them as individuals, which created trust and a sense of security’ (p5).⁵⁹ One YA proposed that familiarity with the new provider could be enhanced if they, ‘Maybe follow you up more at the beginning [entry to adult care]’ (p100).⁵⁰

Increasing family/caregiver involvement

Family involvement in supporting youth from paediatric to adult healthcare increases advocacy for appropriate care and increases access to resources for YAs during transitions.^{53 56 58} YAs reported the valuable and crucial role of their parents/carers in supporting their transition to adult services; [One participant said], My nurses and occupational therapists just didn’t want to start [the transition process], and mum was banging on the door saying, ‘We need to move to adult services’ (p133).⁵³ Families attending appointments with YAs during the transition process were viewed as a beneficial structural support and resource. One YA said, ‘So I think it was good for both of them [caregivers] to be there, so their questions could be answered as well’ (p708).⁵⁵

Improving access to peer support

YAs expressed benefits in networking with peers with a similar diagnosis during the transition process, which could improve their experience.^{48 51 57} YAs suggested the creation of peer mentorship roles as a response to youth feeling ‘nervous’, or to fill a knowledge gap around the transition process from someone who had first-hand experience.^{48 57} Patients expressed most interest, ‘in receiving news regarding their respective diseases, input from actual patients ... and opportunities to network with other patients like themselves’ (p996).⁵¹ Specifically, one participant suggested, ‘... Someone to connect with on your level that knows what you’re going through. I’ve found it useful to talk to other patients ...’ (p720).⁵⁷

Not only did youth express interest in peer mentoring pretransfer, but one post-transfer patient, who had a positive experience, ‘wanted to share advice with individuals facing transition’ (p280).⁴⁸

Implementing transition education preparedness training

For YAs, there are both cognitive and physical skills to be learnt in preparation for a successful transition experience.^{49 55 57 59 60 62} These competencies are required for youth to confidently perform several required tasks of independence (eg, booking their own appointments in adult healthcare).^{52 60} Specific recommendations include: (1) increasing education for youth (and their families) and (2) increasing training for care providers.

Increasing education for youth and their families

YAs recommended learning about the transition process before the actual transfer from paediatric to adult healthcare (eg, insurance and medication management).^{49 60 61} This information could be acquired from print materials or in-person sessions (eg, conferences or workshops).^{57 60 63} One YA suggested that a strategy for improving transition should include, ‘A pamphlet outlining what goes into a visit starting with travel, reservations, clinic appointment’ (p719).⁵⁷ YAs recommended that this educational strategy should involve details about adult clinic procedures and managing expectations.^{59 60} According to YAs, pre-transfer youth were encouraged to begin practicing self-management skills (eg, meeting with their paediatrician alone and learning proactively when to seek support) while in paediatric healthcare.^{49 55} This process was intended to follow a gradual weaning from family involvement.^{51 59 60} Patients’ ‘recommended programming to orient emerging adults to both the logistics and the care practices of the new adult clinic settings, to help shape expectations, and support adjustment’ (p195).⁶²

Increasing training for care providers

Training, referring to enhanced transition-related skills and condition-specific competencies for care providers, was suggested by YAs as a way to prepare youth for the transition from paediatric to adult services.^{56 62} For example, one study exploring coping in YA men as they prepare for transition reported: ‘Parents and young men also felt that clinicians should be knowledgeable of the latest research [...]’ (p76).⁵⁶ In a ‘wish list’ for improving the transition process, patients suggested their adult providers gain ‘expertise in emerging adult care’ (p195).⁶² This training could prepare clinicians for discussions with emerging YAs such as, ‘Hey, you’re an adult, here are some adult-type situations you’re going to run into’ (p194).⁶²

DISCUSSION

An increasing number of children and youth living with chronic conditions are growing up to become adult health service clients. As such, recent guidelines have been



developed by the American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians (AAP/AAFP/ACP), the National Institute for Health and Care Excellence, and Children's Healthcare Canada to facilitate the transition from paediatric to adult healthcare.^{14 23 44} Although these recent guidelines have been developed with input from YAs,^{14 23 44} research suggests that YAs continue to experience difficulty during this transition. Moreover, many research studies continue to focus on improving transitions to adult healthcare with data derived from those without direct lived experience (eg, health providers).^{65–67} This scoping review synthesises recommendations on how to improve the transition from paediatric to adult healthcare as voiced by YAs with chronic conditions who have completed the transition process themselves. Our review identified key recommendations related to improving continuity of care, facilitating patient-centred care, improving access to support and implementing preparedness training for transitions in care. In this discussion, we explore implications in the area of service delivery.

Service delivery implications

During the transition from paediatric to adult healthcare, YAs face health barriers such as fragmented communication between paediatric and adult providers, they experience poorly coordinated care, and they lack the knowledge required to properly manage their health conditions.^{68–70} Recommendations put forth by YAs in this review highlight the need for services that are continuous in nature; patient-centred; and are supported by family, peers, and clinicians. Practice reports and guidelines from the AAP/AAFP/ACP, Children's Healthcare Canada, and the Canadian Paediatric Society on the transition of youth to adult healthcare include recommendations for addressing these same barriers and improving clinical practice outcomes.^{14 44 71} While these guidelines for improving transitions in healthcare have emerged over the past several years, YA experiences captured in this review suggest a gap in their adoption for clinical practice.⁷² Indeed, research has shown that once evidence is published, such as presented within practitioner guidelines, a delay of more than a decade often exists before those recommendations become adopted into clinical practice.^{73 74} Commonly identified barriers for implementing guidelines into practice can be attributed to challenges with dissemination, education, and a lack of written protocols.⁷⁵ Potential strategies for operationalising these transition guidelines may include adopting technology-based tools (eg, electronic medical records) for integrating care across diverse settings, continuing to include YAs in the development of programmes and policies, and implementing evidence-based transitions in care training for care providers.^{44 76 77}

Many of the recommendations captured in this review highlight the need for continuity of care during the transition from paediatric to adult healthcare. Best practice guidelines for improving continuity of care during these

transitions include the use of clinical communication tools such as EMR.¹⁴ EMR adoption is linked with increased adherence to clinical guidelines, improved healthcare efficacy, and enhanced patient-centred care.^{78–80} As illustrated within this review, YAs often transferred from one care setting, such as hospital-based paediatric clinics, to sites such as primary care and community-based settings which may pose risk for the seamless transfer of clinically important information. These risks in information transfer are attributed to each site having its own EMR system infrastructure (eg, single or multiple EMRs) and compatibilities.⁸¹ To fully use clinical decision support tools available in most EMRs, all clinical staff using these tools should: be involved with tool planning (eg, deciding customisations), partake in training and evaluate tool usage.^{80 82} For example, the Plan-Do-Study-Act cycle, an iterative process improvement model, was implemented by a large children's hospital to assess provider adoption of EMR planning tools to improve transitions.^{83 84} This intervention led to an increase in transition planning and readiness.^{83–85}

Beyond the use of technology for closing the communication gap between paediatrics and adult services, YAs reported the need for a designated point person to facilitate the transition process. For instance, a transition coordinator could help with improving the communication and collaboration between providers and facilitate patient-centred care. Indeed, studies suggest that transition coordinators or navigators facilitate access to adult care, improve medical adherence and improve patient self-management skills through education.^{39 86 87} YAs have reported positive experiences in receiving transition coordinator services, provided they begin interacting with the coordinator early enough in the transition process to begin developing a trusting relationship.⁸⁸ Transition guidelines from Canada and the UK, along with recommendations from families, reiterate that this role can promote successful transitions.^{14 23 89}

Providing YAs and their families with support in personalising and coordinating care is an important step in improving the transition from paediatric to adult healthcare; however, this review also underscores the importance of family and peer support. Indeed, guidelines on transitions encourage the support of families for youth and YAs with medical complexity and developmental disabilities during transitions.^{71 90} Our review expands on this recommendation by suggesting that YAs living with chronic conditions be provided with the opportunity for family involvement with their care in adult services as well. YAs also reported that peer support positively impacts health outcomes for this population.⁹¹ For example, YAs with cancer emphasise the importance of peer support; yet express a gap in availability.⁹² Practitioner guidelines encourage establishing peer interventions to provide support and to facilitate self-management for youth and their families using activities such as workshops.^{14 44 71} Furthermore, YA recommendations suggest that it would be most beneficial if peer

programme facilitators had experience with chronic conditions themselves.⁹³

Clearly, building support networks for YAs during this transition is essential; but this review highlights that YAs want to improve their self-management skills prior to transitioning to adult healthcare services as well. Ultimately, clinicians offering patient-centred care supports should intentionally incorporate structured approaches for developing YA competencies in managing their own care and increasing transition preparedness. In fact, studies report that by offering developmentally appropriate health information, youth can become active participants in their care, thus increasing their ability to develop the self-management skills required for care after transition.^{94 95} Moreover, parents have reported struggles in transferring healthcare responsibilities from themselves to their youth; so clinicians can play a vital role in developing their patient's self-management skills.⁹⁶ Clinicians are thus encouraged to support YA patients by regularly tracking their health self-management skills using validated assessment tools to improve patient treatment plan adherence.²⁰

The results of this scoping review suggest that care providers must stay up-to-date with transition-related education in order to provide adequate transitional support. Studies interviewing paediatric residents and specialists found that providers experienced low knowledge and comfort levels with transitions from paediatric to adult care due to a gap in the provision of structured curriculum.^{97 98} This finding is unsurprising given one-third of undergraduate/graduate medical education programmes fail to provide instruction about transition of care.⁹⁹ To overcome this educational gap, curricula in transitional care is advised for pre-licensure and post-licensure programmes and should include paediatric, adult, and general care providers.^{44 100} Fittingly, health training programmes in transitional care for providers in the USA are now offered as part of curriculum for internal medicine-paediatrics residents and as continuing medical education programmes for primary care and subspecialty clinicians.^{44 101} Additionally, care providers are encouraged to explore and apply quality improvement approaches for testing measurable indicators, such as transition planning, in their clinical practices (ie, aided by tools from Got Transition's the Six Core Elements of Health Care Transition 3.0).^{14 44 102} YAs report that this type of provider training could increase awareness surrounding the unique challenges experienced during the transition process.¹⁰³ This training could include content focused on YA development, pediatric-onset diseases, and healthcare transition processes.^{14 44 68 71} Further, current guidelines propose that training should reflect the tenets of family and patient-centred care.^{14 104} While new care provider training programmes based on transition guidelines exist (eg, The Six Core Elements of Health Care Transition), a gap remains in the literature for assessing the effectiveness of provider training within specific systems, patient populations and healthcare settings.^{105–107}

Limitations

The majority of studies that met the inclusion criteria for this review represent health service experiences within a North American context. Also, this review features articles primarily exploring YAs experiences with paediatric tertiary care and adult primary and subspecialty care, with under-representation of other types of clinic settings. In the process of conducting this review, we discovered an absence of studies featuring the experiences of YAs with conditions, such as cancer and developmental disabilities (eg, autism, developmental delays, fetal alcohol syndrome), thus highlighting a gap in this research area. While the search strategy for this review was meant to broadly capture how chronic conditions and/or CCNs are described in the literature, it is possible additional studies about specific conditions are missing from this review. For instance, although our study did not include the keyword 'childhood-onset', some included studies featured this term. Additionally, all studies included within this review were written in English, therefore, a bias in study language was possible. Despite these limitations, this review has highlighted important recommendations for improving the transition from paediatric to adult care and these gaps have important implications for service delivery and research.

CONCLUSION

The 18 qualitative and mixed methods studies examined in this scoping review focused on the care recommendations of YAs with chronic conditions who had transitioned from paediatric to adult healthcare services. This review contributes to the service delivery improvement literature for youth in transition by including the voice of YAs who have experienced the transfer to adult healthcare services. Our review suggests that despite guidelines on transitions in care featuring input from YAs, gaps remain in implementing structured transition policy, planning tools and supports into clinical practice and health systems. Clinicians and decision-makers are encouraged to apply findings from this review to their transition service designs (eg, interventions for furthering and evaluating youth self-management skills). Further research is warranted for assessing how these strategies for improving the quality of care, as recommended by YAs with chronic conditions, can be applied and assessed across different settings to improve patient experience, outcomes and costs of care. The time is past for health delivery decisions to be made without engaging the youth and YAs they serve.

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