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Programmes to support transitions in care for children and youth with complex care needs and their families: a scoping review protocol

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ABSTRACT

Introduction Children and youth with complex care needs (CCNs) and their families experience many care transitions over their lifespan and are consequently vulnerable to the discontinuity or gaps in care that can occur during these transitions. Transitional care programmes, broadly defined as one or more intervention(s) or service(s) that aim to improve continuity of care, are increasingly being developed to address transitions in care for children and youth with CCNs. However, this literature has not yet been systematically examined at a comprehensive level. The purpose of this scoping review is to map the range of programmes that support transitions in care for children and youth with CCNs and their families during two phases of their lifespan: (1) up to the age of 19 years (not including their transition to adult healthcare) and (2) when transitioning from paediatric to adult healthcare.

Methods and analysis The Joanna Briggs Institute methodology for scoping reviews (ScR) will be used for the proposed scoping review. ScR are a type of knowledge synthesis that are useful for addressing exploratory research questions that aim to map key concepts and types of evidence on a topic and can be used to organise what is known about the phenomena. A preliminary search of PubMed was conducted in December 2018.

Ethics and dissemination Ethical approval is not required where this study is a review of the published and publicly reported literature. The research team's advisory council will develop a research dissemination strategy with goals, target audiences, expertise/leadership, resources and deadlines to maximise project outputs. The end-of-grant activities will be used to raise awareness, promote action and inform future research, policy and practice on this topic.

Strengths and limitations of this study

- This paper describes a scoping review protocol that will map the range of programmes that support transitions in care for children and youth with complex care needs (CCNs) and their families during two phases of their lifespan: (1) up to the age of 19 years (not including their transition to adult healthcare) and (2) when transitioning from paediatric to adult healthcare.
- This scoping review will help us to better understand the programmes that have been described in the literature, and to explore patient and health system outcomes that have been measured and described.
- This review will result in the information that may be used to inform decision-making, practice and future research related to transitional care for children and youth with CCNs.
- Our team involves a range of stakeholders, including patients, families, researchers, clinicians, librarians and decision makers, who will provide input and contribute to decision-making during all phases of this review.
- The review includes only published literature, and studies will not be assessed for methodological quality.

INTRODUCTION

Children and youth with complex care needs (CCNs) and their families experience many care transitions over their lifespan and are consequently susceptible to lack of coordination between services or gaps in care that can occur during these transitions. Failure to successfully transition to a new care setting has been shown to lead to higher utilisation of emergency departments,[1] negative experiences of care for all those involved,[2–5] poorer access to care,[1 3–5] fragmentation of care,[1 6–8] deterioration of health due to lack of follow-up visits[1] and highly demanding healthcare interventions.[9–11] Furthermore, an unsuccessful transition from paediatric to adult services can negatively impact education and workplace achievement, which can further lead to risk-taking behaviours associated with morbidity and mortality beyond childhood and throughout the lifespan.[1 12 13]

Transitional care programmes, which include one or more intervention(s) or

service(s) that target children, youth, or families with the goal of improving transitions in care for children or youth with CCNs,[14] are continually being implemented to respond to transitional care needs for children and youth with CCNs. However, this literature has not been examined at a comprehensive level specific to the purpose of this scoping review, which is to map the range of programmes that support transitions in care for children and youth with CCNs and their families during two phases of their lifespan: (1) up to the age of 19 years (not including their transition to adult healthcare) and (2) when transitioning from paediatric to adult healthcare.

BACKGROUND

Approximately 19% of children have special healthcare needs that can result in limitations in their daily lives,[15] with this number dramatically increasing over the past 40 years.[16] Advances in healthcare and technology have increased the lifespan and quality of life of many children with CCNs, allowing more children to live at home, be a part of their community and live into adulthood.[17] CCNs refer to 'multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis. They are individual and contextualised, they are continuing and dynamic and are present across a range of settings, impacted by healthcare structure' (Brenner, p1647).[18] Although these children constitute a small percentage of the paediatric population, they represent a cohort using a high volume of health-related services (eg, tertiary healthcare, social and educational),[19] requiring a coordinated effort by their family and care team.[20–22]

Family members can play a large role throughout transitions in care because they remain a constant source of support, they are actively involved in caregiving, and can act as advocates where necessary.[23] Caring for a child or youth with CCNs can require comprehensive home care, hospitalisations, unscheduled emergency room visits and countless appointments with specialists in and outside of primary care (eg, family physicians, physiotherapists and psychologists).[17 24] In addition, these children, youth and their families experience many transitions in care (eg, between providers, between settings and between stages of illness) over their lifespan. With this, they are consequently susceptible to gaps in care that can occur during these transitions.

A preliminary 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 and revealed that the topic of transitional care programmes (eg, from hospital to community, home care to respite care or from paediatric to adult healthcare) for children (0–19 years), youth (up to 25 years) and their families is a growing field. However, we found no evidence of systematic reviews or protocols that map the range of transitional care programmes for children/youth with CCNs and their families with the same objectives as this review. Recent reviews focus specifically on the barriers, needs, facilitators and/or outcomes of transitional care interventions.[25–30] Furthermore, other reviews are tailored to specific illness presentations and needs (eg, spina bifida and mental health needs),[4 31–38] specific transitions in care (eg, hospital to home) or solely on quantitative or empirical literature (eg, exclude qualitative studies).[20 26 29] For example, Watson and Warady targeted three specific health conditions (eg, cerebral palsy, autism spectrum disorders and diabetes) for their scoping review.[39] Generalisable findings regarding transitional care programmes for children and youth with CCNs and their families have been difficult to extract due to their narrow focus on specific populations; heterogeneity of the interventions and outcome measures and limited descriptions of transitional care programmes. This field is quickly expanding with new evidence becoming available each year. A broad level scoping review is required to begin to make sense of this heterogeneous body of the literature. Mapping the current evidence regarding transitional care programmes for children and youth with CCNs and their families will assist with identifying gaps and create direction for future systematic reviews and research.

REVIEW OBJECTIVES

The objectives have been divided into two areas of transition programmes for children and youth with CCNs. The first objective is to map the range of programmes that have been reported in the literature to support children 19 years of age and under with CCNs and their families during transitions in care, not including their transition to adult healthcare. This would include, for example, transitions from hospital to home, home to school and home care to respite services. The second objective is to map the range of programmes that have been reported in the literature to support youth with CCNs and their families specific to their transition from paediatric to adult healthcare.

REVIEW QUESTIONS

1. What programmes have been reported in the literature to support children 19 years of age and under with CCNs and their families during transitions in care, not including their transition to adult healthcare?
2. What programmes have been reported in the literature to support youth with CCNs and their families as they transition from paediatric to adult healthcare?

METHODS

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (ScR).[40 41] ScR are a type of knowledge synthesis that are useful for addressing exploratory research questions that aim to map key concepts and types of evidence on a

topic and can be used to organise what is known about the phenomena.[40–42] Given the current state of the literature in this area, a scoping review is needed to better understand the range of transitional care programmes that have been described in the literature, and to explore patient and health system outcomes that have been measured and described. This would result in an organising framework that could help summarise the range of research activities in the field and identify gaps and future research questions.

Briefly, the steps within the JBI scoping review framework are: (1) defining and aligning the objective/s and question/s; (2) developing and aligning the inclusion criteria with the objective/s and question/s; (3) describing the planned approach to evidence searching, selection, extraction and charting; (4) searching for the evidence; (5) selecting the evidence; (6) extracting the evidence; (7) charting the evidence; (8) summarising the evidence in relation to the objective/s and question/s and (9) consultation of information scientists, librarians and/or experts throughout.[41] Peters *et al* state that ScR begin by developing an a priori protocol, and have a broad scope related to their inclusion criteria which correspond with the target population, concept and context.[41] This information is presented below.

Prior to commencing the review, we will establish an Advisory Council comprised of key stakeholders, such as researchers, librarians and patients (at least one from each participating province), to oversee project milestones. Our team has adopted the term patient to refer to individuals with personal experience of a health issue and informal caregivers.[43] Given our focus on children and youth and their families, we have engaged parents who have a child with CCNs as members of our research team, hereafter referred to as patients for clarity.

Search strategy

The search strategy will aim to locate published articles. An initial limited search of PubMed and CINAHL was undertaken in December 2018 to identify articles on the topic of interest. The concepts identified in titles and abstracts of relevant articles, and the index terms used to describe the articles were leveraged to develop a full search strategy in each of the included databases (see online supplementary appendix I). To ensure that all relevant literature is identified, the search strategy will undergo the Peer Review of Electronic Search Strategies Guideline Statement.[44] Two library scientists will complete this process, with ARH developing the initial search strategy and SM completing the peer-review process. The search strategy, including all identified keywords and index terms, will be adapted for each identified database. The reference list of all articles selected for inclusion in the review will be screened manually for additional articles of interest.

Information sources

The databases to be searched include PubMed, CINAHL, ERIC, PsycINFO and Social Work Abstracts. Given the broad and international scope of this review, we will not include a search of the grey literature. This will be the focus of a future study.

Inclusion criteria

Participants: This review will consider all the literature on children and youth with CCNs (0–19 years) who have experienced transitions in care prior to transitioning from paediatric to adult healthcare, as well as youth who are engaged in transition programmes to support their transition from paediatric to adult healthcare. Families of children or youth with CCNs will also be included (eg, parents, guardians or other members caring for a child or youth). CCNs refer to 'multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis' (Brenner, p1647).[18] Children and youth with specific health conditions as well as a broader paediatric population with CCNs will be included. Articles will also be included if the target population is being cared for under paediatric care services. Programmes or services that are designed to support children and youth without CCNs and individuals residing in long-term care facilities will not be included.

Concept: The concept of interest for this review is transitional care programmes. For the purpose of this review, transitional care will involve any movement of the child/youth and family between care settings (home to school/childcare and vice versa), care providers (primary care to specialised clinic) or services (home care to respite care; paediatric to adult services). Articles that do not explicitly state their intent to support transitions in care will be excluded. A programme will be defined as one or more interventions or services that target children, youth or their families with the goal of improving transitions in care for children or youth with CCNs. Programmes may be delivered in person or by distance by either a trained or an untrained provider (eg, lay persons).

Context: This review will consider articles where transitional care programmes are delivered anywhere in the child/youth's home community (eg, child/youth's home, school/childcare), neighbouring communities (eg, for children/youth who live in remote and rural areas) or primary hospital/institution (eg, primary care provider's office and tertiary care facility). Articles describing transitional care programmes that are delivered by a range of different modalities (eg, e-health and clinic based) will be considered for inclusion. However, literature sources describing programmes that are delivered exclusively within a hospital setting (such as intrafacility handover) with no community component will not be included. There will be no geographic or temporal limitations placed on this review to allow for the examination of any potential trends in transitional care programmes across time.

Types of sources

This scoping review will consider all types of published literature sources, including experimental and quasi-experimental study designs, such as randomised controlled trials, non-randomised controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case–control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies. Articles using qualitative research designs will also be considered, including but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research. Text and descriptive papers will also be considered for inclusion in this scoping review if sufficient information is provided to discern programme characteristics. Systematic, scoping and literature reviews will not be considered for inclusion in this review; however, the reference lists of relevant reviews will be hand searched for additional articles. Articles published in English and French will be included.

Study selection

Screening for study selection will occur in two stages: title/abstract and then full text. Prior to the screening, all identified citations will be collated in Mendeley to correct citation errors and remove duplicates. All citations will be uploaded into Covidence Systematic Review Software and any undetected duplicates will be removed.[45 46]

To ensure our inclusion and exclusion criteria are uniformly applied, the initial screening will be piloted by two independent reviewers using 5–10 references from our initial search followed by a consensus meeting. On final adjustments, the official title and abstract screening will begin. Titles and abstracts will be screened by two independent reviewers for assessment against the inclusion criteria for the review. For the second stage of screening, all potentially relevant articles identified during the title and abstract screening will be retrieved in full text to be imported into the Covidence Software.[45] The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. The reasons for exclusion of full-text articles will be recorded and reported. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion. If consensus cannot be achieved, a third reviewer will be consulted. The results of the search will be reported in full, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for ScR and presented in a PRISMA flow diagram.[42 47]

Data extraction

Data will be extracted from the articles included in this scoping review by two independent reviewers using a data extraction tool developed by the research team. Extracted data will include specific details about the population, concept, context, study methods and key findings relevant to each of the review objectives. A draft extraction table is provided (see online supplementary appendix II). Articles will be sorted and organised under the two transitions of interest as outlined in our research questions: (1) transitions in care up to the age of 19 years and not including transitioning to adult healthcare and (2) transitions in care from paediatric to adult healthcare services. The data extraction table will be tested by two reviewers with three articles to ensure all relevant information is being captured, followed by a meeting to discuss any modification and revision deemed necessary. Other information that may be deemed relevant by the research team will also be extracted. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion to achieve consensus. If consensus cannot be achieved, a third reviewer will be consulted to make the final decision. Authors of included articles will be contacted to request missing or additional data, where required.

Data presentation

The results of this review will be presented separately by review objective. For each objective, a narrative summary will accompany the tabulated results and will describe how the data relate to the review's overall objectives and questions. This will include the following categories: article identification (eg, author/year); article characteristics (eg, objective and population); programme design (eg, outcomes and focus of transition) and the results (eg, barriers and enablers). We will use the Theory, Model and Framework Comparison and Selection Tool to identify the appropriate framework(s) to organise and categorise extracted intervention and programme descriptions.[48] The data that are presented in the final report will be reflective of the information collected using the data extraction tool (online supplementary appendix II). Further, all information for this scoping review will be presented following the PRISMA-ScR Guidelines.[42] We also used the PRISMA-P reporting guidelines to promote transparency and to ensure that we addressed all the components that are applicable for a scoping review.[47]

Patient and public involvement

Our research team includes a range of stakeholders who will contribute to decision-making during all phases of this review. We will engage a range of stakeholders (beyond our Advisory Council) to provide input on our preliminary findings. This process will begin by identifying key authors from included articles and inviting them to comment on our preliminary findings, either during a telephone interview or by email. Next, a consensus meeting will be held with important knowledge users (eg, patients, clinicians and government) to solicit initial feedback on our findings to provide greater context and understanding of the data. Feedback from our research

experts and knowledge users will be incorporated into our final report.

ETHICS AND DISSEMINATION

Ethical approval is not required where this study is a review of the published and publicly reported literature. In terms of dissemination, the research team's advisory council will develop a research dissemination strategy with goals, target audiences, expertise/leadership, resources and deadlines to maximise project outputs. The end-of-grant activities will be used to raise awareness, promote action and inform future research, policy and practice on this topic. Examples of activities include presenting two conference presentations per objective (eg, at the Canadian Association for Health Services and Policy Research conference and the North American Primary Care Research Group conference); presenting to the Canadian Pediatric Society; sharing findings on the JBI database of systematic reviews and implementation reports, publishing one open access publication per objective (eg, *BMC Public Health* journal); participate in a consensus meeting, initiated through the Advisory Council, share findings through our websites and social media channels and policy briefs.

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Contributors All authors (SD, JAC, SB, AL, ED, RA, AER, SM, ARH and KB) contributed to the project including the design, preparation and editing of the scoping review protocol. SD, SB and AER developed the initial draft of the protocol and, after several iterations with significant input from authors JAC, AL, ED, RA, ARH, SM and KB, all team members approved the final manuscript that was submitted for publishing. In consultation with the research team, an experienced librarian (ARH) developed the search strategy for the scoping review and a second librarian (SM) conducted a peer review of the search strategy. All authors will contribute to the data synthesis and writing of the final scoping review.

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Competing interests None declared.

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