

BMJ Open Programmes to support transitions in community care for children with complex care needs: a scoping review

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ABSTRACT

Objective This scoping review aimed to map the range of programmes in the literature to support children and youth with complex care needs and their families during transitions in care in the community.

Design A scoping review of the literature.

Context This review included programmes that supported the transition in care to home and between settings in the community.

Data sources We implemented our strategy to search five databases: (1) PubMed; (2) CINAHL; (3) ERIC; (4) PsycINFO and (5) Social Work Abstracts. The search was last implemented on 29 April 2021.

Study selection Our search results were imported into Covidence Systematic Review Software. First, two reviewers assessed titles and abstracts against our eligibility criteria. Relevant articles were then retrieved in full and reviewed by two reviewers for inclusion. Disagreements were resolved by a third reviewer.

Data extraction Relevant data were extracted related to population, concept, context, methods and key findings pertinent to our review objective.

Results A total of 2482 records were identified. After our two-stage screening process, a total of 27 articles were included for analysis. Articles ranged in the type of transitions being supported and target population. The most common transition reported was the hospital-to-home transition. Intervention components primarily consisted of care coordination using a teams-based approach. The most reported barriers and enablers to implementing these transition care programmes were related to physical opportunities.

Limitations Included articles were limited to English and French.

Conclusions This review identified important gaps within the literature, as well as areas for future consideration to ensure the effective development and implementation of programmes to support children and youth with complex care needs during transitions in care.

BACKGROUND

There has been a noted increase in the number of children diagnosed with chronic conditions over the past several decades, with an estimated 20% of the paediatric population living with a chronic condition affecting

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review mapped the range of programmes in the community that support children and youth with complex care needs and their families during transitions in care.
- ⇒ We conducted a systematic search of five electronic databases and hand searched relevant reference lists for additional articles.
- ⇒ We leverage the use of multiple theoretical frameworks to help analyse and sort the extracted data.
- ⇒ Given the wide range of conditions that may result in complex care needs, our search strategy may not have captured all potential articles; however, we attempted to mitigate this by including all potential descriptive concepts related to complex care in our search strategy.

their daily functioning.¹ While children can be diagnosed with wide ranging paediatric chronic conditions (eg, developmental disabilities, congenital anomalies), they are frequently unified and characterised by their complex care needs (CCNs), high healthcare usage and functional limitations.² Across the research, practice and policy sectors, this population of children are often referred to by a range of terms, including children with special healthcare needs, children with CCNs and children with complex chronic conditions.³ A recent concept analysis described CCNs as ‘multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis’.³ As such, we adopted the term children and youth with CCNs to refer to the population of interest in this work and to remain inclusive regardless of their respective diagnoses.

Caring for children and youth with CCNs requires considerable health resources spanning across various health services, sectors and settings. These can include, but are not limited to, hospital-based medical



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care, community-based clinics, respite care and educational supports. Continued medical advancements have improved the quality of life for many of these children and have allowed them to successfully transition from hospitals to their homes and home communities.^{2,4} In the community, children and youth with CCNs have upwards of 13 different healthcare providers involved in their outpatient healthcare.⁵ In addition to the variety of specialised healthcare related services, many of these children attend school, recreational activities, day programmes and/or workplaces in their communities. As such, they will experience many transitions between providers and settings across their lifetime. Transitions in care are often described as ‘a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations’ (p.4).⁶ This may include the transition from hospital to home, hospital to long-term care, home to school, paediatric to adult care and many others. The complexity of their needs and diverse nature of their condition(s) place children and youth with CCNs at greater risk for unsafe transitions and gaps in care coordination that can lead to adverse experiences, such as emergency department visits and unscheduled hospital admissions.^{5,7–10}

In recent years, many transitional care initiatives have been developed to support the care needs of children and youth with CCNs and their families.^{11,12} Transitional care initiatives and/or programmes are a set of services/resources designed to support the safe and effective movement between care settings/providers. For example, this may include additional nursing follow-up at home after an inpatient hospital stay.¹³ However, much of this literature is widely dispersed given the vast array of transitional care needs, paediatric conditions and diverse care settings. Furthermore, transitional care programmes may be complex in nature due to the variety of providers and services that can be involved. As such, developing a greater understanding of the key components of these transitional care programmes for children and youth with CCNs, as well as the barriers to implementation, will help optimise intervention design and improve sustainable implementation. Given the rapid growth in this field, it is critical that we characterise the range of transitional care programmes supporting children and youth with CCNs.

An initial search of PROSPERO, PubMed, the Cochrane Database of Systematic Reviews and the Joanna Briggs Institute (JBI) Database of Systematic Reviews and Implementation Reports was conducted to ascertain whether a review of all community transition care programmes and their characteristics had been previously completed. Although evidence syntheses were identified which explored specific transitions in care (eg, hospital to home)¹⁴ and the impact of care transitions on caregivers,¹⁵ we did not identify a comprehensive evidence synthesis that reviewed the range of transitions in care programmes that have been reported for children and youth with CCNs. Mapping the current evidence regarding transitional care programmes in the community for children

and youth with CCNs and their families will assist to identify key intervention components; common barriers and enablers to implementation; and gaps in the literature.

This scoping review reports on one of two objectives outlined in a larger review project exploring all transitional care programmes. This can be read in more detail in the published protocol guiding this work.¹⁶ This report is focused on transitions in care (from hospital to home and/or between community settings) for children and youth with CCNs up to 19 years of age.¹⁶

REVIEW OBJECTIVE AND QUESTIONS

The objective of this review was to map the range of programmes that have been reported in the literature to support children and youth with CCNs and their families during transitions in care. The following research questions will be addressed:

1. What programmes have been reported in the literature to support children and youth with CCNs 19 years of age and under, and their families during transitions in care in their home community?
2. What are the reported key components and/or characteristics of transitional care programmes for children and youth with CCNs and their families?
3. What are the reported barriers and enablers to the implementation of transitional care programmes for children and youth with CCNs?

METHODS

This scoping review followed steps outlined by the JBI Methodology for Scoping Reviews.¹⁷ Scoping reviews are a type of knowledge synthesis that seek to map and examine the body of literature pertaining to a broad topic of interest.^{17,18} Given the breadth of our research questions and the lack of existing evidence to address these questions, a scoping review is critically needed.

The JBI Methodology for Scoping Reviews outlines five main steps for conducting a knowledge synthesis: (1) identify and define the research aim and question(s); (2) create and implement a search strategy; (3) identify and select studies; (4) extract and chart the data and (5) synthesise and amalgamate the review findings.¹⁷

Patient and public involvement

Prior to commencing our review, we created an advisory council composed of researchers, library scientists, clinicians and families to oversee the creation and initiation of the research protocol. By forming this advisory council, we were able to identify the priority need for this scoping review to gain a comprehensive understanding into the current literature exploring transitional care programmes to support this population of children, youth and their families.

Search strategy

An experienced library scientist conducted an initial search of PubMed and CINAHL to identify articles

related to our topic of interest. Based on these articles, key words, concepts and index terms were collected and reviewed to develop our comprehensive search strategy. To increase the rigour and reliability of this review, our search strategy underwent peer review by another library scientist with the Peer Review of Electronic Search Strategies Guideline Statement.¹⁹ The search strategy was then adapted for each selected database and was last implemented on 29 April 2021. A manual search of the reference lists from relevant evidence syntheses and literature reviews captured in our search strategy was completed to screen for additional articles of interest.

Information sources

We implemented our strategy to search five electronic databases: (1) PubMed; (2) CINAHL; (3) ERIC; (4) PsycINFO and (5) Social Work Abstracts. The search strategy for all databases is included as in online supplemental file 1. Given the broad scope of this review, grey literature was not included and will be a focus for future work.

Inclusion criteria

Participants

This review considered all literature on children and youth with CCNs between 0 and 19 years old and their families. We defined CCNs according to Brenner *et al's* conceptual analysis as 'multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis' (p.1647).³ Children and youth with specified health conditions, as well as the broader paediatric population with CCNs, were included.

Concept

The concept of interest for our review was transitional care programmes. This was defined as one or more interventions, services, or acts that support or target any movement between care settings, care providers or services. Articles that did not explicitly state that their programme supported a transition in care were excluded from this review.

Context

This review included articles where the transitional care programme involved a transition from: (1) hospital or other healthcare locations to the home or community settings; or (2) between community settings. However, articles that described transitional programmes delivered exclusively within a hospital setting (eg, intrafacility handover) with no community component were excluded from this review. We included articles regardless of the delivery modality. No geographical or temporal limitations were placed on this review to explore any potential patterns or trends across location and/or time. Articles that discussed transitions from paediatric to adult care were separated and reported on as the aforementioned overarching review.

Types of sources

This scoping review considered all types of published literature, including both empirical and non-empirical reports. Non-empirical reports included any articles that described transition programmes or services but were not formally evaluated by quality initiative or research methods. Any identified evidence syntheses of related concepts were reviewed for additional primary articles. Articles published in the English and French languages were included.

Study selection

All identified citations from our full search strategy were imported in Mendeley and duplicates were removed. The complete reference list was then imported into Covidence Systematic Review Software and any remaining duplicates were removed.

To ensure our eligibility criteria were uniformly applied by all reviewers, members of our review team independently conducted an initial pilot test of our screening tool with 10 citations. Reviewers met to discuss findings and resolve any areas of disagreement. Next, teams of two independent reviewers first conducted screening of the titles and abstracts and then all full-text articles deemed relevant. Disagreements arising from either stage of screening were resolved by a third reviewer.

Date extraction

Data from the included articles were extracted by two independent reviewers using a predetermined data extraction tool developed by the research team. Extracted data included population, concept, context, methods, use of theoretical frameworks, barriers and enablers to implementation and key findings relevant to our review objective. Barriers and enablers were conceptualised as any determinant that was reported to influence the uptake of the transition care programme at any level (eg, family or health system level).²⁰ The data extraction table can be found in our published protocol.¹⁶ Two independent reviewers extracted all relevant information, and any discrepancies were resolved through discussion.

Data analysis

Data were sorted and coded using two theoretical frameworks to aid in answering the review questions: (1) The Effective Practice Organisation of Care (EPOC) Taxonomy of Health Systems Interventions²¹ and (2) The Capability, Opportunity, Motivation-Behaviour (COM-B) Model of Behaviour.²⁰ The EPOC Taxonomy was developed through iterative revisions by Cochrane to help classify health interventions and their implementation strategies. In its development, it was applied to interventions in both high-income to low-income countries to ensure relevancy.²¹ This taxonomy has four main domains: (1) Delivery Arrangement; (2) Financial Arrangements; (3) Governance Arrangements and (4) Implementation Strategies.²¹ Each domain contains various categories and subcategories to classify specific details and information

related to the health interventions under examination (eg, who is providing care, what is being delivered, and where is it taking place).²¹ Using this taxonomy as an analysis framework can help to identify potential gaps in the literature and group similar programmes.²¹ Furthermore, given that these programmes are anticipated to be complex in nature, the EPOC Taxonomy was used to identify and organise intervention components, as well as highlight similarities and variances across reported programmes. The COM-B Model of Behaviour suggests that behaviour change occurs when there is a change in an individual's capability (physical or psychological), opportunity (physical or social) and/or motivation (autonomic or reflective).²⁰ For example, physical opportunities refers to environmental context, structures and resources, whereas psychological capability reflects the knowledge and decision making that influence behaviour.²⁰ This theoretical and evidenced based framework helps to better identify and comprehend the nature of behaviour change, the mechanisms needed to change behaviour and their required actions.²⁰ With this knowledge, the COM-B model can help identify critical areas that should be considered when developing and implementing health programmes.²⁰ We used the COM-B to provide a theoretical basis for classifying and organising reported barriers and enablers to the implementation of transitional care programmes included in our review.²⁰ Two independent reviewers coded data related to intervention components using the EPOC framework and data related to barriers and enablers using the COMB-B model. Reviewers met to resolve any disagreements in coding to achieve consensus. An inductive analysis approach was then used to group and theme recurring and similar barriers and enablers to implementation.²² Descriptive statistics were also run to provide the frequency in which concepts occurred.

RESULTS

Our initial search strategy identified a total of 2482 records. After title and abstract screening, 421 remained for full-text review. Following the exclusion of articles that did not meet our eligibility criteria, a total of 27 articles were included in our analysis (figure 1).

Transitional care programmes

Over 85% of our included articles were conducted in the USA (n=23). The remaining articles originated from Australia (n=2), Canada (n=1) and the UK (n=1). Over 40% of the articles (n=12) specifically targeted the hospital-to-home transition. Other care transitions included supporting transitions within school (n=3); within community settings (n=2); between hospital-to-ambulatory care (n=2); school-to-work (n=1); early intervention programmes-to-pre-school (n=1); inpatient and outpatient care (n=3); hospital-to-community (n=1); tertiary care-to-primary care medical home services (n=1); and transition program-to-community (n=1). A summary

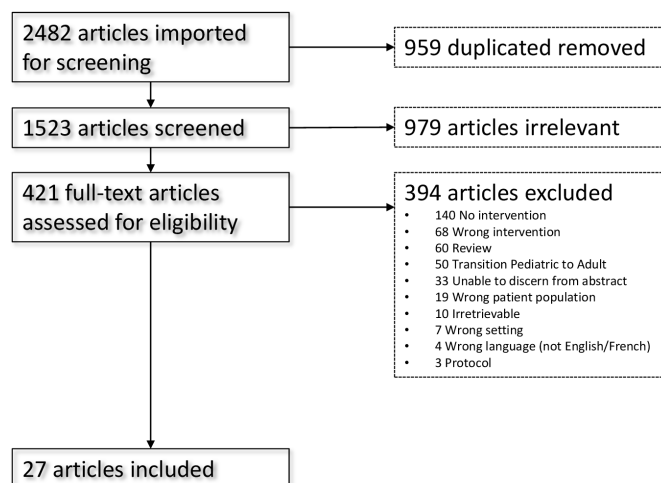


Figure 1 PRISMA diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

of the article characteristics is outlined in online supplemental file 2.

Target population

The reported transitional care programmes support a variety of paediatric populations living with CCNs. This included children and youth with specific diagnoses (eg, children who sustained brain injuries, patients having undergone allogeneic stem cell transplantation, children with cerebral palsy, children with respiratory technology dependence) or specific groups (eg, preschool special education children, high-risk neonatal patients or hospitalised children and youth). Approximately one-third of the programmes targeted the broader population of children and youth with CCNs, irrespective of their specific conditions/diagnoses (n=10).

Key intervention components using EPOC taxonomy

O'Shea *et al* reported on the evaluation and comparison of two transitional care interventions which were coded separately using the EPOC taxonomy. Therefore, there were a total of 28 interventions identified and categorised based on the EPOC framework. Of note only eight articles reported the use a conceptual or theoretical framework underpinning their work. A breakdown of intervention descriptions and identified theoretical frameworks can be found in online supplemental file 3.

The two key intervention components present in the majority of strategies or programmes were case management (n=23) and the use of teams (n=21). Of the overall components included in the EPOC taxonomy (eg, delivery arrangements, financial arrangements, governance arrangements, implementation strategies), the most reported types of information were related to delivery arrangements and implementation strategies (n=28). Financial arrangements were the least reported component. In terms of delivery arrangements, more than half of the interventions discussed case management, communication between providers, use of teams, coordination of care among different providers, continuity of care, care pathways, self-management, decision

making and disease management. Seven interventions discussed governance arrangements, including decision making about what or who is covered, insurance, prescribing, scope of practice and professional competence. Lastly, more than half of our included programmes target healthcare workers, with only two targeting health organisations. A full breakdown of the EPOC analysis can be found in [table 1](#).

Barriers and enablers to programme implementation

The most reported barriers and enablers to programme implementation fell under the COM-B category of ‘physical opportunities’ (n=18), with ‘social opportunities’ being the second most reported category (n=10) ([table 2](#)). The most common barrier within physical opportunities (n=3) was the lack of service coordination, while good communication was the most common enabler in the social opportunities’ category reported in three studies. The remaining coded COM-B categories are listed in descending order of frequency: reflective motivation (n=6); psychological capabilities (n=5); physical capabilities (n=4); and automatic motivation (n=2). In regard to reflective motivation, six articles described the stigma and social isolation that surround individuals with disabilities as a barrier to successful transitions in care. Lack of knowledge by providers about specific illness presentations, as well as the services available to families, was another reported barrier to the implementation of these programmes. There were eight articles that did not report any barriers and enablers to their intervention implementation.^{23–30} Many papers reported barriers and enablers that fell into multiple categories, with two articles reporting within four COM-B categories, six articles reporting within three, nine articles reporting within two, and three articles reporting within one ([table 2](#)). A full breakdown of examples of the barriers and enablers coded in each of the COM-B categories from a variety of papers are highlighted in [table 3](#).

Study designs and outcome measures

Our review included all articles, regardless of their study design. A total of 17 articles reported an empirical evaluation, including the following study designs: retrospective quantitative methods (n=6), qualitative methods (n=4), randomised controlled trials (n=2), quality improvements (n=2), mixed methods (n=2) and prospective quantitative methods (n=1). Of those that reported outcome measures, seven articles reported on provider level outcomes, five articles reported on health system outcomes, four reported patient/family-level outcomes, and one article reported on both. Online supplemental file 2 provides a more detailed breakdown and summary of the study outcomes.

DISCUSSION

Children and youth with CCNs are a growing population within our health and community care systems.² Various health and social resources are needed to support children, youth and families to achieve seamless and safe transitions in care, as well as ensure successful integration

into the community.^{2 4 7 11 31} Without adequate access to the appropriate resources, children and youth are at risk for adverse health outcomes and gaps in their continuity of care.^{4 32} To better understand this concept, we undertook a scoping review to map the range and characteristics of programmes reported in the literature that support children and youth between 0 and 19 years old with CCNs during transitions in care to and between community settings. Our review identified several gaps within the literature, including a limited number of empirical studies and a dearth of programmes identified to support transitions across various community settings. The results of this scoping review also identified areas for future directions to ensure the effective development and implementation of programmes that support the needs of these children and youth during transitions in care.

Most interventions focused on the transition from hospital to home, while few focused on supporting children and youth with CCNs and their families in their home community and/or movement between community settings (eg, school, workplace). This review suggests that most of the transitional care programmes for children and youth with CCNs are designed and implemented to support the hospital to home transition, with other community-based transitions, such as the transition from home to school, poorly understood and/or supported. These transitions in care are imperative, as many individuals with complex needs are cared for in their homes, instead of acute and long-term care settings.^{2 33} Many children and youth with CCNs are attending schools, day programmes, and workplaces; however, our review identified few published articles that focused on programmes to support transition to educational services (eg, public/private schooling)^{27 34–36} or community care (eg, respite care). To accompany this shift in care provision, it is crucial that resources and services are in place to support the transitions encountered by many of these children and youth. However, families often report difficulty in accessing essential community services, such as respite care that can help facilitate family involvement in their communities.³⁷ Furthermore, children and youth with CCNs can face challenges when seeking to fully integrate and participate within schools’ educational and play activities, subsequently impacting educational attainment and quality of life.³⁸ Inclusive education, social integration and access to community system supports are key domains in achieving optimal health for children with medical complexity and their families.³⁹ As more children with CCCNs are being cared for in community, it is critical that programmes are designed and evaluated to support these various community-based care transitions.

Best practice methods for designing successful interventions includes a behavioural analysis to identify barriers and facilitators to implementation, and tailoring strategies to address these behavioural determinants.⁴⁰ We used the COM-B model and EPOC taxonomy to identify known barriers and enablers to programme implementation and existing intervention components being used in practice.

Table 1 EPOC intervention components summary table

Domain	Category	Subcategory	No of interventions (%)
Delivery arrangements	How and when care is delivered	Coordination of care among different providers	20 (71.4)
		Quality and safety systems	9 (32.1)
		Triage	11 (39.3)
	Where is the care provided and changes to the healthcare environment?	Environment	11 (39.3)
		Outreach services	13 (46.4)
		Site of service delivery	14 (50)
		Transportation services	6 (21.4)
	Who provides care and how the healthcare workforce is managed?	Role expansion or task shifting	1 (3.6)
		Self-management	18 (64.3)
		Staffing models	5 (17.9)
Coordination of care and management of care processes	Recruitment and retention strategies for underserved areas	Recruitment and retention strategies for underserved areas	2 (7.1)
		Care pathways	18 (64.3)
	Case management	23 (82.1)	
	Communication between providers	21 (75)	
	Comprehensive geriatric assessment	3 (10.7)	
	Continuity of care	19 (67.9)	
	Discharge planning	14 (50)	
	Disease management	15 (53.6)	
	Integration	2 (7.1)	
	Packages of care	2 (7.1)	
Information and communication technology	Patient-initiated appointment systems	Patient-initiated appointment systems	2 (7.1)
		Procurement and distribution of supplies	4 (14.3)
	Shared care	12 (42.9)	
	Shared decision-making	17 (60.7)	
	Teams	21 (75)	
	Transition of care	28 (100)	
	Health information systems	9 (32.1)	
	The use of information and communication technology	6 (21.4)	
	Telemedicine	3 (10.7)	
	User fees or out of pocket payments	1 (3.6)	
Financial arrangements	Collection of funds	Prepaid funding	1 (3.6)
		Social health insurance	1 (3.6)
Insurance schemes	Private health insurance	Private health insurance	1 (3.6)
		Payment methods for health workers	1 (3.6)
Mechanisms for the payment of health services	Targeted financial incentives for health professionals and healthcare organisations	Fund holding	1 (3.6)
		Incentives for career choices	1 (3.6)

Continued

Table 1 Continued

Domain	Category	Subcategory	No of interventions (%)
Governance arrangements	Authority and accountability for health policies	Decision-making about what or who is covered	2 (7.1)
	Authority and accountability for organisations	Insurance	1 (3.6)
	Authority and accountability for health professionals	Prescribing	1 (3.6)
Implementation strategies		Scope of practice	3 (10.7)
		Professional competence	1 (3.6)
	Interventions targeted at organisations	Organisational culture	2 (7.1)
	Interventions targeted at workers	Audit and feedback	3 (10.7)
		Clinical incident reporting	1 (3.6)
EPOC, Effective Practice Organisation of Care.		Continuous quality improvement	3 (10.7)
		Educational materials	4 (14.3)
		Educational meetings	6 (21.4)
		Educational outreach visits or academic detailing	4 (14.3)
		Clinical practice guidelines	5 (17.9)
		Interprofessional education	6 (21.4)
		Local consensus processes; local opinion leaders	7 (25)
		Reminders	2 (7.1)
		Routine patient-reported outcome measures	1 (3.6)
		Tailored interventions	9 (32.1)
Interventions targeted at specific types of practice, conditions or settings		Health conditions	28 (100)
		Practice and setting	28 (100)

Table 2 Barriers and enablers COM-B analysis summary

Authors	Capabilities		Opportunities		Motivation		Total
	Physical	Psychological	Physical	Social	Reflective	Automatic	
Betz and Redcay (2002) ⁴¹	x	x	x	x			4
Olley <i>et al</i> (2017) ⁵⁵		x	x	x	x		4
Smart <i>et al</i> (2017) ⁵⁶	x		x		x		3
Rutkowski <i>et al</i> (2006) ⁵⁷	x	x	x				3
Myers (2007) ³⁴	x		x	x			3
Gordon <i>et al</i> (2007) ⁵⁸		x	x	x			3
Thrall <i>et al</i> (2012) ³⁵			x	x	x		3
Coller <i>et al</i> (2018) ⁵⁹			x		x	x	3
Kelly <i>et al</i> (2008) ²⁶			x		x		2
Baker <i>et al</i> (2016) ⁶⁰		x	x				2
O'Shea <i>et al</i> (2007) ¹³			x	x			2
Graham <i>et al</i> (2008) ⁶¹			x			x	2
Storgion and Stutts (2000) ⁶²			x	x			2
Moyer <i>et al</i> (2010) ⁶³			x		x		2
Statile <i>et al</i> (2016) ⁶⁴			x	x			2
Stephens (2005) ⁶⁵			x	x			2
Graham <i>et al</i> (2017) ⁶⁶			x				1
Biffi and Biffi (2015) ⁶⁷			x				1
Martel <i>et al</i> (2015) ³⁶				x			1
Total	4	5	18	10	6	2	

COM-B, Capability, Opportunity, Motivation-Behaviour.

Using the COM-B model and the EPOC taxonomy as analysis frameworks revealed an apparent mismatch between the reported barriers to implementing transitional care programmes for children and youth with CCNs and the implementation strategies being used. For instance, many

authors reported barriers related to physical resources and opportunities, such as a lack of service coordination, when implementing transitional care programmes.^{25 28 41} This is consistent with current literature exploring the experiences and barriers to transitioning children and

Table 3 Examples of Barriers and Enablers in Each COM-B category

Category	Subcategory	Total	Example
Capabilities	Physical	4	Learning context: Needs to be in 'real-life' context ⁵⁷ Minimal training r/t early career transitions; provide training ³⁴
	Psychological	5	Lack of knowledge by HCP and families as to resources available ⁴¹ Knowledge of child's condition ⁵⁸
Opportunities	Physical	18	Lack of expertise in the community, for example, school-based services ⁶¹ Lack of service coordination ^{62 64 65} Varying eligibility requirements for services and financial aid, and insufficient resources ⁶² Transportation concerns ⁶⁴ Funding ³⁵ Financial problems experienced by families ⁶⁶ Lack of formal criteria for enrollment in programme ⁵⁸
	Social	10	Family members be engaged in our improvement processes ^{58 64} Lack of communication between Health care providers, educators, client ⁴¹ Good communication facilitated relationships and trust between services and aided supportive counselling ^{34 55 62}
Motivation	Reflective	6	Children with special needs may experience stigmas, social isolation, and an impaired development of social skills, self-esteem, sexuality and sense of identity ³⁵ Action plans for goal setting ⁵⁹
	Automatic	2	Family stress and comfort with medical complexities ⁶¹

COM-B, Capability, Opportunity, Motivation-Behaviour.

youth with medical complexity from the hospital to home settings.^{12 31} Conversely, the majority of implementation strategies are focused on the healthcare provider and child/family level, with few approaches at the organisational and health system level to target those barriers. The EPOC taxonomy further highlighted the dearth of evidence regarding the strategies to secure financial provision to implement and sustain these programmes within the health system. Without the appropriate infrastructure or support at the organisational level, the implementation and sustainability of these programmes in the clinical and community settings are limited.^{42 43} Harnessing frameworks such as the COM-B model and EPOC taxonomy provides a theoretical and conceptual foundation to not only identify these mismatches of barriers and strategies, but also provide a clear indication of next steps.^{44–46} Findings from our work highlight the need for attending to health system level barriers such as sustainable infrastructure and funding when designing transitional care initiatives to support this vulnerable population. This review also highlighted the overall lack of conceptual and theoretical guidance underpinning the transitional care literature for children and youth with CCNs and their families. Forthcoming research can benefit from the theoretical and pragmatic guidance to designing and implementing sustainable transitional care programmes and ensure that challenges are mitigated, and facilitators are amplified.

Collaborating with families as partners in care was identified by this review as an important factor in the development and implementation of transitional care programmes for CCNs (see [table 3](#)). Over the past decade, the importance of patient/family engagement in codesigning care with providers is becoming more widely understood and adopted.^{47 48} Further, fostering partnerships with patients/families and end-users in research evaluating these interventions has been shown to support the development of patient/family identified priorities and ultimately improve health outcomes, services and systems.^{49–52} These partnerships need to be authentically and meaningfully cultivated to mitigate power imbalances, create shared learning environments and build research capacity.⁵³ Engaging children and youth, in particular those with developmental disabilities, as partners in research also presents additional and unique ethical considerations.⁵⁰ New frameworks and strategies are now being developed to help guide researchers in this complex process, challenge ableist assumptions, and ultimately create inclusive research practices.^{50 53} While we specifically highlight the role families play as partners in research and quality improvement, it is also critical to cultivate these meaningful relationships between providers and families in the clinical setting and ensure this is a key component to any clinical initiative. Researchers and policy-makers should be including children and youth with CCNs and their families on their team to ensure the development of a responsive health system to the needs of children, youth and their families during transitions in care.

Limitations

This review considered all articles, regardless of their design. Further, some articles did not report on key aspects related to their programme components and/or implementation. We encourage authors to follow reporting guidelines (ie, Equator Network Reporting Guidelines) to ensure readers can discern critical information related to programme components, implementation strategies, and evaluation methods.⁵⁴ Without this information, replicability of these initiatives is limited. Further, this review considered all articles that reported on supporting children and youth with CCNs regardless of their specific diagnoses. Given the wide range of conditions that may result in CCNs, our search strategy may not have captured all potential articles; however, we attempted to mitigate this by including all potential descriptive concepts related to complex care in our search strategy. We also did not conduct a search of the grey literature, as this work is being undertaken separately due to its potentially large scope. Lastly, including only articles published in English or French language may have limited the international scope of this review.

CONCLUSIONS

It is imperative that the appropriate resources and services are in place to support children and youth with CCNs and their families during the various transitions in care encountered across their lifespan. This review mapped the range and characteristics of programmes being reported in the published literature to support these transitions in care and brought to light areas to explore for future direction. It is encouraging that this review identified a number of programmes designed to support children and youth with CCNs and their families during the essential transition from hospital to home; however, important gaps were also identified. The results from this review call for more empirical research focused on transitions to community and educational-based services. As more children are being cared for in their homes and home communities, transitions to services such as school and respite are imperative to achieve optimal health. Further, there is disconnect between the reported barriers and enablers to implementing these transitional care programmes, their intervention components and selected implementation strategies. Using theoretical frameworks, such as the COM-B Model of Behaviour and EPOC taxonomy, can help identify and map potential barriers and enablers, intervention components and implementation strategies to create more tailored and sustainable interventions to support the transitional care needs of children and families. Moreover, researchers, clinicians and decision-makers must invest the time and effort to authentically engage children and youth with CCNs and their families in the design and implementations of these programmes. Creating inclusive research and clinical teams will aid in the development of transitional care programmes that are attentive to the needs of

children and youth with CCNs and their families and ultimately improve healthcare experiences and outcomes.

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