Journal of Pediatric Psychology, 43(5), 2018, 488–502
doi: 10.1093/jpepsy/jsx142
Advance Access Publication Date: 28 November 2017
Systematic Review

OXFORD

Barriers to Transition From Pediatric to Adult Care: A Systematic Review

Wendy N. Gray,[1] PhD, Megan R. Schaefer,[1] MS, Alana Resmini-Rawlinson,[2] PhD, and Scott T. Wagoner,[1] MA

[1]Auburn University and [2]University of Florida

All correspondence concerning this article should be addressed to Wendy N. Gray, PhD, Auburn University, Thach 226, Auburn, AL 36849, USA. E-mail: wng0001@auburn.edu

Received November 8, 2017; revisions received November 5, 2017; accepted November 5, 2017

Abstract

Objective Transition research in each disease group is developing in its own "silo." A comprehensive review of barriers to transition within and across chronic illness groups is needed to facilitate information sharing and larger-scale efforts to overcome barriers and improve patient care. This study systematically reviews and identifies the barriers to transition from pediatric to adult care across pediatric illness populations. **Methods** Medline, CINAHL, PsychINFO, Social Services Abstracts, Web of Science, and the Cochrane library databases were searched. Peer-reviewed English articles presenting original data on barriers to transition to adult care, focused on a specific pediatric chronic illness population, and conducted in the United States were included. Study design, population, and barriers were extracted. Barriers were categorized according to the Socioecological Model of Adolescent/Young Adult Readiness to Transition. Articles were evaluated for study quality. **Results** Fifty-seven articles were included. The most common barriers to transition fell within the "Relationships" domain (e.g., difficulties letting go of long-standing relationships with pediatric providers) followed by "Access/Insurance" (e.g., difficulty accessing/finding qualified practitioners, insurance issues), and "Beliefs/Expectations" (e.g., negative beliefs about adult care). Barriers related to "Knowledge" (e.g., limited patient/caregiver knowledge about medication/illness and the transition process) and "Skills/Efficacy" (e.g., lack of self-management skills) were also common. While relationship barriers were commonly reported by all, some barriers varied by transfer status (pre- vs. posttransfer). **Conclusions** Each chronic illness group experiences illness-specific challenges but certain barriers transcend chronic illness populations. Suggestions to overcome these barriers are provided.

Key words: adolescents; chronic illness; health care services; transfer; young adult.

Over 90% of children with chronic health conditions will survive into adulthood (Pai & Schwartz, 2011), posing challenges for health care providers to prepare adolescent and young adult patients (AYAs) with the skills necessary to transition to the adult world. Transition is defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (Blum et al., 1993, p. 570). Transition spans pediatric and adult care. Transfer, on the other hand, is a discrete event occurring within transition involving the actual hand-off from the pediatric to adult provider.

In an ideal transition, AYAs receive uninterrupted, developmentally appropriate medical care. Successful transition may mean patients meet specific health outcomes, such as an A1c <7.0% in diabetes (Chiang, Kirkman, Laffel, & Peters, 2014), or demonstrate positive health behaviors, such as high adherence (Annunziato et al., 2007), independent self-management skills (Sobota, Umeh, & Mack, 2015), or attending appointments with an adult provider

(Reid et al., 2004). Unfortunately, transition to adult care is associated with many negative outcomes, such as nonadherence (Pai & Ostendorf, 2011), missed medical appointments (Cole, Ashok, Razack, Azaz, & Sebastian, 2015), and poor health outcomes (Annunziato et al., 2007).

A recent Cochrane review (Campbell et al., 2016) concluded there is currently low evidence for the effectiveness of transition interventions. This, combined with the above negative outcomes, suggests that something is getting in the way of achieving optimal transition outcomes. Thus, to improve transition to adult care, we need to understand what gets in the way (i.e., barriers). Currently, transition research in each disease group is developing independent of other chronic conditions and cross-disease resources are under-utilized. In a national survey of pediatric gastroenterologists, only half were aware of the transition guidelines published by the American Academy of Pediatrics (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, 2002). Less than 15% of those who were aware reported that their approach to inflammatory bowel disease (IBD) transition was "mostly" or "entirely" based on these guidelines (Gray & Maddux, 2016). We know transition does not occur in a vacuum and multiple individuals and broader systems play a role, yet most research on transition has focused on individual variables (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). To move forward, we must move beyond isolated patient variables.

The Socioecological Model of AYA Readiness for Transition (SMART) is an expert-informed, theory- and data-driven model of transition readiness capturing systems-level barriers and facilitators of transition readiness (Schwartz et al., 2011). Barriers to transition include: (1) preexisting factors (sociodemographics and culture, health care access/insurance, health status/risk), and (2) interrelated components (development, knowledge, skills/efficacy, beliefs/expectations, goals, relationships, and psychosocial functioning). SMART is generalizable to different medical conditions and provides the ideal framework to identify barriers to transition within and across chronic illnesses.

The aim of this systematic review is to use SMART to summarize the literature on barriers to transition. A review of this nature is needed to unify the transition literature and go beyond our current focus and understanding of isolated patient variables occurring within isolated chronic illnesses. Existing reviews on transition do not assess barriers (Campbell et al., 2016; Gabriel, McManus, Rogers, & White, 2017) or assess barriers published between 2010 and 2014 (Zhou, Roberts, Dhaliwal, & Della, 2016), resulting in an incomplete picture. This is the first review using a theoretical model and the methodological rigor of a systematic review to capture the entire literature. Based on our research and clinical experience, we expected the most common barriers to occur in the "Relationships" and "Skills/Efficacy" categories of SMART. We conclude with a discussion of research-informed solutions to overcome the most frequently reported barriers.

Method

Search Strategy and Study Selection

On August 23, 2017, the lead author and two professional librarians searched Medline, CINAHL, PsychINFO, Social Services Abstracts, Web of Science, and the Cochrane library. As facilitators of transition listed in SMART are the converse of barriers discussed, and the literature on barriers is larger, we have chosen to focus on barriers to provide a more comprehensive review of the literature and avoid redundancy. The search was not limited by target dates or informant (e.g., AYAs vs. providers) and was designed to broadly capture pediatric chronic illness populations, barriers, and transition to adult care (Online Supplementary Materials). Search terms were chosen based on informal literature searches on transition, the author's expertise, and review of the Handbook of Pediatric Psychology (Roberts & Steele, 2017). References of included articles were manually searched to identify other relevant work.

Included articles were: (1) in English, (2) focused on transition from pediatric to adult health care, (3) focused on AYAs ($\leq$25 years), (4) included a chronic illness group, (5) presented original data on barriers to transition, defined as anything that made the transition to adult care process difficult/challenging, including factors that confused or delayed transfer, and (6) conducted in the United States. This latter criterion was set because transition is highly influenced by one's health care system and the United States health care system significantly differs from that of other countries.

Article titles and abstracts were reviewed by two authors (WG and AR) for relevance, with relevant articles undergoing full review. A consensus vote was required to resolve uncertainties. Studies involving multiple chronic illness populations were included only if the barriers reported could be uniquely tied to a specific population. Studies focusing on developmental disabilities (e.g., autism) were excluded because these populations are qualitatively different in terms of the focus of transition. Most individuals with chronic medical conditions are typically developing, and the focus of transition is on developing independent self-management skills. In individuals with developmental conditions, transition is more broadly

focused on helping the individual assume adult roles in their community (e.g., functional skills related to self-care, obtaining employment; Halpern, 1994).

Data Extraction and Quality Rating

An extraction form created for this study was used to obtain information on the identities (e.g., AYA, parent) and demographics (e.g., age, sex, illness) of participants, transfer status (i.e., pre- or posttransfer to adult care), and the type of barrier reported. Study raters had a master's degree or doctorate in clinical psychology. Authors received training on SMART and the data extraction process, including readings and discussions on SMART, representative examples of barriers within each category, orientation to the data extraction form, and practice coding sample barriers.

Two authors assessed study quality using rubrics adapted from quantitative (Loiselle et al., 2016) and qualitative publications (Tong, Sainsbury, & Craig, 2007; Wu, Thompson, Aroian, McQuaid, & Deatrick, 2016). Mixed-method studies were evaluated by both rubrics. Intraclass correlations (ICC) examined interrater reliability. Descriptive subanalyses and frequency counts identified subgroup-specific themes in barriers, such as differences by disease group or informant (e.g., pretransfer AYAs, posttransfer AYAs).

Results

Search Results

Fifty-seven articles met inclusion criteria. Please see Figure 1 for the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.

Characteristics of Included Studies and Participants

Studies were quantitative ($n = 24$), qualitative ($n = 25$), and mixed-method ($n = 8$). Quantitative research studies had greater samples ($M = 111.83$) than qualitative ($M = 17.40$) or mixed-method studies ($M = 81.72$). Sickle Cell Disease (SCD; $N = 12$), human immunodeficiency virus (HIV; $N = 11$), cancer ($N = 6$), diabetes ($N = 6$), and IBD ($N = 6$) were the most common chronic illnesses. Twenty-nine studies included pretransfer AYAs ($N = 2{,}457$), and 21 included posttransfer AYAs ($N = 1{,}388$). Sixteen studies included pretransition caregivers ($N = 257$), and five included posttransfer caregivers ($N = 51$). Pediatric providers were included in 15 studies ($N = 1{,}125$) and adult providers in nine studies ($N = 398$). Mean AYA age ranged from 14.1 years to 22 years (mean = 18.56 years). Of 38 studies, 34 reported AYA gender, with slightly more females ($N = 668$) than males ($N = 518$). AYA race was reported in half of all studies, with AYAs of African American ($N = 386$) and White/Caucasian ($N = 245$) backgrounds most often included.

Study Quality

Interrater reliability for quantitative and qualitative articles was excellent (ICC = 0.95 and 0.93, respectively). Quantitative study quality averaged 12.48 ± 1.84 (range = 8–16; 18 highest possible). Most studies had clearly stated objectives (95.83%), listed inclusion/exclusion criteria (83.33%), provided basic participant demographic information (87.50%), and discussed study limitations (83.33%), representativeness of their sample (83.30%), and their findings in the context of the broader literature (91.67%). Few identified guiding theories (8.33%), hypotheses (20.83%), reasons for study refusal/decline (16.67%), or reported power calculations (4.17%).

Qualitative articles averaged 16.27 ± 2.97 (range = 8–22; 24 highest possible). All studies had clearly stated objectives, inclusion/exclusion criteria (82.60%), basic demographic information of participants (e.g., age, gender; 95.65%), and descriptions of the interview (86.96%). Most described their approach to data analysis (86.96%), provided representative quotes (91.30%), and discussed the representativeness of their sample (91.30%), study limitations (95.65%), and their findings in the context of the broader literature (91.30%). Few studies identified a guiding theoretical framework (17.39%), provided reasons for study refusal/decline (34.78), pilot tested their interview before use (8.70%), or discussed data saturation (30.43%).

Review of Barriers to Transition According to SMART

Findings are below. Barriers by disease population are briefly summarized in Table I, with an expanded version of this table in the Online Supplementary Materials.

Preexisting Factors

Sociodemographics/Culture (Four Studies)

Unstable living situations (e.g., homelessness) were barriers in diabetes and HIV (Fair, Sullivan, & Gatto, 2011; Pyatak et al., 2014). Not completing high school was a barrier in diabetes (Pyatak et al., 2014). In SCD, older AYA age at the start of the transition process (Andemariam et al., 2014), low parent education, and poverty were barriers (Stollon et al., 2015).

Access/Insurance (28 Studies)

Access/Insurance barriers focused on: (1) difficulty accessing/finding qualified practitioners in the adult care setting, and (2) insurance/finances. Concerns about accessing providers or obtaining a referral to a local qualified adult provider were reported in

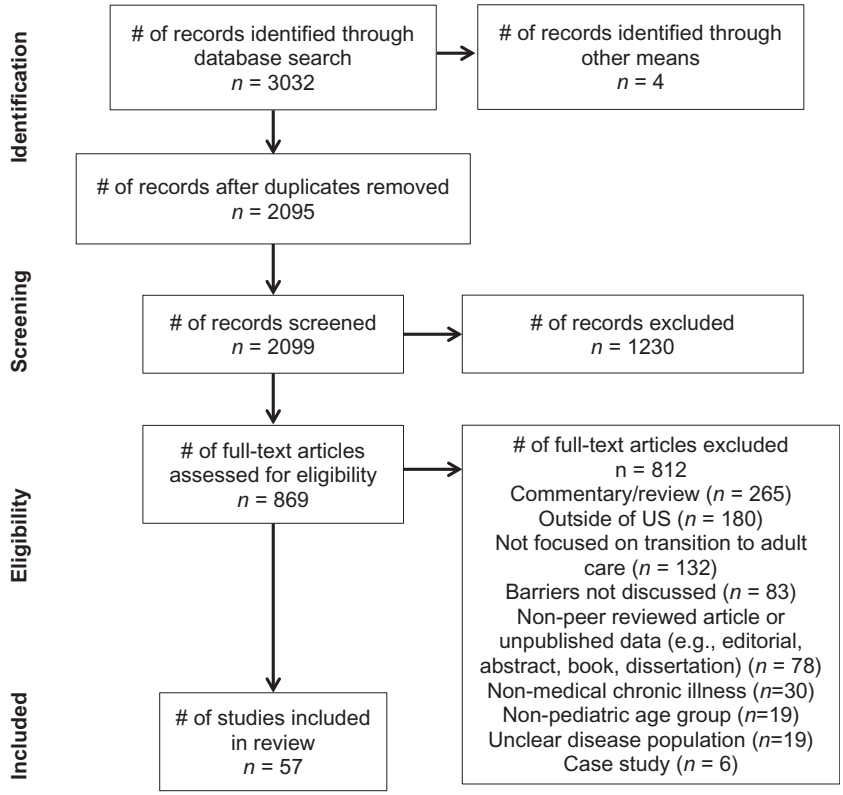

Figure 1. PRISMA flow diagram detailing study selection.

survivors of cancer (Kenney et al., 2017; Quillen, Bradley, & Calamaro, 2017), and AYAs with congenital heart disease (Fernandes et al., 2012), cystic fibrosis (Okumura et al., 2014), diabetes (Agarwal, Garvey, Raymond, & Schutta, 2017; Gee, Smith, Solomon, Quinn, & Lipton, 2007; Hilliard et al., 2014; Pyatak et al., 2014), epilepsy (Camfield, Gibson, & Douglass, 2011), HIV (Wiener, Zobel, Battles, & Ryder, 2007), IBD (Gray & Maddux, 2016; Maddux, Ricks, & Bass, 2017), solid organ transplant (Lochridge, Wolff, Oliva, & O'Sullivan-Oliveira, 2013), and SCD (Andemariam et al., 2014; Mennito, Hletko, Ebeling, Amann, & Roberts, 2014). AYAs with SCD and HIV struggled with adult providers being over 20 miles away (Andemariam et al., 2014) or being inaccessible by bus (Kronschnabel, Puga, & Eaton, 2016; Philbin et al., 2017).

Medical costs and/or insurance issues were barriers in AYAs with asthma (Scal, Davern, Ireland, & Park, 2008), congenital heart disease (Fernandes et al., 2012), diabetes (Agarwal et al., 2017; Garvey et al., 2013), epilepsy (Schultz, 2013), HIV (Gilliam et al., 2011; Philbin et al., 2017; Tanner et al., 2016; Wiener, Kohrt, Battles, & Pao, 2011; Wiener et al., 2007), IBD (Gray & Maddux, 2016; Gray et al., 2015; Maddux et al., 2017), SCD (Hauser & Dorn, 1999; Mennito et al., 2014), and systemic lupus erythematosus (Felsenstein, Reiff, & Ramanathan, 2015) and cancer survivors (Kenney et al., 2017; Quillen et al., 2017). AYAs "aging out" of publically funded or parent-sponsored insurance plans was a common barrier (Hauser & Dorn, 1999; Schultz, 2013; Wiener et al., 2007). After losing coverage, difficulties obtaining or affording insurance (Gray & Maddux, 2016; Maddux et al., 2017; Mennito et al., 2014; Philbin et al., 2017), finding an adult provider who accepted public insurance plans (Agarwal et al., 2017; Camfield et al., 2011; Schultz, 2013), affording out-of-pocket medical costs/medications (Mennito et al., 2014; Wiener et al., 2007), and making sense of contradictory insurance information (Pyatak et al., 2014) were reported. Insurance difficulties resulted in poor continuity of care, owing to delays in receiving treatment or AYAs using the emergency room for routine health issues (Hauser & Dorn, 1999; Philbin et al., 2017; Scal et al., 2008).

Health Status/Risk (11 Studies)

The complexity/instability of the AYA's condition was also a barrier to transition in pediatric cancer (Kenney et al., 2017), congenital heart disease (Fernandes et al., 2012), cystic fibrosis (Flume, Anderson, Hardy, & Gray, 2001; Flume, Taylor, Anderson, Gray, & Turner, 2004), epilepsy (Camfield et al., 2011), HIV (Gilliam et al., 2011), heart/lung transplant (Stabile et al., 2005), IBD (Gray & Maddux, 2016), and systemic lupus erythematosus (Felsenstein et al., 2015). In cystic fibrosis, concern of exposure to infection was

Table I. *Articles Included in Review*

Illness	Article	Method	Demographics/ Culture	Access/ Insurance	Health Status/ Risk	Neurocognition/ IQ	Development	Knowledge	Skills/ Efficacy	Beliefs/ Expectations	Goals	Relationships	Psychosocial Functioning
Asthma	Scal et al., 2008	Quant.		X									
Cancer	Casillas et al., 2010	Qual.								X			
	Bashore & Bender, 2016	Mixed											X
	Kenney et al., 2017	Mixed		X	X	X			X	X		X	
	Mertens et al., 2004	Qual.										X	
	Quillen et al., 2017	Quant.		X									
	Zebrack et al., 2004	Qual.							X				
CKD	Perry et al., 2011	Qual.					X		X			X	X
CHD	Fernandes et al., 2012	Mixed		X	X	X					X	X	X
CF	Boyle et al., 2001	Quant.			X					X		X	
	Flume et al., 2001	Quant.			X	X				X		X	
	Flume et al., 2004	Quant.			X	X						X	
	Okumura et al., 2014	Quant.		X				X	X				X
	Tuchman et al., 2008[a]	Qual.								X			X
Diabetes	Agarwal et al., 2017	Quant.		X						X		X	
	Garvey et al., 2013	Quant.		X									X
	Gee et al., 2007	Qual.		X									
	Hilliard et al., 2014	Mixed		X						X		X	
	Pyatak et al., 2014	Mixed	X	X			X	X	X			X	X
	Ritholz et al., 2014	Qual.											X
Epilepsy	Camfield et al., 2011	Quant.		X	X	X				X		X	
	Schultz, 2013	Qual.		X								X	X
HIV	Fair et al., 2011	Qual.	X					X	X				
	Fair et al., 2012	Mixed					X			X		X	
	Gilliam et al., 2011	Qual.		X	X				X			X	X
	Kronschnabel et al., 2016	Qual.		X						X		X	
	Philbin et al., 2017	Qual.		X			X	X	X	X	X	X	X
	Sharma et al., 2014	Qual.						X					X
	Tanner et al., 2016	Qual.		X								X	X
	Tanner et al., 2017	Mixed							X			X	
	Vijayan et al., 2009	Qual.				X			X	X		X	X
	Wiener et al., 2011	Mixed		X			X	X	X			X	
	Wiener et al., 2007	Quant.		X				X					
HCL	Sliwinski et al., 2017	Qual.						X				X	
IBD	Fishman et al., 2010	Quant.						X				X	
	Gray et al., 2015	Qual.		X						X		X	
	Gray & Maddux, 2016	Quant.		X	X		X	X	X		X		X
	Huang et al., 2012	Quant.							X				
	Maddux et al., 2017	Quant.		X				X	X	X		X	X
	Paine et al., 2014	Qual.					X		X			X	X
SCD	Andemariam et al., 2014	Quant.	X	X	X								
	Bryant et al., 2011	Qual.					X	X	X	X	X	X	X

Table 1. *(continued)*

Illness	Article	Method	Demographics/ Culture	Access/ Insurance	Health Status/ Risk	Neurocognition/ IQ	Development	Knowledge	Skills/ Efficacy	Beliefs/ Expectations	Goals	Relationships	Psychosocial Functioning
	Frost et al., 2016	Qual.								X		X	X
	Hauser & Dorn, 1999	Qual.		X			X	X				X	X
	Latzman et al., 2010	Quant.								X		X	
	Mennito et al., 2014	Quant.		X				X	X	X		X	
	Porter et al., 2014	Qual.					X		X	X	X	X	
	Smith et al., 2011	Quant.						X		X		X	
	Sobota et al., 2014	Quant.											X
	Stollon et al., 2015	Qual.	X			X		X	X	X			X
	Telfair et al., 2004	Quant.						X		X			
	Tuchman et al., 2008[a]	Qual.											X
Transplant	Fredericks et al., 2011	Quant.						X		X		X	
	Heldman et al., 2015	Quant.						X	X				
	Lochridge et al., 2013	Qual.		X	X				X	X		X	
	Stabile et al., 2005	Qual.			X					X			X
SLE	Felsenstein et al., 2015	Quant.	X	X				X				X	

[a]Included multiple chronic illness groups, only those barriers which could be attributed to a specific population are reported.
Qual. = qualitative study; Quant. = quantitative study; Mixed = mixed-method study, CKD = chronic kidney disease; CHD = congenital heart disease; CF = cystic fibrosis; HCL = hypercholesterolemia; IBD = inflammatory bowel disease; SCD = sickle cell disease; SLE = systemic lupus erythematosus.

noted as a barrier (Boyle, Farukhi, & Nosky, 2001). More severe illness was generally associated with greater barriers to transition, but in SCD, AYAs with clinical indicators of milder disease severity (SC or $S\beta^+$ genotypes or no need for chronic transfusion therapy) were less likely to successfully transition (Andemariam et al., 2014).

Neurocognition/IQ (Seven Studies)

Neurocognition/IQ barriers focused on AYA's cognitive/developmental delay as a contraindication to transition in congenital heart disease (Fernandes et al., 2012), cancer (Kenney et al., 2017), cystic fibrosis (Flume et al., 2001; Flume et al., 2004), epilepsy (Camfield et al., 2011), HIV (Vijayan, Benin, Wagner, Romano, & Andiman, 2009), and solid organ transplant (Lochridge et al., 2013).

Interrelated Components of Patients, Parents, and Providers Affecting Transition

Development (10 Studies)

Developmental immaturity was mentioned as a barrier in chronic kidney disease (Perry et al., 2011), diabetes (Pyatak et al., 2014), HIV (Fair, Sullivan, Dizney, & Stackpole, 2012; Philbin et al., 2017; Wiener et al., 2011), IBD (Gray & Maddux, 2016; Paine et al., 2014), and SCD (Bryant, Young, Cesario, & Binder, 2011; Hauser & Dorn, 1999; Porter, Graff, Lopez, & Hankins, 2014). Many adolescents reported pediatric providers and parents forced them to take responsibility too soon, and they did not feel ready (Bryant et al., 2011; Fair et al., 2012; Wiener et al., 2011). Lack of developmental maturity led to delay of transfer, nonadherence, missed appointments, and refusal to manage care independently (Fair et al., 2012; Paine et al., 2014).

Knowledge (19 Studies)

Knowledge barriers included: (1) lack of AYA/caregiver knowledge about medication/illness or the transition process, and (2) a lack of provider knowledge of young adults/pediatric-onset illnesses. Disease knowledge barriers were reported in cancer (Casillas et al., 2010), cystic fibrosis (Okumura et al., 2014), HIV (Fair et al., 2011; Kronschnabel et al., 2016; Philbin et al., 2017; Sharma, Willen, Garcia, & Sharma, 2014; Wiener et al., 2007), IBD (Fishman, Barendse, Hait, Burdick, & Arnold, 2010; Gray & Maddux, 2016; Gray et al., 2015), liver transplant (Fredericks et al., 2011; Heldman et al., 2015), and SCD (Mennito et al., 2014; Telfair, Ehiri, Loosier, & Baskin, 2004). Lack of transition knowledge was a barrier in type 1 diabetes (Pyatak et al., 2014), hypercholesterolemia (Sliwinski et al., 2017), HIV (Kronschnabel et al., 2016), liver transplant (Fredericks et al., 2011), and SCD (Bryant et al.,

2011). Lack of adult provider knowledge of pediatric-onset illness (SCD and diabetes) (Pyatak et al., 2014; Smith, Lewis, Whitworth, Gold, & Thornburg, 2011) or the needs of young adults with HIV (Wiener et al., 2011) were also barriers.

Skills/Efficacy (23 Studies)

Skills and efficacy barriers focused on deficits in: (1) the provider or institution, and (2) AYA self-management. Provider and institutional deficits focused on providers being unable to adequately support transition or coordinate care (Bryant et al., 2011; Gray & Maddux, 2016; Okumura et al., 2014; Paine et al., 2014; Zebrack et al., 2004) owing to lack of time/funding/staff or training in transition issues (Gray & Maddux, 2016), lack of an established transition protocol (Agarwal et al., 2017), limited institutional support, poor provider assessment of AYA skills (Gray & Maddux, 2016; Heldman et al., 2015; Huang, Tobin, & Tompane, 2012; Okumura et al., 2014), or being too busy to focus on transition (Agarwal et al., 2017).

AYA self-management skill deficits focus on poor adherence (Gilliam et al., 2011; Gray & Maddux, 2016; Heldman et al., 2015; Kenney et al., 2017; Porter et al., 2014; Vijayan et al., 2009), lack of independent self-management skills (Frost et al., 2016; Hauser & Dorn, 1999; Kronschnabel et al., 2016; Lochridge et al., 2013; Okumura et al., 2014; Philbin et al., 2017; Sliwinski et al., 2017), low health literacy (Huang et al., 2012), and not knowing how to schedule medical appointments (Fair et al., 2011), access/navigate the adult health care system (Mennito et al., 2014; Pyatak et al., 2014; Tanner et al., 2017; Wiener et al., 2011), or transfer to adult care (Maddux et al., 2017).

Beliefs/Expectations (24 Studies)

Beliefs/expectation barriers included: (1) beliefs about differences between pediatric and adult care, (2) lack of expectations for moving to adult care, (3) perceptions of the transition process, and (4) perceived stigma from adult providers.

Beliefs/expectations about the "serious" or "different" environment of adult care were commonly reported by youth with HIV and their caregivers (Fair et al., 2012). Families of youth with cystic fibrosis (Boyle et al., 2001; Flume et al., 2001), IBD (Gray et al., 2015; Paine et al., 2014), SCD (Bryant et al., 2011; Smith et al., 2011; Telfair et al., 2004; Tuchman, Slap, & Britto, 2008), and solid organ transplantation (Fredericks et al., 2011; Lochridge et al., 2013; Stabile et al., 2005) expressed beliefs that quality of care was poorer in the adult setting because adult care providers spend less time with patients (Camfield et al., 2011; Porter et al., 2014), are less "caring," "knowledgeable," or "experienced" than pediatric providers (Hilliard et al., 2014; Kronschnabel et al., 2016; Latzman et al., 2010; Smith et al., 2011), or may not prioritize their needs in emergency situations (Frost et al., 2016). Beliefs about deficiencies in the adult health care system were also shared by pediatric endocrinologists (Agarwal et al., 2017). A lack of AYA beliefs about transitioning was reported in HIV and SCD (Fair et al., 2012; Mennito et al., 2014). In another study, a small number of AYAs with IBD reported beliefs that medical follow-up in adult care was not a priority/not needed (Maddux et al., 2017). Youth with cystic fibrosis raised concerns about fairness as some AYAs in their 30s remained in pediatric care, while others were transferred earlier (Tuchman et al., 2008). Youth with HIV and cancer expressed beliefs that they would be stigmatized by new providers (Casillas et al., 2010; Sharma et al., 2014; Vijayan et al., 2009).

Goals (Five Studies)

Barriers related to goals were driven by a desire to remain in pediatric care. This was reported in congenital heart disease (Fernandes et al., 2012), HIV (Philbin et al., 2017), IBD (Gray & Maddux, 2016), and SCD (Bryant et al., 2011; Porter et al., 2014).

Relationships (38 Studies)

Barriers emerged between: (1) adolescents and pediatric providers, (2) adolescents and adult providers, (3) pediatric and adult providers, and (4) adolescents and parents.

Concerns related to leaving their pediatric providers and the pediatric environment for a new adult provider were noted in chronic kidney disease (Perry et al., 2011), congenital heart disease (Fernandes et al., 2012), cystic fibrosis (Boyle et al., 2001; Flume et al., 2001; Flume et al., 2004), diabetes (Hilliard et al., 2014; Pyatak et al., 2014; Ritholz et al., 2014), epilepsy (Camfield et al., 2011; Schultz, 2013), HIV (Fair et al., 2012; Gilliam et al., 2011; Kronschnabel et al., 2016; Philbin et al., 2017; Vijayan et al., 2009; Wiener et al., 2011), hypercholesterolemia (Sliwinski et al., 2017), IBD (Gray et al., 2015; Maddux et al., 2017), organ transplant (Fredericks et al., 2011; Lochridge et al., 2013; Stabile et al., 2005), SCD (Bryant et al., 2011; Frost et al., 2016; Hauser & Dorn, 1999; Latzman et al., 2010; Mennito et al., 2014; Smith et al., 2011), and systemic lupus erythematosus (Felsenstein et al., 2015). Thoughts of terminating relationships with pediatric providers provoked anxiety and worry for youth and their families (Bashore & Bender, 2016; Bryant et al., 2011; Camfield et al., 2011; Gilliam et al., 2011; Lochridge et al., 2013; Perry et al., 2011; Porter et al., 2014; Vijayan et al., 2009), as some pediatric providers were

considered "family" (Fair et al., 2012; Gray et al., 2015; Stabile et al., 2005; Vijayan et al., 2009).

Because of strong attachments to pediatric providers, families were hesitant to develop relationships with adult providers (Boyle et al., 2001; Gray et al., 2015; Mennito et al., 2014; Ritholz et al., 2014; Schultz, 2013; Smith et al., 2011; Vijayan et al., 2009), thereby delaying preparation for transfer (Bashore & Bender, 2016). Pediatric providers similarly struggled with letting go of these long-standing relationships, possibly delaying transition (Agarwal et al., 2017; Camfield et al., 2011; Hauser & Dorn, 1999; Kenney et al., 2017; Philbin et al., 2017; Tanner et al., 2016; Wiener et al., 2011). Additionally, disjuncture in the relationship between pediatric and adult providers was endorsed by cancer survivors, leading to less successful transitions (Mertens et al., 2004).

Helicopter/overinvolved parents were reported in diabetes (Hilliard et al., 2014), IBD (Fishman et al., 2010; Gray et al., 2015; Paine et al., 2014), SCD (Frost et al., 2016; Hauser & Dorn, 1999; Tuchman et al., 2008), and solid organ transplant (Lochridge et al., 2013). This type of protective parenting limited self-management learning opportunities for patients, further fostering dependence and thus delayed the transfer (Fishman et al., 2010; Gray et al., 2015; Paine et al., 2014). Pediatric providers were also noted to interfere with adolescent self-management skill development by being overly accommodating and engaging in "hand holding" (Tanner et al., 2017).

Psychosocial Functioning (19 Studies)

Unstable life circumstances were barriers for AYAs with congenital heart disease (Fernandes et al., 2012), IBD (Gray & Maddux, 2016), SCD (Hauser & Dorn, 1999; Stollon et al., 2015), and diabetes (Pyatak et al., 2014). AYAs with IBD also reported depression, anxiety, denial of illness, general life stress, and family functioning (i.e., AYA assisting parents in raising siblings) as barriers (Paine et al., 2014). In diabetes, competing life demands delayed transition (Garvey et al., 2013). Problematic mental health and substance use issues (Gilliam et al., 2011; Tanner et al., 2016; Vijayan et al., 2009) and an absent/unsupportive caregiver (Pyatak et al., 2014; Vijayan et al., 2009) were barriers in HIV and diabetes. AYAs with HIV reported fear and anxiety regarding going to adult clinics (Gilliam et al., 2011; Philbin et al., 2017), concerns of being stigmatized by walking into an HIV clinic (Philbin et al., 2017), and re-disclosure of symptoms to new providers and peer groups (Sharma et al., 2014; Vijayan et al., 2009). AYAs with cystic fibrosis (Okumura et al., 2014), epilepsy (Schultz, 2013), and SCD (Bryant et al., 2011; Frost et al., 2016; Sobota et al., 2014; Tuchman et al., 2008) reported fear and concern about transition. Lack of peers with chronic kidney disease was a barrier in this population (Perry et al., 2011).

Descriptive Subgroup Analyses

Barrier trends by chronic illness

While certain barriers (e.g., knowledge, skills/efficacy) were common across all chronic illness groups, others appeared disease-specific. This included health status/risk and neurocognition/IQ barriers in cystic fibrosis (reported by 60% of studies), and access/insurance barriers in diabetes (83.33% of studies), epilepsy (100% of studies), and heart disease (100% of studies). Beliefs/expectations barriers were highest in organ transplant (75% of studies), followed by SCD and cystic fibrosis (66.67% and 60%, respectively). Skills/efficacy barriers were most common in IBD (66.67% of studies) and HIV (54.55% of studies). Further, while all studies across chronic illness groups reported relationship barriers, they were most frequently reported in cystic fibrosis (80%), organ transplant (80%), diabetes (66.67%), IBD (66.67%), HIV (63.64%), and SCD (58.34%).

Barrier trends by informant

Barriers, such as concern about losing relationships, were common across pretransfer AYAs, posttransfer AYAs, parents, and health care providers. Others were more group-specific. For example, 52% of studies with pretransfer AYAs and 53% of studies with pediatric providers reported concerns about adult provider expertise and experiencing a reduced quality of care in the adult setting (Beliefs/Expectations). This concern was rarely voiced among posttransfer AYAs or adult providers. Studies with posttransfer, versus pretransfer, AYAs endorsed more Access and Insurance barriers such as finding an adult provider (43%) and affording health care costs (33%). Posttransfer AYAs were also more likely to acknowledge deficits in their own knowledge and self-management skills (35%). Studies of providers (43%) and caregivers (33%) similarly noted deficits in AYAs' self-management skills. Overinvolved caregivers (30%) were frequently reported as a barrier in posttransfer AYAs, though no pretransfer AYAs noted parenting styles as problematic. Twenty-nine percent of studies with pediatric providers reported health status/risk barriers, and 30% cited neurocognitive barriers but this was not a theme in other groups.

Discussion

While each chronic illness group experiences disease-specific challenges, certain barriers transcend chronic illnesses such as relationships, belief/expectations, skills/efficacy, knowledge, and access/insurance

Table II. *Research-Informed Recommendations for the Most Commonly Reported Barriers*

Barrier	Solutions
Relationships	• Allow patients interactions with adult providers before transfer (Boyle et al., 2001) • Create joint clinic visits attended by pediatric and adult providers (Cadario et al., 2009, Nakhla et al., 2009)
Beliefs/expectations	• Allow patients interactions with adult providers before transfer (Boyle et al., 2001) • Create a structured transition plan (Cadario et al., 2009) or utilize Individualized Transition Plan templates (McDonagh et al., 2006) • Connect patients with peers who have already transferred (Sobota et al., 2015) • Provide tours of the adult clinic (Hankins et al., 2012)
Skills/efficacy	• Begin transition preparation in early adolescence (Allemang et al., 2017) • Provide education on transitioning responsibility (Annunziato et al., 2008) • Encourage independent visits with the adolescent (Reid et al., 2004) • Use technology to target disease knowledge and other self-management behaviors (Breakey et al., 2014; Huang et al., 2014) • Regularly assess and discuss transition readiness (Zhou et al., 2016) • Improve coordination of care between medical teams (Suris et al., 2017)
Access/insurance	• Employ a transition coordinator (McDonagh et al., 2006) • Utilize a system or transition "navigator" to help AYAs prepare for transfer and posttransfer (Allemang et al., 2017; Van Walleghem et al., 2008)

barriers. Table II provides research-informed strategies to address these barriers.

The most frequently reported barrier focused on relationships between adolescents, their parents, pediatric providers, and adult providers. Adolescents feared losing their relationships with their pediatric providers and forming new relationships with adult providers. Research has demonstrated that meeting adult providers before transfer reduces numerous AYA and parent concerns, especially those that pertain to losing relationships with pediatric providers (Boyle et al., 2001). Establishing a system where pediatric providers communicate with adult providers before, and a few months after, transfer may reduce AYA feelings of abandonment and increase trust of new providers (Wiener et al., 2011). Joint clinics in which the AYA is seen by both the pediatric and adult provider before transferring to adult care may also help (Cadario et al., 2009).

Beliefs about the difference between pediatric and adult services were cited by all respondents as barriers to transition. Pediatric provider ambivalence or negative beliefs about adult care may inadvertently communicate to AYAs that transition is something to be feared. Families should be educated about the differences between pediatric and adult care, with emphasis on the benefits of adult care (e.g., developmentally appropriate care, AYA treated like an adult, less time-consuming clinic visits). Transition should be discussed as a positive event, similar to a graduation. As previously mentioned, facilitating meetings between AYAs and adult providers and providing tours of the adult setting may help to alleviate concerns. Meeting with posttransition peers has also been recommended (Fredericks et al., 2011).

Knowledge and skills/efficacy barriers both fall under the umbrella of self-management. Illness education is commonly provided at the time of diagnosis, and it is assumed that the patient is well-informed about his/her illness in adolescence. Knowledge was a common barrier, however, suggesting that continual education of youth and their families is needed. Relational barriers fostering dependency were often cited as impediments to AYA self-management skills. Parents should receive guidance on how to gradually transition responsibility for disease management to their adolescent well in advance of transfer (Annunziato et al., 2008). Pediatric providers can promote AYA transition readiness by beginning transition preparation in early adolescence (Allemang et al., 2017), seeing AYAs alone for part of the visit (Reid et al., 2004), adopting a structured transition plan (Cadario et al., 2009), and regularly assessing transition readiness (Zhou et al., 2016).

Barriers related to access/insurance are considered less amenable to change, and large-scale policy changes are needed to overcome these barriers. Small-scale changes within institutions can address some, but not all, insurance barriers. For example, a social worker hired as a transition coordinator can help AYAs with insurance issues (Allemang et al., 2017), connect them with needed resources, and educate AYAs on how to navigate complex systems (e.g., health care, insurance) and advocate for themselves (Shanske, Arnold, Carvalho, & Rein, 2012). Additionally, as access/insurance barriers are also experienced by posttransfer AYAs, having a social worker on the adult side may also be helpful (Van Walleghem, MacDonald, & Dean, 2008).

Critique of the Literature

While certain quantitative (Boyle et al., 2001; Fernandes et al., 2012; Hilliard et al., 2014; Wiener et al., 2007) and qualitative (Gray et al., 2015; Porter

et al., 2014) studies were of high quality, most were of low-to-moderate quality. Many of the quantitative studies presented survey-based descriptive data, and less than a quarter were hypothesis-driven. Qualitative studies received low marks for not reporting their reasons for study refusal or discussing data saturation. While the former speaks to the generalizability of findings, the latter speaks to our confidence that the findings obtained have captured a complete picture of the construct assessed.

Surprisingly, no leading model is guiding research in this area. Only 6 of 57 studies used a theoretical framework (Gray et al., 2015; Hilliard et al., 2014; Okumura et al., 2014; Paine et al., 2014; Porter et al., 2014; Stollon et al., 2015). Three studies used the SMART model (Schwartz et al., 2011), which also guides this review. Other models, each used in one study, include the Process-Person-Context-Time model (Bronfenbrenner, 2005), the Diabetes Transition Framework (Hanna, 2012), and a combination of several health and nonhealth models.

Strengths and Limitations

Strengths of this review include use of a structured approach to the identification, review, and inclusion of articles, thereby enhancing replicability. We incorporated studies with diverse methodologies into our review, evaluated study quality, and used a published, theoretical framework to organize and guide the presentation of our data. Use of such a framework facilitated our ability to synthesize the existing data both within and across illness groups. While the former serves as a concise summary of the literature within each chronic illness population, the latter provides the opportunity to identify barriers common to several, if not all, groups and forge larger system-level collaborations to overcome these barriers. With regard to limitations, it was not possible to quantify articles with various methodologies. Because of this, all articles in this review were weighed equally with respect to their findings. As qualitative research often precedes quantitative research in developing research areas, we felt it was important to include both to present a comprehensive picture of the literature. Study heterogeneity, though necessary for a comprehensive review, prevented meta-analysis.

While using a theoretical framework provided an excellent structure to the existing literature, at times, certain barriers appeared to fit into more than one category. This occurred most often between the Relationships and Psychosocial Functioning categories and the Goals and Beliefs/Expectations categories. For example, if an AYA reported anxiety associated with losing the relationship with his/her pediatric provider, a strong case could be made that it belonged in Psychosocial Functioning (e.g., emotions related to the transition process) domain. However, as this barrier was focused on the relationship between the AYA and provider and not the general transition process, one could also argue for its inclusion in the Relationship category. In the few instances in which this occurred, discussion among all study authors occurred until a consensus was reached, and a rule was established on how to handle further coding issues of similar nature.

Bias is also a concern. Published, peer-reviewed research articles might be qualitatively different from those studies that remain unpublished, and researcher interest in certain barriers might bias their methodology to specifically solicit report of these barriers. Participants may also be biased toward discussing those barriers they feel most intensely and may not report other "minor" barriers. One's current status (pre- vs. posttransfer) or role (AYA, parent, clinician) might impact the barriers emphasized. As the transition research is more developed in some populations than others, we cannot assume that the most common barriers reported in this review also apply to those chronic illnesses that have not been the focus of as much transition research (e.g., juvenile rheumatoid arthritis, obesity). For this reason, Table I presents barriers by chronic illness. Finally, articles were required to explicitly identify factors as barriers to transition to be included. Reviewers were not allowed to infer that a factor was a barrier if it was not identified as one by the authors. This was done to reduce subjective bias and optimize objectivity but may have resulted in the exclusion of some articles.

Recommendations for Future Research

It is time to move past descriptive work and begin theory- and hypothesis-driven research. We need to understand how the experience of barriers impacts objectively measured transition outcomes, such as time to transfer, AYA transfer readiness, and health care outcomes and costs. Currently, there is no measure to assess barriers to transition. Creation of such a measure would improve assessment of barriers beyond whether a barrier has occurred to include the extent to which a barrier impacts transition. Finally, we must include all relevant stakeholders in transition research as focusing only on one subgroup (e.g., AYAs) captures a small piece of the numerous interrelated systems involved in transition. Diversifying research to include illness populations that have received less attention in the transition literature and individuals from diverse backgrounds is needed. Following this, future work can determine which barriers, if targeted, generate the most benefit.

Recommendations for Clinical Practice

We strongly believe that clinical and research efforts should go hand in hand. Currently, there is no existing

infrastructure to facilitate collaborations across chronic illnesses. Fostering collaborations across institutions and disease populations to share innovative solutions is an important clinical direction that can open the way to sharing resources from many of the currently developing transition interventions. An online repository or use of preexisting, disease-specific multi-institutional networks (e.g., Diabetes Research in Children Network) can facilitate this. Additional areas in need of clinical work include establishing best practices in transition to adult care and training health care staff in transition, including how to have frank discussions with families about the transition process, introducing transition early in adolescence, assessing for transition barriers, and regularly measuring adolescent and family progress toward independent disease management. Such changes may lead to the greatest improvements in overcoming barriers to transition centered on AYA knowledge deficits, inaccurate beliefs/expectations, and relationships.

This is only the starting point of what we hope to be a much larger dialogue. Linking transition efforts to posttransfer outcomes is critical if we are to evaluate the efficacy and cost-savings of transition intervention services. However, this remains a challenge owing to difficulties tracking AYAs across institutions, lack of established posttransfer markers of success within some chronic illnesses, and limited reimbursement for transition-related services. Such work is needed, however, if we are to optimize the effectiveness of transition programs and AYA health outcomes.

Supplementary Data

Supplementary data can be found at: http://www.jpepsy.oxfordjournals.org/.

Funding

Funding provided by a grant from the Crohn's and Colitis Foundation awarded to the first author (#285083).

Conflicts of interest: None declared.

References

Agarwal, S., Garvey, K. C., Raymond, J. K., & Schutta, M. H. (2017). Perspectives on care for young adults with type 1 diabetes transitioning from pediatric to adult health systems: A national survey of pediatric endocrinologists. *Pediatric Diabetes*, *18*, 524–531. doi: 10.1111/pedi.12436

Allemang, B., Allan, K., Johnson, C., Cheong, M., Cheung, P., Odame, I., … Kuo, K. (2017). Comprehensive structured transition program with dedicated transition navigator reduced lost to follow-up and improved medication adherence in adolescents and young adults with Sickle Cell Disease and Thalassemia. *Journal of Adolescent Health*, *60*, S40–S41. doi: 10.1016/j.jadohealth.2016.10.263

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110(Suppl. 3)*, 1304–1306.

Andemariam, B., Owarish-Gross, J., Grady, J., Boruchov, D., Thrall, R. S., & Hagstrom, J. N. (2014). Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. *Pediatric Blood and Cancer*, *61*, 697–701. doi: 10.1002/pbc.24870

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 Transplant*, *11*, 608–614. doi: 10.1111/j.1399-3046.2007.00689.x

Annunziato, R. A., Emre, S., Shneider, B. L., Dugan, C. A., Aytaman, Y., McKay, M. M., & Shemesh, E. (2008). Transitioning health care responsibility from caregivers to patient: A pilot study aiming to facilitate medication adherence during this process. *Pediatric Transplantation*, *12*, 309–315. doi: 10.1111/j.1399-3046.2007.00789.x

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. *Journal of Pediatric Oncology Nursing*, *33*, 111–118. doi: 10.1177/1043454215590102

Blum, R. W. M., 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. *Journal of Adolescent Health*, *14*, 570–576. doi: 10.1016/1054-139X(93)90143-D

Boyle, M. P., Farukhi, Z., & Nosky, M. L. (2001). Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatric Pulmonology*, *32*, 428–436.

Breakey, V. R., Ignas, D. M., Warias, A. V., White, M., Blanchette, V. S., & Stinson, J. N. (2014). A pilot randomized control trial to evaluate the feasibility of an Internet-based self-management and transitional care program for youth with haemophilia. *Haemophilia*, *20*(6), 784-793. doi:10.1111/hae.12488

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage.

Bryant, R., Young, A., Cesario, S., & Binder, B. (2011). Transition of chronically ill youth to adult health care: Experience of youth with hemoglobinopathy. *Journal of Pediatric Health Care*, *25*, 275–283. doi: 10.1016/j.pedhc.2010.02.006

Cadario, F., Prodam, F., Bellone, S., Trada, M., Binotti, M., Trada, M., … Aimaretti, G. (2009). Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. *Clinical Endocrinology*, *71*, 346–350. doi: 10.1111/j.1365-2265.2008.03467.x

Camfield, P. R., Gibson, P. A., & Douglass, L. M. (2011). Strategies for transitioning to adult care for youth with Lennox-Gastaut syndrome and related disorders. *Epilepsia*, *52*, 21–27. doi: 10.1111/j.1528-1167.2011.03179.x

Campbell, F., Biggs, K., Aldiss, S. K., O'neill, P. M., Clowes, M., McDonagh, J., ... Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD009794.pub2

Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., & Zeltzer, L. K.; Padres Contra El Cáncer. (2010). Transitioning childhood cancer survivors to adult-centered healthcare: Insights from parents, adolescent, and young adult survivors. *Psychooncology*, *19*, 982–990. doi: 10.1002/pon.1650

Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 Diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care*, *37*, 2034–2054. doi: 10.2337/dc14-1140

Cole, R., Ashok, D., Razack, A., Azaz, A., & Sebastian, S. (2015). Evaluation of outcomes in adolescent Inflammatory Bowel Disease patients following transfer from pediatric to adult health care services: Case for transition. *Journal of Adolescent Health*, *57*, 212–217. doi: 10.1016/j.jadohealth.2015.04.012

Fair, C. D., Sullivan, K., Dizney, R., & Stackpole, A. (2012). "It's like losing a part of my family": Transition expectations of adolescents living with perinatally acquired HIV and their guardians. *Aids Patient Care and Stds*, *26*, 423–429. doi: 10.1089/apc.2012.0041

Fair, C. D., Sullivan, K., & Gatto, A. (2011). Indicators of transition success for youth living with HIV: Perspectives of pediatric and adult infectious disease care providers. *AIDS Care*, *23*, 965–970. doi: 10.1080/09540121.2010.542449

Felsenstein, S., Reiff, A. O., & Ramanathan, A. (2015). Transition of care and health-related outcomes in pediatric-onset systemic lupus erythematosus. *Arthritis Care and Research*, *67*, 1521–1528. doi: 10.1002/acr.22611

Fernandes, S. M., Khairy, P., Fishman, L., Melvin, P., O'sullivan-Oliveira, J., Sawicki, G. S., ... Landzberg, M. J. (2012). Referral patterns and perceived barriers to adult congenital heart disease care: Results of a survey of U.S. pediatric cardiologists. *Journal of the American College of Cardiology*, *60*, 2411–2418. doi: 10.1016/j.jacc.2012.09.015

Fishman, L. N., Barendse, R. M., Hait, E., Burdick, C., & Arnold, J. (2010). Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clinical Pediatrics*, *49*, 1129–1133. doi: 10.1177/0009922810379042

Flume, P. A., Anderson, D. L., Hardy, K. K., & Gray, S. (2001). Transition programs in cystic fibrosis centers: Perceptions of pediatric and adult program directors. *Pediatric Pulmonolology*, *31*, 443–450.

Flume, P. A., Taylor, L. A., Anderson, D. L., Gray, S., & Turner, D. (2004). Transition programs in cystic fibrosis centers: Perceptions of team members. *Pediatric Pulmonology*, *37*, 4–7. doi: 10.1002/ppul.10391

Fredericks, E. M., Dore-Stites, D., Lopez, M. J., Well, A., Shieck, V., Freed, G. L., ... Magee, J. C. (2011). Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. *Pediatric Transplantation*, *15*, 414–424. doi: 10.1111/j.1399-3046.2011.01499.x

Frost, J. R., Cherry, R. K., Oyeku, S. O., Faro, E. Z., Crosby, L. E., Britto, M., ... Jain, A. (2016). Improving Sickle Cell transitions of care through health information technology. *American Journal of Preventive Medicine*, *51*, S17–S23. doi: http://dx.doi.org/10.1016/j.amepre.2016.02.004

Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics*, *188*, 263–269.e215. doi: http://dx.doi.org/10.1016/j.jpeds.2017.05.066

Garvey, K. C., Wolpert, H., Laffel, L., Rhodes, E., Wolfsdorf, J., & Finkelstein, J. (2013). Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care. *Endocrine Practice*, *19*, 946–952. doi: 10.4158/ep13109.or

Gee, L., Smith, T. L., Solomon, M., Quinn, M. T., & Lipton, R. B. (2007). The clinical, psychosocial, and socioeconomic concerns of urban youth living with diabetes. *Public Health Nursing*, *24*, 318–328. doi: 10.1111/j.1525-1446.2007.00640.x

Gilliam, P. P., Ellen, J. M., Leonard, L., Kinsman, S., Jevitt, C. M., & Straub, D. M. (2011). Transition of adolescents with HIV to adult care: Characteristics and current practices of the adolescent trials network for HIV/AIDS interventions. *Journal of the Association of Nurses in AIDS Care*, *22*, 283–294. doi: 10.1016/j.jana.2010.04.003

Gray, W. N., & Maddux, M. H. (2016). Current transition practices in pediatric IBD: Findings from a national survey of pediatric providers. *Inflammatory Bowel Diseases*, *22*, 372–379. doi: 10.1097/mib.0000000000000642

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*, 1641–1651. doi: 10.1097/mib.0000000000000419

Halpern, A. S. (1994). The transition of youth with disabilities to adult life: A position statment of the Division on Career Development and Transition, The Council for Exceptional Children. *Career Development for Exceptional Individuals*, *17*, 115–132.

Hankins, J. S., Osarogiagbon, R., Adams-Graves, P., McHugh, L., Steele, V., Smeltzer, M. P., & Anderson, S. M. (2012). A transition pilot program for adolescents with sickle cell disease. *Journal of Pediatric Health Care*, *26*(6), e45-49.

Hanna, K. M. (2012). A framework for the youth with type 1 diabetes during the emerging adulthood transition. *Nursing Outlook*, *60*, 401–410. doi: http://dx.doi.org/10.1016/j.outlook.2011.10.005

Hauser, E. S., & Dorn, L. (1999). Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, *25*, 479–488.

Heldman, M. R., Sohn, M. W., Gordon, E. J., Butt, Z., Mohammed, S., Alonso, E. M., & Levitsky, J. (2015). National survey of adult transplant hepatologists on the pediatric-to-adult care transition after liver

transplantation. *Liver Transplantation*, *21*, 213–223. doi: 10.1002/lt.24044

Hilliard, M. E., Perlus, J. G., Clark, L. M., Haynie, D. L., Plotnick, L. P., Guttmann-Bauman, I., & Iannotti, R. J. (2014). Perspectives from before and after the pediatric to adult care transition: A mixed-methods study in type 1 diabetes. *Diabetes Care*, *37*, 346–354. doi: 10.2337/dc13-1346

Huang, J. S., Tobin, A., & Tompane, T. (2012). Clinicians poorly assess health literacy-related readiness for transition to adult care in adolescents with inflammatory bowel disease. *Clinical Gastroenterology and Hepatology*, *10*, 626–632. doi: 10.1016/j.cgh.2012.02.017

Huang, J. S., Terrones, L., Tompane, T., Dillon, L., Pian, M., Gottschalk, M., Bartholomew, L. K. (2014). Preparing adolescents with chronic disease for transition to adult Care: A technology program. *Pediatrics*, *133*(6), e1639-e1646. doi:10.1542/peds.2013-2830

Kenney, L. B., Melvin, P., Fishman, L. N., O'sullivan-Oliveira, J., Sawicki, G. S., Ziniel, S., … Fernandes, S. M. (2017). Transition and transfer of childhood cancer survivors to adult care: A national survey of pediatric oncologists. *Pediatric Blood and Cancer*, *64*, 346–352. doi: 10.1002/pbc.26156

Kronschnabel, K., Puga, A., & Eaton, L. (2016). Preparing to transition from pediatric to adult HIV-related care: Qualitative assessment and model development. *Vulnerable Children and Youth Studies*, *11*, 146–159. doi: 10.1080/17450128.2016.1189020

Latzman, R. D., Majumdar, S., Bigelow, C., Elkin, T. D., Smith, M. G., Megason, G. C., … Iyer, R. (2010). Transitioning to adult care among adolescents with sickle cell disease: A transitioning clinic based on patient and caregiver concerns and needs. *International Journal of Child and Adolescent Health*, *3*, 537–545.

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*, 81–89.

Loiselle, K., Lee, J. L., Szulczewski, L., Drake, S., Crosby, L. E., & Pai, A. L. H. (2016). Systematic and meta-analytic review: medication adherence among pediatric patients with sickle cell disease. *Journal of Pediatric Psychology*, *41*, 406–418. doi: 10.1093/jpepsy/jsv084

Maddux, M. H., Ricks, S., & Bass, J. (2017). Patient and caregiver perspectives on transition and transfer. *Clinical Pediatrics*, *56*, 278–283. doi: 10.1177/0009922816649590

McDonagh, J. E., Shaw, K. L., & Southwood, T. R. (2006). Growing up and moving on in rheumatology: Development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Journal of Child Health Care*, *10*(1), 22-42. doi:10.1177/1367493506060203

Mennito, S., Hletko, P., Ebeling, M., Amann, L. A., & Roberts, J. (2014). Adolescents with sickle cell disease in a rural community: Are they ready to transition to adulthood?. *Southern Medical Journal*, *107*, 578–582.

Mertens, A. C., Cotter, K. L., Foster, B. M., Zebrack, B. J., Hudson, M. M., Eshelman, D., … Oeffinger, K. C. (2004). Improving health care for adult survivors of childhood cancer: Recommendations from a delphi panel of health policy experts. *Health Policy*, *69*, 169–178. doi: https://doi.org/10.1016/j.healthpol.2003.12.008

Nakhla, M., Daneman, D., To, T., Paradis, G., & Guttmann, A. (2009). Transition to adult care for youths with diabetes mellitus: Findings from a Universal Health Care System. *Pediatrics*, *124*(6), e1134-1141. doi:10.1542/peds.2009-0041

Okumura, M. J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., … Kleinhenz, M. E. (2014). Improving transition from paediatric to adult cystic fibrosis care: Programme implementation and evaluation. *BMJ Quality and Safety*, *23*, i64–i72. doi: 10.1136/bmjqs-2013-002364

Pai, A. L. H., & Ostendorf, H. M. (2011). Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: A literature review. *Childrens Health Care*, *40*, 16–33. doi: 10.1080/02739615.2011.537934

Pai, A. L. H., & Schwartz, L. A. (2011). Introduction to the special section: Health care transitions of adolescents and young adults with pediatric chronic conditions. *Journal of Pediatric Psychology*, *36*, 129–133. doi: 10.1093/jpepsy/jsq100

Paine, C. W., Stollon, N. B., Lucas, M. S., Brumley, L. D., Poole, E. S., Peyton, T., … Schwartz, L. A. (2014). Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the prospectives of providers. *Inflammatory Bowel Diseases*, *20*, 2083–2091.

Perry, E. E., Zheng, K., Ferris, M. E., Torres, L., Bickford, K., & Segal, J. H. (2011). Adolescents with chronic kidney disease and their need for online peer mentoring: A qualitative investigation of social support and healthcare transition. *Renal Failure*, *33*, 663–668. doi: 10.3109/0886022x.2011.589949

Philbin, M. M., Tanner, A. E., Chambers, B. D., Ma, A., Ware, S., Lee, S., & Fortenberry, J. D.; The Adolescent Trials Network. (2017). Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: Using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. *AIDS Care*, *29*, 1227–1234. doi: 10.1080/09540121.2017.1338655

Porter, J. S., Graff, J. C., Lopez, A. D., & Hankins, J. S. (2014). Transition from pediatric to adult care in sickle cell disease: Perspectives on the family role. *Journal of Pediatric Nursing*, *29*, 158–167. doi: 10.1016/j.pedn.2013.10.002

Pyatak, E. A., Sequeira, P. A., Whittemore, R., Vigen, C. P., Peters, A. L., & Weigensberg, M. J. (2014). Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with type 1 diabetes. *Diabetic Medicine*, *31*, 1615–1624. doi: 10.1111/dme.12485

Quillen, J., Bradley, H., & Calamaro, C. (2017). Identifying barriers among childhood cancer survivors transitioning to adult health care. *Journal of Pediatric Oncology Nursing*, *34*, 20–27. doi: doi: 10.1177/1043454216631953

Reid, G. J., Irvine, M. J., McCrindle, B. W., Sananes, R., Ritvo, P. G., Siu, S. C., & Webb, G. D. (2004). Prevalence and correlates of successful transfer from pediatric to adult

health care among a cohort of young adults with complex Congenital Heart Defects. *Pediatrics*, *113*, e197–e205. doi: 10.1542/peds.113.3.e197

Ritholz, M. D., Wolpert, H., Beste, M., Atakov-Castillo, A., Luff, D., & Garvey, K. C. (2014). Patient-provider relationships across the transition from pediatric to adult diabetes care: A qualitative study. *The Diabetes Educator*, *40*, 40–47. doi: 10.1177/0145721713513177

Roberts, M. C., & Steele, R. G. (Eds). (2017). *Handbook of Pediatric Psychology* (5th ed.). New York, NY: Guilford Press.

Scal, P., Davern, M., Ireland, M., & Park, K. (2008). Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *Journal of Pediatrics*, *152*, 471–475. doi: 10.1016/j.jpeds.2007.10.004

Schultz, R. J. (2013). Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. *Journal of Pediatric Health Care*, *27*, 359–366. doi: 10.1016/j.pedhc.2012.03.004

Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: Care, Health, and Development*, *37*, 883–895. doi: 10.1111/j.1365-2214.2011.01282.x

Shanske, S., Arnold, J., Carvalho, M., & Rein, J. (2012). Social workers as transition brokers: Facilitating the transition from pediatric to adult medical care. *Social Work in Health Care*, *51*, 279–295. doi: 10.1080/00981389.2011.638419

Sharma, N., Willen, E., Garcia, A., & Sharma, T. S. (2014). Attitudes toward transitioning in youth with perinatally acquired HIV and their family caregivers. *Journal of the Association of Nurses in AIDS Care*, *25*, 168–175. doi: 10.1016/j.jana.2013.01.007

Sliwinski, S. K., Gooding, H., de Ferranti, S., Mackie, T. I., Shah, S., Saunders, T., & Leslie, L. K. (2017). Transitioning from pediatric to adult health care with familial hypercholesterolemia: Listening to young adult and parent voices. *Journal of Clinical Lipidology*, *11*, 147–159. doi: http://dx.doi.org/10.1016/j.jacl.2016.11.001

Smith, G. M., Lewis, V. R., Whitworth, E., Gold, D. T., & Thornburg, C. D. (2011). Growing up with sickle cell disease: A pilot study of a transition program for adolescents with sickle cell disease. *Journal of Pediatric Hematology/Oncology*, *33*, 379–382. doi: 10.1097/MPH.0b013e318211bb2e

Sobota, A., Akinlonu, A., Champigny, M., Eldridge, M., McMahon, L., Telfair, J., & Sprinz, P. (2014). Self-reported transition readiness among young adults with sickle cell disease. *Journal of Pediatric Hematology/Oncology*, *36*, 389–394. doi: 10.1097/MPH.0000000000000110

Sobota, A., Umeh, E., & Mack, J. W. (2015). Young adult perspectives on a successful transition from pediatric to adult care in Sickle Cell Disease. *Journal of Hematology Research*, *2*, 17–24. doi: 10.12974/2312-5411.2015.02.01.3

Stabile, L., Rosser, L., Porterfield, K. M., McCauley, S., Levenson, C., Haglund, J., & Christman, K. (2005). Transfer versus transition: Success in pediatric transplantation brings the welcome challenge of transition. *Progress in Transplantation*, *15*, 363–370.

Stollon, N. B., Paine, C. W., Lucas, M. S., Brumley, L. D., Poole, E. S., Peyton, T., … Schwartz, L. A. (2015). Transitioning adolescents and young adults with Sickle Cell Disease from pediatric to adult health care: Provider perspectives. *Journal of Pediatric Hematology/Oncology*, *37*, 577–583. doi: 10.1097/mph.0000000000000427

Suris, J. C., Larbre, J. P., 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. doi:10.1111/cch.12405

Tanner, A. E., Philbin, M. M., DuVal, A., Ellen, J., Kapogiannis, B., & Fortenberry, J. D. (2016). Transitioning HIV-positive adolescents to adult care: Lessons learned from twelve adolescent medicine clinics. *Journal of Pediatric Nursing*, *31*, 537–543. doi: http://dx.doi.org/10.1016/j.pedn.2016.04.002

Tanner, A. E., Philbin, M. M., Ma, A., Chambers, B. D., Nichols, S., Lee, S., & Fortenberry, J. D. (2017). Adolescent to adult HIV health care transition from the perspective of adult providers in the United States. *Journal of Adolescent Health*, *61*, 434–439. doi: http://dx.doi.org/10.1016/j.jadohealth.2017.05.011

Telfair, J., Ehiri, J. E., Loosier, P. S., & Baskin, M. L. (2004). Transition to adult care for adolescents with sickle cell disease: Results of a national survey. *International Journal of Adolescent Medicine and Health*, *16*, 47–64. doi: 10.1515/IJAMH.2004.16.1.47

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*, 349–357. doi: 10.1093/intqhc/mzm042

Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*, *34*, 557–563. doi: 10.1111/j.1365-2214.2008.00844.x

Van Walleghem, N., MacDonald, C. A., & Dean, H. J. (2008). Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 Diabetes. *Diabetes Care*, *31*, 1529–1530. doi: 10.2337/dc07-2247

Vijayan, T., Benin, A. L., Wagner, K., Romano, S., & Andiman, W. A. (2009). We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*, *21*, 1222–1229. doi: 10.1080/09540120902730054

Wiener, L. S., Kohrt, B. A., Battles, H. B., & Pao, M. (2011). The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. *Journal of Pediatric Psychology*, *36*, 141–154. doi: 10.1093/jpepsy/jsp129

Wiener, L. S., Zobel, M., Battles, H., & Ryder, C. (2007). Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based

care services: Assessing transition readiness. *Social Work in Health Care*, *46*, 1–19. doi: 10.1300/J010v46n02_01

Wu, Y. P., Thompson, D., Aroian, K. J., McQuaid, E. L., & Deatrick, J. A. (2016). Commentary: Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, *41*, 493–505. doi: 10.1093/jpepsy/jsw032

Zebrack, B. J., Eshelman, D. A., Hudson, M. M., Mertens, A. C., Cotter, K. L., Foster, B. M., … Oeffinger, K. C. (2004). Health care for childhood cancer survivors. *Cancer*, *100*, 843–850. doi: 10.1002/cncr.20033

Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services—An integrative review. *Journal of Clinical Nursing*, *25*, 3113–3130. doi: 10.1111/jocn.13326