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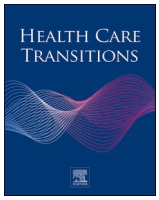

Letting go/ moving on: A scoping review of relational effects on transition to adult care

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ABSTRACT

Objective: The objective of this scoping review was to assess the extent of the literature on how relational components in pediatric care contribute to the transition process and transfer outcomes.
Background: Relationships between patients, parents and pediatric providers are a frequently cited barrier in transition to adult care. A scoping review aimed to identify studies focused on how the relationship between patients/parents and pediatric providers related to transition from pediatric to adult healthcare and explore the nature and depth of the evidence.
Methods: Search terms were identified through a combination of medical librarian term harvesting and expert input. Four databases were searched with a combination of keyword and controlled vocabulary: PubMed, CINAHL, PsycINFO, and Web of Science. In order to reduce the risk of bias, each record was reviewed by two independent clinical experts in both the screening and full-text review stages. No database filters were applied during the searching process.
Results: The initial search strategy resulted in 13,121 records. After removal of duplicates, 271 moved on to full text review, and 152 met inclusion criteria as related to both transition from pediatric to adult medical care and relationships between pediatric providers and patients/families.
Conclusions: This scoping review aimed to identify available literature on relationships between pediatric providers and patients/families. Variable levels of research were identified, with little formal study of interventions. The majority described relationship issues as barriers, either on the part of providers, patients, parents or a combination of these. Several highlighted relationship ties as facilitators in the transition, an important consideration in determining interventions.

1. Introduction

Transition to adult health services is a cornerstone of a normal, developmental process, as health needs change for individuals as they age.[1] However, youth with and without special health care needs (SHCN) receive very limited support for this transition.[2] For youth with special health care needs, this developmental milestone has been recognized as a priority[3,4], especially with new advances in medical technology that have improved the lives of children with previously life-limiting chronic conditions.[5,6] The first consensus statement on transition from the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) was developed in 2002.[7] It was updated in 2011[8] to include practical guidance, from which the GotTransition core elements of transition were developed.[9] In 2018, the consensus statement was further updated to include quality improvement recommendations, noting specific barriers related to relationships.[10] The consensus statement was reaffirmed in 2023, with updated references but no change to content.[10]

The literature reviews of these statements report multiple barriers to transition. Relational factors were identified from both the patient/family perspective as well as the clinician perspective as significant

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barriers. From the patient/family perspective, it was reported that the "most prominent barrier mentioned by youth with SHCN and parents and/or caregivers is difficulty leaving their pediatric clinicians with whom they have had a long-standing relationship". [10] An identified theme from the clinician perspective was reported as "concerns regarding loss of strong relationships with previous clinicians (patient, parent, and/or staff)".[10]

With over twenty years of examination of the important topic of relationship impact on transition, significant questions remain, with variable levels of evidence presented.

Current literature, including systematic reviews[11–13], quality improvement/implementation recommendations[14–16], and position statements[17–20] have described multiple barriers in the transition process for patients moving from pediatric healthcare to adult oriented systems. Much has been well described, distilled, and studied in the transition literature regarding broad challenges with considerations of pragmatics, insurance and reimbursement concerns, social determinants of health, familiarity, access to specialized care and models for skill building, lack of time, insufficient and ineffective infrastructure, lack of multidisciplinary teams, and timelines[10]. There is less research that has specifically examined the relevance of or articulated appreciation of the nuanced relational roles among families and the medical team, which is woven into the fabric of the therapeutic alliance over time. As clinical social workers who often facilitate the process of transition, the authors have interest in better understanding the description and characterization of these specific relationships as distinct and crucial factors in transition planning and continuity of care through ultimate transfer of care.

The identified relationships involve connections between and among multiple parties involved in transition, including pediatric providers, adult providers, patients and parents. The pediatric health care provider is responsible for the care of a young adult prior to their transition from pediatric to adult care. In this setting, the pediatric provider typically interacts primarily with the patient along with the patient's family. As part of the transition process, the patient will establish a connection with the adult provider. Given the patient-focused approach in adult care, the patient's relationship with an adult provider will be central, with less active engagement with the family on the part of the new provider. Navigating this shift also impacts the relationship between young adults and their parents, as empowering patients to advocate for themselves involves stepping back on the part of parents. Acknowledging the mutual connection of a shared patient, the pediatric and adult providers may also connect for continuity of care. Recognizing the breadth and depth of connections throughout transition, there is special focus on the relationship between pediatric providers and patients and their families as the change in this continuity is the basis of pediatric to adult health care transition. While leaving this relationship is identified as a primary challenge for successful transition[10] this important connection can also be a model for what works well and is a potential transition facilitator.

The power of these relational aspects are intrinsic in the therapeutic engagement formed in pediatric care and thus potentially have strong impacts on the transition and transfer process. While attachment and emotional facets have been acknowledged in the literature[10], there has been less exploration about the specific and uniquely relational factors that impact providers, patients, and parents and the dynamics among these stakeholders. Understanding the existing literature on relational elements at various stages of the transition process may better inform future models and allow for a less distressing and more satisfying transfer from pediatric to adult health care.

To assess the prevalence of relational constructs recognized and described as central to the transition process, a scoping review was identified as the most appropriate research method. The objective of this scoping review was to assess the extent of the literature specific to the uniquely relational components present in pediatric care as a central contributor to the transition process and transfer outcomes. Understanding the ways in which relational factors can serve as facilitators and/or barriers of transition planning and outcomes may help in the development of future models and best practice for pediatric health care clinicians.

1.1. Review questions

How does existing literature address the role of relational aspects in transition of care? How do relational variables affect the patient, parent, and provider experience of ultimate care transfer? What gaps exist in the literature on relational factors in transition of care across all health care systems and practice landscapes?

For the purposes of this literature review, the population, intervention, comparators and outcomes (PICO) frameworks to inform the review objectives are presented below.

Population	Intervention	Comparison	Outcome
Patients and parents transitioning from pediatric to adult health care Providers transitioning their patients from pediatric to adult health care	Relational factors and emotional attachments for providers, parents/ caregivers, and patients	Transition factors that do not mention, include, or consider relational factors and emotional attachments for providers, parents/ caregivers, and patients	Patient and provider experience of transition

2. Methods

A preliminary search of PubMed, CINAHL, PsycINFO, and Web of Science was conducted, and no current or underway systematic reviews or scoping reviews on the topic were identified. Search terms were then identified through a combination of librarian term harvesting and expert input. These four databases were searched with a combination of keyword and controlled vocabulary searching, using search strategies written in the syntax of each database. To reduce the risk of bias, two independent clinical experts reviewed each record in both the screening and full-text review stages. No database filters were applied during the searching process.

The search was run on September 13, 2021 and 11,353 individual records were identified. The databases searched were PubMed, CINAHL, PsycINFO, and Web of Science and 1672 duplicates were removed through Covidence's duplicate removal. Titles and abstracts of 9681 records were screened in Covidence. Each record was screened by two independent clinical experts, social workers with subject matter expertise in transition, and conflicts were resolved through group assessment. After screening, 238 records met the inclusion criteria and the full-text of each record was assessed by two independent clinical experts. After full-text assessment, 127 records were included in the review.

A follow up search was run on October 26, 2023 to identify any newly published articles; 1768 records were identified and 146 duplicates were removed. Of the newly published articles, 33 of these records met the inclusion criteria. The full-text articles were reviewed and 24 of these were included in the review. Articles focused on physical health care needs of transition age youth in chronic care, complex care or primary care settings were included. Specific age parameters were not required for inclusion. Instead, our inclusion model was process based requiring explicit mention of a transition from pediatric to adult care such that the population addressed was anywhere from early teens through adulthood. The articles included patients in both inpatient and outpatient settings. Potential relationships that could have been examined were (1) parent with pediatric provider, (2) patient with pediatric provider, (3) parent with patient (4) parent with adult provider, (5) patient with adult provider, and (6) pediatric provider with adult provider. Given this review's focus on clinical care during the transition

period which specifically includes the pediatric provider as the point of continuity, we included only articles that addressed the relationships with pediatric providers, both (1) parent with pediatric providers and (2) patient with pediatric providers. Many addressed both (1) and (2) and several additionally addressed some or all of the other four relationships, but if it was exclusively about one of the others, it was not included. For example, articles focused exclusively on parent-child relationships in the transition process were not included. Articles focusing exclusively on mental health care were excluded with the recognition that mental health care is complex and, while it may have similar or parallel processes to physical health transitions, there are structural differences in the systems of care.

One record was ultimately pulled back in based on expert opinion and author knowledge of full article content. This article was included in the original search results but did not meet the title and abstract inclusion criteria. The author is the lead author of this review.

A PRIMSA diagram of the total numbers from both searches is included (see Fig. 1). The PRISMA diagram was edited to include the one article that was pulled into the result set based on expert opinion. Level of evidence was determined based on the hierarchy of evidence as outlined by Melnyk & Fineout-Overholt.[21]

3. Results

Review of over 11,000 abstracts ultimately led to 152 full text articles that discussed the identified concept of relational issues in the transition from pediatric to adult medical care. Articles were included when they directly articulated the existence or effects of long-standing relationships with providers, related feelings of trust and feeling known, and similar concepts (i.e. providers were "like family"). Articles that discussed only familiar places or processes were not included; the relationship with the provider had to be mentioned. The authors differentiated between relational aspects and pragmatic support provided. While relationships are frequently cited as a barrier in transition literature, this review found only six articles that were entirely dedicated to the topic (see Table 1). Three were qualitative studies[23–25]. One commentary presented recommendations for practice based on personal experience[26], one on review of ethical theory[27], and one on application of clinical terminations[28]. A significant number of authors called out relational aspects of transition as a specific theme (108 articles; see Table 1). Twenty eight articles had some discussion of relational aspects, without the authors calling it out a specific theme (see Table 1), and there were 10 articles in which it was simply mentioned with no further development. (See Table 1). Also listed in the table is the level of evidence on a seven-level hierarchy.[21] There were no articles found in levels 1 and 2 which require evidence of randomized control trials. A few articles were coded as Level 3, as they were systematic reviews of evidence where included articles were rated. Several were Level 5, including systematic reviews of descriptive and qualitative studies or meta-syntheses. Primarily, the articles included in this scoping review were Level 6 (evidence from a single descriptive or qualitative study, evidence based practice, evidence based quality improvement or quality improvement projects) or Level 7 (evidence from the opinion of authorities and/or reports of expert committees, reports from committees of experts and narrative and literature review).

The relationship between patients, families, and pediatric providers was most frequently identified as a barrier to transition. However, the relational aspects between patient, family and pediatric provider were also cited as an occasional facilitator. As part of the article extraction process, the authors noted whether articles identified the relationship as a barrier, neutral to the transition process, or as a facilitator, and from which stakeholder's perspective. Table 2 illustrates that frequency of articles that mention barriers, neutral statements or facilitators within articles, with the possibility that an article could call out more than one (e.g. as both a barrier and facilitator).

Relationships were portrayed as barriers from multiple perspectives. Table 3 provides illustrative examples of barriers, facilitators and neutral concepts from patient, parent, pediatric provider and adult

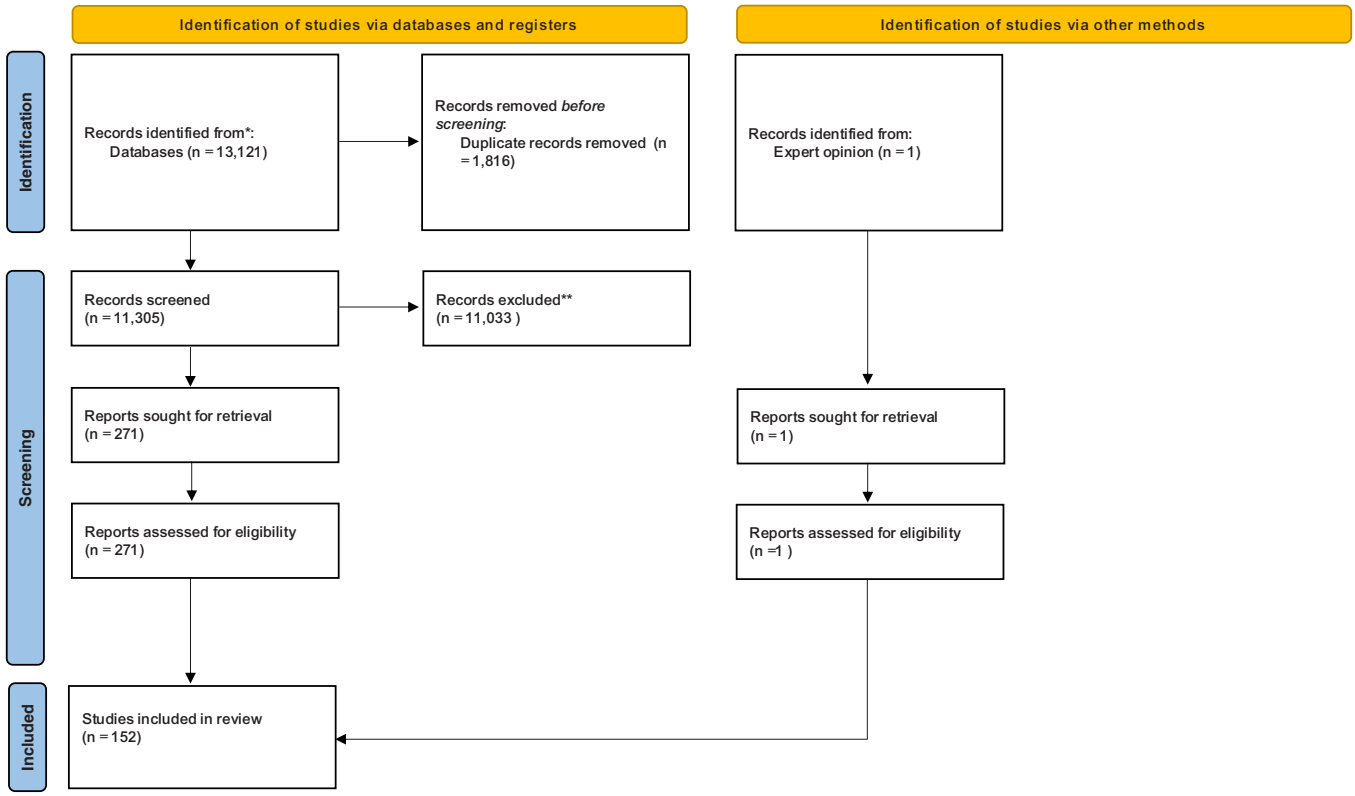

Fig. 1. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources [22]

Table 1
Level of Description of Relational Aspects.

Author (s)	Title	Category	Level of Evidence
[29]	Transition of Care Provided for Adolescents with Special Health Care Needs (Consensus Statement)	Concept Merely Mentioned	Level 7
[30]	Applying Specialist Nurse Skills to Improve Epilepsy Adolescent Transition Services	Concept Merely Mentioned	Level 6
[31]	Psychosocial Challenges/Transition to Adulthood	Concept Merely Mentioned	Level 7
[32]	Development and Implementation of an Adolescent Epilepsy Transition Clinic	Concept Merely Mentioned	Level 6
[33]	Challenges in the Transition of Care Process for Patients with Dravet and Lennox-Gastaut Syndromes	Concept Merely Mentioned	Level 7
[34]	Transition Readiness in Adolescents and Emerging Adults with Diabetes: The Role of Patient-Provider Communication	Concept Merely Mentioned	Level 7
[35]	Transition of Care to Adult Neuroimmunology	Concept Merely Mentioned	Level 7
[36]	Healthcare Coordination and Transition for Individuals with Genetic Conditions	Concept Merely Mentioned	Level 6
[37]	Transition from Pediatric to Adult Medical Care: A survey in young persons with inflammatory bowel disease	Concept Merely Mentioned	Level 6
[38]	From Transmission to Transition: Lessons Learnt from the Thai Paediatric Antiretroviral Programme	Concept Merely Mentioned	Level 6
[39]	Transition from pediatric to adult healthcare services for young adults with chronic illnesses: the special case of human immunodeficiency virus infection	Concept Discussed	Level 7
[40]	Defining Transition Success for Young Adults with Inflammatory Bowel Disease According to patients…	Concept Discussed	Level 6
[41]	Growing Up: Not an Easy Transition-Perspectives of Patients and Parents regarding Transfer from a Pediatric Liver Transplant Center to Adult Care	Concept Discussed	Level 6
[42]	Scoping review of neurogenic bladder patient-reported readiness and experience following care in a transitional urology clinic	Concept Discussed	Level 3
[43]	Transition from paediatric to adult-orientated care for adolescents with cystic fibrosis	Concept Discussed	Level 7
[44]	Graduation Day: Healthcare Transition From Pediatric to Adult	Concept Discussed	Level 7
[45]	Transition from paediatric to adult care for patients with sickle cell disease	Concept Discussed	Level 6
[46]	That eagle covering me: transitioning and connected autonomy for emerging adults with cystinosis	Concept Discussed	Level 6
[47]	Transitioning Care of an Adolescent With Cystic Fibrosis: Development of Systemic Hypothesis Between Parents, Adolescents, and Health Care Professionals	Concept Discussed	Level 6
[48]	The pediatric social worker really shepherds them through the process: Care team members' roles in transitioning adolescents and young adults with HIV to adult car	Concept Discussed	Level 6
[49]	Essen transition model for neuromuscular diseases	Concept Discussed	Level 6
[50]	Topical review: Transitional services for teens and young adults with attention-deficit hyperactivity disorder: A process map and proposed model to overcoming barriers to care	Concept Discussed	Level 7
[51]	Physicians as barriers to successful transitional care	Concept Discussed	Level 7
[52]	Transition of pediatric liver transplant recipients to adult care: patient and parent perspectives	Concept Discussed	Level 6
[53]	Health Care Transition Preparation and Experiences in a US National Sample of Young Adults With Type 1 Diabetes	Concept Discussed	Level 6
[54]	Care of adolescents in transition	Concept Discussed	Level 7
[55]	Educate, communicate, anticipate-practical recommendations for transitioning adolescents with IBD to adult health care	Concept Discussed	Level 7
[56]	Systems thinking perspectives applied to healthcare transition for youth with disabilities: a paradigm shift for practice, policy and research	Concept Discussed	Level 7
[57]	Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams	Concept Discussed	Level 6
[58]	The adolescent with sickle cell anemia	Concept Discussed	Level 7
[59]	Inflammatory bowel disease in transition: challenges and solutions in adolescent care	Concept Discussed	Level 7
[60]	Navigating being a young adult with cerebral palsy: a qualitative study	Concept Discussed	Level 6
[61]	Destination unknown: Parents and healthcare professionals' perspectives on transition from pediatric to adult care in down syndrome	Concept Discussed	Level 6
[62]	Inflammatory Bowel Disease Nurses' Perspectives: Prioritizing Adolescent Transition Readiness Factors	Concept Discussed	Level 6
[63]	"That's True Love:" Lived Experiences of Puerto Rican Perinatally HIV-Infected Youth within Their Families' Context	Concept Discussed	Level 6
[64]	Qualitative study of facilitators and barriers for continued follow-up care as perceived and experienced by young people with congenital heart disease in Sweden	Concept Discussed	Level 6
[65]	Parents' views on and need for an intervention during their chronically ill child's transfer to adult care	Concept Discussed	Level 6
[66]	The transition experience of epilepsy patients/families: results of a telephone survey	Concept Discussed	Level 6
[67]	Transitioning from pediatric to adult care and the HIV care continuum in Ghana: a retrospective study	Author identified Salient Theme	Level 6
[68]	Transition from Pediatric to Adult Centered Care: Lessons from the Literature and the Trenches	Author identified Salient Theme	Level 7
[69]	Perspectives on care for young adults with type 1 diabetes transitioning from pediatric to adult health systems: A national survey of pediatric endocrinologists	Author identified Salient Theme	Level 6
[70]	Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study	Author identified Salient Theme	Level 3
[71]	Challenges in transitioning adolescents and young adults with rheumatologic diseases to adult Care in a Developing Country - the Brazilian experience	Author identified Salient Theme	Level 6

(continued on next page)

Table 1 (*continued*)

Author (s)	*Title*	*Category*	*Level of Evidence*
[72]	Transition of care to adult services for pediatric solid-organ transplant recipients	Author identified Salient Theme	Level 7
[73]	Transitions in Pediatric Gastroenterology: Results of a National Provider Survey	Author identified Salient Theme	Level 6
[74]	Health care transition planning: A potpourri of perspectives from nurses	Author identified Salient Theme	Level 6
[75]	Health care transition in congenital heart disease: the providers' view point	Author identified Salient Theme	Level 7
[76]	Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views	Author identified Salient Theme	Level 6
[77]	Transition, It's More Than Just An Event: Supporting Young People With Type 1 Diabetes	Author identified Salient Theme	Level 6
[78]	Journeying from nirvana with mega-mums and broken hearts: the complex dynamics of transition from paediatric to adult settings	Author identified Salient Theme	Level 6
[79]	Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities	Author identified Salient Theme	Level 6
[80]	Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults	Author identified Salient Theme	Level 6
[81]	Adolescents With Congenital Heart Disease and Their Parents Needs Before Transfer to Adult Care	Author identified Salient Theme	Level 6
[82]	Easing the transition of HIV-infected adolescents to adult care	Author identified Salient Theme	Level 7
[83]	"You think it's hard now…It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services	Author identified Salient Theme	Level 6
[84]	Healthcare needs of adolescents with congenital heart disease transitioning into adulthood: a Delphi survey of patients, parents, and healthcare providers	Author identified Salient Theme	Level 6
[85]	Barriers in transitioning urologic patients from pediatric to adult care	Author identified Salient Theme	Level 7
[86]	Transitioning adolescents to adult nephrology care: a systematic review of the experiences of adolescents, parents, and health professionals	Author identified Salient Theme	Level 5
[87]	Transitions from pediatric to adult rheumatology care for juvenile idiopathic arthritis: a patient led qualitative study	Author identified Salient Theme	Level 6
[88]	Transition from pediatric to adult health care for young adults with neurological disorders: parental perspectives	Author identified Salient Theme	Level 6
[89]	Transfer is not a transition - voices of Jamaican adolescents with HIV and their health care providers	Author identified Salient Theme	Level 6
[90]	Health Care Transition for Youth Living With HIV/AIDS	Author identified Salient Theme	Level 5
[91]	Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: A scoping review	Author identified Salient Theme	Level 5
[92]	Knowledge of disease markers and quality of patient-provider interaction among adolescents with perinatally acquired HIV: implications for transition to adult care	Author identified Salient Theme	Level 6
[93]	"It's like losing a part of my family": transition expectations of adolescents living with perinatally acquired HIV and their guardians	Author identified Salient Theme	Level 6
[94]	Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis	Author identified Salient Theme	Level 5
[95]	Transition of Care and Health-Related Outcomes in Pediatric-Onset Systemic Lupus Erythematosus	Author identified Salient Theme	Level 6
[96]	Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: Results of a clinician survey at a free-standing pediatric hospital	Author identified Salient Theme	Level 6
[97]	Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective	Author identified Salient Theme	Level 6
[98]	Clinician perceptions of transition of patients with pediatric-onset chronic disease to adult medical care	Author identified Salient Theme	Level 6
[99]	Referral patterns and perceived barriers to adult congenital heart disease care: results of a survey of U.S. pediatric cardiologists	Author identified Salient Theme	Level 6
[100]	The Importance of Meanings of Antiretroviral Treatment and Care Providers for Adherence and Transitioning to Adult Services Among Youth With Perinatally Acquired HIV	Author identified Salient Theme	Level 6
[101]	Adherence to transition guidelines in European paediatric nephrology units	Author identified Salient Theme	Level 6
[102]	A qualitative study of transitioning patients with hydrocephalus from pediatric to adult care: fear of uncertainty, communication gaps, independence, and loss of relationships	Author identified Salient Theme	Level 6
[103]	Health Care Transition Perceptions Among Parents of Adolescents with Congenital Heart Defects in Georgia and New York	Author identified Salient Theme	Level 6
[104]	Status of the transition/transfer process for adolescents with chronic diseases at a national pediatric referral hospital in Argentina	Author identified Salient Theme	Level 6
[105]	Adult Provider Perspectives on Transition and Transfer to Adult Care: A Multi-Specialty, Multi-Institutional Exploration	Author identified Salient Theme	Level 6
[106]	Barriers to Transition From Pediatric to Adult Care: A Systematic Review	Author identified Salient Theme	Level 3
[107]	Concerns, Barriers, and Recommendations to Improve Transition from Pediatric to Adult IBD Care: Perspectives of Patients, Parents, and Health Professionals	Author identified Salient Theme	Level 6
[108]	HIV positive youth's healthcare transition from pediatric to adult service: nursing implications	Author identified Salient Theme	Level 6
[109]	5 years after introduction of a transition protocol: An evaluation of transition care for patients with chronic bladder conditions	Author identified Salient Theme	Level 6

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Table 1 (*continued*)

Author (s)	*Title*	*Category*	*Level of Evidence*
[110]	Transitioning adolescents with sickle cell disease to adult-centered care	Author identified Salient Theme	Level 6
[111]	Healthcare system barriers to long-term follow-up for adult survivors of childhood cancer in British Columbia, Canada: a qualitative study	Author identified Salient Theme	Level 6
[112]	Transition from paediatric to adult care: a qualitative study of the experiences of young adults with type 1 diabetes	Author identified Salient Theme	Level 6
[113]	Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership	Author identified Salient Theme	Level 7
[114]	Patient and parent perspectives on transition from paediatric to adult healthcare in rheumatic diseases: an interview study	Author identified Salient Theme	Level 6
[115]	Meeting the needs of young people with diabetes: an ongoing challenge	Author identified Salient Theme	Level 6
[116]	Transition from pediatric to adult care among patients with epilepsy: Cross-sectional surveys of experts and patients in Korea	Author identified Salient Theme	Level 6
[117]	Transition clinics: an observational study of themes important to young people with inflammatory bowel disease	Author identified Salient Theme	Level 6
[118]	Ethical considerations in transition	Author identified Salient Theme	Level 7
[119]	Transition and transfer of childhood cancer survivors to adult care: A national survey of pediatric oncologists	Author identified Salient Theme	Level 6
[120]	A national survey of transition from pediatric to adult healthcare providers for adolescents and young adults with type 1 diabetes: perspectives of pediatric endocrinologists in Korea	Author identified Salient Theme	Level 6
[121]	Transitions in the lives of young people with complex healthcare needs	Author identified Salient Theme	Level 6
[122]	Transition from child to adult care in an outpatient clinic for adolescents with juvenile idiopathic arthritis: An inductive qualitative study	Author identified Salient Theme	Level 6
[123]	South African healthcare provider perspectives on transitioning adolescents into adult HIV care	Author identified Salient Theme	Level 6
[124]	Toward a better understanding of transition from pediatric to adult care in type 1 diabetes: A qualitative study of adolescents	Author identified Salient Theme	Level 6
[125]	Transition of patients with mucopolysaccharidosis from paediatric to adult care	Author identified Salient Theme	Level 7
[126]	Transitioning to adult care among adolescents with sickle cell disease: a transitioning clinic based on patient and caregiver concerns and needs	Author identified Salient Theme	Level 6
[127]	Experiences of young people living with type 1 diabetes in transition to adulthood: The importance of care provider familiarity and support	Author identified Salient Theme	Level 6
[128]	Defining "Community" from the Perspectives of Individuals with Sickle Cell Disease in Rural Georgia	Author identified Salient Theme	Level 6
[129]	Primary Care Providers Involvement in Caring for Young Adults with Complex Chronic Conditions Exiting Pediatric Care: An Integrative Literature Review	Author identified Salient Theme	Level 3

Table 1 (*continued*)

Author (s)	*Title*	*Category*	*Level of Evidence*
[130]	Adolescents and Adults With Congenital Heart Disease: Why Are They Lost to Follow-Up?	Author identified Salient Theme	Level 7
[131]	Parental Perspectives on Health Care Transition in Adolescent and Young Adult Survivors of Pediatric Cancer	Author identified Salient Theme	Level 3
[132]	Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies	Author identified Salient Theme	Level 5
[133]	Adolescents growing with HIV/AIDS: experiences of the transition from pediatrics to adult care	Author identified Salient Theme	Level 6
[134]	Patient and Caregiver Perspectives on Transition and Transfer	Author identified Salient Theme	Level 6
[135]	Transition from paediatric to adult services: experiences of HIV-positive adolescents	Author identified Salient Theme	Level 6
[135]	Transition from pediatric to adult services: Experiences of HIV-positive adolescents	Author identified Salient Theme	
[136]	Strategies to improve outcomes of youth experiencing healthcare transition from pediatric to adult HIV care in a large U.S. city	Author identified Salient Theme	Level 6
[137]	Transition of patients with childhood onset epilepsy: Perspectives from pediatric and adult neurologists	Author identified Salient Theme	Level 6
[138]	'You're 18 now, goodbye': the experiences of young people with attention deficit hyperactivity disorder of the transition from child to adult services	Author identified Salient Theme	Level 6
[139]	Patient, Caregiver, and Provider Perceptions of Transition Readiness and Therapeutic Alliance during Transition from Pediatric to Adult Care in Epilepsy	Author identified Salient Theme	Level 6
[140]	Defining success in transitions from pediatric to adult chronic pain care: A descriptive qualitative study of perspectives of young adults living with chronic pain	Author identified Salient Theme	Level 6
[141]	Transition experience of young adults with inflammatory bowel diseases (IBD): a mixed methods study	Author identified Salient Theme	Level 6
[142]	The role of resilience in healthcare transitions among adolescent kidney transplant recipients	Author identified Salient Theme	Level 6
[143]	Transitional-age youth with chronic medical and mental health conditions	Author identified Salient Theme	Level 7
[144]	Epilepsy: addressing the transition from pediatric to adult care	Author identified Salient Theme	Level 7
[145]	Challenges to Diabetes Self-Management in Emerging Adults With Type 1 Diabetes	Author identified Salient Theme	Level 6
[146]	Follow-up care provider preferences of adolescent and young adult cancer survivors	Author identified Salient Theme	Level 6
[147]	Health care transition: youth, family, and provider perspectives	Author identified Salient Theme	Level 6
[148]	Transition from paediatric to adult ophthalmology services: what matters most to young people with visual impairment	Author identified Salient Theme	Level 6
[149]	Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents	Author identified Salient Theme	Level 6

(*continued on next page*)

Table 1 (*continued*)

Author (s)	*Title*	*Category*	*Level of Evidence*
[150]	Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers	Author identified Salient Theme	Level 6
[151]	Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative interview study of survivors	Author identified Salient Theme	Level 6
[152]	Transitioning Adolescents and Young Adults with Spina Bifida to Adult Healthcare: Initial Findings from a Model Program	Author identified Salient Theme	Level 6
[153]	Addressing transition to adult health care for adolescents with special health care needs	Author identified Salient Theme	Level 6
[154]	Life beyond pediatrics. Transition of chronically ill adolescents from pediatric to adult health care systems	Author identified Salient Theme	Level 7
[155]	Perspectives from primary health care providers on their roles for supporting adolescents and young adults transitioning from pediatric services	Author identified Salient Theme	Level 6
[156]	Parental experiences of transitioning their adolescent with epilepsy and cognitive impairments from pediatric to adult health care	Author identified Salient Theme	Level 6
[157]	Social workers as transition brokers: facilitating the transition from pediatric to adult medical care	Author identified Salient Theme	Level 7
[158]	The transition from pediatric to adult health care in young adults with spina bifida: Demographic and physician-related correlates	Author identified Salient Theme	Level 6
[159]	Transitioning Adolescents and Young Adults With Sickle Cell Disease From Pediatric to Adult Health Care: Provider Perspectives	Author identified Salient Theme	Level 6
[160]	Challenges of the Transition from Pediatric Care to Care of Adults: "Say Goodbye, Say Hello"	Author identified Salient Theme	Level 7
[161]	Health Care Transition in Youth With Type 1 Diabetes and an A1C > 9 %: Qualitative Analysis of Pre-Transition Perspectives	Author identified Salient Theme	Level 6
[162]	Transition of the adolescent from the children's to the adults' diabetes clinic	Author identified Salient Theme	Level 7
[163]	Transition to adult care: Experiences and expectations of adolescents with a chronic illness	Author identified Salient Theme	Level 6
[164]	Transition of the adolescent patient with rheumatic disease: issues to consider	Author identified Salient Theme	Level 6
[165]	Transition from pediatric to adult medical services for young people with chronic neurological problems	Author identified Salient Theme	Level 7
[166]	Qualitative study exploring the perspectives of emerging adults with type 1 diabetes after transfer to adult care from a paediatric diabetes centre in Montreal, Canada	Author identified Salient Theme	Level 6
[167]	Needs of children with a chronic bladder in preparation for transfer to adult care	Author identified Salient Theme	Level 6
[168]	Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers	Author identified Salient Theme	Level 6
[169]	We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine	Author identified Salient Theme	Level 6
[170]	"Are these adult doctors gonna know me?" Experiences of transition for young people with a liver transplant	Author identified Salient Theme	Level 6
[171]	Healthcare transition in pediatric liver transplantation: The perspectives of pediatric and adult healthcare professionals	Author identified Salient Theme	Level 6
[172]	Patient Perspectives on Nurse-led Consultations Within a Pilot Structured Transition Program for Young Adults Moving From an Academic Tertiary Setting to Community-based Type I Diabetes Care	Author identified Salient Theme	Level 6
[27]	The Transition from Paediatric to Adult Health Care Services for Young Adults with a Disability: An Ethical Perspective	Major premise/ Exclusively about	Level 7
[25]	Transition From Pediatric and Adolescent HIV Care to Adult HIV Care and the Patient-Provider Relationship: A Qualitative Metasynthesis	Major premise/ Exclusively about	
[26]	Cliff or Bridge: Breaking up with the paediatric healthcare system	Major premise/ Exclusively about	Level 7
[28]	Putting the Good in Goodbye: The Pediatrician's Role in Framing a Positive Transition to Adult Care	Major premise/ Exclusively about	Level 7
[24]	"A Bridge Over Troubled Water": Nurses' Leadership in Establishing Young Adults' Trust Upon the Transition to Adult Renal-Care - A Dual-Perspective Qualitative Study	Major premise/ Exclusively about	Level 6
[173]	Patient-Provider Relationships Across the Transition From Pediatric to Adult Diabetes Care A Qualitative Study	Major premise/ Exclusively about	Level 6

Table 2
Frequency of Relational factors as Barriers, Neutral or Facilitators from Stakeholder Perspectives.

	Patient	Parent	Pediatric Provider	Adult Provider
Barrier	108	70	65	15
Neutral	9	2	4	1
Facilitator	27	10	22	19

provider perspective.

Patients identified relational aspects most often as a barrier. They reportedly struggled with strong feelings of loss:

"Focus group participants highlighted the importance of the strong, longstanding relationships they had built with their pediatric rheumatologists. For many patients, their pediatric rheumatology team had played a pivotal role in their development, and participants mourned the loss of this relationship when they were required to see a new physician"[87].

"Young adults with T1D often have long-standing relationships with their pediatric providers. Indeed, 64 % of T1D patients between the ages of 18 & 30 who were still in pediatric care noted they had avoided transitioning to adult care due to an emotional attachment to their pediatric provider."[113].

There were references to a pediatric provider's inability to let go:

"Pediatric physicians often develop close relationships with patients and their families, fostering a strong mutual bond of caring and trust. As a result, pediatric gastroenterologists themselves can be a barrier to transition"[68];.

"In keeping with studies in other contexts, a barrier to the transition

Table 3
Concepts of Relational Factors as Barriers, Neutral or Facilitator from Stakeholder Perspectives.

	Patient	Parent	Pediatric Provider	Adult Provider
Barrier	Loss of close & long-standing relationships including feelings of abandonment, anger & grief Expectation of significant effort to build new relationship with adult provider ("hard to start over")	Loss of long-standing, trusting relationships and support systems Loss of control: fear that adult provider will not listen to or value their expertise (as compared with active involvement in pediatric care)	Loss of close & long-standing relationships Difficulty letting go as feeling of protective attachment	Mismatch in expectations as patients are less prepared to advocate for themselves (overreliance on others) Strong relationships with pediatric providers impedes connecting with new adult provider
Neutral (neither barrier nor facilitator, just "is")	Comfortable relationship with pediatric care provider Important to have good rapport	End of meaningful relationship Important aspect of trauma-informed care is honoring the relational component	Acknowledge shared experiences to provide closure Complex process of interactions in continual relationships	Consultation style (problem-focused) and communication interactions
Facilitator	Feeling known, safe & attached to pediatric provider may transfer to adult provider ("I know I can build relationships") Learning strategies from pediatric provider focusing on autonomy & independence may transfer to adult provider ("I know I can advocate for myself")	Experiencing strong & positive relationship with pediatric provider may transfer to adult provider Perceiving strong & positive relationship between pediatric and adult providers with clear transfer process contributes to feeling secure with adult provider (trust the referral)	A caring relationship, providing opportunities to discuss care, may be model for adult oriented care and future relationships Lack of attachment may contribute to greater readiness to transition/leave current provider	More patient-centered approach affirms value of autonomy & collaboration (treats patients "like adults") Collaborative, rather than pediatric/paternalistic, approach reduces "feeling judged"

process was the healthcare provider's difficulty in letting go of relationships with their adolescent patients. Healthcare providers felt a strong, protective attachment towards their adolescent patients, whom they considered vulnerable"[123].

There were also several papers noting concerns from patients and parents that the new team would not know them as well:

"After transfer, the loss of relationship with the paediatric team was considered a barrier to transition care as it required an increased effort to build a new therapeutic relationship with the adult care team"[166].

"Caregivers regretted losing a valued and trusted provider"[83].

Parents further identify a barrier related to the ambiguity of their new role with the adult team:

"Additional issues identified were the parents losing their own support system and anticipating their own role change, although not understanding how it might change"[110].

A smaller number of papers also discussed ways that the relationship between patients/parents and pediatric providers served as a facilitator in modelling how trusting relationships and communication could be built:

"participants who were pediatric providers repeatedly cited trusting relationships between the patient and provider as a facilitator to successful transition. They explained that when patients were comfortable discussing treatment plans and asking questions openly, they were more likely to be successful when they transferred to an adult provider"[159].

Importantly, when relationships were identified as patronizing, patients reported this as facilitating transition, because they looked forward to a more empowered, and less passive, relationship with an adult provider.

"Patients valued how adult providers' collaborative conversations promoted their involvement and accountability compared with "parent-centric" interactions with pediatric providers. Participants reported feeling less judged by adult providers than pediatric providers"[44].

4. Discussion

This scoping review looked broadly at how research examined the effects of relationships on the pediatric to adult transition context. While 152 were eventually identified as meeting criteria for inclusion, very few were exclusively about the topic of relationships in transition.

Relational aspects of the patient/provider relationship were identified as both barriers and facilitators from every stakeholder perspective. Distilling the reasons behind when relationships were seen in each way may lead to possible interventions to improve the transition process through better understanding and/or modification of these relational aspects. It is important to acknowledge that while the strength of relationships between providers and patients and families are widely seen as beneficial to pediatric care, these same strengths may actually serve as a barrier to transition. Numerous papers suggest that all stakeholders seem to experience strong emotions that inhibit their ability to move readily toward transfer[25,123,166,83,53]. Quotes from articles underscored sadness at the end of a relationship, fear of the unknown, and lack of confidence that there would be the same level of understanding with adult providers. Patients felt that pediatric providers "got them"; while parents felt they have developed a therapeutic working relationship with someone and may fear that they will be excluded from conversations in the future. These areas may serve as useful targets for future intervention development. Specifically, being able to acknowledge these feelings in a formal way as part of a transition process may improve coping for all involved. In addition, fears can be addressed directly with psychoeducation provided to both normalize and also better prepare everyone for transition.

Providers often felt protective of their treatment plans or proud of their clinical, research or relational efforts and did not wish to say goodbye[29.30]. This strong connection between a pediatric provider and a patient can serve as a barrier in some circumstances, but it can also enhance the feelings of autonomy, confidence and self-efficacy that are central to an ultimately successful transfer of care. Where there is a trusting relationship with a pediatric provider, patients can learn to honestly communicate questions and concerns and practice skill building through the transition years. Several studies suggested that, with a lived experience of a healthy relationship with a medical provider, patients could move into adult care prepared to build a rapport that feels supportive and nurture a similar therapeutic alliance[26,159].

Research suggests that patients who have good relationships with their pediatric providers possess insight into what is important to them and can hope to build an equally successful relationship with a new provider over time[26,28]. One area in which interventions and education may be useful is to emphasize ways that the transition to adult care can be empowering for the young adult patient. The more patient-centred approach in adult medicine can often feel reaffirming with respect to autonomy and collaboration, as opposed to an often less empowering and occasionally paternalistic or prescriptive approach in pediatrics, where providers and team members may do more for the patient and pull in parents more directly and for longer than the youth may desire. Framing the shift in this way is another intervention to be considered.

One unique aspect of this study is that all reviewers were licensed

social workers. In a multi-disciplinary role, clinical social workers bear witness to the many dimensions that impact the transition experience for families, patients, and medical caregivers, including the strong emotional connections formed[174]. Clinical social workers and other mental health clinicians are trained to approach patient encounters with a lens that recognizes experiences, perceptions, and health/illness narratives unique to each individual, which enables the scaffolding of strong working relationships with patients. This underpinning promotes and distinguishes relationships as core to medical social work practice[175]. The quality and influence of the relationship and dyads between the patient and medical provider resonate with social workers, as they reflect codified professional values and identities[176]. In a medical model, clinical social workers are frequently the psychosocial providers fully embedded within care teams, encountering patients during various longitudinal medical touchpoints. Psychologists and other mental health providers may be focused on specific, discrete consult-driven assessments. All mental health clinicians are trained that termination is an important part of the therapeutic process, something that is particularly relevant to transition work. A 'person-in-environment' perspective in social work is a well-established practice-guiding principle that highlights the importance of understanding of behavior within environmental contexts; the health care system is one of these concentric rings impacting relational variables. Health-care transition considerations include multiple environments and relationships within these systems. Social workers inherently have this whole environment lens in their scope of role. As part of interdisciplinary care teams, they are well positioned to help navigate the relational aspects of transition.

There were limitations to the study. As with any scoping review, otherwise relevant articles may have been missed in abstract review stage that did not meet pre-articulated criteria. It was noted that one of the authors of this scoping review had an article that focused exclusively on relationship that was ultimately included based on expert opinion and consensus of the authors, but the abstract itself did not accurately describe the key concepts that aligned with criteria. It would not have made it through review if the team had not been thoroughly aware of the precise and overt content. There is the potential that other abstracts similarly did not mention the search terms and additional pertinent articles were missed. Although not included in this review, the transition from child to adult mental health services came up frequently in the abstract review and, given the focus on the therapeutic relationships in mental health treatment, is an additional important area to explore. A strength of the study is that the study team was composed entirely of medical social workers with interest and experience in the area of transition practice. Social workers are trained to understand relational factors and the potential nuances involved with the termination process within the dynamic of said relationships.

5. Conclusion

The relationship between patients, parents and pediatric providers is a frequently mentioned topic in the transition literature. While the majority of studies describe these important relationships as barriers, some highlight relationships as facilitators in transition. However, there is very little research focused exclusively on the topic of relationships that includes any formal study of interventions, with no randomized control studies found and the majority of the studies in levels 6 and 7 according to the hierarchy of evidence coding. Further research on potential interventions are needed, especially research focused on leveraging the identified facilitators to improve the transition process. In addition to reducing the identified barriers, such strengths based models may serve as a useful way to improve transition outcomes across various fields of practice.

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Ethical Statement

Hereby, I, Susan Shanske, consciously assure that for the manuscript "Letting Go/ Moving On: A Scoping Review of Relational Effects on Transition to Adult Care" the following is fulfilled:

2) This material is the authors' own original work, which has not been previously published elsewhere. Early data was presented in poster format at the Health Care Research Consortium Symposium in October, 2023 in Houston, TX.
3) The paper is not currently being considered for publication elsewhere.
4) The paper reflects the authors' own research and analysis in a truthful and complete manner.
5) The paper properly credits the meaningful contributions of co-authors and co-researchers. No AI was used at any point in the manuscript creation.
6) The results are appropriately placed in the context of prior and existing research.
7) All sources used are properly disclosed (correct citation). Literally copying of text must be indicated as such by using quotation marks and giving proper reference.
8) All authors have been personally and actively involved in substantial work leading to the paper, and will take public responsibility for its content.

The violation of the Ethical Statement rules may result in severe consequences.

I agree with the above statements and declare that this submission follows the policies as outlined in the Guide for Authors and in the Ethical Statement.

CRediT authorship contribution statement

Teresa Hickam: Writing – review & editing, Investigation, Conceptualization. **Salihah Hanson:** Writing – review & editing, Investigation, Conceptualization. **Lynne Helfand:** Writing – review & editing, Investigation, Conceptualization. **Colleen Hayden:** Writing – review & editing, Investigation. **Jennifer Cuadra:** Writing – review & editing, Investigation, Conceptualization. **Judy Bond:** Writing – original draft, Investigation, Conceptualization. **Janis Arnold:** Writing – original draft, Methodology, Investigation, Conceptualization. **Susan Shanske:** Writing – original draft, Methodology, Investigation, Conceptualization. **Alexandria Cronin:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Colleen Huysman:** Writing – review & editing, Investigation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

No data was used for the research described in the article.

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