



BMJ Open School reintegration following hospitalisation for children with medical complexity and chronic disease diagnoses: a scoping review protocol

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ABSTRACT

Introduction Schools play a significant role in children's social, emotional and intellectual well-being. For children with medical complexity (CMC) and chronic disease diagnoses (CDD), an absence from school due to prolonged hospitalisation places them at risk for greater social exclusion and poorer academic outcomes than their healthy counterparts. Processes that support the school reintegration of children with complex and chronic medical conditions currently lack consistency and identified evidence-based practices. This scoping review aims to integrate the relevant literature on current reintegration procedures as well as assess stakeholders' perceived challenges related to children with CMC and CDD's return to school following hospitalisation. Finally, information will be synthesised regarding parental and child involvement in reintegration strategies.

Methods and analysis The current scoping review follows the five-stage framework proposed by Arksey and O'Malley (2005). The search syntax will be applied in Medline, Web of Science, PsycInfo, Education Resource, ERIC, CINAHL and SocIndex. Peer-reviewed journal articles will be included without the restriction of publication year or language. However, only children and adolescents aged 4–18 with CMC and CDD, who have been out of school for 2 weeks or more and reintegrated into a non-hospital school setting will be included. Articles will be screened by two authors based on the outlined eligibility criteria. Data will be summarised qualitatively and where applicable, visualisation techniques such as tables, graphs and figures will be implemented to address approaches, strategies and outcomes related to reintegration to school following hospitalisation.

Ethics and dissemination The current study comprises available publications and does not collect primary data. For this reason, ethics approval is not necessary. The results of this scoping review will be prepared and submitted for publication in a peer-reviewed journal and presented at future conferences to key stakeholders focusing on educational accessibility and inclusion.

BACKGROUND

Children's development and well-being are largely influenced by their environment^{1 2} and globally, over one billion children spend the majority of their day attending either a

Strengths and limitations of this study

- Novel comprehensive review approach reaching literature not included in previous reviews.
- The inclusion of articles will be published from English speaking journal articles.
- This review is limited by the information shared by the authors in terms of barriers and facilitators of school reintegration programmes.

primary or secondary school.³ Therefore, investigating the experiences of children in schools has important implications for research and policy. Research has shown that attending school leads to improved emotional regulation and the development of prosocial behaviours, likely attributable to the opportunities for social and intellectual stimulation.⁴ Time out of school, in contrast, has shown to have detrimental effects on children's mental health, well-being and educational outcomes.⁴ Furthermore, children who are absent from school due to illness are at an increased risk of experiencing negative outcomes.⁵

Numerous studies have addressed the importance of reintegration following hospitalisation of children. For example, Clemens and colleagues found that adolescents who required specific accommodations or modifications to schedules to perform optimally, faced stigma from peers and that these social challenges are best addressed proactively through the assignment of a school re-entry counsellor who can liaison the reintegration between hospital and school.⁶ Research has disproportionately focused on the importance of reintegration strategies for children with psychological disorders and a limited number of physical conditions, such as cancer, burn recovery and traumatic/acquired brain injury.^{6–11} Additional research attention is required with children who have

a chronic illness and/or medical complexity because they are more likely to require adequate planning and supportive processes for school reintegration.⁵

In 2018, there were 171 786 hospitalisations among Canadians under the age of 18, alone.¹² Of these children, there is a growing proportion who are characterised as children with medical complexity (CMC) who live with greater than one significant chronic health problem that, by definition, involves multiple organ systems resulting in multifaceted dysfunction, a significant need for healthcare services and, often, dependence on medical technologies.^{13–19} Collectively, research suggests that CMC medical conditions cause them to miss greater than 15 days of school within one academic year.⁵ Another classification of children at risk of pervasive hospitalisation is children with chronic disease(s) diagnoses (CDDs). A major definition for CDDs is outlined by Wijlaars *et al* as ‘any health problem requiring clinical follow-up for >12 months in 50% or more of cases’.²⁰ Children with CDDs have almost a 35% increased risk of precarious social and academic development.²¹ The origin of these risks that children with physical health conditions experience are distinct from children with developmental disabilities and merit separate investigation and solutions²² as hospitalisation and time absent from school has unique implications for children’s psychosocial well-being and developmental outcomes.²³

For example, CMC and CDD use medical technologies for their survival and health management. An important consideration for this population is the degree of self-management CMCs possess and to what extent educators and school administrators can be expected to play a role in the management of CMCs’ ongoing health management needs. One study reviewed literature on CMC by applying The Pediatric Self-Management Model,^{18 24} which can be used to ascertain patients’ ability to manage their own care needs through greater understanding of their condition(s). Important predictors for improved adjustment to new medical technologies were identified, such as whether families of CMC viewed the technology as a ‘puzzle’ to solve versus a burden.¹⁸ Given that most educators of CMC will not be trained to operate various medical technologies, this research highlights the importance of having school reintegration plans that are tailored to each student’s needs and circumstances. These plans should consider the level of ongoing care management and the degree to which the child can handle their care independently.

A preliminary scoping review helped identify relevant variables in the assessment of hospital-to-home transition for CMC.¹⁹ The investigators elected to assess stakeholder perceptions on the usefulness of transition plans since while there are numerous benefits of transition of care plans, it is possible that stakeholders find them less effective in the CMC population given the regularity and unpredictability of rehospitalisation. An important finding from this scoping review was that all included studies concluded that transition of care plans are useful in optimising communications between caregivers and healthcare providers.¹⁹ Next steps could include

determining if the purported improved communication extends to involved educators in this study.

The impetus for this scoping review is based on a lack of national school reintegration programmes or standards for CMC. There are potentially many reasons for this discrepancy. One reason may be more practical, such as the lack of provincial funding for such an initiative. Other factors though shed light on the complexity of such an undertaking. The range of medical conditions and circumstances for which school-aged children might require hospitalisation cannot be universally addressed in a singular programme or protocol. A major priority for children who have been hospitalised for an extensive period of time is a successful school reintegration. The physical and psychological effects of hospitalisation will vary from child to child creating individual challenges to reintegration. For example, a child who was hospitalised once carries the burdensome trauma attached to that event as well as the challenge of learning all of the curricula they missed during hospitalisation. Nevertheless, if such a student is otherwise healthy, it is unlikely that the student will face further hospitalisations. In this case, school reintegration will likely be a top priority for the student’s educational and health teams and be a more straightforward process. In children with chronic and recurring illnesses though, there is added complexity in predicting future hospitalisations and reintegrations as well as the additive trauma and growing disruptions to a child’s education from serial hospitalisations. Previous research has demonstrated that CMC are frequently hospitalised. In fact, some research has suggested that the 30-day hospital readmission rate for CMC was nearly 24%.¹⁹ This further supports the aims of this scoping review which will inform school reintegration protocols for this unique population.

While there is existing literature on the reintegration of students for certain causes for hospitalisation, such as burns and cancer,^{9 10} the current literature does not encompass the range of CMC and CDD and their unique experience. These complexities also extend to academic support and gauging who is responsible for planning and executing the transition. An important tenet of school reintegration identified in the psychological literature is the executive coordination among all relevant medical and educational professionals providing support to children.^{6 8 23}

Some children with complex educational needs have academic supports in place involving teaching staff who have the training to work with such students.²⁵ By contrast, a child with a physical illness, but no learning or intellectual disabilities, may return to their standard learning environment without the required resources to make their return seamless. Another explanation for the lack of a comprehensive school reintegration programme is that medical advances have outpaced the stakeholders involved in the design of such a programme. Currently, over 80% of children with cancer will survive and the survival of certain individual cancers is far higher

than that rate.¹⁰ In the past, it may have been feasible for healthcare providers and educators to ignore the relevance of school integration when many critically ill children did not survive.¹⁰ For this reason, it is timely to advocate for best practices that support children's lives post-hospitalisation.

While there have been efforts to design school reintegration programmes at a local or individual level, their results and success have seldom been assessed cumulatively; a necessary step to delineate the evidence to inform a broader reintegration programme. Canter *et al* conducted a systematic review in 2012 to assess school re-entry in children with chronic illness. However, the final analysis only featured content on four medical conditions and 75% of the papers were solely focused on cancer.¹⁰ Other research has shown that school reintegration has been oversaturated with the assessment of patients with cancer, burns and other major causes of illness.^{9–11 23} This has created a notable gap in the literature on school reintegration for patients with other, less-studied conditions, such as CMC. To address this knowledge gap, our investigation will examine this by expanding the inclusion criteria with a focus on CMC.

METHODS AND ANALYSIS

Protocol design

The current protocol was developed using the methodological framework proposed by Arksey and O'Malley (2005)²⁶ and further examined by Joanna Briggs Institute.²⁷ In addition, this protocol follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review (PRISMA ScR; online supplemental appendix 1). The study search will be conducted in November 2021 and the project is expected to be completed in June 2022.

Stage 1: identify the research question

An environmental scan of the literature was conducted to inform our research questions. For the purpose of this review, we will focus on children (4–18 years) following discharge who reintegrate into an out-of-hospital school setting.

Based on the initial exploration of the literature, the following research questions were developed:

1. What are current practices of reintegration into the school setting of hospitalised children with CMC and CDD? When are these practices typically applied (ie, before and/or during hospitalisation)? Which practices have been effective in CMC and CDD if any?
2. How is school reintegration planned and what steps are taken to optimise the execution of school reintegration plans? How do stakeholders manage follow-up of reintegration plans?
3. What are the reported barriers to reintegration into the school setting of hospitalised children with CMC and CDD?

4. Who is responsible for the reintegration planning and implementation process? Who are the key stakeholders?
5. Are parents involved in reintegration planning and/or implementation? What role do parents play?
6. Are children involved in reintegration planning and/or implementation? What role do children assume? Based on a child's right to participate in decisions, how are they involved in the planning, execution and follow-up stages?

Stage 2: search for relevant studies

Following Arksey and O'Malley's²⁶ framework, the second stage of the scoping review aimed to identify and develop inclusion criteria to be used when selecting studies for the review. These criteria helped inform the search syntax.

The scoping review will include published studies from the following databases: Medline, PsycInfo, Web of Science, Education Resource, ERIC, CINAHL and SocIndex. Reference lists of relevant studies will be checked to ensure that all applicable articles will be included.

Based on the initial exploratory research, the following eligibility criteria were implemented:

- ▶ Type of publication: journal articles.
- ▶ Publication year: any.
- ▶ Language: all.
- ▶ Study population: children and adolescents, aged 4–18 years.
- ▶ Types of articles: primary studies, systematic reviews, meta-analyses, scoping reviews, evidence maps, rapid reviews, literature reviews, evidence syntheses, reviews of reviews, narrative reviews and critical reviews.
- ▶ Setting: out-of-hospital school settings.
- ▶ Time away from hospital: 2 weeks or more.⁵

An academic librarian trained in review strategies was consulted regarding the most appropriate subject heading terms and how to modify them across databases. The search syntax for each database was finalised and included terms concerning the most frequently studied medical conditions such as 'Juvenile', 'Burns', 'Neoplasms', 'Arthritis', 'Congenital' and 'Hereditary'. Broader terms were applied to capture other conditions such as 'Neonatal disease', 'Abnormalities', 'Exceptional', 'Disease', 'Disorder', 'Serious illness', 'Complex medical', 'Chronic disease', 'Multiple chronic conditions', 'Medical complexity', 'Surgery', 'Traumatic', 'Paediatric' and 'Paediatric' were included. To search for the study population, the terms 'High School', 'Middle School', 'Preschool', 'Kindergarten', 'Elementary School', 'Nursing School', 'Day care', 'School' and 'Education' were included. To search for research involving key stakeholders in school reintegration for CMC, the terms 'Student', 'Patient', 'Doctor', 'Physician', 'Nurse', 'Occupational Therapist', 'Speech Therapist', 'Speech Language Pathologist', 'Child and Youth Workers', 'Teacher', 'Principal', 'Early Childhood Educator', 'Teaching Assistant', 'Social Worker', 'Psychologist', 'Multidisciplinary', 'Interdisciplinary', 'Cross-professional', 'Collaboration', 'School Liaison',

'Hospital Educator', 'Child Life', 'School Nurse', 'Parent', 'Guardian' and 'Caretaker' were included. Finally, reintegration and transition terms such as 'Re-entry', 'Reintegration', 'Transition', 'Return to' and 'Education' were included. Articles will then be retrieved from each database and imported into Covidence, the online systematic review platform. For an example of the search syntax for reintegration and the stakeholders applied in the database Medline, please see online supplemental appendices 2 and 3, respectively.

Stage 3: selection of relevant studies

The third stage of Arksey and O'Malley's²⁶ framework aims to identify the selection of relevant studies. Following the consolidation of articles generated from the searches across databases, duplicates will be removed. Two members of the team (SB, CS) will independently screen the titles and abstracts of all articles to determine which articles meet the eligibility criteria devised in the second stage. Following the abstract screening, full texts will be retrieved for full-text review. Disagreements

Table 1 Variables to chart

Main category	Subcategory	Description
Authors		
Title		
Year		
Journal		
Country		Country data collected from in the study
Age of children	Mean age	The arithmetic average of all children included
	The age range	Difference between oldest and youngest child
Number of children		Total number of children included in the study
Grade		School grade
School type		Type of school child is attending (ie, out-of-hospital school, public school, private school)
Classroom type		Type of classroom children were integrated into
Diagnosis		The medical diagnosis of a child
Length of diagnosis		How long the child has had the diagnosis
Reason for absence		The reason that child had to be away or postponed from attending school
Limitations/accommodation		Functional limitations and/or required accommodations on reintegration into school
Length of absence	Length of hospitalisation	Length of time child was removed from school
	Length between hospital and school	Length of time between hospitalisation and reintegration (ie, time spent at home and details pertaining to homebound instruction if pertinent to the student's reintegration plan)
	Number of hospitalisations	Number of hospitalisations a student has experienced (or is anticipated to experience) over the past academic year causing absence from school for 2 weeks or longer each time
Integration procedure	Professional facilitating integration	The professional members of the team responsible for the integration of the child (ie, child-life, paediatrician, social worker)
	Length of integration	Length of time integration into school took place
	Process of integration	Procedure or process of integration (ie, planned before or implemented during hospitalisation)
	Child involvement	Child's role in their integration into school and steps taken to ensure a patient-centred approach
	Parent/caregiver involvement	Parent/caregiver's role in their child's integration into school
Outcome of integration	Reintegration plan	Details on accommodations implemented to support school reintegration including if the plan address all accommodation needs and if the plan involved the use of interactive technologies (ie, robots, tele-education and so on)
	Type of outcome investigated	Determinant(s) of successful integration (ie, child well-being, academic success)
	Description of outcome	The information provided on the outcome of integration as defined in the study
	Barriers to integration	Reported barriers to integration
	Key facilitators of integration	Key aspects that enhanced the success of integration into the school setting including incorporating student perspectives into the reintegration plan

about study eligibility will be discussed between the two reviewers until a consensus is reached. If a consensus is unable to be reached, a third party will be consulted (DK, KD). Study selection is reported using a PRISMA ScR flow chart taken from Tricco and colleagues (2018) and will be updated once each stage is complete.²⁸

Stage 4: Charting the data

Based on the preliminary investigation of the data, 16 categories have been identified that will be used for the literature screening when determining the inclusion of the articles (table 1). For each article, descriptive information (ie, title, author, journal and year of publication) and type of publication will be extracted independently by two authors (SB, CS). Furthermore, participant characteristics will be collected. Information regarding the process and barriers to reintegration will be tabled. The framework will be pilot tested by two authors on a sample of the study to ensure coding is extracted consistently. If there are discrepancies, then the framework will be revised accordingly. Questions related to the extraction procedure will be discussed and disagreements will be resolved through team consultations.

Following training and agreement by the team members, independent reviews of the articles and extraction will occur. To ensure inter-rater reliability, a sample of 20% of the articles will be double reviewed and discussion will occur between the two reviewers. Discrepancies in extracted data will be discussed and if consensus cannot be reached a third party will be included.

Stage 5: Summarising the results

Following the extraction of data, statistical and thematic analysis of results will be conducted to summarise the current literature pertaining to school reintegration among CMC. In particular, the common challenges within school reintegration and barriers to successful reintegration will be presented. Similarly, constituents of school reintegration following hospitalisation and evidence-based protocols will be discussed and assessed per feasibility for implementation. Important stratification of results (by age/grade, diagnosis and school characteristics) will be performed to ensure that the suggestions for reintegration guidelines are accurate and effective. Furthermore, the identification of effective tenets of reintegration will also expose domains that remain understudied and merit continued investigation. The results will be presented through a combination of descriptive analysis, tables, charts, figures and other visual tools as needed.

Ethics and dissemination

The current study comprises available publications and does not collect primary data. Therefore, this study does not require formal ethics approval from the Research Ethics Board. The results of this scoping review will be prepared and submitted for publication in a peer-reviewed journal for readership by key stakeholders (eg,

patients, parents, teachers, physicians, social workers, child and youth workers, nurses, child life specialists and speech language pathologists) and presented at future conferences focusing on educational accessibility and inclusion of CMC. Furthermore, this scoping review will form the basis of identifying evidence-based practice for school reintegration and policy and future research initiatives.

Patient and public involvement

No patients were involved in the preparation of this scoping review protocol but will be engaged during future stages of this research. Experts in the field were involved in the development of research questions and outcomes, further to consultation with their interdisciplinary colleagues who work with CMC and CDD and their families. To ensure patient and family perspectives are highlighted, we have included child and family involvement in reintegration plan formation. The authors plan to disseminate the results to patients and families by sharing the results with local paediatric hospitals, school authorities, public and private schools that serve CMC and CDD, school bridging programme practitioners and preservice educators. This scoping review is the first step to form a best practice guideline for school reintegration following hospitalisation.

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