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Scoping Review on Transitions in the Context of Pediatric Palliative Care

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Abstract

Background: Children with complex and chronic conditions receiving palliative care will likely experience many transitions during their life and their treatments. Transition periods for children with life-limiting conditions and their families can be bewildering and highly anxiety-inducing. However, clinical observations seem to point to a more heterogeneous care offer, including a lack or discontinuity of services, at the expense of their quality of life.

Objective: This paper aims to establish a portrait of the existing literature and identify research gaps on the multiple transitions experienced by this population.

Design: A scoping review is provided, following a PRISMA protocol. MEDLINE, PubMed and CINAHL were consulted. The search strategy is based on three key concepts: (1) palliative care/complex condition, (2) child/adolescent, and (3) transition. Articles were screened with the help of Covidence.

Results: A total of 72 articles are included for analysis. The aimed population is either identified by age group or by medical status. Respondents are most often parents rather than the children themselves. Transitions include: reaching adulthood, changes in care environment, changes in medical status, and school integration.

Conclusion: The discussion notices a definitional murkiness about transitions and highlights the fact that the multifaceted and complex nature of transition over time is largely ignored. New research should involve a diversity of participants and include children's voices. Recommendations include clearer concept definitions, health care policies that adopt an ecosystemic approach, and professional training in the systemic family approach in palliative care.

Keywords: pediatric palliative care; transition; scoping review; children with complex condition

Introduction

Globally, among the 21 million children in need of a palliative approach around the world, "an estimate of more than 8 million would require some degree of specialized children palliative care."¹ A study from 2015 suggested that in Canada 9.8 out

of every 10 000 children might benefit from pediatric palliative care (PPC) services.² Moreover, in 2016, based on a population of 7 826 123 children aged 19 years or younger, the proportion who received specialized PPC was 18.3%.³

The World Health Organization considers palliative care for children (or PPC) as "the active total care of the child's

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body, mind, and spirit, and involves giving support to the family.”⁴ The Quebec standards of practice for PPC are inspired by the Association for Children with Life-threatening or Terminal Condition and their Families (ACT). The ACT uses the following definition for PPC:

Pediatric palliative care is active, comprehensive care, encompassing physical, psychological, social, and spiritual dimensions. The aim of palliative care is to help maintain the best possible quality of life for the child and to offer support to the child’s family; this includes relief of the child’s symptoms, respite services for the family and care up to the time of death and during the bereavement period. Bereavement care is part of palliative care, whatever the cause of death, including trauma and loss in the perinatal period.⁵

PPC includes end-of-life care, but not exclusively. The goal of PPC is to both offer relief for symptoms of disease, and to optimize quality of life, both for children and their family members. Although curative treatments may not be yet available, medical and technological advances in recent decades have made it possible to better manage children’s symptoms permitting them to live longer and more comfortably. A significant number of children receiving PPC are identified as children with medical complexity (CMC)⁶ as they live with rare diseases that are often undiagnosed, or complex and chronic health conditions. A specific definitional framework for identifying CMC includes substantial family needs, severe functional limitations, chronic condition or medical fragility and high health care use. According to a report published in 2006, 53.8% of child mortalities in Quebec between 1997 and 2001 were associated with complex chronic conditions.⁵ According to the most recent data available, in Quebec nearly 350 000 children are affected by a rare disease.⁷

The child and their family will experience a series of transitions as their lives unfold alongside the child’s medical condition. The concept of transition has been defined as: “a passage from one fairly stable state to another fairly stable state, and it is a process triggered by a change.”⁸ These transitions include, for example, the movement from one hospital unit to another, or from hospital to home and include other types of transitions such as the shift from one developmental stage to another, from being an only child to having siblings or from being medically stable to dying. When addressing transitions for children facing life-limiting health conditions, it is important to recognize that these transitions are shaped by various factors, including the child’s developmental stage, the trajectory of the illness, the life cycle of the family, and the intricacies of health care organization. The progression of the family through one transition period to another will require its members to adjust and adapt to new realities. A variety of contextual factors will influence how smooth a transition will be. It is reasonable to expect that transitions can be notably more complex for a child with a severe illness and their family, primarily because of the ongoing and specialized care that their situation typically demands.

Both the clinical experiences of the co-authors and our preliminary investigation of the literature revealed that transition periods for children with life-limiting conditions and their families can be bewildering and highly anxiety-inducing. In Quebec, PPC standards suggest that “particular attention must be paid to the transition periods between health care providers, to the episodes of care and to the care settings.”⁵ In these contexts, continuity and coordination of care and services become

particularly important. A decade later, one of the four guiding principles of the *Plan de développement 2015–2020 en soins palliatifs et de fin de vie* from the Ministère de la Santé et des Services Sociaux specifies that services must “be part of a continuum of care where people’s needs and choices are placed at the heart of the planning, organization and delivery of services.”⁹ However, clinical observations seem to point to a more heterogeneous care offer, including a lack or discontinuity of services. The 2020–2025 plan now focuses on equity in palliative care, aiming to ensure the accessibility of palliative and end-of-life care services (priority 5) and improving the organization of PPC (priority 7).⁷

The 2020–2025 report notes that the small numbers of children and adolescents in some geographical regions in palliative and end-of-life care make it difficult to develop such expertise in rural or less populated areas.⁷ Questions are raised about access and continuity of care. The transition from pediatric to adult care is also often mentioned by practitioners as unsatisfactory. Yet transition processes involved in disease with a potentially fatal outcome do not seem to be the subject of many studies. Researchers from the pediatric axis of the *Réseau québécois de recherche en soins palliatifs et de fin de vie* were interested in studying the experiences of transitions lived by children with complex chronic illnesses receiving palliative care as well as the experience of members of their families. This paper aims to establish a portrait of the existing literature and identify research gaps on the multiple transitions experienced by this population.

Method

To address this aim, a methodological framework for scoping reviews was applied to map research conducted on transition experiences in PPC.¹⁰ Thomas and colleagues¹¹ propose that scoping reviews are a type of knowledge synthesis that uses a systematic and iterative approach to identify and synthesize an existing or emerging body of literature on a given topic. Scoping reviews aim to map the extent, range, and nature of the literature, as well as to determine possible gaps in knowledge on a topic.¹² The scoping review process we followed consists of the following main stages: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (4) collating, summarizing, and reporting the results.¹³ Details of our process follow.

Stage 1: Identifying the research question

This study was guided by the following research question: What is the state of knowledge about the different experiences of transition in PPC lived by children and young adults, according to their perspectives and those of their families? Two secondary questions complete the main question: (1) How are the transitions experienced in PPC defined? (2) What are these transitions in PPC?

Stage 2: Identifying relevant studies

On the recommendation of a university librarian, three electronic databases were consulted: (1) MEDLINE, (2) PubMed and (3) CINAHL. The search strategy was based on three key concepts: (1) palliative care/complex condition, (2) child/adolescent, and (3) transition. It involved the use of specific keywords and terms adapted to the thesaurus of each

database. The database searches were programmed to locate peer-reviewed studies published in English and French between January 2000 and September 2021. Search strategy tables can be found in Supplementary Data.

Stage 3: Study selection

The resulting reference list was uploaded to Covidence, a systematic review software. Duplicates were identified and removed before the transfer of the data to Covidence. The team of researchers ($n = 12$) contributed to all stages of the screening process, using PRISMA guidelines. First, teams of two reviewers independently screened the title and abstract of each study for relevance to the scoping review, and studies that did not fit the scoping review criteria were removed. Then, teams of two reviewers screened the full texts of the included studies to establish their eligibility in the scoping review. Articles not selected by consensus were then reevaluated by a three-member sub-committee. Team meetings were held to clarify concepts and ensure consistency throughout the process. In the end, consensus was reached on all articles.

Eligibility criteria. The Quebec 2006 norms in PPC informed our research. The norms consider six different groups of children and families, presented in Table 1.

The target population for this scoping review included children (from 0 to 18 years old) in need of palliative care and living with a complex medical condition. The review focused on groups one through five as identified by the PPC Standards.⁵ The sixth group focuses on grieving families, a topic outside of the scope of the current study. When articles addressed the situation of grieving families, we only included them if they focused on transition experiences before the death of a child with a complex medical condition. Inclusion and exclusion criteria are described in Table 2.

Stage 4: Charting the data

An analysis grid was developed by consensus of the research team and was used to collect data from included articles. The researchers divided up the articles to be analyzed among themselves. Regular team meetings allowed time and space for questions and revisions of the data collected. The analysis chart can be found in Supplementary Data.

Stage 5: Collating, summarizing, and reporting the results

Data collected from the individual worksheets (one worksheet by article) were then compiled in an Excel file. Each section of the Excel file was analyzed by teams of two or three researchers (e.g., two researchers analyzed and coded study objectives, and another team analyzed and coded definitions of transition).

Results

In total, 2065 documents were identified, among which 72 studies were included for analysis (Table 3). PRISMA report is illustrated in Figure 1.

Data overview

Documents were research articles ($n = 71$) and included one thesis ($n = 1$). Over half of the articles that were identified were published after 2015 ($n = 53$). Roughly half of the research included in the scoping review was conducted in North America (USA and Canada) (45). The United Kingdom (11) and Ireland (5) were also significant contributors. Additionally, five studies had contributions from multiple countries ($n = 5$).

The types of research included qualitative ($n = 44$) and quantitative studies ($n = 3$), mixed methods ($n = 14$), and reviews ($n = 11$). Most of the surveyed articles focused on qualitative research.

Research respondents are commented further.

Research objectives

Study objectives were coded using inductive thematic analysis. Thematic analysis aims to identify, analyze, and present patterns (themes) in the data collected during the study.^{59,72} Six primary themes emerged from the objectives stated in the selected articles, each representing a series of sub-themes (Table 4).

Aimed populations

The populations targeted by the research correspond to the groups studied, who should benefit from the advances made possible by the research.

TABLE 1. CHILDREN AND FAMILIES IN NEED OF PALLIATIVE CARE⁵

Category	Group of children and families
1.	Children with conditions for which curative treatment is possible. Palliative care may be necessary during periods of uncertainty or when curative treatments are ineffective. (e.g., cancer, significant cardiac, renal or hepatic damage).
2.	Children with conditions where premature death is inevitable. These children may require long periods of intensive treatment to prolong life and enable them to participate in activities normal for children their age (e.g., cystic fibrosis, muscular dystrophy).
3.	Children with progressive conditions with no hope of recovery. Treatments offered to these children are palliative only and may last for years. (e.g., Batten disease, mucopolysaccharidosis).
4.	Children with severe neurological problems, accentuating their vulnerability and increasing the risk of complications that could lead to an unforeseeable deterioration in their condition, but considered nonprogressive (e.g., accidents with neurological damage, severe cerebral palsy).
5.	Newborns with very limited life expectancy.
6.	Members of a family who have lost a child unexpectedly because of illness, a situation caused by an external cause or a loss during the perinatal period.

TABLE 2. INCLUSION/EXCLUSION CRITERIA OF REVIEWED STUDIES

	<i>Types of participants</i>	<i>Concepts</i>	<i>Types of sources</i>
INCLUSION	Newborns, children, adolescents, young adults eligible (criteria 1–5 of the Norms) for pediatric palliative care and their family members and caregivers	Experience of a transition-the biopsychosocial and spiritual experience of all types of transition	Academic journals (original article/research, case study, scoping review, systemic review) Languages (English/French)
EXCLUSION	The article focuses exclusively on healthcare professionals	The article focuses exclusively on the medical treatment or pathophysiological aspect of the child's condition	Editorials, letters to the editor, comments to the editor, comments on magazines and magazine texts, program description

Populations-data organization

Among the 72 articles selected for our scoping review, two main characteristics emerge from the designation of populations: the first identifies young people or the link that the targeted people have with young people; the second briefly describes the medical situation.

Populations by age or place in the family

According to our query, only 1 article primarily deals with the organization of services, and 3 others focus on caregivers. Numerous articles target family members of children with complex illnesses (23), but based on our selection criteria, all the articles focus on one or many children's age groups. The identification of age groups is not always consistent, leading to disparities in the way populations are identified. To ensure clarity, we have retained the terms used by the authors. We have grouped "neonates," "infants" and "babies" (11) into a single category. The age of the "children" is not always specified (34). In other articles, the range of age associated with "children" varies. The expression "young people" (10) is used broadly with no specific age. In summary, several terms occasionally refer to the same populations, whereas, conversely, a single term may sometimes indicate different age groups.

"Children" is the category most studied in the articles that we retained. Among the studies we reviewed, young adulthood (15) and adolescence (14) appear to be more prominent compared to younger children (Table 5). This could be linked to the phenomenon of transition from pediatric to adult health care services, which has received more attention compared to other types of transition.

Populations by medical status

The selected publications also focus their research on children with specific medical conditions or characteristics. Once again, the terminologies are not always consistent with each other. Identifying possible groupings or categories is challenging, and the labels are not mutually exclusive. As expected, most articles explicitly state that their research revolves around children (including young people, adolescents, or young adults) living with a complex health condition ($n = 17$). Some mention life-limiting conditions ($n = 16$) or a life-threatening condition ($n = 7$) and others refer to fatal or terminal conditions ($n = 6$). There is also a discussion about complex chronic condition ($n = 4$) or critical illness ($n = 3$). A handful of studies focus on

children with specific diagnoses: cancer ($n = 6$), genetic diseases ($n = 5$), muscular dystrophy (1), spina bifida (1) and dermatomyositis (1).

In some instances, articles focus on the specific needs of pediatric patients rather than on their condition ($n = 14$). Some studies examine populations based on the care setting, like intensive care ($n = 9$), palliative care at home ($n = 2$), long-term hospitalization ($n = 1$), or respite care ($n = 1$). A few studies also focused on children posttransplant ($n = 4$) and survivors ($n = 2$). Finally, some studies delve into the transitions experienced by children and their families during the illness after the children's death ($n = 3$). It is important to note that these categories are not mutually exclusive, which accounts for the total number of results surpassing our scoping review sample of 72 articles (Table 6).

Overall, what appears to differ is the perspective of the research. For instance, some focus on the child's condition (person, diagnosis, etc.) whereas others concentrate on the required care (intervention) (action). Time might be a crucial factor, reflecting the experience of the children (care trajectories), whereas, in other cases, space is emphasized, considering the availability and organization of resources (PICU vs. home).

Research respondents

Given our focus on a pediatric population, often reliant on adults or third-party assistance, the respondents in the studies we located were not members of the target population. Data on research respondents is available on Table 3.

Research respondents were mostly identified as parents. We identified 30 articles where parents counted among different respondents and 18 articles where only the parents' views were included. In 3 articles, mothers were the only respondents. Sick children, adolescents or young adults counted among the respondents in 14 articles. Sick children were the only respondents in 7 articles. Health care professionals counted among the respondents in 23 articles. We did not consider articles with health care professionals as the only respondents. In 6 articles, families and loved ones (i.e., grandparents, close friends) were included. Community partners and school professionals were included in 3 articles.

Transitions

Four primary transition categories emerged from the 72 articles, delineating the experiences of children and their families: The first category involves changes in the care

TABLE 3. LIST OF THE ARTICLES SELECTED FOR THE SCOPING REVIEW

<i>First author</i>	<i>Years and citation</i>	<i>Country</i>	<i>Method</i>	<i>Respondents^a</i>
Aagaard H.	2018 ¹⁴	DEN	REV	Others
Amidi-Nouri AZ.	2008 ¹⁵	US	QL	Parents only
Bally JM.	2018 ¹⁶	CA	QL	Others
Barling JA.	2014 ¹⁷	AUS	QL	Parents; Families and loved ones
Barone S.	2020 ¹⁸	CA+US	QL	Parents; Healthcare professionals
Beresford B.	2014 ¹⁹	UK	QL	Sick children only
Biffi SE.	2015 ²⁰	US	MX	Families and loved ones
Breneol S.	2017 ²¹	CA	REV	Others
Brenner M.	2015 ²²	IRE	QL	Parents only
Brouwer M.	2020 ²³	NL	QL	Parents only
Burke SO	2000 ²⁴	CA	QNT	Parents only
Butler AE.	2017 ²⁵	AUS	QL	Parents only
Coats H.	2016 ²⁶	US	QL	Parents only
Colville G.	2009 ²⁷	UK	MX	Parents
Cook K.	2013 ²⁸	CA	QL	Children, adolescents or sick young adults
Curran JA.	2020 ²⁹	CA	MX	Parents; Healthcare professionals
Davies B.	2004 ³⁰	CA	MX	Parents
Desai AD.	2016 ³¹	US	QL	Healthcare professionals
Dick PT.	2004 ³²	CA	MX	Parents; Healthcare professionals
Doucet S.	2020 ³³	CA	REV	Others
Engler J.	2020 ³⁴	GER	QL	Parents only
Erby LH.	2006 ³⁵	US	QL	Parents only
Falck AJ.	2016 ³⁶	US	QL	Parents; Healthcare professionals
Góes FBG.	2017 ³⁷	BR	QL	Parents; Children, adolescents or sick young adults; Healthcare professionals
Gomes Viana AC.	2019 ³⁸	BR	QL	Mothers only
Grinyer A.	2007 ³⁹	UK	QL	Children, adolescents or sick young adults
Heller KS.	2005 ⁴⁰	US	QL	Parents; Families and loved ones
Henderson CM.	2017 ⁴¹	US	QL	Parents; Healthcare professionals
Hutcheson, S.	2018 ⁴²	IRE	QL	Parents; Children, adolescents or sick young adults; Healthcare professionals
Janvier A.	2006 ⁴³	CA	MX	Parents only
Jarvis JM.	2019 ⁴⁴	US	QL	Healthcare professionals
Jindal-Snape D.	2019 ⁴⁵	SCO	MX	Families and loved ones
Johnston B.	2016 ⁴⁶		REV	Others
Joly E.	2015 ⁴⁷	CA	REV	Others
Jordan J.	2015 ⁴⁸	IRE	QL	Parents only
Kerr H.	2020 ⁴⁹	IRE	MX	Healthcare professionals; Community partners and School professionals
Kerr H.	2018 ⁵⁰	IRE	MX	Parents; Children, adolescents or sick young adults; Healthcare professionals
Kerr H.	2017 ⁵¹	IRE+UK	REV	Others
Kirk S.	2014 ⁵²	UK	QL	Parents; Children, adolescents or sick young adults; Healthcare professionals
Lakshmanan A.	2019 ⁵³	US	QL	Parents only
Leary JC.	2020 ⁵⁴	US	QL	Parents only
Lerret SM.	2015 ⁵⁵	US	QNT	Parents only
Lerret M.	2017 ⁵⁶	US	MX	Parents
Leyenaar JK.	2017 ⁵⁷	US	QL	Parents; Healthcare professionals
Lindsay S.	2014 ⁵⁸	CA	QL	Parents; Children, adolescents or sick young adults; Healthcare professionals; Community partners and School professionals
Livermore P.	2019 ⁵⁹	UK	QL	Children, adolescents or sick young adults
Lynch TA.	2017 ⁶⁰	US	QL	Mothers only
MacDonald H.	2008 ⁶¹	CA	QL	Parents; Healthcare professionals
Mai K.	2020 ⁶²	US	QL	Parents; Families and loved ones
Manning JC.	2014 ⁶³	UK	REV	Children, adolescents or sick young adults
Mantler T.	2020 ⁶⁴	CA	REV	Others
Markwalter DW.	2019 ⁶⁵	US	QL	Parents; Healthcare professionals
Meaux JB.	2014 ⁶⁶	US	QL	Parents; Children, adolescents or sick young adults
Montgomery K.	2016 ⁶⁷	US	REV	Others

(continued)

TABLE 3. (CONTINUED)

<i>First author</i>	<i>Years and citation</i>	<i>Country</i>	<i>Method</i>	<i>Respondents^a</i>
Noyes J.	2018 ⁶⁸	UK	QL	Children, adolescents or sick young adults; Healthcare professionals; Families and loved ones
Østerlund CS.	2005 ⁶⁹	US	QL	Parents; Children, adolescents or sick young adults
Rennick JE.	2008 ⁷⁰	CA	QL	Parents; Children, adolescents or sick young adults; Healthcare professionals
Rennick JE.	2019 ⁷¹	CA	QL	Parents only
Roy S.	2021 ¹⁴	US	QL	Families and loved ones
Samwell B.	2012 ²³	UK	QL	Others
Steele AC.	2013 ⁷²	CA+US	QL	Parents
So S.	2014 ⁷³	CA	MX	Parents only
Tamburro RF.	2011 ⁷⁴	US	QL	Parents only
Tan JS.	2012 ¹³	US	QL	Parents only
Toly VB	2019 ⁷⁵	US	MX	Mothers only
Vanclooster S.	2018 ⁷⁶	BELG	REV	Parents; Healthcare professionals; Community partners and School professionals
Van Orne J.	2018 ⁷⁷	US	QNT	Healthcare professionals
Waldboth V.	2016 ⁷⁸	SW+UK	REV	Others
Wells F.	2013 ⁷⁹	UK	QL	Sick children only
Wells S.	2017 ⁸⁰	US	MX	Parents only
Williams LJ.	2021 ⁸¹	US	MX	Parents; Healthcare professionals
Young L.	2018 ⁸²	UK	QL	Parents; Healthcare professionals

^aDoctoral thesis; all the other references are scientific articles.

MX, Mixed methods; REV, Review; QL, Qualitative; QNT, Quantitative.

environment, the second pertains to the transition into adulthood, the third focuses on transitions associated with the illness itself, and the fourth relates to school integration (Table 7). It is important to note that a single article may cover multiple transition categories.

Specifically, 16 articles address the transition experienced during the shift to adulthood. Regarding transitions in the care environment, 19 articles address the transition from hospital to home, six discuss the transfer of children or adolescents between intensive care to acute care (or vice versa), one is associated with various environments and a third is related to a palliative care home (family respite). The illness-related category encompasses four sub-categories: the first concerns the child's or young person's developmental ($n = 4$ articles), the second involves the organization and planning of care ($n = 12$ articles), the third examines the care trajectory ($n = 11$ articles) and the last addresses end-of-life, death, and bereavement ($n = 1$ article). Only one article is devoted to the fourth category, which deals with school integration. The same article may concern two transitions.

Discussion

In our scoping review, we aimed to explore the existing understanding of various transition experiences encountered by children and adolescents with medical complexity, ranging from 0 to 18 years old, who receive PPC. Our search was confined to studies that examined the viewpoints of both the youth and their family members. Alongside this primary goal, we sought to outline how PPC transition experienced by children with medical complexity are conceptualized in the literature, as well as to identify the specific types of transitions highlighted in research on PPC. Out of the 2064 studies screened, our review ultimately included 72 articles. It is important to note that most of these studies primarily focused on the transition experiences in palliative care from the perspective of

parents. Most studies in our sample predominantly examined the transition experiences in palliative care from the perspective of parents. Additionally, our findings revealed two key points: (1) notable inconsistencies among age groups and other categories and (2) challenges in precisely identifying groups with distinct or specific health conditions.

Research trends

Over the past two decades, there has been a notable surge in research interest regarding the transition experiences of children and youth in PPC. This shift can be attributed to advancements in medical technology⁸⁸ which have necessitated the establishment of programs and services to cater to the needs of this emerging population of children who now surviving and thriving into adulthood. The studies in our review primarily originated from researchers in North America and the United Kingdom, with a smaller representation from South American and European countries. This trend could be clarified by the language of publication specified in our inclusion criteria (English and French), as well as by the growing trend of research groups in these countries (i.e., Health Hub in Transition [Canada], Got Transition [USA]).

Definitional murkiness

Overall, there appears to be murkiness concerning the definition of transition across the studies we reviewed. Only 22 articles within our review provided a clear and specific definition of the transition that was the focal point of their study. The objectives of the studies varied, ranging from examining family experiences of health care transition to investigating changes in health status and transfers from one setting to another (such as transfer to palliative care or transition to school). Despite attempts to clarify these concepts, there remains a conceptual slippage where references

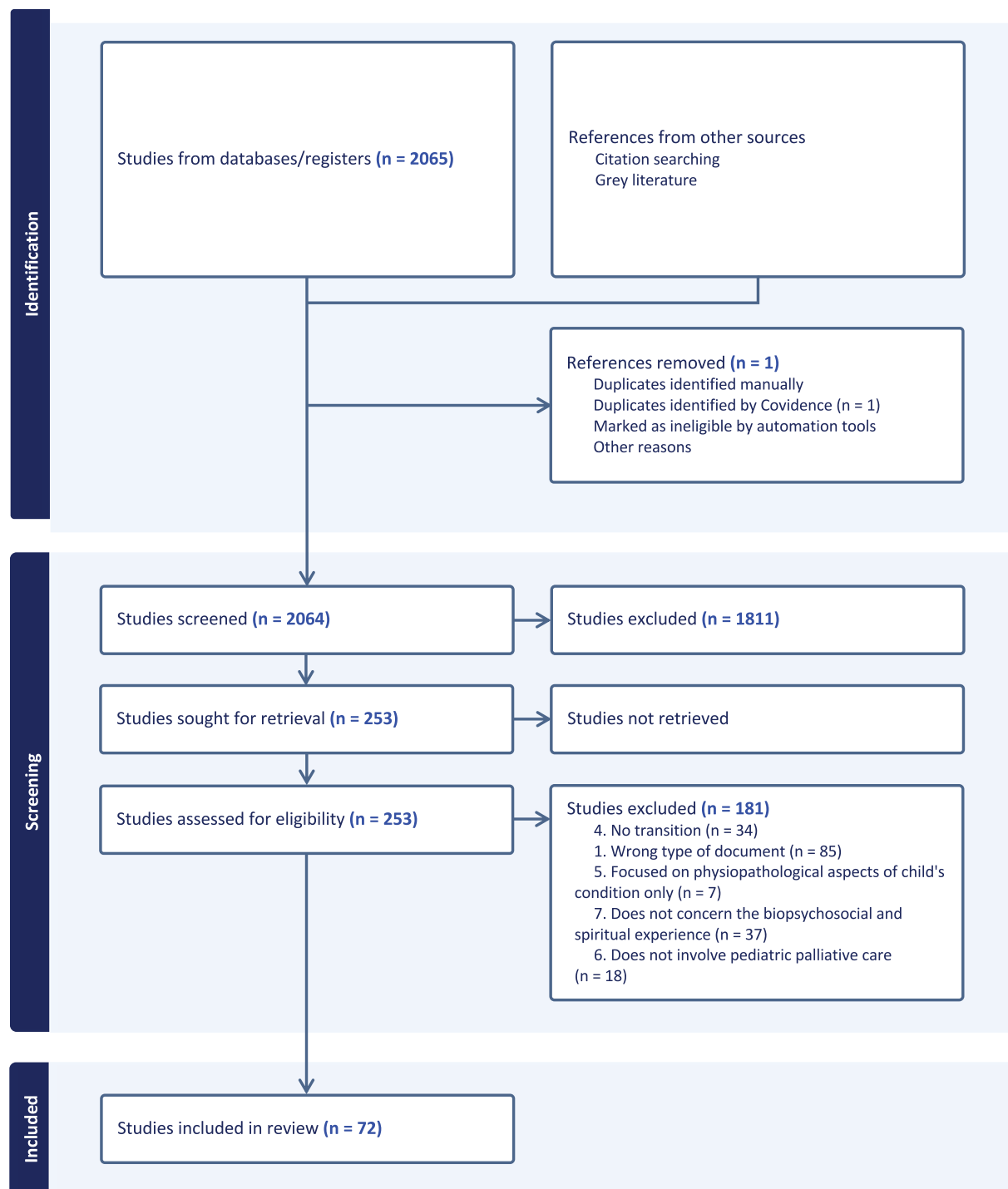


FIG. 1. PRISMA report from Covidence.

to transitional care encompass various aspects, including transfers of care, such as the shift from pediatric to adult services or transfers from hospital to home. Betz and colleagues⁸⁹ have recently initiated a conversation on this issue, emphasizing the repercussions of not explicitly defining and operationalizing these distinctions. Amid this conceptual ambiguity, we did find several studies that explicitly referred to the concept of transition as outlined by Meleis,⁸ a definition that guided our study.

Complexity ignored

We also observed that while various types of transfers and transitions have been the focus of research, such as the period of when a child leaves the hospital to go home or between intensive care and the hospital ward, these events are often studied in isolation. Transition, however, is a process that unfolds over time and space. Monitoring the experiences of children and families as they navigate through different stages

TABLE 4. RESEARCH OBJECTIVES

Primary code	Sub-Code	Article #
Types of transition	Transition and transfer from health care facility to home	14,23,15,25,31,37,39,40,44,58,68,70,74
	Pediatric to adult health care transition	42,48,57,65,71
	Transition to palliative care	52,62
Experience	Transition and school	79
	Parents' and caregivers' experience of caring for a child with CMC	18,26,35,38,54,61,69
	Youth experience of living with CMC	17,22,34,36,41,82
	Parents' and families' experience of bereavement	19,53,60,66
	Family experience of transition	20,28,77
Programmes	Parent-professional relationships and collaborations	24
	Program evaluation	27,29,30,45,49,50,55,75,80
	Mapping transition process	73,43
Improving transitions	Innovations in transition programs	56
	Recommendations	32,46,67,78,81
	Needs and challenges to facilitate transitions	47,51,63,76
Process	Preparing and planning transition	64
	Trajectories and life cycle	33,21
	Parent-professional collaboration	16
	Parenting	83
Measurement	Temporality	84
	Development measurement	85,86

(i.e., developmental, situational, health status, and family organization) requires an awareness of the evolving contexts over time.

The complexity introduced by these changes seems to be somewhat obscured in our sample of studies. This may be partly attributed to methodological trends within this sample, consisting mostly of cross-sectional observational studies with limited designs aimed at exploring the multifaceted and complex nature of transition over time. Directing research attention to temporality, context, and previous experiences could add depth to study findings. Currently, these aspects are overlooked, as are the various needs of the child and family, along with the factors that shape their experiences. In this regard, we believe that transitions should be studied in their complexity, as recommended by Hodiamont and colleagues.⁹⁰

As advancements in health care lead to longer life spans for children, this progress must be accompanied by corresponding social innovations intended to assist this population (and their families). This could be achieved through the establishment of appropriate social programs and services that effectively address the actual needs of these children and families. Transition, when

comprehensively defined, should encompass the complete complexity of the child's life trajectory and that of their family. Attending to this complexity in research can aid decision-makers in formulating corresponding social policies that cater to genuine needs, and in allocating resources toward the creation of relevant policies and programs.

Lack of diversity in study participants

Another significant trend observed in our sample pertains to the participants involved and the voices highlighted in discussions about transition experiences. Our review uncovered a prevalent focus on the perspectives of parents, with a particular emphasis on mothers. However, some research indicates gender disparities in the challenges of parenting a child with health concerns.^{91,92} The absence of fathers within parent samples in research might falsely imply that they are either challenging to reach, unwilling to participate in research, or that their experiences closely mirror those of mothers, thus rendering their inclusion seemingly inconsequential and of minimal value in understanding parenting dynamics.⁹³ However, recent studies

TABLE 5. POPULATIONS BY AGE OR PLACE IN THE FAMILY

Population	Categories	Total articles	Article #
Children	Children (Age not specified)	34	23,31,25,15,68,40,26,69,79,35,61,36,53,19,20,24,77,49,50,27,29,75,80,43,56,81,46,78,76,33,47,64,83,87
	Young people (Age not specified)	10	23,48,42,65,52,17,41,19,55,78
	Young adults (From 19 years old)	15	44,42,52,57,65,71,38,34,28,30,73,51,21,84,86
	Adolescents (12–18 years old)	14	39,15,58,71,65,69,38,22,34,82,41,66,32,84
	Early childhood and childhood (1–12 years old)	9	39,74,70,22,66,45,32,63,85
	Infants, babies, neonates (Less than 1 year old)	11	14,39,74,37,62,18,54,60,45,67,16
Families	Parents	16	14,25,15,68,70,69,35,54,53,19,24,50,45,33,83,87
	Families	3	40,61,29
	Mothers of infants	2	37,62
	Guardians	1	70
	Siblings	1	66
Caregivers		3	27,32,47
Organization		1	73

TABLE 6. POPULATIONS ACCORDING TO THEIR MEDICAL CHARACTERISTICS

Type of condition	Total articles	Article #
Complex health condition, medical complexity, medically complex	17	39,31,42,65,36,60,28,20,49,50,27,75,80,67,78,76,83
Life-limiting medical condition, complex life-limiting condition	16	15,48,42,57,52,61,53,77,55,30,73,76,21,84–86
Life-threatening condition	7	71,52,62,61,53,81,63
Terminal condition, end-of-life, dying	6	26,38,53,19,77,63
Complex chronic condition	4	65,36,60,56
Critically ill	3	32,64,85
Chronic illness	1	65,17,33
Chronic critical illness	1	35
Complex pediatric trauma	1	46
Very premature	1	18
<i>Specific diagnosis</i>		
Cancer	5	79,26,38,34,19
Genetic disease	5	44,69,54,17,16
Others	3	58,69,22
<i>Special care or needs</i>		
Complex care needs, complex and medically fragile needs, special care needs, techno-dependent child, tracheostomy, rehabilitation, renal replacement therapy	14	23,74,25,68,70,37,82,43,46,78,51,47,83,87
<i>Places of care</i>		
PICU, NICU	9	14,40,62,35,77,32,67,64,85
Palliative care at home	2	75,56
Long hospitalization	1	45
Respite	1	29
<i>Specific periods or times in the care trajectory</i>		
Posttransplant	4	58,68,82,87
Had died	3	66,24,63
Critical illness survivors, cancer survivors	2	41,32
Received Beantalk program	1	45

PICU, pediatric intensive care unit; NICU, neonatal intensive care unit.

suggest the contrary. When included as participants in research, fathers express appreciation for the opportunity to share their distinct parenting experiences⁹⁴ and are willing and capable of discussing their personal and emotional experiences in parenting.⁹⁵ Consequently, it appears imperative to develop tailored recruitment strategies to ensure the meaningful inclusion of fathers in research on parenting and families, thereby facilitating the enhancement of family support programs and policies.

Missing children's voices

Remarkably, none of the studies examined in our review focused on the viewpoint of the child or adolescent experiencing transitions, portraying children as objects (i.e.,: passive recipients of care) rather than subjects (i.e.,: persons with their own interests, ambitions, and experiences). Therefore, it appears essential and pertinent to adopt an approach that positions the child as an active social actor participant with agency.⁹⁶ This perspective acknowledges children's capacity to act, articulate their concerns, and

actively reflect on their social environment. Methodological guidance can be derived from the interdisciplinary field of childhood ethics,^{97–99} or research on participatory research methods involving children.¹⁰⁰ Integrating children who utilize various forms of self-expression as co-designers or participants in research that concerns them¹⁰¹ along with efforts that support children in expressing themselves independently of adults.¹⁰² Thus, it is imperative to develop strategies that generate knowledge rooted in children's experience, rather than crafting narratives about them.

Limitations

The research team behind this study boasted a diverse array of competencies across various fields, significantly enhancing the overall process. Collaborative and consensus-driven work necessitates significant time and relational investment from all participants. Consequently, the research proved to be a distinctive, enriching, and stimulating experience. However, this valuable

TABLE 7. IDENTIFIED TRANSITION CATEGORIES

Transition categories	Total articles	Subcategories	Articles
1. Related to the care environment	19	From hospital to home	23,25,31,39,44,74,68,70,20,49,50,27,75,56,46,67,78,47,87
	6	From intensive care to acute care (or vice versa)	14,40,37,32,64,85
	1	Various environments	77
	1	Palliative care home (family respite)	29
2. Reaching adulthood	16		44,42,48,52,57,65,71,82,17,28,55,30,73,51,84,86
3. Illness-related	12	Organization and planning of care	15,70,62,69,35,27,29,45,75,80,81,63
	11	Care trajectory	26,38,18,22,54,61,41,43,33,16,83
	7	End-of-life, death, and bereavement	26,19,53,60,66,24,76
3. Illness-related	4	Developmental	58,34,21,84
4. School integration	1		79

approach also posed certain limitations: the extensive scoping review extended for more than 2 years. It is plausible that more recent research on the topic has been published since the conclusion of this study.

Recommendations

Several recommendations emerge from this scoping review, covering various topics including research, health care organization and clinical practice. In terms of research, based on the articles reviewed, it would be essential to consider the voice of children wherever possible, and not solely rely on those of parents. Beyond the focus on children's voices, there are also unexplored aspects concerning fathers, as participants recruited for family research tend to be mothers. Furthermore, there appears to be confusion between the terms "transition" and "transfer." It is therefore important to distinguish between them, as these two concepts have distinct meanings and implications for the children and their families. Another research-related recommendation could be for researchers to provide a clear definition of transition, reflect on its complexity and consider disciplinary and interdisciplinary approaches in studying it.

Regarding recommendations related to health care organizations, the development of both local and ministerial policies that adopt an ecosystemic approach, considering the child and their environment, could be proposed to encompass the complexity of transition situations. The reviewed articles have highlighted that pediatric interventions and care should be family-centered, not solely focused on the children. The complexity of transitions experienced by the children and their families extends beyond the family circle, encompassing different systems in the ecosystem (micro, macro, and meso) and the relationships between them. Therefore, a more comprehensive approach should be favored when working with children and their families.

Finally, in terms of clinical recommendations, training in the systemic family approach to palliative care, both in pediatric and adult contexts, could be beneficial for health care professionals and ultimately contribute to the well-being of children and their families.

Conclusion

This article aimed at mapping research on transition in PPC among children living with a medically complex condition. Two secondary questions complete the main question: (1) How are the transitions experienced in PPC defined? (2) What are these transitions in PPC? A scoping review was carried out according to PRISMA protocol and analyzed pertinent literature. Among the 72 articles studied, the review revealed a definitional murkiness relative to "transitions"—often making no distinction between transfers and transitions. Four categories of transition were outlined from the literature: transition related to the care environment, reaching adulthood, transition related to the illness, and school integration. Recommendations highlight that research on transitions in PPC with children facing medical complexity would benefit in better clarifying the studied concepts, being more inclusive of children's voice, considering families' and children's life complexity and including a stronger diversity of participants.

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Authors' Contributions

E.C.: Conceptualization, funding acquisition, methodology, formal analysis, investigation, validation, writing — original draft and revision (lead), project administration, supervision. J.C.: Conceptualization, funding acquisition, methodology, formal analysis, investigation, validation, writing — original draft and revision. C.S.: Conceptualization, funding acquisition, methodology, formal analysis, investigation, validation, writing — original draft and revision. M.B.: Methodology, formal analysis, investigation, validation, writing — original draft and revision, visualization. A.B.: Methodology, formal analysis, investigation, validation, writing — original draft and revision. M.D'A.: Methodology, formal analysis, investigation, validation, writing — original draft and revision. V.R.: Methodology, formal analysis, investigation, validation, writing — original draft and revision. D.U.: Formal analysis, investigation, validation, writing — original draft and revision. G.F.: Methodology, formal analysis. F.Bergeron: Methodology, resources, data curation, visualization. F.Bonenfant: Formal analysis, investigation.

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Supplementary Material

Supplementary Data

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