



Review

Strategies to support transitions from hospital to home for children with medical complexity: A scoping review



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ABSTRACT

Background: Children with medical complexity constitute a small but resource-intensive subgroup of children with special health care needs. Their medical fragility and resource-intensive needs put them at greater risk for inadequate transitions from hospital to home-based care, and subsequent adverse outcomes and hospital re-admissions.

Objective: This scoping literature review was conducted to map empirically researched interventions, frameworks, programs or models that could inform or support the transition from hospital to home for children with medical complexity.

Design: We conducted a scoping review using the methodology outlined by the Joanna Briggs Institute.

Data sources: In consultation with an experienced librarian, we searched PubMed, EMBASE and CINAHL for English-language articles published from the date of origin to February 2016. We also hand-searched four high impact journals and searched the reference lists of relevant articles.

Review methods: Two reviewers independently screened the literature results according to inclusion criteria. Empirically designed studies that targeted children < 18 years old who were specifically defined as medically complex or fragile and transitioning from acute care to home were included. Data were extracted using a predefined tool. Quality appraisal of the articles was conducted using the mixed methods appraisal tool (MMAT). Thematic analysis was carried out to identify existing patterns or trends in the included studies.

Results: Of the 2088 abstracts retrieved, 14 studies met the inclusion criteria. Following analysis, we identified three major categories of interventions: Comprehensive care plans (n = 3), Complex Care Programs (n = 8) and Integrated delivery models (n = 3). The overall quality of included studies was moderate, with 21% (n = 3) scoring 0.25, 29% (n = 4) scoring 0.50, 43% (n = 6) scoring 0.75, and 7% (n = 1) scoring 1.0.

Conclusions: In the absence of evidence-based guidelines to ensure adequate transitions from hospital to home for children with medical complexity, identification of potential models to support this transition is imperative. We identified interventions, frameworks, models and programs in the literature that might inform the development of such guidelines; however, there is a need for consensus around the definition for children with medical complexity and the limited number of these studies and lack of high quality of evidence signals the need for further research to improve the transition from hospital to home and ultimately, improve patient and family outcomes.

What is already known about the topic?

- Children with medical complexity are a small but resource intensive population within the health care system.
- Their medical fragility and resource-intensive needs put them at greater risk for inadequate transitions from hospital to home-based care, and subsequent adverse outcomes and hospital re-admissions

What this paper adds?

- We identified a limited number of empirical studies examining interventions, frameworks, models, or programs to inform or support the transition from hospital to home for children with medical complexity
- These studies highlight the importance in developing and implementing a nursing care coordinator role to assure successful

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transitions from hospital to home for these children.

- This review identifies the development of integrated solutions for this population encompassing family-identified needs, and supporting positive outcomes along the continuum from hospital to home and community based care.

1. Background

Children with medical complexity have been a population of interest for both research and policy development over the past number of decades. This is largely due to advances in medical treatment allowing children with congenital complications and chronic conditions to live longer (Cohen and Friedman, 2012). The impact of children with medical complexity on the health care system is difficult to quantify due in part to the multiple terms and definitions that exist in the literature, including: children with complex chronic conditions, medically complex or fragile children, children with complex medical needs, children with complex health conditions, and children with medical complexity (Cohen et al., 2011). Cohen et al. (2011) proposed a definitional framework that outlines four broad characteristics common to this population: 1. Needs (the substantial family-identified health care service needs); 2. Chronic conditions (1 or more severe/medically fragile conditions); 3. Functional limitations (the variety of physical limitations due to the condition); 4. Health care use (the high use of health care resources). To date, it is unclear how this definitional framework has been used across research initiatives for this unique population.

Children with medical complexity are frequently hospitalized, and require substantial resources (Cohen et al., 2012a,b, 2011; Dewan and Cohen, 2013). A retrospective study of hospital admissions for children in the United States (US) showed that 10.1% of admissions in 2006 were for children with complex chronic conditions (Simon et al., 2010). These admission account for over 25% of paediatric hospital days, over 37% of paediatric hospital charges, and 43% of deaths (Simon et al., 2010). Additionally, children with complex chronic conditions are often dependent on medical technologies to sustain life, and account for up to 92% of procedures related to technology dependence (Simon et al., 2010). Hospital discharge data from Ontario, Canada, identified that although children with medical complexity account for only 0.67% of children in Ontario, they account for almost one third of the entire province's child health spending (Cohen et al., 2012a,b). Thirty-day hospital readmission was as high as 23.7% for children with multiple complex chronic conditions and technology dependence, and accounted for 27.2% of costs post discharge (Cohen et al., 2012a,b). The same study found that 36% of children with medical complexity receive home care services in Ontario, Canada, and these children receive care from a median of 13 outpatient physicians and subspecialists (Cohen et al., 2012a,b).

Health policies over the last few decades have supported the shift in location of care from hospital and institutional settings to primary care in the community for children with chronic health care needs (Kirk, 1999). As a result, children with complex chronic conditions with intensive and specialized health care needs are frequently cared for in the home. In fact, hospitalization data suggest that as many as 89% of patients with significant complex chronic conditions are discharged to home (Berry et al., 2013). This complex care provision outside of the hospital setting has serious implications for families, and community health care providers (Kirk, 1999). These implications can include emergency department visits, which frequently result in hospital admission or direct admission to paediatric intensive care units (O'Mahony et al., 2013).

Due to the multiple individuals involved in the care for this population including parents, caregivers, and health care providers (Cohen et al., 2012a,b), multi-faceted and interdisciplinary approaches may be essential in improving the transition from hospital to home for this high-resource population. However, the literature regarding the

transition from hospital to home for this population is widely dispersed and to our knowledge has not previously been synthesized. The objective of this scoping review is to identify and characterize the existing empirical evidence for interventions, models, frameworks or programs that inform or support the transition process from hospital to home for children with medical complexity.

2. Methods

Scoping reviews allow for the examination of broad areas of interest “to identify gaps in the evidence, clarify key concepts, and report on the types of evidence that address and inform practice in a topic area” (Joanna Briggs Institute, 2015). We chose this methodology as we sought to identify and characterize all forms of the empirical literature on interventions, frameworks, programs or models that could inform or support the transition from hospital to home for children with medical complexity. We followed the Joanna Briggs Institute Methodology for Scoping Reviews to conduct this scoping review of the existing literature (Joanna Briggs Institute, 2015).

2.1. Research question

What interventions, models, frameworks or programs have been empirically evaluated to inform or support the transition process from hospital to home for children with medical complexity?

2.2. Data sources and search strategy

An experienced librarian aided in developing and implementing the search strategy in three electronic databases of PubMed, EMBASE and CINAHL (see Supplementary file). The search strategy was supplemented by a hand search of four high impact journals, JAMA Pediatrics, Health Policy and Planning, Journal of Pediatrics and BMJ Quality and Safety. These journals were chosen to capture an international scope of published literature and cover a diverse range of medical topics, patient safety, and quality improvement research. The previous five years of publications (February 2011–February 2016) were screened by title and abstract for relevant articles. Further, the reference lists of literature review papers and included articles were scanned for additional articles.

2.3. Eligibility criteria

Only studies with an empirical design (qualitative, quantitative, or mixed methods) were included in this scoping review. The population of interest included children less than 18 years of age specifically defined as medically complex or fragile. Articles were reviewed if they included an intervention, model, framework, or program (hospital or community-based) that aimed to inform or support hospital to home transitions.

Excluded from review were single case studies, commentaries or reports that did not have an evaluative component in their design. Review articles were also excluded, but bibliographies of relevant reviews were scanned for potential inclusion. Studies related to transitions of complex paediatric patients within or between inpatient facilities were excluded, as were those related to transitions from paediatric to adult care.

We excluded studies that addressed transitions for specific subsets of the children with medical complexity population with defined illness presentations (i.e. pre-term infants, children with cardiovascular illness), as the aim of this scoping review was to capture existing interventions, models, frameworks, or programs that are applicable to the broader medically complex population. We also excluded studies on children with special health care needs as they encompass a broader range of children with chronic conditions and our scope focused specifically on medically complex or fragile children.

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