Winter 3-20-2020

Self-Management and Quality of Life in Young Adults After Healthcare Transition

Jennifer Fay Herbert
DePaul University, jenniferfaylevin@yahoo.com

Recommended Citation

Herbert, Jennifer Fay, "Self-Management and Quality of Life in Young Adults After Healthcare Transition" (2020). *College of Science and Health Theses and Dissertations*. 361.
https://via.library.depaul.edu/csh_etd/361

Self-Management and Quality of Life in Young Adults After Healthcare Transition

Jennifer Herbert, DNP, MS, RN

DePaul University

Abstract

The transition from pediatric to adult healthcare has become healthcare concern of increasing importance as more adolescents with chronic conditions survive to adulthood requiring continuing care. In order to understand the current status of healthcare transition (HCT), we identified the HCT services received by young adults, their existing healthcare self-management skills and how skills correlated with their quality of life. A correlational and retrospective cross-sectional online survey of English-speaking young adults in the United States ages 18-26 with at least one pediatrically diagnosed chronic condition was conducted August-October 2019. Participants completed a healthcare transition feedback survey, the TRANSITION-Q self-management skills evaluation and the PedsQL Well-Being and Generic Core Measures quality of life surveys. A total of 72 completed survey responses were included in the final analysis with a participant group that reported 26 pediatrically diagnosed chronic conditions; the three most reported conditions were asthma (n = 16), diabetes (n = 17), and cystic fibrosis (n = 8). A majority (54.2%) of participants indicated that they felt "very prepared" to transition to adult care and the average TRANSITION-Q skills score (25.51, SD = 6.45) was only 65.4% of the maximum possible score. Increased TRANSITION-Q scores were associated with increased trust and interaction in patient-provider relationships during HCT. A small negative correlation was found between TRANSITION-Q scores and Generic Core measure quality of life scores ($r = -0.27$, $p = 0.026$). Participants with cystic fibrosis showed increases quality of life scores with more independence in selected self-management skills compared with participants with asthma, diabetes, and the overall sample which demonstrated decreases. This study demonstrates the continuing nature of HCT into young adulthood and that interactions which build rapport and trust with a pediatric healthcare provider increase the acquisition of self-management skills. The relationship between self-management skills and quality of life is related to condition type and further research is needed to outline the relationship.

Keywords: Healthcare transition, self-management, quality of life, young adults, chronic illness

Introduction

Over the last four decades, the transition from pediatric to adult healthcare has become an arena of increasing study. Children with chronic conditions are increasingly living into adulthood. In the United States, more than 90% of these children survive into adulthood. As a result, more than 500,000 adolescents transition to adult healthcare each year (McPhetters et al., 2014) and healthcare transition (HCT) needs have become a priority for research.

Beginning in the late 1980's, HCT began to be outlined as a distinct process. The United States Surgeon General published conference proceedings, which outlined HCT as a complex and organized process requiring extensive patient, provider and family commitment and resources (McGrab & Millar, 1989). Over the next two decades, the elements of HCT became more defined in the literature and provided evidence-based elements to define HCT. Research addressed a number of elements including the transition needs and experiences of adolescents, young adults (AYAs) and their families, the design of transition programs, the development of tools to measure and evaluate HCT, data from transition programs and the role of providers in HCT (Betz, 2004).

As research on healthcare transition has become more available, detailed policy recommendations have been crafted by multiple organizations. In 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) released a joint clinical report to provide guidance to clinicians on how to facilitate HCT. It described the goal of HCT as the maximization of the lifelong functioning and potential of AYA by meeting their needs with uninterrupted and developmentally appropriate, healthcare services (American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), & American College of Physicians (ACP), 2002). Numerous domains were addressed in the guidance including patient self-care competencies, logistics of transfer such as insurance coverage and medical records, and the facilitation of communication between the patient and all providers.

While guidance on the elements of transition to adult healthcare is available, studies show that transition needs are not met for the majority of this population (McManus et al., 2013). Because the HCT encompasses a large variety of needs and domains, it is complex and can lack organization. Care barriers such as developmental challenges, lack of family and social support, and an absence of coordination between pediatric and adult healthcare services have been reported (Sharma, O'Hare, Antonelli, & Sawicki, 2014). Pediatric care is usually family-centered and multidisciplinary with generous support from a team of providers that is not a feature of adult healthcare. There a disconnection between the identified needs of AYAs during HCT and the services currently available or prioritized in the healthcare system. Dwyer-Matzky, Blatt, Asselin and Wood (2018) found that a large variety of transition needs including support in self-management, were never given to AYAs. Further work is needed to find ways to consistently meet the needs of AYA as they complete HCT.

The systemic barriers to a healthcare transition (HCT) that satisfies the goal of maximizing functioning and potential in the context of continuous healthcare are large. They require time and intensive systems-level approach to address. It is, therefore, important to understand the current status of HCT in order to more effectively improve the process. In addition, the identification of transition services received and skills that correlate with better healthcare-related quality of life can inform the creation and targeting of HCT interventions. In order to address that goal, this study examined the HCT services young adults received prior to transition and their current self-management skills to identify which services impacted the acquisition of skills. It also looked at whether healthcare self-management skills impacted quality of life for young adults with chronic conditions.

Literature Review

Outcomes of Healthcare Transition

In order to effectively evaluate the results of healthcare transition (HCT) in research, defined indicators for success need to be identified. Skills in effectively self-managing the medical and psychosocial aspects of living with a chronic condition are most often frequently examined indicator. In an international survey of healthcare transition experts, discussing adolescent and young adult (AYA) self-management with patients and families was identified as an essential element of healthcare transition. Evaluation and continuing attention to self-management even after healthcare transition was explicitly agreed on as an important indicator of successful transition (Suris & Akre, 2015). In addition, other indicators that might be included in self-management such as the patient presenting for follow-up care and attending scheduled visits in adult care were also agree upon as important factors (Suris & Akre, 2015).

Quality of life is also considered important as a more far-reaching outcome of HCT, whether stated implicitly or explicitly. Fair et al. (2016) conducted a survey of healthcare transition experts in diverse disciplines and parents and caregivers of adolescents and young adults (AYAs) with chronic conditions and generated a proposed list of transition outcomes. The items achieving the most agreement on the list were optimal quality of life and self-managing one's own condition. Suris and Akre (2015) identified discussing and assessing quality of life as a potential key element of successful HCT, but did not reach the level of majority consensus among the clinicians surveyed. However, implicit outcome priorities that spoke to quality of life such evaluation for maintenance or improvement of disease control were included in the final agreement.

Focusing on these outcomes and the correlations between them, engages with information considered of high importance in evaluating healthcare transition. In order to better understand the current literature regarding both these outcomes, each was examined individually in the context of healthcare transition in adolescents and young adults. They were also examined together both outside and within the context of healthcare transition together to understand the known relationships between the two.

Healthcare Transition and Self-Management

The ability to self-manage and the acquisition of self-management skills in healthcare transition (HCT) are viewed as a continuous process that occurs prior to transition, during transition and after transition. Prior to HCT, Meaux et al. (2014) found that younger adolescents focused on acquiring knowledge and skills while older adolescents focused on management activities and working with providers. Prior to transition, self-management is examined as an element of transition readiness. It is viewed as a group of skills and/or behaviors required to fully participate in an adult-oriented healthcare environment (Uzark et al., 2015). van Staa, van der Stege, Jedeloo, Moll and Hilberink (2011) found that a positive perception of transition readiness (i.e. stated readiness to use adult healthcare) by adolescents and young adults (AYAs) was significantly associated with greater perceived self-management skills, particularly higher scores on feeling capable of functioning independently in a healthcare setting.

During transition to adult healthcare, increases in self-management skills are determined by age. Syed et al. (2016) found that AYA pediatric cancer survivors showed greater scores on self-management skill assessments with increasing age, living in a single parent household and female gender. Bingham, Groh, Boehmer, and Banks (2015) found that older age correlated with greater self-reported management skills and increased independence over life skills. Whitfield, Fredericks, Eder, Shpeen and Alder (2015) found that most AYA with inflammatory bowel disease (IBD) could complete more than 80% of the evaluated self-management behaviors independently by 18 years old.

However, increased self-management skills are not always correlated with improvements in health outcomes. Fredericks et al. (2010) found that perceived self-management skills and assumption of responsibility in AYA liver transplant patients increased with age, but conversely was associated with poor quantitative outcomes such as immunosuppressant levels below target range. As adolescents and young adults assumption of responsibility for care increased with age, non-adherence to treatment regimen increased when compared to younger patients with the same condition (Fredericks et al., 2010). In addition, self-management skills did not increase in all domains necessary for optimal outcomes. While AYAs had higher levels of self-management skills with greater age, they may also had deficits in important areas such as the ability to recognize and manage acute condition changes (Whitfield, Fredericks, Eder, Shpeen, & Adler, 2015).

Self-management skills are also associated with the AYA's chronic condition during transition. Williams et al. (2011) found that age was less correlated with self-management skills when a diverse population of AYAs was considered including neurological diagnoses that impacted development. While age was not significantly associated with self-management, greater independent behaviors in non-medical domains were also significantly associated with greater medical self-management skills. Beal et al. (2016)

found that health-related skills were significantly lower in patients with diagnoses of Turner syndrome, autism spectrum disorder, or spina bifida than those with type 1 diabetes mellitus. The effect was more pronounced when in AYAs with behavioral or cognitive deficits.

After HCT, self-management is regarded as the completion of a gradual reallocation of all healthcare responsibilities to the young adult. The young adult continued to have greater needs for community and family support in order to facilitate independence and autonomy (Hilliard et al, 2016). Quantitative studies suggest that the self-management skills of young adults still required more support and were not as extensive as an older adult. However, research in the known literature provided only limited benchmarks for the ideal level of independent self-management skills expected of a fully transitioned young adult. Fishman, Mitchell, Lakin, Masciarelli, and Flier (2016) found that adults with IBD age 25-55 years old showed high levels of independence in obtaining medical care and higher levels of medication knowledge (>90%). This is in contrast to the approximately 80% seen in AYA in these areas (Whitfield, Fredericks, Eder, Shpeen, & Alder, 2015). Thus, there remains a post-HCT difference between the self-management skills of young adults and older adults.

Healthcare Transition and Quality of Life

Research evaluating quality of life as an independent outcome of healthcare transition (HCT) is more limited than research evaluating self-management. In a review of available evidence on transition interventions, the most commonly evaluated outcomes were self-care skills and treatment adherence whereas quality of life was an evaluated measure in only three out of 43 studies included (Gabriel, McManus, Rogers, & White, 2017). Two studies in the known literature examined quality of life without any HCT interventions specific conditions and a small number of other studies examine quality of life with some degree of HCT intervention or multiple chronic conditions.

Condition-specific studies showed variable impacts from transitioning on adolescent and young adult (AYA) populations. Sundell, Bergstrom, Hedlin, Ygge and Tunsater (2011) found that quality of life changed before and after HCT when gender and disease severity were considered in AYAs with asthma. AYA men in healthcare transition with asthma had initially higher health-related quality of life (HRQOL) scores than their female counterparts, but over two- and five-year follow-up this effect disappeared. The same effect was seen with AYAs initially diagnosed with more severe disease compared with milder disease. At five-year follow-up, the differences in quality of life were not significant. Silvestri et al. (2016) found that more severe disease manifestation and anxiety during the period of HCT was associated with reduced quality in AYAs with Tourette syndrome.

Studies of quality of life with HCT interventions or multiple conditions also showed variable HRQOL outcomes. Schmidt, Herrmann-Garitz, Bomba and Thyen (2016) did not find a significant relationship between a generic transition intervention and healthcare quality of life in the participants. The authors noted that this may have been the result of low intervention dose given the generally high level of transition care available to the participant population in Germany. Sattoe, Hilberink, van Staa and Bal (2014) found that AYAs with less social development and independence had higher quality of life compared with more independent peers after transition. When chronic conditions impacted the educational or vocational opportunities of AYAs, they reported correspondingly lower quality of life (Sattoe, Hilberink, van Staa & Bal, 2014).

While, Heery, Sheehan and Coyne (2016) found variable effects on HRQOL when accounting for chronic condition or gender. Overall, AYAs had lower physical well-being and social/peer support post-transition to adult care. Females reported lower physical and psychological well-being than males prior to transition, but did not significantly differ after transition. AYAs with CF improved their physical well-being after transition, but adolescents and young adults with type 1 diabetes mellitus and congenital heart disease reported lower physical well-being after transfer. While, Heery, Sheehan & Coyne (2016) examined a group of adolescents and young adults who had received heterogeneous transition services. Some participants received targeted interventions such as transition clinics and transition coordinators and some received simple logistics support such as referral letters for adult care. They did not examine the direct effect of healthcare transition interventions on healthcare-related quality of life.

Given the existing literature on HRQOL and HCT, the general effect of HCT on quality of life in AYAs could not be determined. It was also difficult to determine which, if any, particular transition services might produce an impact on quality of life given that variability is seen based on gender, chronic condition type and severity, and social independence.

Self-Management and Quality of Life in Adolescents and Young Adults

The exact relationship between quality of life and self-management in adolescents and young adults (AYAs) outside the context of healthcare transition (HCT) is not frequently examined in the known literature. In adult patients with chronic illness, Jonkman et al. (2016) found that self-management interventions succeeding in improving health-related quality of life (HRQOL) at both six- and twelve-months post-intervention compared with usual care, although the effect was less pronounced over time. The positive effect on HRQOL was maintained with most types of interventions including those that focused on medication management, symptom monitoring, goal setting and lifestyle changes.

In a similar analysis of research conducted on pediatric patients with chronic physical conditions, self-management interventions had an unclear effect on quality of life. Of 13 studies examined, half showed a significant positive or trending positive effect from a self-management intervention and half did not (Bal et al., 2016). The studies analyzed also included diverse interventions targeting symptom management, disease knowledge, adherence, management of daily life and school or work attendance. Of those that showed a positive effect, all the self-management interventions were focused on influencing medical management tasks (Bal et al., 2016). Notably, the study strength for quality of life studies included was high and therefore the variability in effect may be more attributable to the diversity of interventions. This suggests the need to determine exactly which self-management skills should be targeted in order to produce an impact on quality of life.

Healthcare Transition, Self-Management, and Quality of Life

Healthcare transition (HCT) studies that incorporated evaluation of both self-management skills and health-related quality of life (HRQOL) in adolescents and young adults (AYAs) echoed the variability seen in research examining each outcome individually. Self-management and quality of life in the known literature were almost exclusively evaluated as the target and the result of a HCT intervention. Two exceptions were noted in the literature. One study found evaluated a direct relationship between self-management skills and quality of life. Uzark et al. (2015) did not find a significant relationship between psychosocial quality of life and self-management skills assessment in patients with congenital heart disease when evaluated for transition readiness. No comparison with post-transition to adult healthcare of self-management skills or quality of life was conducted. Bal et al. (2016), as discussed above, examined an HCT population, but did not specifically look at HCT interventions for self-management.

Condition-specific self-management and quality of life HCT intervention studies showed variability in impact on quality of life similar to the quality of life in HCT studies. Tong, Gow, Wong, Henning, and Carroll (2015) found no significant impact on kidney disease-specific measure of quality of life or medication adherence with a HCT intervention emphasizing self-management skills. They noted that the results of qualitative interviews did indicate a trend toward increased optimism and self-efficacy with peer interaction that might result in increased self-management skills.

Other studies found increasing in self-management skills, but no effect on quality of life or a condition-dependent effect. Schmidt, Herrmann-Garitz, Bomba and Thyen (2016) found that a transition intervention with AYAs diagnosed with inflammatory bowel disease (IBD), cystic fibrosis (CF) and type 1 diabetes (T1DM) increased self-management and self-efficacy over a year, but did not increase quality of life. The authors suggested that the homogeneity of the sample with regard to a high level of access to care may have reduced the impact on quality of life. Schmidt et al. (2018) found that a peer-group transition intervention for AYAs with inflammatory bowel disease (IBD) and type 1 diabetes (T1DM) significantly improved self-management skills and HRQOL was significantly improved only for the IBD cohort. It was unclear what portion of the transition intervention contributed to this difference and how that might be associated with the increase in self-management skills.

The studies examined were notably lacking in information on the relationship of self-management skills to quality of life in the context of HCT. In addition, there was an unexplored potential to explore which HCT interventions can impact both quality of life and self-management skills and do so reliably across conditions as is seen in research with adult patients. Overall evidence in the literature is lacking that describes which components of transition services or interventions contribute most to self-management skills in young adults with chronic conditions. In addition, there is little information on what self-management skills contribute most to improving health-related quality of life in this population.

Theoretical Framework

The theoretical framework for this study was derived from the Pediatric Self-Management Model created by Modi et al. (2012). The model describes self-management in the setting of a chronic condition as operating within four domains: individual, family, community, and healthcare system. Each of the domains has modifiable and non-modifiable influences on self-management behaviors through cognitive, emotional, and social processes. Self-management behaviors then proceed linearly to adherence frequency and adherence produces outcomes on both an individual and a system-level (Modi et al., 2012). Figure 1 below illustrates this model.

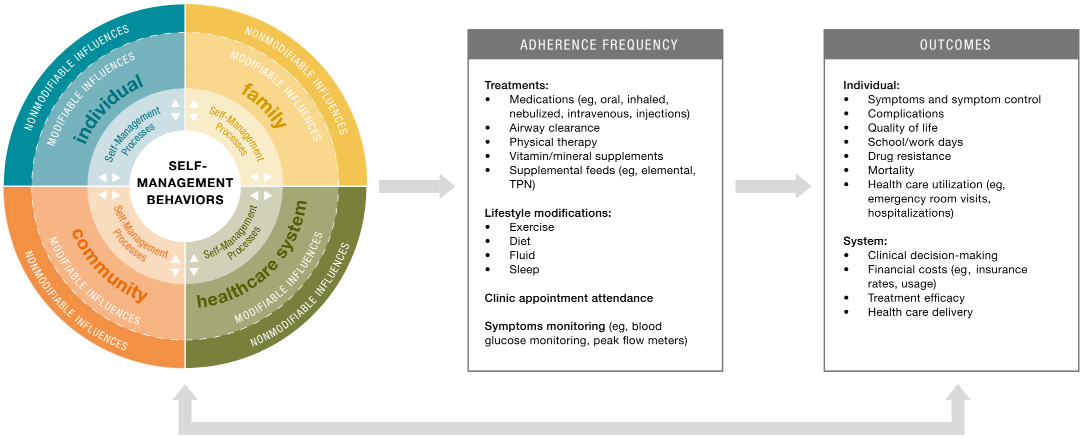

Figure 1. The pediatric self-management model. Reprinted from "Pediatric Self-Management: A Framework for Research, Practice, and Policy" by A.C. Modi et al., 2012, *Pediatrics, 129,* p. e476.

For the purpose of this study, the domain influences examined was the healthcare system. The modifiable influences were examined by evaluating the transition services received by the young adult. The non-modifiable influences were evaluated by examining the demographic factors such as gender, race/ethnicity, income, insurance status, and chronic diagnosis. The resulting self-management behaviors influenced by this domain are evaluated using a healthcare self-management instrument. A single individual-level outcome is evaluated, quality of life, with a healthcare quality of life instrument. This data is then examined based on the relationship described in the framework to quantify the impact of healthcare influences on self-management behaviors and self-management behaviors on the outcome.

Methods

The design of this study used a correlational and retrospective cross-sectional survey to evaluate the healthcare self-management skills and quality of life of young adults after completing transition to an adult healthcare environment and the transition services received prior to transition. Participants for the study were recruited with these inclusion criteria: age from 18 to 26 years old, a minimum of one self-identified pediatric onset chronic condition, English-speaking, residing in the United States, and receiving healthcare services with at least one adult provider. A sample size of a minimum of 100 and a maximum of 250 participants was set.

The survey for this research was conducted in an internet-based format hosted by Qualtrics. Recruitment for participants was conducted from August to October 2019 via the posting of a recruitment poster in public spaces at five non-school based Erie Family Health Centers in Chicago and on social media groups dedicated to chronic conditions. The targeted groups were the Cystic Fibrosis public group, Rolling with Spina Bifida, Chronic Illness in Young Adults (18-35 year olds), Type 1 Diabetes Support Group and Crohn's & Ulcerative Colitis Support Group. Participants were given a small incentive for completion of the survey.

Participants were asked to complete a four-part online questionnaire with a total of 67 questions. The demographic questions for the survey included the participant's gender, age, ethnicity, occupational status, income, insurance status, educational attainment, pediatric onset chronic condition, age at diagnosis, and use of adult healthcare providers. To assess transition services received, the second portion of the survey was the Healthcare Transition Feedback (HCTF) instrument created by the Center for Health Care Transition Improvement (www.GotTransition.org), a joint organization created by the United States

Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. The survey was created to evaluate the healthcare transition services received by adolescents and young adults and their adherence to the organization's evidence-based Six Core Elements of Healthcare Transition.

The third portion was TRANSITION-Q, healthcare transition-specific instrument which was developed and validated to measure self-management skills in adolescents and young adults. The instrument consists of 14 items pertaining to healthcare self-management with answers on a Likert-type scale indicating that a given task is performed "never", "sometimes", or "always." The fourth portion was the Pediatric Quality of Life (PedsQoL) General Well-Being Index and Generic Core instruments. The Generic Core has a total of 23 items with four subscales: Physical, Emotional, Social and School/Work Function. The sub-scales can be used separately or as an aggregate with the Emotional, Social, and School/Work Function scales combined to become the Psychosocial Health instrument. One open-answer qualitative question was included at the end of the survey with a freeform box and ask "How do you think changing to adult healthcare providers has impacted your life?" The open-ended question was included to provide further depth to the analysis of how healthcare transition impacts quality of life.

Results

A total of 250 participants started the survey during the data collection period with 108 participants ultimately submitted the survey for a total completion rate of 43.2%. Of the 108 submitted surveys, 72 participants met the inclusion criteria and were included in the analysis. The participants reported a total 26 different conditions diagnosed before 18 years old. The most commonly reported conditions were diabetes (23.6%), asthma (22.2%), and cystic fibrosis (11.1%). The remaining 23 conditions were reported by less than 5% of participants (Table 2). The demographic breakdown of participants is noted in Table 1 through 2.

Table 1a

	Mean	SD	Min	Max

Age (Years)	22.54	1.82	18	25
Income (in thousands)	29.34	20.25	0	80
Age at Initial Diagnosis	10.09	5.05	0	17
Age When Started Using Adult Providers	18.51	2.24	13	25

Table 1b

Gender	Female	33	45.8%
	Male	39	54.2%
Race or Ethnicity	Asian	5	7.2%
	Black	10	14.5%
	Hispanic	8	11.6%
	White	46	66.7%
Employment or Schooling	Full-time employee	20	27.8%
	Full-time student	26	36.1%
	Full-time student, Full-time employee	2	2.8%
	Full-time student, Part-time employee	2	2.8%
	Part-time employee	7	9.7%
	Part-time student	9	12.5%
	Part-time student, Full-time employee	1	1.4%
	Part-time student, Part-time employee	5	6.9%
Education	Associate's degree	13	18.1%
	Bachelor's degree	27	37.5%
	Graduate or professional degree	3	4.2%
	High school diploma/GED	9	12.5%

	Some college	19	26.4%
	Some high school	1	1.4%
Insurance Coverage	Private insurance covering your parents and yourself	12	17.4%
	Private insurance covering yourself	23	33.3%
	Public insurance (Medicare, Medicaid, etc.)	34	49.3%
Do you use healthcare providers who specialize in caring for adults?	Yes, for all healthcare services	28	38.9%
	Yes, for most healthcare services	33	45.8%
	Yes, for some healthcare services	11	15.3%

Table 2

		N	%
Chronic Condition Diagnosed Prior to Age 18 (N = 72)	Anemia	1	1.4%
	Asthma	16	22.2%
	Cardiomyopathy	1	1.4%
	Cerebral palsy	1	1.4%
	Cerebrovascular disease	1	1.4%
	Child growth hormone deficiency	1	1.4%
	Chronic fatigue syndrome	1	1.4%
	Chronic glomerulonephritis	1	1.4%
	Chronic hepatitis	3	4.2%
	Chronic liver disease	1	1.4%
	Chronic obstructive pulmonary disease	1	1.4%
	Coronary heart disease	1	1.4%

	Crohn's disease	1	1.4%
	Cystic fibrosis	8	11.1%
	Diabetes	17	23.6%
	Epilepsy	1	1.4%
	Hyperlipidemia	1	1.4%
	Hypertension	1	1.4%
	Hypothyroidism	2	2.8%
	Juvenile arthritis	4	5.6%
	Leukemia	2	2.8%
	Myocarditis	1	1.4%
	Obesity	1	1.4%
	Psoriasis	2	2.8%
	Systemic lupus erythematosus	1	1.4%
	Ulcerative colitis	1	1.4%

Notably, the participants reported a high percentage of college education including bachelor's degrees (37.5%), associate's degrees (18.1%), and some college (26.4%). Insurance coverage was close to evenly split between public and private sources of insurance and income level varied widely (range: $0 – $80,000) with a mean income of $29,340 (*SD* = $20,250).

On average participants were initially diagnosed with a chronic condition at 10.09 years (*SD* = 5.05) and began using adult healthcare providers at 18.51 years (*SD* = 2.24). Overall, participants in this study reported high levels of preparedness for healthcare transition with the majority indicating that they were "very prepared" (54.2%) to change to adult providers (Table 3). This information is consistent with the responses received to the open-ended question of how changing to adult healthcare providers impacted participants. The majority of the responses received (70.6%) indicated a neutral or positive opinion of the transition with only 25.5% commenting on difficulties with transition, increased responsibilities or treatment burdens.

Responses to the Healthcare Transition Feedback (HCTF) instrument showed a majority of participants received each of the 13 healthcare transition items listed (Table 3). The most received services included receiving information on the age policy for transition (89.7%), working collaboratively to create a plan to meet needs and goals (87.5%) and creating a medical summary (87.3%).

Table 3

How often did your pediatric healthcare provider explain things in a way that was easy to understand?	Sometimes	19.7%
	Usually	54.9%
	Always	25.4%
How often did your pediatric healthcare provider listen carefully to you?	Sometimes	26.4%
	Usually	37.5%
	Always	36.1%
Did your pediatric healthcare provider respect how your customs or beliefs affect your care?	A little	11.1%
	Some	48.6%
	A lot	40.3%
Did your pediatric healthcare provider discuss with you or have a policy that informed you at what age you needed to change to a new provider?	No	10.3%
	Yes	89.7%
Did you talk with your pediatric healthcare provider without your parent or guardian in the room?	No	12.7%
	Yes	87.3%
Did your pediatric healthcare provider actively work with you to gain skills to manage your own health and healthcare? (For example: to know your medications and their side effects, know what to do in an emergency?)	A little	6.9%
	Some	61.1%
	A lot	31.9%
Did your pediatric healthcare provider actively work with you to think about and plan for the future? (For example: take time to discuss future plans for education, work, relationships and living independently?)	A little	7.0%
	Some	63.4%
	A lot	29.6%
How often did you schedule your own appointments with your pediatric healthcare provider?	Never	2.8%
	Sometimes	54.9%
	Usually	33.8%

	Always	8.5%
Did your pediatric healthcare provider explain legal changes in privacy, decision-making, and consent that happen at age 18?	No	11.1%
	Yes	88.9%
Did your pediatric healthcare provider actively work with you to create a plan to meet your healthcare needs and goals?	No	12.5%
	Yes	87.5%
Did your pediatric healthcare provider create and share a medical summary with you?	No	12.7%
	Yes	87.3%
Did your pediatric healthcare provider have information about community resources?	No	21.4%
	Yes	78.6%
Did your pediatric healthcare provider assist you in identifying an adult healthcare provider to transfer to?	No	22.5%
	Yes	77.5%
Did you feel prepared to change to an adult healthcare provider?	Not prepared	2.8%
	Somewhat prepared	43.1%
	Very prepared	54.2%

Reponses to the TRANSITION-Q instrument did not indicate a majority of participants “always” or “often” engaged in any of the 13 healthcare management skills (Table 4). The most frequent “always” responses were for “I look for an answer when I have a question about my health” (40.3%) and “I talk about my health condition to people when I need to” (35.7%). “Often” was chosen for skills by a larger portion of participants with the largest percentages for “I talk to a doctor or nurse when I have health concerns” (50.0%) and “I ask the doctor or nurse questions” (48.6%). The mean total score on the TRANSITION-Q was 25.51 (*SD* = 6.45) out of a maximum of 39.

Table 4

		%
I answer a doctor's or nurse's questions	Never	1.4%
	Sometimes	33.3%

	Often	45.8%
	Always	19.4%
I make decisions about my health	Never	1.4%
	Sometimes	25.0%
	Often	47.2%
	Always	26.4%
I am in charge of taking any medicine that I need	Never	2.8%
	Sometimes	26.4%
	Often	43.1%
	Always	27.8%
I talk to a doctor or nurse when I have health concerns	Never	2.8%
	Sometimes	19.4%
	Often	50.0%
	Always	27.8%
I look for an answer when I have a question about my health	Never	0.0%
	Sometimes	12.5%
	Often	47.2%
	Always	40.3%
I talk about my health condition to people when I need to	Never	5.7%
	Sometimes	18.6%
	Often	40.0%
	Always	35.7%
I ask the doctor or nurse questions	Never	0.0%
	Sometimes	26.4%
	Often	48.6%
	Always	25.0%
I speak with the doctor instead of someone speaking for me	Never	2.8%
	Sometimes	29.2%
	Often	45.8%

	Always	22.2%
I summarize my medical history when I am asked to	Never	2.8%
	Sometimes	31.9%
	Often	30.6%
	Always	34.7%
I see the doctor or nurse on my own during my appointment	Never	8.3%
	Sometimes	27.8%
	Often	38.9%
	Always	25.0%
I drop off or pick up my prescriptions when I need medicine	Never	2.8%
	Sometimes	30.6%
	Often	43.1%
	Always	23.6%
I travel to my own doctor's appointments	Never	4.2%
	Sometimes	34.7%
	Often	26.4%
	Always	34.7%
I book my own doctor's appointments	Never	1.4%
	Sometimes	26.4%
	Often	40.3%
	Always	31.9%

Due to the sample size for other conditions, condition-specific comparisons of responses on the TRANSITION-Q and HCTF instruments were only conducted for asthma (n = 16), cystic fibrosis (n = 8), and diabetes (n = 17). Of the three conditions, the only notable differences in response percentages on both instruments were in the cystic fibrosis group. On the HCTF instrument, 62.5% (n = 5) of the cystic fibrosis group reported that their pediatric healthcare provider helped them “a lot” with gaining skills to manage their own health compared to 12.5% (n = 2) in the asthma group, 35.3% (n = 6) in the diabetes group, and 31.9% (n = 23) of other participants. On the TRANSITION-Q instrument, the cystic fibrosis group had a majority of "always" responses for 8 out of 13 skills including "I look for an answer when I have a question about my health" (100%, n = 8) and "I book my own doctor's appointments" (87.5%, n = 7). The mean TRANSITION-Q scores were 23.69 (*SD* = 6.68) for asthma, 26.29 (*SD* = 7.47) for diabetes, 30.43 (*SD* = 6.4) for cystic fibrosis, and 24.9 (*SD* = 5.33) for all other conditions. However, analysis of variance did not show a significant condition-specific effect on mean TRANSITION-Q scores overall [F(3,66) = 2.039, p = 0.117].

In order to determine the impact of receiving transition services on healthcare self-management skills, a comparison was made between group responses on the HCTF instrument and the TRANSITION-Q. Significant differences were found in mean TRANSITION-Q scores based on the responses to five of the HCTF instrument questions (Table 5). A Tukey HSD post-hoc analysis for conducted on all significantly different groups. Post-hoc analysis of Q1 and Q2 indicated that the increase in mean score between participants indicating "always" and "sometimes" and "always" and "usually" was statistically significant.

Table 5

HCTF Question	Response	Mean TRANSITION-Q Score	One-way ANOVA
Q1: How often did your pediatric healthcare provider explain things in a way that was easy to understand?	Sometimes	22.08 (*SD = 4.65)*	F (2,66) = 8.746, p < 0.0005
	Usually	24.38 (*SD* = 6.00)	
	Always	30.29 (*SD* = 6.14)	
Q2: How often did your pediatric healthcare provider listen carefully to you?	Sometimes	22.95 (*SD* = 6.47)	F (2, 67) = 6.636, p = 0.002
	Usually	24.08 (*SD* = 6.18)	
	Always	28.96 (*SD* = 5.38)	
Q6: Did your pediatric healthcare provider actively work with you to	A little	20 (*SD* = 5.79)	F (2,67) = 9.584, p < 0.0005
	Some	24.07 (*SD* = 5.94)	

gain skills to manage your own health and healthcare?	A lot	29.86 (*SD* = 5.42)	
Q7: Did your pediatric healthcare provider actively work with you to think about and plan for the future?	Not at all	16.00 (N/A)	F (2,66) = 3.863, *p*= 0.013
	A little	26.00 (*SD* = 8.86)	
	Some	24.13 (*SD* = 6.01)	
	A lot	29.16 (*SD* = 5.50)	
Q8: How often did you schedule your own appointments with your pediatric healthcare provider?	Never	25.00 (*SD* = 1.41)	F (2,65) = 3.942, *p* = 0.012
	Sometimes	23.49 (*SD* = 5.61)	
	Usually	27.92 (*SD* = 6.59)	
	Always	31.50 (*SD* = 8.81)	

For Q1, there was an increase in mean score between the "sometimes" and "always" responses of 8.2 (95% CI, -13.35 to -3.08, *p* = 0.001) and the "usually" and "always" responses of 5.91 (95% CI, -9.96 to -1.86, *p* = 0.002). For Q2, there was an increase in mean score between the "sometimes" and "always" responses of 6.01 (95% CI, -10.38 to -1.64, *p* = 0.004) and the "usually" and "always" responses of 4.88 (95% CI, -8.90 to -0.86, *p* = 0.013). No significant increase was found for either question between "sometimes" and "usually". Similarly for Q6, there was an increase in mean score of 9.86 (95% CI, =16.75 to -2.97, *p* = 0.003) between "some" and "a lot" and an increase of 5.79 (95% CI, -9.46 to -2.12, *p* = 0.001). In Q7, the only significant relationship seen is the increase from "some" to "a lot" of 5.03 (95% CI, -9.02 to -1.03, *p* = 0.010). In Q8, there was an increase in mean score from "sometimes" to "usually" of 4.43 (95% CI, -8.61 to -0.24, *p* = 0.034). No other significant relationships were found in any of the post hoc analysis.

To determine the overall relationship between healthcare self-management skills and quality of life, TRANSITION-Q scores were correlated with the scores on the Pediatric Quality of Life Well-Being Index (WBI), Generic Core (GC), Psychosocial Health (PSH), and Physical Health (PH) instruments. There was a small negative correlation between TRANSITION-Q scores and GC scores (*r* = -0.27, *p* = 0.026) and a moderate negative correlation between TRANSITION-Q scores and PH scores (*r* = -0.31, *p* = 0.01). In addition, the four quality of life instrument mean scores were compared based on the responses for each individual skill on the TRANSITION-Q (Table 6a and 6b). Four individual skills had significant relationships to some of the quality of life instruments, but no one skill showed significant effects on all four measures.

Table 6a

TRANSITION-Q Skill	**Response**	**Mean PedsQoL Well-Being Score**	**ANOVA**	**Mean PedsQoL Generic Core Score**	**ANOVA**
Skill 1: I answer a doctor's or nurse's questions	Never	N/A		19.00 (N/A)	F (3,68) = 3.51, *p* = 0.02
	Sometimes			61.92 (*SD* = 15.37)	
	Often			48.88 (*SD* = 21.80)	
	Always			48.57 (*SD* = 18.575)	
Skill 4: I talk to the doctor or nurse when I have health concerns	Never	N/A		N/A	
	Sometimes				
	Often				
	Always				
Skill 11: I drop off or pick up my prescriptions	Never	54.50 (SD = 0.71)	F (3,68) = 3.29, *p*= 0.026	N/A	
	Sometimes	68.36 (SD = 15.85)			

when I need medicine	Often	62.48 (SD = 11.25)			
	Always	74.59 (SD = 16.71)			
Skill 13: I book my own doctor's appointments	Never	N/A		86.00 (N/A)	F (3,68) = 2.97, *p* = 0.038
	Sometimes			61.47 (*SD*= 17.98)	
	Often			49.83 (*SD* = 18.50)	
	Always			47.78 (*SD*= 21.59)	

Table 6b

TRANSITION-Q Skill	**Response**	**Mean PedsQoL Psychosocial Health Score**	**ANOVA**	**Mean PedsQoL Physical Health Score**	**ANOVA**
Skill 1: I answer a doctor's or nurse's questions	Never	20.00 (N/A)	F (3,68) = 2.89, *p* = 0.042	19.00 (N/A)	F (3,68) = 4.42, *p* = 0.007
	Sometimes	59.67 (*SD* = 15.33)		66.79 (*SD* = 19.27)	
	Often	47.55 (*SD* = 21.36)		51.45 (*SD* = 23.35)	
	Always	49.50 (*SD* = 19.24)		46.86 (*SD* = 18.97)	
Skill 4: I talk to the doctor or nurse when I have health concerns	Never	N/A		47.00 (*SD* = 26.87)	F (3,68) = 2.82, *p* = 0.046
	Sometimes			68.79 (*SD* = 21.17)	
	Often			54.94 (*SD* = 20.92)	
	Always			47.05 (*SD* = 23.75)	

Skill 11: I drop off or pick up my prescriptions when I need medicine	Never	N/A	N/A	
	Sometimes			
	Often			
	Always			
Skill 13: I book my own doctor's appointments	Never	N/A	94.00 (N/A)	F (3,68) = 4.18, *p* = 0.009
	Sometimes		66.95 (*SD* = 21.08)	
	Often		52.24 (*SD* = 20.15)	
	Always		47.61 (*SD* = 22.92)	

Overall, the results of the analysis showed that mean quality of life scores decreased as responses indicated that the participant engaged a skill more frequently with the exception of Skill 11. A Tukey HSD post-hoc analysis for conducted where possible on all significantly different groups. For Skill 4, the mean score on the PH instrument decreased by 21.74 between the “sometimes” and the “always” respondents (95% CI, 1.65 to 41.83, *p* = 0.029). For Skill 11, the mean score on the WBI increased by 12.1 between “often” and “always” (95% CI, -23.32 to -0.89, *p* = 0.029).

To determine if there were any differences in the effect of transition services received on healthcare self-management skills, the asthma, diabetes, and cystic fibrosis groups were analyzed individually. The significant results are summarized below in Table 7. No single transition service had a significant effect on the TRANSITION-Q scores all three condition-specific groups. However, all the noted significant effects followed the same trend as the participants as a whole. Post hoc analysis was not able to be conducted due to the group sizes. In general, the more frequently a service was received, a corresponding increase occurred in the mean TRANSITION-Q scores.

Table 7

Condition	**HCTF Question**	**Response**	**Mean TRANSITION-Q Score**	**One-way ANOVA or *t*-Test**
Asthma	Q2: How often did your pediatric healthcare provider explain things in a way that was easy to understand?	Sometimes	19.00 (*SD* = 4.80)	F (2, 13) = 7.22, *p* = 0.008
		Usually	22.00 (*SD* = 4.78)	
		Always	30.40 (*SD* = 5.27)	
Asthma	Q8: How often did you schedule your own appointments with your pediatric healthcare provider?	Never	n/a	F (2,13) = 4.00, *p* = 0.044
		Sometimes	21.36 (*SD* = 5.66)	
		Usually	27.00 (*SD* = 5.60)	
		Always	36.00 (N/A)	
Cystic Fibrosis	Q13: Did your pediatric healthcare provider assist you in identifying an adult healthcare provider to transfer to?	No	23.00 (*SD* = 4.24)	*t* (5) = 2.91, *p* = 0.033
		Yes	33.40 (*SD* = 4.28)	
Diabetes	Q1: How often did your pediatric healthcare provider explain things in a way that was easy to understand?	Sometimes	19.00 (*SD* = 7.07)	F (2,14) = 6.25, *p* = 0.011
		Usually	24.10 (*SD* = 6.47)	
		Always	33.60 (*SD* = 3.36)	
Diabetes	Q6: Did your pediatric healthcare provider actively work with you to gain skills to manage your own health	A little	14.00 (N/A)	F (2,14) = 4.21, *p* = 0.037
		Some	24.50 (*SD* = 6.85)	
		A lot	31.33 (*SD* = 5.20)	
Diabetes	Q13: Did your pediatric healthcare provider assist you in identifying an adult healthcare provider to transfer to?	No	18.00 (*SD* = 5.89)	*t* (15) = 3.180, *p* = 0.006
		Yes	28.85 (*SD* = 5.98)	

Correlation between the TRANSITION-Q scores and the Pediatric Quality of Life instruments did showed a moderate negative correlation between the Physical Health scores in the asthma group and TRANSITION-Q scores. No other significant correlations were noted for the asthma group and none were found in the cystic fibrosis or diabetes groups. As with the overall sample, the four quality of life instrument mean scores were compared based on the responses for each individual skill on the TRANSITION-Q. Post hoc analysis was not possible due to the group sizes. The significant effects of transition skills on the quality of life measures for each condition-specific group are list in Tables 8a to 8c.

Table 8a

Cystic Fibrosis							
TRANSITION-Q Skill	**Response**	**Mean PedsQoL Generic Core Score**	**ANOVA**	**Mean PedsQoL Psychosocial Health Score**	**ANOVA**	**Mean PedsQoL Physical Health Score**	**ANOVA**
Skill 1: I answer a doctor's or nurse's questions	Never	n/a	F (2,5) = 9.07, *p* = 0.022	n/a	F (2,5) = 8.84, *p* = 0.023	N/A	
	Sometimes	39.00 (N/A)		38.00 (N/A)			
	Often	30.80 (*SD* = 11.63)		31.60 (*SD* = 11.04)			
	Always	71.00 (*SD* = 9.90)		74.50 (*SD* = 11.50)			
Skill 6: I talk about my health condition to people when I need to	Never	n/a	F (1,5) = 6.65, *p* = 0.049	N/A		N/A	
	Sometimes	n/a					
	Often	29.80 (*SD* = 16.57)					
	Always	54.00 (*SD* = 43.84)					
Skill 9: I summarize my medical history when asked to	Never	N/A		N/A		n/a	F (2,5) = 6.19, *p* = 0.044
	Sometimes					41.00 (N/A)	
	Often					26.25 (SD= 13.32)	
	Always					59.67 (SD = 10.97)	
Skill 10: I see the doctor or nurse on my own during my appointment	Never	N/A		N/A		44.00 (N/A)	F (2,5) = 8.43, *p* = 0.025
	Sometimes					n/a	
	Often					20.33 (*SD* = 7.51)	
	Always					55.00 (*SD* = 12.94)	

Table 8b

Asthma							
TRANSITION-Q Skill	**Response**	**Mean PedsQoL Generic Core Score**	**ANOVA**	**Mean PedsQoL Psychosocial Health Score**	**ANOVA**	**Mean PedsQoL Physical Health Score**	**ANOVA**
Skill 3: I am in charge of taking any medicine that I need	Never	N/A		N/A		94.00 (N/A)	F (3, 12) = 4.63, *p* = 0.023
	Sometimes					75.71 (*SD* = 10.18)	
	Often					66.67 (*SD* = 19.86)	
	Always					47.40 (*SD* = 18.24)	
Skill 4: I talk to a doctor or nurse when I have health concerns	Never	49.00 (N/A)	F (3, 12) = 7.09, *p* = 0.005	39.00 (N/A)	F (3, 13) = 6.82, *p* = 0.006	66.00 (N/A)	F (3, 12) = 5.35 p= 0.014
	Sometimes	79.00 (*SD* = 6.08)		78.00 (*SD* = 3.61)		81.33 (*SD* = 10.97)	
	Often	70.50 (*SD*= 11.89)		70.13 (*SD* = 12.51)		72.88 (*SD* = 15.73)	
	Always	39.50 (*SD* = 18.07)		38.00 (*SD* = 20.80)		42.00 (*SD* = 13.61)	
Skill 12: I travel to my own doctor's appointments	Never	86.00 (N/A)	F (3, 12) = 4.03, *p* = 0.034	82.00 (N/A)	F (3, 12) = 3.81, *p* = 0.04	N/A	
	Sometimes	73.14 (*SD*= 11.94)		73.29 (*SD* = 12.59)			
	Often	45.20 (*SD* = 20.18)		42.60 (*SD*= 20.74)			
	Always	61.33 (*SD* = 13.05)		59.33 (*SD* = 18.45)			

Table 8c

Diabetes			
TRANSITION-Q Skill	**Response**	**Mean PedsQoL Well Being Score**	**ANOVA**
Skill 1: I answer a doctor's or nurse's questions	Never	n/a	F (2, 14) = 4.34, *p* = 0.034
	Sometimes	53.00 (*SD* = 7.57)	
	Often	76.13 (*SD*= 14.93)	
	Always	68.4 (*SD* = 11.91)	

Notably, while the asthma group follows the trend of the whole sample with more frequent skill use generally resulting in decreases in mean scores on the quality of life instruments, this is not the case with the diabetes and cystic fibrosis groups. In the cystic fibrosis group, more frequent use of four skills resulted in increased mean scores on at least one of the quality of life instruments. In the diabetes group, increases in the mean Well-Being Index score were seen as well.

Discussion

The responses to the Healthcare Transition Feedback (HCTF) instrument indicate that the largest number of participants received transition services that could occur in a single encounter such as being provided with a medical summary or discussing an age policy for transitioning to an adult provider. However, the services received prior to transition with the impact on self-management skills scores were related to the participants' relationship with the pediatric healthcare provider. These included areas such as a pediatric provider who listened and was easy to understand and actively helped with self-management skills attainment and future planning. Participants that received these services more frequently had higher mean scores on the TRANSITION-Q instrument. This is consistent with other studies that found that the relationship with the pediatric healthcare provider has an integral role in the development of self-management skills. (Bal et al., 2016).

The responses to the TRANSITION-Q instrument did not show a majority of participants "always" using any of the 13 skills, however greater than 60% of participants used all 13 skills "always" or "often" combined. The mean score on the TRANSITION-Q of 25.51 (*SD* = 6.46) is 64% of the maximum score of 39. In addition, only 38.9% of the sample indicated that they used adult providers for all healthcare services. This indicates that healthcare transition and the acquisition of self-management skills is still incomplete for this participant group. This consistent with other transition studies which found that self-management skills are positively correlated with age (Syed et al., 2016, Whitfield, Fredericks, Eder, Shpeen, & Alder, 2015) and continue to increase beyond the healthcare transition period (Uzark et al, 2015). Overall, no single skill showed a greater frequency or importance within the sample.

While there were not many differences in services received between the condition-specific groups, the cystic fibrosis group had a higher mean skills score and a higher percentage of the group received “a lot” help with future planning. In addition, while no healthcare self-management skills were “always” used in the majority by all participants, the cystic fibrosis had this majority for eight out of 13 skills and one skill that all participants in the group always displayed: “I look for an answer when I have a question about my health.” This suggests that active and forward-thinking transition planning and skills acquisition may have a higher importance with this group, potentially due to the medically-demanding nature of the condition.

The effect of healthcare self-management skills on quality of life in the participant group in this study was visible, but contrary to the expected outcome. There was small negative correlation between TRANSITION-Q scores and scores on the quality of life Generic Core measures compared with other studies that found positive correlations or no impact on quality of life with self-management skills (Bal et al., 2016, Uzark et al., 2015). In addition, it is important to note that the quality of life Generic Core measure the aggregate of two sub-set measures. The first is the Psychosocial Health quality of life measure, which did not have a significant correlation with TRANSITION-Q scores. However, a moderate negative correlation between TRANSITION-Q scores and the Physical Health quality of life scale was present. This suggests that increased self-management may negatively impact overall quality of life, particularly when only physical functioning is considered.

This discrepancy may be related to the observed gap between the perception of preparedness and actual transition readiness. While 54.2% of the participants reported that they felt “very prepared” for transition to adult care, the average score on the TRANSITION-Q was only 65.4% of the highest possible score even after transition has occurred. Whitefield, Fredericks, Eder, and Alder (2015) reported that despite the perceived ability of young adults to independently manage their healthcare, there are often important skills that are missed or inadequate after healthcare transition. This is also seen in the impact of individual skills on quality of life. Four individual transition skills showed a significant impact with only one, Skill 1, impacting quality of life on three out of four measures. Greater demonstration of Skill 1 – I answer a doctor’s or nurse’s questions – resulted in lower quality of life scores on the Generic Core, Psychosocial Health, and Physical Health instruments. This suggests that despite more frequently independently performing Skill 1, participants are not communicating effectively with their healthcare providers in order to maintain optimum quality of life and physical function. The discrepancy between the perceived ability to independently self-manage and optimally self-management results likely contributes to the decrease in quality of life.

Within the condition-specific groups for asthma, cystic fibrosis and diabetes, the effect of transition skills on quality of life is inconsistent between groups. The results for the asthma group showed the same moderate negative correlation between TRANSITION-Q scores and the Physical Health quality of life instrument. For skills with significant impact on quality of life, the asthma group also showed decreases in quality of life scores for more frequently utilized skills. However, both the cystic fibrosis group and the diabetes group showed no significant correlation between skills scores and quality of life scores. They also showed increased quality of life scores where skills had a significant impact. This suggests that condition-dependent effects on quality of life can be seen with healthcare self-management skills. It may be possible to improve quality of life for certain conditions by improving specific skills as an alternative to focusing on more broad skill acquisition with further research.

Overall, this study demonstrates that interactions which build rapport and trust with a pediatric healthcare provider as well as consistent effort to encourage skill building and future planning have the most impact on the acquisition of self-management skills. It also demonstrates that the relationship between self-management skills and quality of life is likely confounded by other influences. Further research is needed to outline the relationship and to determine if self-management skills can be used to improve quality of life the setting of specific chronic pediatric conditions. To better elucidate the relationship between self-management skills and quality of life, case-control interventional research could be conducted that would target an intervention to improve one particular self-management skill. This would then be tracked to evaluate participants' independent function in that skill prior to, during and after transition to adult healthcare along with their quality of life. This could then be compared with a non-intervention group as well as conducted with groups based on specific chronic conditions. This would allow for a limited intervention to demonstrate value at increasing self-management skills and quality of life.

Limitations

There were several limitations to this study. A high percentage of surveys were not completed (56.8%) and of those completed 33.3% had to be excluded from analysis as they did not meet the inclusion criteria. This is likely the result of the length of the survey instrument and the study design which allowed for a self-select population combined with a financial incentive. As a result of the exclusions, the overall study population size was smaller than intended and resulted in only a small number of participants reporting the same chronic conditions. This reduced the power of the condition-specific analysis. In addition, while the sample was relatively demographically diverse, the overall education level was high with a significant majority of participants (82%) reporting at least some college education. The preponderance of higher level education suggests the availability of resources and support systems that increase the acquisition and frequency of use of self-management skills and represent a homogeneity in quality of life.

Implications for Advanced Practice Nursing

This research offers significant implications for advanced practice nursing in the design of interventions for healthcare transition as well as practice implications for working with adolescents and young adults with chronic conditions. It emphasizes the importance of dedicating clinical time to assisting adolescent and young adult patients with understanding the long-term management of their health and building a relationship that facilitates learning and increased independence for the patient. It also highlights the importance of continue to encourage the acquisition of self-management skills in young adult patients even as adult healthcare providers once healthcare transition has been completed. For the design of healthcare transition interventions, it emphasizes that interventions that allow greater support and interaction with providers will have a larger impact on healthcare self-management skills then information alone. It highlights that self-management skills can have an impact on quality of life, but that other factors such as effective communication need to be considered to create an improvement.

References

American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), & American College of Physicians (ACP). (2002). A consensus statement on healthcare transitions for young adults with special healthcare needs. *Pediatrics, 110*(supp 3), 1304-1306.

Bal, M.I., Sattoe, J., Roelofs, P., Bal, R., van Staa, A., & Miedema, H.S. (2016). Exploring the effectiveness and effective components of self-management interventions for young people with chronic physical conditions: A systematic review. *Patient Education and Counseling, 99,* 1293-1309. doi:10.1016./j.pec.2016.02.012

Betz, C.L. (2004). Transition of adolescents with special healthcare needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, *27*, 179-241.

Bingham, C. A., Scalzi, L., Groh, B., Boehmer, S., & Banks, S. (2015). An assessment of variables affecting transition readiness in pediatric rheumatology patients. *Pediatric Rheumatology*, 1-8. doi:10.1186/s12969-015-0040-x

Dwyer-Matzky, K., Blatt, A., Asselin, B., & Wood, D.L. (2018). Lack of preparedness for pediatric to adult-oriented healthcare transition in hospitalized adolescents and young adults. *Academic Pediatrics, 18*(1), 102-110.

Fair, C., Cuttance, J., Sharma, N., Maslow, G., Wiener, L., Betz, C., … & Ferris, M. (2016). International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatrics, 170*(3), 205-211. doi:10.1001/jamapediatrics.2015.3168

Fishman, L. N., Mitchell, P. D., Lakin, P. R., Masciarelli, L., & Flier, S. N. (2016). Are expectations too high for transitioning adolescents with IBD? Examining adult medication knowledge and self-management skills. *Journal of Pediatric Gastroenterology and Nutrition*, *63*(5), 494–499. https://doi.org/10.1097/MPG.0000000000001299

Fredericks, E.M., Dore-Stiles, D., Well, A., Magee, J.C., Freed, G.L., Shieck, V., &

Lopez, M.J. (2010). Assessment of transition readiness skills and adherence in pediatric liver transplant patients. *Pediatric Transplantation, 14,* 944-953. doi:10.1111/j.1399-3046.2010.01349.x

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.e15. https://doi.org/10.1016/j.jpeds.2017.05.066

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*(2), 346–354. https://doi.org/10.2337/dc13-1346

Jonkman, N.H., Schuurmans, M.J., Groenwold, R.H.H., Hoes, A.W., & Trappenburg, J.C.A. (2016). Identifying components of self-management interventions that improve health-related quality of life in chronically ill patients: Systematic review and meta-regression analysis. *Patient Education and Counseling, 99,* 1087-1098. doi:10.1016/j.pec.2016.01.022

Klassen, A.F., Grant, C., Barr, R., Brill, H., Kraus de Camargo, O., Ronen, G.M., … & Gorter, J.W. (2014). Development and validation of a generic scale for use in transition programmes to measure self-management skill in adolescents with chronic health conditions. *Child: Care, Health and Development, 41*(4), 547-558. doi:10.1111/cch.12207

McGrab, P. & Millar, H. (Eds.). (1989). *Growing up and getting medical care: Youth with special healthcare needs.* Washington, D.C.: National Center for Networking Community-Based Services, Georgetown University Child Development Center.

McManus, M.A., Pollack, L.R., Cooley, C., McAllister, J.W., Lotstein, D., Strickland, B., Mann, M.Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics, 131,* 1090-1097.

McPheeters, M., Davis, A.M., Taylor, J.L., Brown, R.F., Potter, S.A., & Epstein, R.A.

(2014). *Transition care for children with special health needs: Technical brief, no. 15*. Rockville, MD: Agency for Healthcare Research and Quality.

Meaux, J. B., Green, A., Nelson, M. K., Huett, A., Boateng, B., Pye, S., … & Riley, L. (2014). Transition to self-management after pediatric heart transplant. *Progress in Transplantation*, *24*(3), 226-233. doi:10.7182/pit2014911

Modi, A.C., Pai, A.L., Hommel, K.A., Hood, K.K., Cortina, S., Hilliard, M.E., … & Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics, 129*(2), e473-e485.

Sattoe, J., Hilberink, S., van Staa, A., & Bal, R. (2014). Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *Journal of Adolescent Health, 54*, 397-403. doi:10.1016/j.jadohealth.2013.09.017

Schmidt, S., Herrmann-Garitz, C., Bomba, F. & Thyen, U. (2016). A multi-center prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Education and Counseling, 99*, 421-428. doi:10.1016/j.pec.2015.10.024

Schmidt, S., Herrmann-Garitz, C., Bomba, F. & Thyen, U. (2016). A multi-center prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Education and Counseling, 99*, 421-428. doi:10.1016/j.pec.2015.10.024

Schmidt, S., Markwart, H., Bomba, F., Muehlan, H., Findeisen, A., Kohl, M., … & Thyen, U. (2018). Differential effect of a patient-education transition intervention in adolescents with IBD vs. diabetes. *European Journal of Pediatrics, 177*, 497-505. doi:10.1007/s00431-017-3080-z

Sharma, N., O'Hare, K., Antonelli, R. C., & Sawicki, G. S. (2014). Transition care: Future directions in education, health policy, and outcomes research. *Academic Pediatrics, 14*(2), 120-127. doi:10.1016/j.acap.2013.11.007

Silvestri, P.R., Chiarotti, F., Baglioni, V., Neri, V., Cardona, F., & Cavanna, A.E. (2016).

Health-related quality of life in patients with Gilles de la Tourette syndrome at the transition between adolescence and adulthood. *Neurological Science, 37*, 1857-1860. doi:10.1007/s10072-016-2682-y

Sundell, K., Bergstrom, S.-E., Hedlin, G., Ygge, B.-M., & Tunsater, A. (2011). Quality of Life in adolesecents with asthma, during the transition from child to adult. *The Clinical Respiratory Journal, 5*, 195-202. doi:10.1111/j.1752-699X.2010.00218.x

Suris, J.-C. & Akre, C. (2015). Key elements for, and indicators of, a successful transition: An international delphi study. *Journal of Adolescent Health, 56,* 612-618. doi:10.1016/j.jadohealth.2015.02.007

Syed, I.A., Nathan, P.C., Barr, R., Rosenberg-Yunger, Z.R.S., D'Agostino, N.M., & Klassen, A.F. (2016). Examining factors associated with self-management skills in teenage survivors of cancer. *Journal of Cancer Survival, 10,* 686-691. doi:10.1007/s11764-016-0514-y

Tong, A., Gow, K., Wong, G.., Henning, P., & Carroll, R. (2015). Patient perspectives of a young adult renal clinic: A mixed-methods evaluation. *Nephrology*, *20*, 352-359. doi:10.111/nep.12396

Uzark, K., Smith, C., Donohue, J., Yu, S., Afton, K., Norris, & Cotts, T. (2015). Assessment of transition readiness in adolescents and young adults with heart disease. *The Journal of Pediatrics, 167*(6), 1233-1238. doi:10.1016/j.jpeds.2015.07.043

van Staa, A., van der Stege, H.A., Jedeloo, S., Moll, H., & Hilberink, S.R. (2011). Readiness to transfer to adult care of adolescents with chronic conditions: Exploration of associated factors. *Journal of Adolescent Health, 48,* 295-302. doi:10.1016/j.jadohealth.2010.07.009

Varni, J.W. (2017). The PedsQL measurement model for the pediatric quality of life inventory: Publications. Retrieved from http://www.pedsql.org/PedsQL-Publications.doc on April 15, 2018.

While, A.E., Heery, E., Sheehan, A.M., & Coyne, I. (2016). Health-related quality of life of young people with long-term illnesses before and after transfer from child to adult healthcare. *Child: Care, Health and Development, 43*(1), 144-151. doi:10.1111/cch.12410

Whitfield, E. P., Fredericks, E. M., Eder, S. J., Shpeen, B. H., & Adler, J. (2015). Transition readiness in pediatric patients with inflammatory bowel disease: A patient survey of self-management skills. *Journal of Pediatric Gastroenterology and Nutrition*, *60*(1), 36–41. https://doi.org/10.1097/MPG.0000000000000555

Williams, T.S., Dunseith, C., Mah, J.K., Blackman, M., Latter, J., Mohamed, I., … & Thornton, N. (2011). Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. *International Journal of Child and Adolescent Health, 3*(4), 527-535