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Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: A scoping review

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ABSTRACT

Background: Health care transition (HCT) has become increasingly important as adolescents and young adults (AYAs) with complex medical conditions now live well into adulthood but little attention has been given to parents of AYAs preparing for HCT.
Objective: This scoping review aimed to identify and synthesize information on parental facilitators and barriers to health care transition readiness.
Eligibility criteria: English-language, peer-reviewed original studies focused on the parents' experience of HCT were included. Studies were excluded if AYAs were not anticipated to be independent or if AYAs had only mental health disorders.
Charting methods: Parent-reported facilitators and barriers were identified in each study and then categorized to identify common themes.
Results: Themes related to parental facilitators included evidence of coordination between pediatric and adult levels of care, healthcare provider guidance for HCT, and parental awareness and acceptance of natural seasons of life. Themes related to parental barriers included relationship loss, loss of parental role, lack of knowledge and/or skills, and concerns related to the health care system in general.
Conclusion: Common facilitators and barriers were found across studies, regardless of medical diagnosis. Relationships and role change figure prominently in parents' perceptions of the HCT experience and their readiness for their AYA children to transition. These findings suggest potential areas for future research inquiry as well as potential nursing interventions designed to aid parents through HCT.

Introduction

Near the end of the twentieth century health care transition (HCT) for adolescents and young adults (AYAs) garnered increased attention (White & McManus, 2018). In the years since, many resources have been developed to support health care transition (HCT) efforts in the United States. Proper transition planning is a recognized health care objective of the Healthy People, 2020 effort (Barriers to health care, 2022). The phenomenon of HCT, defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems" (Blum et al., 1993, p. 570), is not localized to the United States; other developed countries around the world are working toward efforts to facilitate smooth transitions for AYAs (Escherich et al., 2017; Gabay & Tarabeih, 2020).

Though smooth transitions are important for all AYAs, HCT becomes more crucial when the AYA in question has a chronic health condition. Little more than half a century ago children with diseases such as cystic fibrosis or sickle cell disease often did not survive into adulthood, and pediatric cancers were considered nearly impossible to treat (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Smith & Reaman, 2015). Pediatric health care providers have become more successful at diagnosing and treating chronic conditions, and treatments have become more sophisticated and effective. As a result, an increasing number of AYAs with medically complex conditions must navigate the transition from pediatric to adult health care providers.

Historically, we have prepared AYAs for this important transition poorly. The lack of preparation has negative implications for the health of chronically ill AYAs. Immediately post transition, AYAs with chronic health conditions have poorer adherence to medication regimens (Annunziato et al., 2007). During the years following transition, they experience a number of complications, including more frequent and

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longer hospitalizations (Blinder et al., 2013; Nakhla et al., 2009), transplanted organ rejection (Andreoni et al., 2013), general decline in overall health (Prior et al., 2014), long-term effects related to treatments for prior illnesses such as pediatric cancer, and higher rates of mortality from conditions such as sickle cell disease (Lorenzi et al., 2011; Psihogios et al., 2019; Quinn et al., 2010).

The Social-ecological Model of AYA Readiness to Transition (SMART) identifies modifiable and non-modifiable factors that influence transition readiness of those involved (Schwartz et al., 2013). This model describes the complex interplay between those factors and the triad at the center of the process (composed of patient, parent(s), and provider). Though more recent studies better acknowledge the influence of each member of this triad on the transition process, early literature on HCT often focused on the perspective of the pediatric care provider as the expert regarding patient readiness to transition (Magrab & Millar, 1989). The bulk of recent literature has focused on the patient member of this triad. As the focus shifted to the patients themselves, parents and providers were often interviewed or surveyed simply to solicit their input regarding the readiness of the AYA for transition (Nandakumar et al., 2018; Nazareth et al., 2018). The role parents play and their needs during the HCT process have been downplayed or overlooked by researchers. However, parents exert a strong influence on their AYA children and, as such, can either facilitate or hinder health care transition preparation. It is important, therefore, to consider factors that influence parental readiness for their child's HCT.

Parents of children and adolescents with medically complex conditions become experts in their children's care (Balling & McCubbin, 2001). It is not unusual for parents to stop working and make the management of their child's medical condition a full-time occupation (Heaton et al., 2005). A majority of parents are heavily involved in every aspect of their child's care (Clarizia et al., 2009). Over time and exposure, parents become quite adept at managing their child's complex medical condition. They memorize medication schedules, make and attend all appointments, and partner with health care providers to ensure that their child's health and quality of life are as good as possible. Typically, by the time children with medical complexities become AYAs, their parents are veritable experts on their medical condition.

It is one thing to be an expert, but it is another thing to prepare your successor to take over. As with many other life transitions, parents play a pivotal role in preparing their AYAs for HCT (Allemang et al., 2019). Parents who have developed their illness-managing expertise over potentially many years often have little or no preparation in how to assist their children in learning sufficient self-management skills that would allow the children to take over the management of their own care. According to Byrnes (2018), the family is where transition readiness begins. Even as they help prepare their AYAs for HCT, parents are experiencing a transition of their own (Heath et al., 2017). Their role in the health care experience of their children, of necessity, changes during the process of HCT. In successful HCT, parents eventually stop managing the medications (both daily administration and refills) and making the appointments for their children. They should stop carrying the discussion with the health care providers during appointments. Parents need to prepare themselves for the possibility that their AYA may ask them not to attend these appointments, as the AYA becomes competent to manage their own care.

Evidence suggests that it is not always easy for parents to navigate their own role changes during this transition preparation period (Betz et al., 2015). AYAs have pointed to parental control, or reluctance to empower their AYA, as a factor that hinders their transition preparation and/or readiness (Bashore & Bender, 2016). Buckner (2018) suggests that health care providers should help parents understand how they can assist in the process of transition and its preparation, and parents have indicated that this guidance would be welcome. In a review of qualitative studies related to parental experiences of HCT, Heath et al. (2017) found that parents of AYAs across a diverse range of complex medical conditions reported similar experiences. However, this study stopped short of categorizing experiences as a help or a hinderance to the parents' own readiness for transition. As health care professionals seek new and innovative ways to assist with HCTs, they need to know what factors and experiences parents find helpful and what experiences negatively impact their readiness for HCT.

After years of managing the health care experiences of their child, embracing a more passive, supervisory role might be challenging for parents; therefore, it becomes important to ensure that parents are prepared for this transition. Believing that parental readiness for the HCT of their AYA children can be of vital significance in the transition readiness of the children themselves, the objective of this scoping review is to explore and categorize literature that focuses on parents and their experience in the transition of AYAs with chronic medical conditions in order to identify barriers and facilitators to parents' readiness for their child's transition. Gaining this type of knowledge regarding the parents' experience of their child's transition can lead to a more complete understanding of the HCT process in general and guide interventions that will assist parents with their own transition readiness. This objective lends itself to a scoping review, as research into parental readiness for HCT is nascent; this review allows us to map the current state of the literature and identify areas for further research.

Methods

Information sources and search strategy

A systematic search for published peer-reviewed, English-language literature was conducted along with a search of the reference lists for retrieved publications to identify published papers specifically addressing the perspective of parents of children transitioning to adult health care. The databases deemed relevant and subsequently searched by the librarian were OVID MEDLINE, EMBASE (OVID), and Cumulative Index to Nursing and Allied Health Literature (CINAHL; EBSCO), PsycINFO (EBSCO), and Sociological Abstracts (Pro Quest). These databases were searched from inception through June 3, 2020, utilizing a combination of keywords and controlled vocabulary for the concepts addressing "parents" and "care transitions", which was adapted to each database by the librarian. Two sample search strategies that demonstrate the combination of keywords and vocabulary can be seen in the Appendix. The keywords and vocabulary were determined by the librarian and other authors. In addition, a hand search of reference lists of articles was used to discover publications not identified in the database searches. A total of 1292 articles were found with 801 left to review after deduplication. The search results and study selection process are illustrated in Fig. 1.

Study selection

Inclusion criteria were peer-reviewed original studies published in English, articles that addressed parents' perspective and experience of HCT, and studies including parents of medically complex AYAs. Exclusion criteria were publications such as conference abstracts, editorials, and review articles, as well as publications that focused on non-healthcare-related aspects of the transition to adulthood (such as moving away from home or beginning college). In addition, studies of parents of AYAs with mental health disorders (as opposed to physical health complications) were excluded. Finally, any study that focused on parents of AYAs that, due to physical or intellectual disabilities, were not expected to achieve independence in adulthood was also excluded. As a result of the title and abstract review, 532 records were excluded. Articles that focused on a transition in health care that was unrelated to that of transition from pediatric to adult health care providers and articles that did not involve parents in the study made up the majority of those excluded during title and abstract review. JE conducted the title and abstract as well as the full-text reviews.

The full texts of 269 articles were reviewed in order to determine if they fully met inclusion criteria if it was unclear from the abstract.

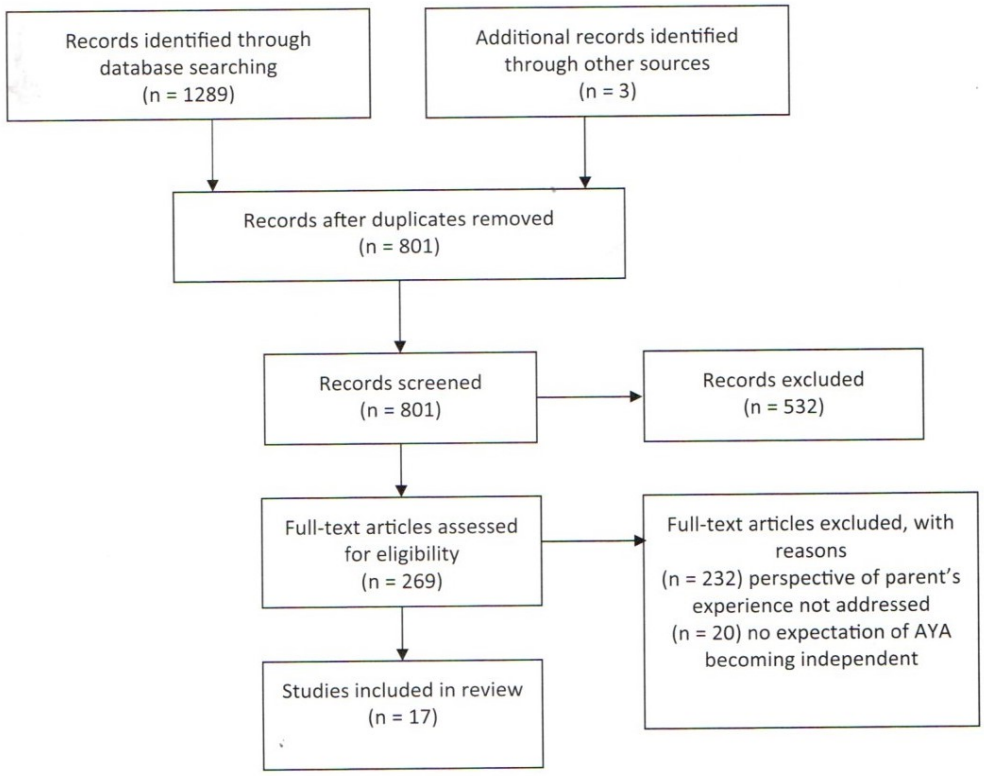

Fig. 1. PRISMA flowchart.

Articles were included if they described the parent's perspective of their own experience related to their child's HCT. Articles that did not discuss the parents' own experiences or perceptions were excluded. Several articles presented parents' feelings or perceptions regarding their child's experience related to transition; these were also excluded. Studies that discussed only a health care providers' observations of parents' experiences were removed for the purpose of this review as well. A total of 252 articles were excluded after this full-text review.

Data collection & analysis

Seventeen articles were included in the final review. For each article, we identified the country where the study was conducted and the type of research (qualitative, quantitative, mixed methods) conducted. Though most studies included AYAs or health care providers as well as parents, this review considered only the results pertinent to the parental experience of HCT. The 17 articles included were thoroughly reviewed for parental perspectives related to their HCT experience. In the first step, parental experiences and perceptions were identified. Next, these experiences and perceptions were initially categorized as facilitators (i.e., factors or events that increased parental readiness or positive feelings regarding the HCT) or barriers (i.e., factors or events that decreased parental readiness or positive feelings regarding the HCT) by the first reviewer. The second reviewer reviewed the experiences and perceptions to rate whether they were facilitators or barriers. Once consensus was reached, the respective groups were then analyzed, and themes emerged among the facilitators and barriers. The results were synthesized within each of these identified themes.

Results

Despite the frequent acknowledgement of the importance of the parents' role in HCT, there are few studies that seek to present the voice of the parent or that attempt to understand how parents of AYAs with medically complex conditions experience HCT. Of the 17 articles reviewed, 15 were original research and two were quality improvement projects. Of the 15 original research studies, ten were qualitative, three were quantitative, and two utilized mixed methods. See Table 1 for a description of the studies. The qualitative studies primarily utilized structured or semi-structured interviews, while both the quantitative studies and the quality improvement projects utilized surveys. Though few of the studies focused solely on the parents of AYAs with medically complex conditions who experienced a HCT, all of the articles in this review presented the parental perspective of the HCT.

While there was a broad range of medically complex conditions ($n = 13$) represented across the studies, those conditions most commonly included were diabetes mellitus ($n = 3$) and rheumatoid arthritis ($n = 3$). The less-frequently represented conditions were congenital heart disease ($n = 2$), spina bifida ($n = 2$), cystic fibrosis ($n = 1$), chronic liver disease and/or transplant ($n = 2$), irritable bowel disease ($n = 1$), autism ($n = 1$), Duchenne muscular dystrophy ($n = 1$), pediatric cancer ($n = 1$), and kidney disease ($n = 1$). In all, 13 of the studies focused on a single diagnosis group, and 4 of the studies included a variety of chronic illnesses, including hematological disorders, solid organ transplants, and other conditions already listed. The studies also represented a variety of geographical locations. While most studies took place in the United States ($n = 5$), there were also studies from Canada ($n = 3$), United Kingdom ($n = 3$), Sweden ($n = 2$), Ireland ($n = 1$), France ($n = 1$), Switzerland ($n = 1$), and the Netherlands ($n = 1$).

In keeping with the objective of this scoping review, parental perspectives were analyzed, themes identified, and results categorized into one of two categories: parental facilitators or parental barriers to HCT readiness. While there could be other categories, we focused on these specific categories because they can potentially enhance our

Table 1
Summary of studies.

Authors	Country	Type of study	Sample	Parental facilitators identified	Parental barriers identified
Berry et al. (2013)	USA	Qualitative	AYAs with spina bifida: N = 15 (ages 14–30) Parents of same: *N* = 14	Acceptance of own mortality (child needs to be able to care for him/herself)	Fear of poor coordination of care between specialties Lack of expertise related to chronic condition in adult health care provider population
Bratt et al. (2018)	Sweden	Qualitative	Parents of AYAs with CHD: *N* = 18	Getting information about HCT sooner Being involved in transition planning Visiting adult clinic before HCT	Learning to adapt to new role and hand over responsibility to AYA Knowing the right time to begin process Grief related to AYA growing up; missing their "child"
Burstom et al. (2016)	Sweden	Qualitative	AYAs with CHD: N = 13 Parents of same: N = 12	Relief to shift responsibility	Security in relationship with pediatric provider Loss of a vital role as a parent of a child with CHD
Chandra et al. (2015)	USA	Quality Improvement	YAs with chronic liver disease of liver transplant: *N* = 12 Parents of same: *N* = 19	Parental support groups Parents letting the children do their own self care	
Coyne et al. (2018)	Ireland	Mixed Methods	Parents of AYAs with CF: *N* = 59	Transition clinic. Advanced warning of transfer	Parental information deficits. Other simultaneous/momentous life changes (ex: preparing for university)
Fernandes et al. (2014)	USA	Mixed Methods	AYAs with pediatric onset illnesses, including cancer, DM, CHD, IBD, CF, JRA, & hematological disorders: *N* = 155 Parents of same: *N* = 104		Parental attachment to pediatric institution and/or provider
Gray et al. (2015)	USA	Mixed Methods	AYAs with IBD: N = 15 Parents of same: *N* = 16 Pediatric providers: *N* = 13	Instructions to parents in how to "let go" and support children Support from those who have already been through the transition	Loss of highly valued relationship with pediatric provider
Kuhlthau et al. (2016)	USA	Quantitative	Parents of AYAs with ASD: *N* = 183		Lack of information on transition process
Lindsay et al. (2016)	Canada	Qualitative	Adolescents with SB: N = 9 (ages 14–21) YAs with SB: N = 12 Parents of same: *N* = 11	Youth gradually taking more control of their own situation	Fear of leaving pediatric provider and the comfort of the familiar
Lindsay et al. (2017)	Canada	Qualitative	YAs with DMD: N = 5 Parents of same: N = 5 Providers of same: *N* = 7	Effective communication between the pediatric and adult health care centers Multi-disciplinary collaboration	Leaving the familiar pediatric and family-centered system
Lochridge et al. (2013)	Scotland	Quality Improvement	AYA recipients of solid-organ transplants: N = 10 (age 16+) Parents of same: N = 10	Meeting adult providers before the transfer of care	Worry about losing relationship with pediatric provider Concerns of being too involved in their child's care
McCann et al. (2014)	Scotland	Qualitative	AYA pediatric cancer survivors: N = 12 Parents of same: N = 12	Opportunity to meet the adult team prior to transfer of care	Worry that AYA will not be able to manage his/her own condition
Morsa et al. (2020)	France	Qualitative	Parents of chronically ill AYAs, diagnoses included DM, liver transplant: *N* = 22 Providers of same: *N* = 26		Role of parents is not clearly defined and they feel a need to redefine their role during transition
Nicholas et al. (2018)	Canada	Qualitative	AYAs with chronic kidney disease: *N* = 28 Parents of same: N = 28	Early meetings and introduction to adult team in order to facilitate understanding of adult processes In person or online peer support	Pediatric providers' delay in addressing support availability in the adult health care environment and how to access it
Suris et al. (2017)	Switzerland	Quantitative	Parents of chronically ill YAs, diagnoses included DM, JRA: *N* = 72	Transition planning that considers and meets needs of parents Good coordination between pediatric and adult services	
van Staa et al. (2011)	Netherlands	Qualitative	AYAs with chronic health conditions, including DM, SB, CHD, CF, JRA, SCD, hemophilia: *N* = 24 Parents of same: N = 24	Involvement in decision-making regarding transition, especially regarding timing of it	Hard to leave "safety" of pediatric team Differences between the pediatric and adult provider systems; poor coordination

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Table 1 (*continued*)

Authors	Country	Type of study	Sample	Parental facilitators identified	Parental barriers identified
Wright et al. (2017)	United Kingdom	Qualitative	Providers: $N = 17$ Parents of AYAs post liver transplant: $N = 9$	Contact from adult center prior to transfer	Conflict between wanting to allow AYA to be independent and doubting AYA's ability to manage his/her own condition Termination of role as key player in the management of AYA's condition Loss of familiar pediatric provider team

understanding of factors that could help or hinder a parent of an AYA in the process of HCT. The initial pass and categorization of facilitators or barriers was conducted by JE, who then worked with SA to ensure author agreement and consensus. The social-ecological theory (Bronfenbrenner, 1977), which acknowledges the complex reciprocity at work between individuals and their environments, was influential in identifying and categorizing the findings into cohesive themes. A summary of the findings, organized by theme, can be seen in Table 2. Parental facilitators were those attributes of transition programs or those experiences and/or attitudes that parents reported helpful as they moved through the HCT process with their children. Four themes emerged among facilitators: evidence of coordination between the pediatric and adult levels of care, health care providers' intentional preparation of parents for transition, parental awareness of the natural seasons of life, and other. Parental barriers were those attributes or factors that hindered parental readiness for their child's HCT. Four themes emerged among the barriers: relationship loss, parental identity tied to the caregiver role, lack of knowledge or skills, and concern about the health care system in general.

Facilitators

The first theme among the facilitators of parental transition readiness was evidence of coordination between the pediatric and adult levels of care. This was identified in seven studies as a factor that helped facilitate parental HCT readiness. Parents in most of these studies cited an opportunity to meet the new adult provider prior to the transfer of care as a positive experience (Bratt et al., 2018; Lochridge et al., 2013; McCann et al., 2014; Nicholas et al., 2018; Wright et al., 2017). Parents in these studies mentioned that meeting the members of the team (Lochridge et al., 2013; Nicholas et al., 2018) and developing relationships with the new adult providers prior to the transfer of care was very important (Wright et al., 2017). In one study (Bratt et al., 2018), parents had an opportunity to visit the outpatient adult clinic with their adolescents and spoke of that experience as an effective facilitator to transition readiness. In two studies, parents were comforted, and their own readiness facilitated, just to see evidence that the pediatric and adult providers were communicating and coordinating their AYA's transition (Lindsay et al., 2017; Suris et al., 2017).

The second theme was the preparation for HCT facilitated through the health care provider. Parents not only welcomed knowledge of coordination between the pediatric and adult providers, but also appreciated intentional efforts by the health care team to prepare them (the parents) for their child's transition. Parental preparation took various forms. The parents in two studies mentioned timely notifications of both the timing and process of transition as facilitators (Bratt et al., 2018; Coyne et al., 2018). The parents said they desired to be informed at an early stage so that they could prepare for the approaching HCT. However, it was not clear what was meant by early stage. In other studies, parents discussed being included in the planning as a facilitator to their readiness. They wanted to be involved in the decision making (van Staa et al., 2011) and planning of transition (Bratt et al., 2018). One study had parents who knew they needed to transfer management responsibilities to their children but expressed a need for health care providers to proactively guide them in how to do this (Gray et al., 2015). Parents also mentioned peer support groups that their health care providers either had organized or recommended as excellent facilitators (Chandra et al., 2015; Gray et al., 2015; Nicholas et al., 2018). Parents acknowledged a need to connect with other parents, both those

Table 2
Facilitator and barrier themes to parental health care transition readiness.

Facilitators	Barriers
Evidence of coordination between pediatric and adult care	Relationship loss
(Scheduled) orientation to adult clinic	Leaving the pediatric provider(s)
Meet adult providers prior to AYA's transfer	Grief related to AYA growing up
Aware of communication between pediatric and adult provider	
Health care provider guidance for HCT	Parental identity tied to caregiver role
Receiving information about the HCT in a timely fashion	Loss of familiar role
Being included in the HCT planning	New parental role
Health care provider referral to a peer support group	
Receiving instructions on how to "let go"	
Acceptance of seasons of life	Lack of knowledge and/or skills
Letting the AYA assume responsibility for their health care	Not knowing the right timing for HCT
Awareness of own mortality	Parents' knowledge deficit about disease and management
Relief from having less responsibility	Parents' concern about AYA's ability to self-manage
Other	Health care system
Awareness of multi-disciplinary and/or cross-specialty collaboration among adult providers	Perceived lack of coordination between pediatric and adult providers
Availability of transition clinic	Concern about adult providers' skills and/or abilities to manage pediatric disease

Note. AYA = adolescent and young adult; HCT = health care transition.

who were currently going through the HCT process with their children and those who have been through the process. Parents cited both in-person and online peer support as helpful (Nicholas et al., 2018).

A third major theme was that of parental awareness and acceptance of the natural seasons of life. Parental readiness for their child's HCT was facilitated by acknowledging the "natural order" of things, which allowed many parents to gradually hand over responsibility for the management of care to their AYAs. Several parents pointed to an awareness that it was necessary and important for their children to assume responsibility for their own health, and HCT was viewed as a part of the natural process. In two studies, parents saw a gradual assumption of responsibilities by the AYA for their own care as a facilitator to the parent's transition readiness (Chandra et al., 2015; Lindsay et al., 2016). In another study (Berry et al., 2013), one parent poignantly stated, "I won't be alive for the rest of her life," and used that fact to help him embrace HCT and its representation of a shift in responsibility. Parents in one study identified a benefit of transitioning, saying it was a relief to have less responsibility (Burstom et al., 2016).

Other facilitators identified in single studies offer valuable suggestions for preparing parents for transition. Parents in one study cited the strong collaboration across several pediatric disciplines as an enabler of a good HCT, as the transition was smooth and not fragmented (Lindsay et al., 2017). Parents in another study cited the existence of a transition clinic as a great bridge between pediatric and adult care (Coyne et al., 2018).

Barriers

Perhaps unsurprisingly, parents in these studies identified more barriers to their readiness than facilitators. The first and most common theme by far among the barriers was relationship loss. For parents in one study (Bratt et al., 2018), they grieved the loss of their "little one," almost lamenting that their child was growing up. However, in 9 of the 17 studies, parents pointed to the anticipated loss of connection to the pediatric provider or institution as a major barrier to their transition readiness (Bratt et al., 2018; Burstom et al., 2016; Fernandes et al., 2014; Gray et al., 2015; Lindsay et al., 2016; Lindsay et al., 2017; Lochridge et al., 2013; van Staa et al., 2011; Wright et al., 2017). Specifically, parents mentioned feeling secure (Bratt et al., 2018) and comfortable (Lindsay et al., 2016) with their child's pediatric provider and/or institution and expressed concerns about leaving behind people and places to which they were attached (Fernandes et al., 2014) and entering a less familiar environment where they were unknown (Lindsay et al., 2017; van Staa et al., 2011; Wright et al., 2017). Interestingly, parents appeared to have more concerns about losing the relationships with pediatric providers than did their AYAs (Lochridge et al., 2013).

While relationships and worry about losing them represented the most frequently cited barrier, a second important theme that arose was that of parental identity tied to the caregiver role. Specifically, two studies highlighted parents expressing a sense of loss of their familiar role relative to their child's health care (Burstom et al., 2016; Wright et al., 2017). One parent felt that her role as a parent of a child with a chronic condition was vital, but that she would lose the attention once her child transitioned (Burstom et al., 2016). Others felt that the time of transfer would signal an end to their role as a key player (Wright et al., 2017). Parents in other studies focused more on their new role than the role they were leaving behind. Those parents felt that their new role might feel "empty" (McCann et al., 2014), or that they might need assistance as they attempted to redefine their new role (Morsa et al., 2020).

Parents not only cited loss of comfortable relationships and roles as barriers, but also presented a third major theme among barriers to their HCT readiness: lack of knowledge or skills. In several studies, parental knowledge was lacking (Bratt et al., 2018; Coyne et al., 2018; Kuhlthau et al., 2016; Nicholas et al., 2018). Bratt and colleagues found that parents expressed uncertainty about the correct timing for the stages of HCT, believing that timing was crucial to success and that knowledge of when the time was right was not inherent in parents. Parents in several studies professed a knowledge deficit related to the HCT process itself (Coyne et al., 2018; Kuhlthau et al., 2016; Nicholas et al., 2018). While parents in one study spoke generally about a lack of understanding about the process of HCT (Kuhlthau et al., 2016), parents in other studies were more specific in their concerns. They did not understand how the process worked, or how their own rights would change in relation to health information, decision-making, and other legalities (Coyne et al., 2018). They also expressed concerns that health care providers were delayed in sharing with parents and families how to access different support systems in the adult health care environment (Nicholas et al., 2018). Parental knowledge deficits were not the only ones mentioned by parents as barriers to transition readiness. They also expressed worries related to their children's self-management abilities, and these worries represented barriers for parents (Bratt et al., 2018; McCann et al., 2014; Wright et al., 2017). Specifically, parents were concerned about giving up control (Bratt et al., 2018) because they were worried that their children might not be able to recognize if something was wrong with their health (McCann et al., 2014) and that their children might not be able to manage their own care as patients in the adult health care system (Wright et al., 2017).

Concerns related to the health care system in general represent a final theme related to HCT barriers for parents. In two studies, parents spoke of "choppy" care, both between pediatric and adult providers and between different specialists on the adult side (Berry et al., 2013; van Staa et al., 2013). The parents were unsettled by the apparent lack of coordination of care, and it presented a barrier to their readiness for the HCT. Finally, parents cited concerns about adult providers' skills and/or abilities to manage "pediatric" diseases (Berry et al., 2013).

Discussion

Overall, parents of AYAs with medically complex conditions across a range of developed nations and representing a wide variety of medical diagnoses reported similar feelings related to facilitators and barriers to their readiness for their child's HCT. Most of the research in this field has been qualitative in nature, and it serves to help share the perspective of parents related to HCT of their AYA children so that researchers better understand barriers and facilitators to HCT readiness among parents. In this review, 10/17 studies were qualitative. As many of the themes identified among the facilitators and barriers to parental readiness relate to factors identified by the SMART (Schwartz et al., 2013), the findings lend credence to the applicability of that model to the parent member of the triad specifically.

The most common theme throughout the studies, seen in both parent-reported facilitators as well as parent-reported barriers is that of relationship, considered by the SMART to be a factor that is amenable to intervention (Schwartz et al., 2013). Parents found a significant barrier in leaving the comfort of their child's pediatric provider. However, relationships worked as facilitators of parental readiness for transition when the parents and their children had an opportunity to meet (and begin relationship-building) with adult providers prior to the transition. Relationships also came into play when parents considered whether or not their child's pediatric and adult providers were engaged in a relationship of sorts, communicating and coordinating the transfer of care of their AYA. The perception of a strong, positive relationship between pediatric and adult providers was a facilitator. Likewise, the observation or perception that this relationship did not exist, or was not as strong, presented as a barrier to parental readiness to transition.

As familiar relationships were being left behind and new ones established, parents expressed awareness of a need to change roles. Though roles are not specifically listed in the SMART (Schwartz et al., 2013), the model does list beliefs and expectations, as well as relationships, as modifiable factors. Many expectations regarding a future experience center on roles, especially on how roles and relationships can change

over time. Whether considering the change as a loss of a comfortable and hard-earned role, or planning to take on an unfamiliar new role, most parents felt that the necessary role change was a barrier to their own readiness for their AYA's HCT. According to role theory, roles are often taken on and off as needed. However, there are times when a role-person merger occurs wherein individuals internalize a role and fail to compartmentalize it (Turner, 2001). When this happens, the individual is resistant to leaving a role behind even when it makes sense to do so. Those experiencing role-person merger also struggle to compartmentalize the role to specific needed situations. According to Turner (2001), this is more likely to happen when one invests a great deal of time or makes many sacrifices in the acquisition of a role. Parents of medically complex AYAs often fit this description, placing them at higher risk for role-person merger. Recognizing this potential risk, health care providers can work with parents and encourage them to explore other aspects of their own lives in order to reduce the likelihood of parental role-person merger, which could interfere with readiness for HCTs of their AYAs. Not only are parents of transitioning AYAs asked to leave behind a dearly held role, but they are also tasked with adopting a new role, which could leave them feeling inadequate. Meleis (1975), in her work related to transitions theory and nursing, addressed this challenge associated with various transitions. She identified role insufficiency as difficulty in understanding or executing a role and suggested that nurses were well situated to assist with role supplementation, which is an intentional process of assisting someone in learning a new role. In the case of parents of AYAs in HCT, it could mean assisting parents in learning how to navigate their new role. The difficulty experienced by some parents in adapting to new roles could cause feelings of inadequacy, distress, and anxiety. As such, the psychosocial/emotions factor in the SMART could be relevant to these potential negative consequences of role change. (Schwartz et al., 2013).

Though parents in most studies acknowledged the need for a gradual handover of responsibilities to their children, most also admitted to struggling with either the timing or the operationalization of said handover. This struggle points to the SMART factor of knowledge (Schwartz et al., 2013). Parents looked to health care providers to assist them with this timing, trusting the expertise of the health care providers, who have gone through transition before. The Six Core Elements of Health Care Transition™ developed by Got Transition®, (White et al., 2020) could assist health care providers in establishing a timeline in partnership with parents. The Six Core Elements, developed with input from both pediatric and adult physicians as well as youth and families, recommend beginning as early as age 12 with discussions related to transition policy (timing and process). Throughout the next two to four years, providers work with patients to track their progress and assess skills relevant to self-management and transition readiness of the patient. Providers then begin to operationalize a HCT plan and then either transfer to a new adult care provider or integrate an adult model of care with an existing provider. Finally, providers consider transition complete when the AYA is consistently receiving ongoing care from an adult care provider (See Fig. 2). At each of these stages, health care providers could more intentionally incorporate parents in an effort to meet their needs along with the needs of their AYA children. During the initial discussion regarding the timing and process of transition, health care providers could remind parents that ensuring patient readiness is a gradual process and offer them a proposed timeline for the AYA taking on new responsibilities in their own care. The underlying message would be that parents should be gradually relinquishing responsibility. As the adolescent's progress toward transition readiness is tracked, the parents can more clearly see areas in which they need to encourage more autonomy in their child. This process relates to the SMART factor of skills/self-efficacy in two ways (Schwartz et al., 2013). First, if providers guide parents on how to assist their AYAs throughout the transition period, then parents' self-efficacy in facilitating transition could be enhanced. Second, as parents encourage their children to be more autonomous and perform an increasing number of self-care skills independently, the AYA's self-efficacy should grow.

Involving parents more intentionally in the Six Core Elements can meet another identified need: to be involved in the planning of transition. Parents articulated that they needed to be part of the transition planning and process, not just receivers of instructions. Providers could ask for parental input at each stage and partner with parents to ensure that parents are comfortable with the timing of HCT. Involving parents in the planning could also help overcome the knowledge deficit that many parents reported as a barrier to their transition readiness, whether the knowledge deficit is related to the transition process itself or even related to their child's medical condition. As providers work to ensure that AYAs have sufficient knowledge of their medical condition and its management, parents can work alongside and learn about the condition while they learn even more about their AYA's ability to self-manage. This increase in knowledge should lead to greater comfort among parents and increased readiness for the HCT of their AYA.

This scoping review has limitations. There is always a possibility that relevant publications were overlooked. One reviewer was primarily responsible for the title and abstract review as well as the full text review of the smaller subset of publications. While all identified themes were reviewed by two authors (JE and SA), most of the winnowing of articles was performed by JE. Another limitation is that no scoping review could present every feeling, experience, or emotion expressed by parents across the studies included. The authors attempted to capture those experiences and feelings that were most representative of the group as a whole and that were identified by parents as either a help or a hinderance to their experience of HCT. Finally, several of the articles included in the scoping review were themselves limited by either small sample sizes, limited geographic range, or convenience sampling. Including publications in the review that represented a wide geographical area as well as parents of AYAs with many and varied diagnoses helped compensate for the limitations inherent in the individual studies themselves.

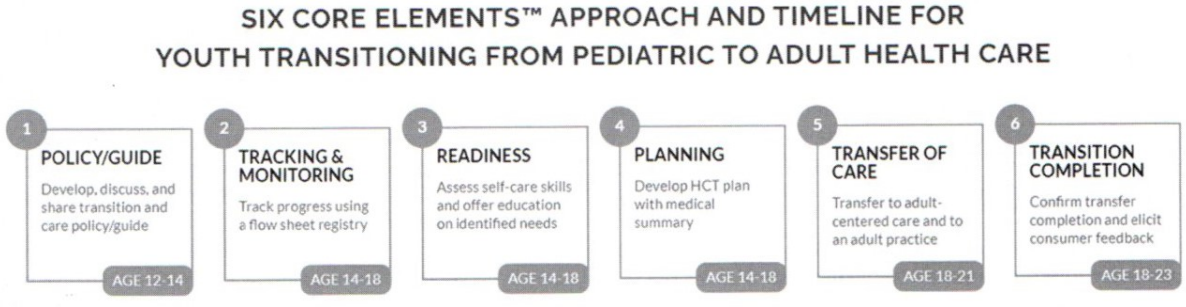

Fig. 2. Six core elements of health care transition™ (White et al., 2020).

Conclusion and suggestions for future studies

The themes identified in this scoping review enhance our understanding of the parents' experience of HCT. The themes also meshed well with several of the factors identified by the SMART (Schwartz et al., 2013), which suggests that this model might provide a useful framework when considering interventions to increase parental readiness for HCT, especially given the SMART's focus on the complex interplay of patients, parents, and providers at the center of the model. The results of this review, combined with knowledge gained through other studies of parents, patients, and providers involved in HCT, contribute to a more comprehensive understanding of all stakeholders in the HCT process and suggest some potentially beneficial interventions to help prepare parents for their AYA's HCT. However, parents remain the least studied member of the patient, provider, parent triad identified at the center of the SMART (Schwartz et al., 2013). Future studies are needed to measure HCT readiness of parents and identify those parental attributes and/or experiences that are most closely linked with HCT readiness. Interventions intended to prepare parents for transition are needed so that parents can prepare their AYA children for HCT. Better HCTs should lead to improved health across the lifespan as medically complex AYAs enter into adulthood and beyond.

Author's statement

In accordance with the recommendations found on the International Committee of Medical Journal Editors' website, we offer the following authors' statement.

Both JE and SA made substantial contributions to the conception or design of the work.

RB and JE participated in acquisition of data for the work.

JE and SA performed analysis and interpretation of data for the work.

JE and SA were primarily responsible for drafting the work or revising it critically for important intellectual content, and RB assisted with the draft as well.

All authors gave final approval of the version to be published (JE, RB, and SA).

JE agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of Competing Interest

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The authors report no conflict of interest.

Appendix A. Appendix

Search History—OVID MEDLINE.

Search history sorted by search number descending

# ▲	Searches
1	exp parent/
2	exp child parent relation/
3	("Parent" or "Parents" or "Father" or "Fathers" or "Mother" or "Mothers").ab,kw,ti.
4	transitional care/
5	transition to adult care/
6	("Care Transition" or "Care Transitions" or "Healthcare Transitions" or "Healthcare Transition" or "Pediatric Transition" or "Pediatric Transitions" or "Transfer to Adult Care" or "Transfer to Adult Healthcare").ab,kw,ti.
7	4 or 5 or 6
8	1 or 2 or 3
9	7 and 8

Search History—CINAHL.

#	Query
S11	S9 AND S10
S10	S4 OR S8
S9	S5 OR S6
S8	"Parent" or "Parents" or "Father" or "Fathers" or "Mother" OR "Mothers"
S7	S5 OR S6
S6	"Care Transition" or "Care Transitions" or "Healthcare Transitions" or "Healthcare Transition" or "Pediatric Transition" or "Pediatric Transitions" or "Transfer to Adult Care" or "Transfer to Adult Healthcare"
S5	(MH "Transitional Care")
S4	S1 OR S2 OR S3
S3	(MH "Parent-Child Relations+")
S2	(MH "Parenting") OR (MH "Parental Behavior")
S1	(MH "Parents+")

References

Allemang, B., Dimitropoulos, G., Samuel, S., Mackie, A., & Morgan-Maver, E. (2019). More than simply "letting go": Stakeholder perspectives on parental roles in health care transition. *Journal of Adolescent and Family Health*, *10*(1), 1. https://scholar.utc.edu/jafh/vol10/iss1/1.

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine (2002). A consensus statement on health care transition for young adults with special health care needs. *Pediatrics*, *110*, 1304–1306.

Andreoni, K. A., Forbes, R., Andreoni, R. M., Phillips, G., Stewart, H., & Ferris, M. (2013). Age-related kidney transplant outcomes: Health disparities amplified in adolescence. *JAMA Internal Medicine*, *173*(16), 1524–1532. https://doi.org/10.1001/jamainternmed.2013.8495.

Annunziato, R. A., Emre, S., Shneider, B., Barton, C., Dugan, C. A., & Shemesh, E. (2007). Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation*, *11*(6), 608–614. https://doi.org/10.1111/j.1399-3046.2007.00689.x.

Balling, K., & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiveing needs and valuing parental expertise. *Journal of Pediatric Nursing*, *16*(2), 110–119. https://doi.org/10.1053/jpdn.2001.23157.

Barriers to health care (2022). Office of Disease Prevention and Health Promotion. https://www.healthypeople.gov/2020/topics-objectives/objective/dh-5.

Bashore, L., & Bender, J. (2016). Evaluation of the utility of a transition workbook in preparing adolescent and young adult cancer survivors for transition to adult services: A pilot study. *Journal of Pediatric Oncology Nursing*, *33*(2), 111–118. https://doi.org/10.1177/1043454215590102.

Berry, J. G., Kusminsky, M., Foley, S. M., Hobbs, N., Queally, J. T., Bauer, S. B., ... Weitzman, E. R. (2013). Strategic directions for transition to adulthood for patients with spina bifida. *Journal of Pediatric Neurology*, *11*(2013), 211–220. https://doi.org/10.3233/JPN-130624.

Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing*, *21*(3), 362–412. https://doi.org/10.1177/1074840715595024.

Blinder, M. A., Vekeman, F., Sasan, M., Trahey, A., Paley, C., & Dugh, M. S. (2013). Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs. *Pediatric Blood & Cancer*, *60*(5), 828–835. https://doi.org/10.1002/pbc.24459.

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, *14*, 570–576. https://doi.org/10.1016/1054-139x(93)90143-d.

Bratt, E. L., Burstrom, A., Hanseus, K., Rydberg, A., & Berghammer, M. (2018). Do not forget the parents—Parents' concerns during transition to adult care for adolescents with congenital heart disease. *Child: Care, Health and Development*, *44*, 278–284. https://doi.org/10.1111/cch.12529.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513–531.

Buckner, L. G. (2018). Healthcare transition from the family perspective. In A. C. Hergenroeder, & C. M. Wiemann (Eds.), *Health care transition: Building a program for adolescents and young adults with chronic illness and disability* (pp. 43–54). Cham, Switzerland: Springer International Publishing AG. https://doi.org/10.1007/978-3-319-72868-1_5.

Burstom, A., Ojmyr-Joelsson, M., Bratt, E., Lundell, B., & Nisell, M. (2016). Adolescents with congenital heart disease and their parents: Needs before transfer to adult care. *Journal of Cardiovascular Nursing*, *31*(5), 399–404. https://doi.org/10.1097/JCN.0000000000000288.

Byrnes, I. Y. S. (2018). Healthcare transition from the AYASHCN's perspective. In A. C. Hergenroeder, & C. M. Wiemann (Eds.), *Health care transition: Building a program for adolescents and young adults with chronic illness and disability* (pp. 33–42). Cham, Switzerland: Springer International Publishing AG. https://doi.org/10.1007/978-3-319-72868-1_4.

Chandra, S., Luetkemeyer, S., Romero, R., & Gupta, N. A. (2015). Growing up: Not an easy transition—Perspectives of patients and parents regarding transfer from a pediatric

liver transplant center to adult care. *International Journal of Hepatology, 2015*, Article 765957. https://doi.org/10.1155/2015/765957.

Clarizia, N. A., Chahal, N., Manlhiot, C., Kilburn, J., Redington, A. N., & McCrindle, B. W. (2009). Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent, and health care provider. *Canadian Journal of Cardiology, 25*, e317–e322. https://doi.org/10.1016/s0828-282x(09)70145-x.

Coyne, I., Malone, H., Chubb, E., & While, A. E. (2018). Transition from paediatric to adult healthcare for young people with cystic fibrosis: Parents' information needs. *Journal of Child Health Care, 22*(4), 646–657. https://doi.org/10.1177/1367493518768448.

Escherich, G., Bielack, S., Maier, S., Braungart, R., Brummendorf, T. H., Freund, M., ... Dirksen, U. (2017). Building a national framework for adolescent and young adult hematology and oncology and transition from pediatric to adult care: Report of the inaugural meeting of the "AjET" working group of the German society for pediatric oncology and hematology. *Journal of Adolescent and Young Adult Oncology, 6*(2), 194–199. https://doi.org/10.1089/jayao.2016.0075.

Fernandes, S. M., O'Sullivan-Oliveira, J., Landzberg, M. J., Khairy, P., Melvin, P., Sawicki, G. S., ... Fishman, L. N. (2014). Transitioning and transfer of adolescents and young adults with pediatric onset chronic disease: The patient and parent perspective. *Journal of Pediatric Rehabilitative Medicine, 7*(91), 43–51. https://doi.org/10.3233/PRM-140269.

Gabay, G., & Tarabeih, M. (2020). "A bridge over troubled water": Nurses' leadership in establishing young adults' trust upon the transition to adult renal-care—A dual-perspective qualitative study. *Journal of Pediatric Nursing, 6*(2), 194–199. https://doi.org/10.1016/j.pedn.2020.02.004.

Gray, W. N., Resmini, A. R., Baker, K. D., Holbrook, E., Morgan, P. J., Ryan, J., ... Hommel, K. A. (2015). Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflammatory Bowel Diseases, 21*(7), 1641–1651. https://doi.org/10.1097/MIB.0000000000000419.

Heath, G., Farre, A., & Shaw, K. (2017). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling, 100*(1), 76–92. https://doi.org/10.1016/j.pec.2016.08.011.

Heaton, J., Noyes, J., Sloper, P., & Shah, R. (2005). Families' experiences of caring for technology-dependent children: A temporal perspective. *Health & Social Care in the Community, 13*(5), 441–450. https://doi.org/10.1111/j.1365-2524.2005.00571.x.

Kuhlthau, K. A., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M., & van der Weerd, E. (2016). Health care transition services for youth with autism spectrum disorders: Perspectives of caregivers. *Pediatrics, 137*(S2), S158–S166. https://doi.org/10.1542/peds.2015-2851N.

Lindsay, S., Fellin, M., Cruickshank, H., McPherson, A., & Maxwell, J. (2016). Youth and parents' experiences of a new inter-agency transition model for spina bifida compared to youth who did not take part in the model. *Disability and Health Journal, 9*(2016), 705–712. https://doi.org/10.1016/j.dhjo.2016.05.009.

Lindsay, S., McAdam, L., & Mahendiran, T. (2017). Enablers and barriers of men with Duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital. *Disability and Health Journal, 10*(2017), 73–79. https://doi.org/10.1016/j.dhjo.2016.10.002.

Lochridge, J., Wolff, J., Oliva, M., & O'Sullivan-Oliveira, J. (2013). Perceptions of solid organ transplant recipients regarding self-care management and transitioning. *Pediatric Nursing, 39*(2), 81–89.

Lorenzi, M. F., Xie, L., Rogers, P. C., Pritchard, S., Goddard, K., & McBride, M. L. (2011). Hospital-related morbidity among childhood cancer survivors in British Columbia, Canada: Report of the childhood, adolescent, young adult cancer survivors (CAYACS) program. *International Journal of Cancer, 28*(7), 1624–1631. https://doi.org/10.1002/ijc.25751.

Magrab, P. R., & Millar, H. E. C. (1989). *Surgeon General's conference growing up and getting medical care: Youth with special health care needs: A summary of conference proceedings.* Washington, D. C: Georgetown University Child Development Center.

McCann, L., Kearney, N., & Wengstrom, Y. (2014). It's just going to a new hospital . . . that's it. Or is it? An experiential perspective on moving from pediatric to adult cancer services. *Cancer Nursing, 37*(5), E23–E31. https://doi.org/10.1097/NCC.0b013e3182a40f99.

Meleis, A. I. (1975). Role insufficiency and role supplementation: A conceptual framework. *Nursing Research, 24*(4), 264–271.

Morsa, M., Gagnayre, R., Pomey, M., Deccache, C., & Lombrail, P. (2020). Developmentally appropriate patient education during transition: A study of healthcare providers' and parents' perspective. *Health Education Journal, 79*(4), 377–389. https://doi.org/10.1177/00178919888559.

Nakhla, M., Daneman, D., To, T., Paradis, G., & Guttmann, A. (2009). Transition to adult health care for youths with diabetes mellitus: Findings from a universal health care system. *Pediatrics, 124*, e1134–e1141. https://doi.org/10.1542/peds.2009-0041.

Nandakumar, B. S., Fardell, J. E., Wakefield, C. E., Signorelli, C., McLoone, J. K., Skeen, J., ... Cohn, R. J. (2018). Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care. *Supportive Care in Cancer, 26*, 2743–2750. https://doi.org/10.1007/s00520-018-4077-5.

Nazareth, M., Hart, L., Ferris, M., Rak, E., Hooper, S., & van Tilburg, M. A. L. (2018). A parental report of youth transition readiness: The parent STARx questionnaire (STARx-P) and re-evaluation of the STARx child report. *Journal of Pediatric Nursing, 38*, 122–126. https://doi.org/10.1016/j.pedn.2017.08.033.

Nicholas, D. B., Pinsk, M., Hamiwka, L., Kaufman, M., Samuel, S., & Molzahn, A. E. (2018). Examining the transition from child to adult care in chronic kidney disease: An open exploratory approach. *Nephrology Nursing Journal, 45*(6), 553–559.

Prior, M., McManus, M., White, P., & Davidson, L. (2014). Measuring the "triple aim" in transition care: A systematic review. *Pediatrics, 134*(6), e1648–e1661. https://doi.org/10.1542/peds.2014-1704.

Psihogios, A. M., Schwartz, L. A., Deatrick, J. A., Ver Hoere, E. S., Anderson, L. M., Wartman, E. C., & Szalda, D. (2019). Preferences for cancer survivorship care among adolescents and young adults who experienced health care transitions and their parents. *Journal of Cancer Survivorship, 13*, 620–631. https://doi.org/10.1007/s11764-019-00781-x.

Quinn, C. T., Rogers, Z. R., McCavit, T. L., & Buchanan, G. R. (2010). Improved survival of children and adolescents with sickle cell disease. *Blood, 115*, 3447–3452. https://doi.org/10.1182/blood-2009-07-233700.

Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., ... Deatrick, J. A. (2013). Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatrics, 167*(10), 939–946. https://doi.org/10.1001/jamapediatrics.2013.2223.

Smith, M. A., & Reaman, G. H. (2015). Remaining challenges in childhood cancer and newer targeted therapies. *Pediatric Clinics of North America, 62*, 301–312. https://doi.org/10.1016/j.pcl.2014.09.018.

van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development, 37*(6), 821–832. https://doi.org/10.1111/j.1365-2214.2011.01261.x.

Suris, J. C., Larbre, J., Hofer, M., Hauschild, M., Barrense-Dias, Y., Berchtold, A., & Akre, C. (2017). Transition from paediatric to adult care: What makes it easier for parents? *Child: Care, Health and Development, 43*(1), 152–155. https://doi.org/10.1111/cch.12405.

Turner, R. H. (2001). Role theory. In J. H. Turner (Ed.), *Handbook of sociological theory* (pp. 233–254). Klewer Academic/Plenum Publishers.

White, P., Schmidt, A., Shorr, J., Ilango, S., Beck, D., & McManus, M. (2020). *Six Core Elements of Health Care Transition™ 3.0. Washington, DC: Got Transition.* The National Alliance to Advance Health.

White, P. H., & McManus, M. A. (2018). Introduction: Historical perspectives, current priorities, and healthcare transition processes, evidence, and measurement. In A. C. Hergenroeder, & C. M. Wiemann (Eds.), *Health care transition: Building a program for adolescents and young adults with chronic illness and disability, (pp. 3–11)*. Springer International Publishing AG. https://doi.org/10.1007/978-3-319-72868-1_1.

Wright, J., Elwell, L., McDonagh, J. E., Kelly, D. A., & Wray, J. (2017). Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services. *Pediatric Transplantation, 21*, Article e12760. https://doi.org/10.1111/petr.12760.