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The Effect of Transition Readiness Interventions on Adolescents with Diabetes when Transitioning from Pediatric to Adult Clinic

Kimberly Walker

University of Kentucky, kimwalker7@live.com

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DNP Final Project Report

The Effect of Transition Readiness Interventions on Adolescents with Diabetes when
Transitioning from Pediatric to Adult Clinic

Kimberly Walker

University of Kentucky

College of Nursing

Fall 2017

Dianna Inman DNP, RN, APRN, CPNP, PMHS, PMHNP – Committee Chair

Leslie Scott PhD, APRN, PPCNP-BC, CDE, MLDE - Committee Member

Deborah Howard MSN, APRN, CDE – Committee Member/Clinical Mentor

Dedication

This work and project is dedicated to my husband and my children, who have supported me through this journey, who have tolerated my exhaustion, my stress, and who have worked together as a team so we could accomplish this dream. This is for my mom who has prayed for me, encouraged me, and been one of my biggest cheerleaders. This is to my brother, sister, and their families for their encouraging words. To my friends who have gone on therapeutic shopping trips and lunches with me; those definitely were beneficial. This is to my supervisor who has always been super flexible with my full time job and an understanding that I am sure most supervisors do not possess. This is to my God who has listened to my countless prayers and given me a peace that sent me in this direction from the beginning. This is also to my church family that has supported me through countless prayers. This is to any high school student, mom, dad, and anyone out there in the world who feels they cannot achieve their dreams. I am here to tell you as sure as I stand here today you can.

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Abstract

PURPOSE: The purpose of this study was to initiate a transition readiness program which uses motivational interviewing at the Pediatric Endocrinology Clinic located within the UK HealthCare Kentucky Clinic. An evaluation of this program was conducted by assessing participant outcomes related to readiness for transitioning.

METHODS: This study was a quasi-experimental one group pretest posttest design to assess the effectiveness of transition readiness interventions on adolescent readiness and confidence in transition of care at the Pediatric Endocrinology Clinic located at the Kentucky Clinic. The sample consisted of 14 patients.

RESULTS: No statistical significance was found in the TRAQ tool and the Transition Readiness Assessment Questionnaire pre-/post-intervention due to the small sample size and the number of study subjects who were lost to follow up. The intervention of motivational interviewing and the establishment of a plan of care was completed for 64% of the study subjects. The Transition Registry was utilized to track study subjects for each stage of the study.

CONCLUSION: Statistical significance was not found due to a small sample size; however, there is clinical importance in the fact that establishing formal policies within clinics to guide and assist with training, and creating a standardized transition process, will guide healthcare providers and allow for more successful transitions. Therefore, formal practices and programs that address when to identify and assess the knowledge of a transitioning youth will allow for a well-prepared, well-thought out, time invested transition period. More research is needed to further understand the factors surrounding transition of care, and future researchers should develop controlled, large sample size studies to help providers understand how to utilize these factors.

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Introduction

Transition of care for pediatric patients with chronic illnesses who are moving into adulthood has been a topic of study for many years. Through research best methods have been identified to establish an evidence based approach to ensure a seamless transition. Transitional care is defined as a focused, intentional movement of adolescents and young adults with chronic conditions from child-centered clinics to adult-oriented clinics (Blum et al., 1993). Adolescents with chronic illnesses are not only dealing with the illnesses themselves, they are also experiencing what Erik Erickson called identity versus role confusion, which is an important psychological stage in which the adolescent learns the role he or will inhabit as an adult (McLeod, 2013).

Although transition of care is a well-researched topic, a standard of care has yet to be produced and implemented. It is estimated that approximately 10 to 20 million children have a chronic illness, this increased number is due to advancing technology that allows these children to live well into adulthood (“Chronic”, n.d.). Therefore, addressing the barriers that prevent successful transitions for children with chronic illnesses will promote their health and well-being (US Department of Health and Human Services, n.d.). Hence, the aim of this project was to implement and evaluate the impact of a formal transition of care program.

Background

It is estimated that 29 million adults are living with diabetes and 89 million have prediabetes in the U.S. (Centers for Disease Control and Prevention [CDC], & National Center for Chronic Disease Prevention and Health Promotion, 2016). Over the past decade there has been an increasing frequency of youth diagnosed with diabetes in the U.S., with over 195,000 of individuals under 20 years of age being diagnosed with the disease (Centers for Disease Control

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and Prevention [CDC], & National Center for Chronic Disease Prevention and Health Promotion, 2014). Moreover, it is estimated that nearly 25,000 new cases of diabetes will be diagnosed in individuals under 20 years of age each year (CDC & National Center for Chronic Disease Prevention and Health Promotion, 2014).

Estimated costs of chronic disease management make up approximately 75% of the healthcare costs in the U.S., and the healthcare cost of diabetes management is approximately \$174 billion (CDC, 2011). With over 90% of the children/adolescents in the U.S. diagnosed with a chronic illness and 750,000 of these children/adolescents transitioning from the pediatric to the adult world each year (Reiss & Gibson, 2002; Scal & Ireland, 2005; Sawicki et al., 2009) an effective transition program is imperative to negate these climbing healthcare costs.

The adolescent years are considered to be a challenging developmental time; when coupled with a chronic disease, the transition period from adolescence to adulthood can seem especially daunting. An adolescent with a chronic disease is at high risk for failure to transition (Chu, Maslow, von Isenburg, & Chung, 2015; McManus et al., 2013). Unfortunately, only half of these high risk, chronically ill adolescents are adequately prepared for transition (McManus, 2013; Lostein et al., 2013). This lack of preparation leads to poor health outcomes that could have been prevented with adequate transitional preparation (Callahan & Cooper, 2010).

This problem is evident among adolescents with diabetes, who require lifelong routine medical care to reduce the risk of diabetes complications that will increase their healthcare costs and reduce quality of life (Lostein et al., 2013). This care regimen requires the adolescent to adequately self-manage their disease. However, in current transition readiness programs, less than half of pediatric clinic providers regularly administer a transition readiness questionnaire and less than 20% of the programs nurture an atmosphere of self-management skills (Sawicki et

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al., 2009). Transition readiness programs can close the gap by preparing the adolescent to transfer to adult care.

Successful, transition in adolescents with chronic illness requires planned preparation and timing (American Academy of Pediatrics [AAP] & American College of Physicians-American Society of Internal Medicine [ACP-ASIM], 2002). Implementation of transitional strategies for adolescents and young adults with chronic illnesses includes the following: implementing organized, team-based transition programs that include patients and their caregivers in the process; implementing and using resources that are currently lacking in this population, and decreasing preventable mortality and morbidity (AAP & ACP-ASIM, 2002; Callahan & Cooper, 2010). Currently, many adolescent clinics do not have transitional care programs that allow for the implementation of these strategies to facilitate better outcomes across the growing adolescents life span. This project implemented a formal transition program known as Got Transition. The implementation process employed a formal transition registry to identify all eligible adolescents, assessed confidence and readiness through formal questionnaires, and initiated an individualized plan of care for each adolescent that was jointly created by the provider and adolescent. This process will begin to close the knowledge gap that currently exists in the diabetic adolescent population within the Pediatric Endocrinology Clinic at UK HealthCare's Kentucky Clinic.

Purpose

According to research, a formal transition of readiness program can improve the transition from a pediatric clinic to an adult clinic in adolescents with chronic illnesses (McManus et al., 2013). The purpose of this project was to initiate a transition readiness program involving motivational interviewing at the Pediatric Endocrinology Clinic located at the

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UK Health Care Kentucky Clinic. The goals of this program, designed to successfully ready patients for the transition from pediatric to adult clinic were:

- 1) Increase Transition Importance and Confidence assessment scores by 20% from pre intervention to post intervention.
- 2) Increase Transition Readiness Assessment Questionnaire (TRAQ) scores by 20% from pre intervention to post intervention.
- 3) Development of an individualized plan of care for 90% of identified adolescents.

Methods

This study was a quasi-experimental, one group pretest posttest design to assess the effect of transition readiness intervention on adolescent patients at the Pediatric Endocrinology Clinic, with regard to their readiness to transition from pediatric to adult care and their confidence in their ability to do so. Changes in adolescent readiness and confidence were assessed through the pre/posttest of the TRAQ tool and the Transition Importance and Confidence questionnaire before and after the educational intervention of motivational interviewing and the establishment of an individualized plan of care. The Transition Importance and Confidence questionnaire was also given to the patients' parents/guardians to obtain input on their children's knowledge of diabetes management.

Setting

This program was carried out at the Pediatric Endocrinology Clinic, located at the Kentucky Clinic in Lexington, KY, which is a part of Kentucky Children's Hospital-UK Health Care. The clinic sees approximately 2,500 patients every year. This also includes a traveling clinic in Eastern Kentucky. The clinic is staffed with five medical doctors and two advanced

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practice nurses. The clinic also houses a variety of clinic staff, educators, nutritionists, a research nurse, counselors, and other specialists to meet the needs of each child.

Sample

To examine the effect of the intervention, a population sample of individuals between the ages of 16-21 was selected. After a modification to include adolescents down to the age of 14 the total sample size included 14 adolescents between the ages of 14-18. The pre- and post-implementation outcomes were compared for the enrolled individuals. To meet the inclusion criteria for the sample group, participants had to have a diagnosis of type I or type II diabetes mellitus, require insulin to control their diabetes, and speak English. Individuals were excluded from the sample group if they only required oral medications to control their diabetes and had an A1C > 10. However, after reviewing exclusion criteria a modification was completed to include individuals with A1C > 10.

Data Collection

Prior to study implementation, approval from the University of Kentucky Institutional Review Board (IRB) were obtained. This study used a quasi-experimental design. Patients were identified through the electronic medical record (EMR) outpatient system. Questionnaires were administered through the Qualtrics research software. An Excel spreadsheet was used to track completion of study the intervention. Data were then extracted from the software into SPSS22 and Excel for analysis. Demographical data including ethnicity, age and gender were collected from the EMR.

Data Analysis

Descriptive statistics, including frequency distributions, means, and range was used to describe patients' demographic characteristics. Continuous variables measured pre- and post-

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intervention was compared using the Paired-Samples *t*-tests. Classification tables were used to evaluate associations between categorical variables pre- and post-intervention. All analysis was conducted using SPSS version 22; an [*alpha*] level of .05 was used for statistical significance throughout.

Results

Sample Characteristics

A total of 14 patients with insulin dependent diabetes were enrolled in the study. Table 1 represents the descriptive characteristics for the 14 patients enrolled. The mean age was 16.4 years old, with a range from 14-18 years of age. The majority of patients were female (64%) and Caucasian (79%).

Transition Registry

Of the 14 patients who participated only five completed the entirety of the study. Nine completed the pre-intervention and intervention portions of the study and a total of five were lost to follow-up. The registry was a good tracking tool to monitor progress of subjects throughout the study. It allowed the investigator to track patient appointments, ascertain which participants completed the intervention, and take note of the ages of the participants in order to determine how close they were to transitioning to an adult clinic (See Figure 1).

Transition Readiness Assessment Questionnaire (TRAQ) Tool

The TRAQ was given pre- and post- intervention a tool to measure knowledge readiness. The tool can be broken down into five subscales: managing meds, appointment keeping, tracking health issues, talking with providers, and managing daily activities (See Figure 2). A paired-samples *t*-test was conducted on each subscale and the overall scores. (See Table 3)

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The impact of the intervention on adolescents' knowledge of medication management did not produce statistically significant scores from pre-intervention ($M = 14.4$, $SD = 3.21$) to post-intervention ($M = 13.6$, $SD = 4.04$), $p = .872$. The mean medication management score decreased by 0.8, indicating that the adolescents may not know as much about medication management post-intervention as they had indicated pre-intervention.

The impact of the intervention on an adolescents knowledge about appointment keeping did not produce statistically significant scores from pre-intervention ($M = 15$, $SD = 3.87$) to post-intervention ($M = 13.6$, $SD = 4.16$), $p = .882$. The appointment keeping score decreased by 1.4 indicating that the adolescents may not have known as much about appointment keeping post-intervention as they had indicated pre-intervention.

The impact of the intervention on adolescents knowledge about tracking health issues did not produce statistically significant scores from pre-intervention ($M = 14.4$, $SD = 3.78$) to post-intervention ($M = 13.4$, $SD = 4.28$), $p = .711$. The tracking health issues score decreased by 1.0 indicating that the adolescents may not have known as much about tracking health issues post-intervention as they had indicated pre-intervention.

The impact of the intervention on adolescents knowledge about talking with providers did not produce statistically significant scores from pre-intervention ($M = 14.6$, $SD = 3.91$) to post-intervention ($M = 13$, $SD = 4.64$), $p = .895$. The talking with providers score decreased by 1.6 indicating that the adolescents may not have known as much about talking with providers post-intervention as they had indicated pre-intervention.

The impact of the intervention on adolescents knowledge about managing daily activities did not produce statistically significant scores from pre-intervention ($M = 14.8$, $SD = 3.7$) to post-intervention ($M = 12.8$, $SD = 4.87$), $p = .979$. The managing daily activities score

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decreased by 2 indicating that the adolescents may not have known as much about managing daily activities post-intervention as they had indicated pre-intervention.

The impact of the intervention on adolescents overall TRAQ score did not produce statistically significant scores from pre-intervention ($M = 78, SD = 13.3$) to post-intervention ($M = 72.4, SD = 19.1$), $p = .566$. The overall TRAQ score decreased by 5.6 indicating that the adolescents may not have known as much about their transition knowledge readiness post-intervention as they had indicated pre-intervention.

Transition Readiness Assessment for Youth and Parents

The first section of the transition readiness tool measures how important and confident the adolescent feels about the transitioning process; it is scored on a 10-point Likert scale. The impact of the intervention on an adolescents importance score did not produce statistically significant scores from pre-intervention ($M = 9.6, SD = 1.342$) to post-intervention ($M = 9.6, SD = 1.673$), $p > 0.99$. The impact of the intervention on adolescents confidence scores did not produce statistically significant scores as the p-value is 0.70; however, the pre-intervention mean score was 8 and the post-intervention mean score was 8.6, which showed a 0.6 increase. This indicated that the adolescents may have experienced a slight increase in confidence from pre- to post- intervention. (See Table 4)

The second part of the questionnaire asks 23 questions that measure self-management skills on a 3-point ordinal response scale (I can do this, I can't do this, I need someone to do this for me; See Figure 3). For an evaluation of this tool frequency distributions were used to describe any gains in knowledge that may have occurred pre/post intervention. In the preceding paragraphs the questions were divided into groups to indicate no change in knowledge, an increase in knowledge or a decrease in knowledge.

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All of the study subjects stated “I can do this” to the following statements pre- and post-intervention: I can explain my medical needs to others; I know my symptoms, including ones that I quickly need to see a doctor for; I know my allergies to medicines, and medicines I should not take; I have a way to get to my doctor’s office; and I know to show up 15 minutes before the visit to check in. This response group indicates that the study subjects already possessed a general knowledge of these skills, and suggests that the intervention had no bearing on their responses.

For certain statements, many of the study subjects stated “I can do this” pre-intervention but decided on the response “I can’t do this” post-intervention. These included the following: I know my medical needs; I know what to do in case I have a medical emergency; I know my own medicines, what they are for, and when I need to take them; I understand how health care privacy changes at age 18 when I am legally an adult; and I have a copy of my current plan of care. This change pre/post intervention may have occurred because the study subject realized through motivational interviewing that they did not know how to manage these skills and needed to continue to learn or improve upon them.

For some of the skill statements, an equal number of subjects stated “I can do this” or “I can’t do this” pre- and post-intervention, indicating no change. These included: I can explain to others how my customs and beliefs affect my health care decisions and medical treatment; before a visit I think of questions to ask; I know where to go to get medical care when the doctor’s office is closed; and I know how to get referrals to other providers, and where my pharmacy is and how refill my medicine.

The following self-management skills presented varied responses pre/post intervention among study subjects. Some of the subjects who stated they knew a skill prior to the

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intervention then stated that they needed to learn the skill post intervention. Conversely, in the same group, subjects who stated they needed to learn a skill pre-intervention stated they could now do the skill post-intervention. The skills in this grouping were: I know where to get blood work or x-rays if my doctor orders them, I know where my pharmacy is and how to refill my medications, I know how to fill out medical forms, I make my own doctor appointments, I carry important health information with me every day, I have a plan so I can keep my health insurance after 18 or older, and my family and I have discussed my ability to make my own health care decisions at age 18.

Subjects stated “I can do this” post-intervention to the following statements: I know or I can find my doctor’s phone number, and I have a file at home for my medical information. This increase shows that the intervention of motivational interviewing may have increased the subject’s knowledge on these skills. None of the study subjects answered the self-management statements with “I need someone to do this for me” pre- or post-intervention indicating that even if they did not know that particular self-management skill, they were willing to learn.

Parents were given this same questionnaire to assess what they felt their children knew about their self-management skills in comparison to what the children felt they knew about those same skills. However, only three parents participated in the questionnaire; therefore, there were not enough data to analyze comparative responses. Although when evaluating the means of the parents’ response to the importance and confidence questions and comparing them to the means of the adolescents it was noted that an inverse relationship was present. The parents mean score for how important they felt it was to their adolescent to transition by the age of 22 was 8.3 but the adolescents mean score for how important it was to them to transition by the age of 22 was 8.1. Inversely, the parents mean score for how confident they felt their adolescent was to

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transition was 5.8 but the adolescents mean score for how confident they felt about transitioning was 6.1. These correlations indicate that parents and adolescents alike need to be educated and prepared for the transition process as parents may not know what their adolescents knowledge about their disease process is rather have an assumption (See Figure 4).

Motivational Interview and Plan of Care Intervention

The intervention portion of the study consisted of motivational interviewing followed by the development of an individualized plan of care for each study subject. The intervention took place at each study subject's second visit, after the completion of the pre-intervention questionnaire that was completed at the first visit. The outcome was to complete a plan of care for 90% of the study subjects; however, due to appointment cancellations only 64% of the study subjects completed the plan of care (See Table 2).

Discussion

The purpose of this project was to develop an effective way to prepare chronically ill adolescents to transition from pediatric to adult clinics. Due to technical advances developed in recent decades, our chronically ill youth are now living well into their adult years. However, with this longer life span there is a great need to improve upon the transitions from the pediatric world in health care to the adult world. Evidence confirms that many pediatric specialty clinics lack in a transition readiness program (Hopper, Dokken, & Ahmann, 2014). To ensure more successful transitions, adolescents and caregivers in pediatric specialty clinics need health care providers to address this issue (Hopper et al., 2014).

A number of research studies underscore this need, and highlight specific consequences of poor transitions in this population. For example, an increase in HbA1c has been observed among those who had no transitional assessment or support through the transition of care process

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(Lotstein, McPherson, Strickland, & Newacheck, 2005; Van Walleggem, MacDonald, & Dean, 2008). After the implementation of transition readiness tools such as, transition readiness assessment questionnaires (Sawicki et al., 2009), motivational interviewing (Channon et al., 2007), and transition programs using at least one of the six Got Transition core elements (Chu et al., 2015), more successful transition of adolescents from the pediatric clinic setting to the adult clinic setting occurred (Sawicki et al., 2009; Channon et al., 2007; Chu et al., 2015). Thus, providing transition readiness tools to providers is an important means of enhancing their ability to assist their adolescent patients in transitioning to adult care clinics.

Overall, the study results and data analysis did not show any statistical significance or improvement in knowledge for the group of study participants. However, this could be due to the small enrollment numbers as each study participant was receptive to the learning assessment tools and to the idea of establishing a goal to improve an area of their health. In addition, all the study participants seemed eager to determine what they knew about their health.

Transition Registry

A transition registry is important for identification, tracking, and monitoring an adolescent from the beginning of the transition process to the end. Got Transition.org discusses the importance of providers establishing standards to identify transitioning youth and entering their data into the registry (2017). Tracking and monitoring the progress of an adolescent's transition journey allows the provider to evaluate the adolescent's knowledge of their own self-care and provides the ability to adjust the plan of care accordingly. Frequent evaluation produces improved patient outcomes and in the case of transition of care, successful transitions (McManus et al., 2015).

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Transition Readiness Assessment for Youth and Parents

Family and adolescent readiness is an important assessment that needs to be completed to ensure a successful transition (Cooley, Sagerman, & American Academy of Pediatrics [AAP], 2011). As Cooley et al. (2011) point out, it is important for health care providers to assess the parents'/caregivers' readiness for change, as for most pediatric patients the caregiver has been the one constant in life. The authors also discuss the importance of identifying the parents'/caregivers' role throughout the adolescent's transition to adulthood, as this can be a complicated and emotional time for the parent/caregiver. It is also important for providers and parents/caregivers to recognize that the adolescent is the driver of change; therefore, assessing their confidence and readiness for self-management using validated tools will assist the provider in identifying what goals the adolescent is willing to set and creating a plan of care that will empower the adolescent for success (Cooley et al., 2011; Sawicki et al., 2009).

Transition Readiness Assessment Questionnaire (TRAQ) Tool

In order to successfully prepare an adolescent patient to transition to an adult clinic, it is important to have an instrument that measures the abilities needed to successfully transition from pediatric to adult healthcare and the improvements the patient has achieved in other areas such as education, work, and daily life. The use of a self-administered tool would provide a measurement of individual transitional readiness skills that each child should possess before beginning the transition process; this tool would serve as a reference point for the physician (Sawicki et al., 2009). The Transition Readiness Assessment Questionnaire (TRAQ) is a tool that will allow physicians to assess the adolescent's readiness for transition. The TRAQ is a self-administered tool that takes only minutes for youth to complete and can also be completed by caregivers to obtain their view of their children's abilities (Sawicki et al., 2009). The tool

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addresses five main topics, which are; appointment keeping, tracking health issues, talking with providers, and managing daily activities. This tool is appropriate for youth as it is short and concise, and the verbiage used is on a level that is easily understood. To further meet the specific needs of the targeted adolescent group it may be beneficial to set up an electronic application where the questionnaire could be completed on a smart phone or computer. This type of delivery would further tailor the questionnaire to the adolescent population. The creation of an electronic application would also allow for delivery of “notifications” that could serve as reminders or provide education about the patient’s illness. When implementing a tool for the adolescent population, it is imperative that the tool seems convenient and to their lifestyle to ensure maximum compliance.

Motivational Interview and Plan of Care Intervention

Motivational interviewing, one of many evidence based interventions, is a patient-centered technique to change health behaviors by surveying and resolving doubt (Miller & Rollnick, 2003). In adolescents with type 1 diabetes, motivational interviewing has been implemented into practice to improve diabetes self-management and decrease HbA1C (Channon et al., 2007). The success behind motivational interviewing lies in four principles that health care providers are required to follow (Erickson, Gerstle, & Feldstein, 2005). These four principles are described by Miller and Rollnick (2003) as sincere expression of empathy, development of difference between the adolescent’s existing behavior and his or her management goal, not reacting defensively to the adolescent’s resistance, and supporting the adolescent’s self-efficacy. These four principles of motivational interviewing have been shown over time to increase the adolescent’s confidence and ability to manage and improve their diabetes (Miller & Rollnick, 2003; Channon et al., 2007).

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Motivational interviewing has been shown to be an effective method to improve self-management when working with adolescents (Channon et al., 2007). Nine of the 14 subjects in this study participated in motivational interviewing and completed the individualized plan of care. Each of the participants who completed the intervention were receptive to the interview process and eager to choose something they could improve on. Interestingly, most of the adolescents were more apt to choose a goal that allowed them to utilize technology. Most chose reminders for appointments, for when to refill medications, and for when to take medications, all things that they could set up in their smart phones. Utilizing this technology in the future to encourage adolescent buy-in may be useful.

Limitations

Several limitations were identified in the design of this study. First, the low participation rates, single location, and small sample size limit the generalizability of the findings. The sample size was limited by a short two-week enrollment window. During the time of enrollment statewide KPREP testing was being given and schools discouraged children from missing school; therefore, many patients were considered “no shows” or simply rescheduled for a time after the enrollment period. In the pediatric endocrinology clinic most patients are only seen quarterly. The infrequency of appointments along with the three-time points needed, the likelihood of patients rescheduling, and the limited amount of time to conduct the study were all limitations that interfered with the ability to complete study data. A small sample size can make it difficult to find a statistical difference in pre- and post-interventions.

The questionnaires were another limitation of this study. One of the main concerns when individuals are asked to complete a questionnaire is the possibility that they may not complete all of the questions asked. The similarity of the questionnaires could also be a concern as they both

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addressed transition readiness. However, they used different scoring scales that could produce conflicting data.

Recommendations for Future Studies

Recommendations for future studies include gathering key stakeholders, enrolling larger numbers, using one validated transition tool, and scheduling a longer study time frame.

Gathering key stakeholders to give input on a policy to create a transition of care program in their clinic would allow for greater buy in and compliance, in turn producing more successful transitions. Validated assessment tools are proven to be effective in collecting valuable information from patients that can assist the medical provider in formulating a plan that will allow for the most successful transitions. To assist health care providers in providing meaningful transition processes that include assessment tools and policies, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians have created a formal transition program (Cooley, 2013). This program is called Got Transition; it assists providers by using six core elements that allow the provider, the youth and the parents/caregivers to jointly plan a successful transition course (Cooley et al., 2011). These core elements include transition policy, tracking, monitoring, readiness assessment tools, transition planning, transfer of care and transfer completion (Cooley et al., 2011). Following the six core elements of Got Transition is improving transitions for youth with chronic illnesses through joint efforts and strategic planning (McManus et al., 2013). To obtain more statistically significant data, pre/post quasi-experimental and longitudinal studies using the Got Transition elements that include large study samples will be important in order to validate the implementation of a formal transition program like Got Transition into practice.

Conclusion

The goal of this study was to demonstrate the impact of a formal transition readiness program in preparing chronically ill adolescents who will soon be transitioning from pediatric to adult care clinics. The use of formal policies within clinics to guide and assist with training and a standardized transition process will allow for more successful transitions and give guidance to the provider as to when the best time to transition is the adolescent. For instance, we do not know the magic number for an adolescent to transfer to an adult clinic; however, it is known that when an adolescent is not properly prepared the transition will not be successful. Therefore, formal practices and programs that address when to identify and assess the knowledge of a transitioning youth will allow for a well-prepared, well-thought out, time invested transition period. An evaluation of these practices will need to be completed periodically to evaluate effectiveness, patient satisfaction and clinical outcomes. It is critical that researchers design and implement research studies to ascertain transition services that facilitate improved self-efficacy, improved glycemic control, and other health-related outcomes for adolescents who will soon be young adults. More research is needed to further understand the factors surrounding transition of care and to utilize those factors to develop future controlled, large sample size studies.

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Table 1. Demographic characteristics of the study sample at baseline (n=14)

	<i>Mean (range) or n (%)</i>
Age	16.4 (14-18)
Gender	
Male	5 (36%)
Female	9 (64%)
Race	
White	11 (79%)
African American	1 (7%)
Other	2 (14%)

Table 2. Motivation Interview and Plan of Care Developed (n=14)

	<i>Yes (%)</i>	<i>No (%)</i>
Plan of Care	9(64%)	5 (36%)

Table 3. Results of TRAQ (n=5)

Variables	Pre Mean (SD)	Post Mean (SD)	P
Managing Medications	14.4 (3.21)	13.6 (4.04)	.872
Appointment Keeping	15 (3.87)	13.6 (4.16)	.882
Tracking Health Issues	14.4 (3.78)	13.4 (4.28)	.711
Talking with Providers	14.6 (3.91)	13 (4.64)	.895
Managing Daily Activities	14.8 (3.70)	12.8 (4.87)	.979
Overall Score	78 (13.3)	72.4 (19.1)	.566

Table 4. Results of Transition Readiness Assessment Importance and Confidence over time (n=5)

Transition Importance & Confidence	Pre Mean (SD)	Post Mean (SD)	p
Q1	9.60 (1.342)	9.60 (1.673)	>0.99
Q2	8.00 (2.345)	8.60 (1.817)	0.70

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Figure 1. Transition Registry

TRANSITION REGISTRY												
	Age	Study ID	Gender	Diagnosis	Baseline Visit Date			Visit 1 Date		Final Study Visit		
					TRAQ Date Completed	Transition Importance and Confidence Date Completed	Parent-Transition Importance and Confidence Date Completed	MI Completed	Plan of Care Completed	TRAQ Date Completed	Transition Importance and Confidence Date Completed	Parent-Transition Importance and Confidence Date Completed
1	18	001-LNF-A	M	Type 1 DM	4/25/2017	4/25/2017	4/25/2017	7/26/2017	7/26/2017	10/30/2017	10/30/2017	X
2	16	002-BAF-A	M	Type 1 DM	4/25/2017	4/25/2017	4/25/2017	7/26/2017	7/26/2017	10/31/2017	10/31/2017	10/31/2017
3	18	003-KT-A	M	Type 1 DM	4/26/2017	4/26/2017	N/A	7/26/2017	7/26/2017	NSH	NSH	NSH
4	16	004-AAS-A	F	Type 2 DM	4/26/2017	4/26/2017	4/26/2017	7/26/2017	7/26/2017	11/1/2017	11/1/2017	11/1/2017
5	18	005-ENJ-A	F	Type 1 DM	4/26/2017	4/26/2017	N/A	X	X	Lost	To	Follow
6	16	006-JLS-A	M	Type 1 DM	4/26/2017	4/26/2017	4/26/2017	X	X	Lost	To	Follow
7	16	007-ZEHK-A	F	Type 1 DM	4/26/2017	4/26/2017	4/26/2017	7/26/2017	7/26/2017	NSH	NSH	NSH
8	15	008-KJP-A	M	Type 1 DM	5/1/2017	5/1/2017	5/1/2017	X	X	Lost	To	Follow
9	14	009-KLHP-A	F	Type 1 DM	5/1/2017	5/1/2017	5/1/2017	9/19/2017	9/19/2017	X	X	X
10	14	010-CNG-A	F	Type 1 DM	5/2/2017	5/2/2017	5/2/2017	8/2/2017	8/2/2017	11/2/2017	11/2/2017	11/2/2017
11	17	011-MKM-A	F	Type 1 DM	5/2/2017	5/2/2017	5/2/2017	X	X	Lost	To	Follow
12	17	012-KFT-A	F	Type 1 DM	5/2/2017	5/2/2017	5/2/2017	8/2/2017	8/2/2017	10/4/2017	10/4/2017	10/4/2017
13	17	013-EMP-A	F	Type 1 DM	5/3/2017	5/3/2017	5/3/2017	X	X	Lost	To	Follow

THE EFFECT OF TRANSITION READINESS

Figure 2. *Transition Readiness Assessment Questionnaire (TRAQ)*

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes *your* skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes *your* skill level. Check here if you are a parent/caregiver completing this form.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					

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<i>Talking with Providers</i>					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
<i>Managing Daily Activities</i>					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Figure 3. *Transition Readiness Assessment for Youth*



Transition Readiness Assessment for Youth Six Core

Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date: _____

Study ID: _____

Transition Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

How confident do you feel about your ability to prepare for/change to an adult doctor?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
---------	---	---	---	---	---	---	---	---	---	-----------

My Health *Please check the box that applies to you right now.*

	<i>Yes, I know this</i>	<i>I need to learn</i>	<i>Someone needs to do this... Who?</i>
I know my medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain my medical needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my symptoms including ones that I quickly need to see a doctor for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my own medicines, what they are for, and when I need to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines and medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how health care privacy changes at age 18 when legally an adult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, I think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to go to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a file at home for my medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a copy of my current plan of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get referrals to other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where my pharmacy is and how to refill my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get blood work or x-rays if my doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan so I can keep my health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family and I have discussed my ability to make my own health care decisions at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 4. *Transition Readiness Assessment for Parents and Caregivers*



Transition Readiness Assessment for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date: _____
Study ID: _____

Transition Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it for your child to prepare for/change to an adult doctor before age 22?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
How confident do you feel about your child's ability to prepare for/change to an adult doctor?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health *Please check the box that applies to your child right now.*

	<i>Yes, he/she knows this</i>	<i>He/she needs to learn</i>	<i>Someone needs to do this... Who?</i>
My child knows his/her medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child can explain his/her medical needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what to do in case he/she has a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows his/her own medicines, what they are for, and when he/she needs to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows his/her allergies to medicines and medicines he/she should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows he/she can see a doctor alone as I wait in the waiting room.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child understands how health care privacy changes at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

My child knows or can find his/her doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child makes his/her own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, my child thinks about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a way to get to his/her doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to go to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a file at home for his/her medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a copy of his/her current plan of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get referrals to other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where his/her pharmacy is and how to refill his/her medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to get blood work or x-rays if his/her doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a plan to keep his/her health insurance after ages 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I have discussed his/her ability to make his/her own health care decisions at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I have discussed a plan for supported decision-making, if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>