

Adolescents with Chronic Kidney Disease: Transition to Adult Care Program Development

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Table of Contents

- I. Title Page
- II. Abstract
- III. Background of the Problem
- IV. Purpose
- V. Theoretical Framework
- VI. Literature Review
- VII. Methodology
 - A. Design, Sample, Setting
 - B. Data Collection/ Procedures
 - C. Program Evaluation
- VIII. Human Subjects Protection
- IX. Data Analysis
 - A. Results
 - B. Discussion
- X. Limitations
- XI. Plans for Translation
- XII. Implications for Future Practice
- XIII. Conclusions
- XIV. References
- XV. Appendices
 - A. Appendix A. Tables
 - 1. Table 1- Demographics

2. Table 2. Correlation of TRxANSITION Scale™ Items with Domain Scores

3. Table 3. Correlation of TRxANSITION Scale™ scores of Each Item with Overall
Total Scores

4. Table 4 : BUN and Creatinine Levels

B. Appendix B. Literature review

1. Evidence Rating

2. Evidence Review Appraisal for Quality (Strengths and Weaknesses)

3. Summary Evidence Rating Review

C. Appendix C.- Figure 1- Middle Range Transition Theory

D. Appendix D. Project Timeline

E. Appendix E. Transition Policy

F. Appendix F. NAAAH Tool- Transition Readiness Questionnaire

G. Appendix G. Treatment Plan

H. Appendix H. Educational Handouts

I. Appendix I. Email Permission

J. Appendix J. UNC TRxANSITION Scale

K. Appendix K. UNC TRxANSITION Answer Guide

Abstract

Problem: Increasing numbers of children with chronic conditions, including those with Chronic Kidney Disease (CKD) survive into adulthood (Watson, 2012; Ferris, Gipson, Kimmel and Eggers, 2006). A diagnosis of CKD also includes many comorbidities in a vulnerable population. Without a structured approach, poorly managed healthcare transition (HCT) from pediatric-to adult-focused care, can be fatal or have consequences such as losing a kidney transplant. Recognizing the barriers to HCT emphasizes the need for a collaborative effort by pediatric and adult-focused providers. HCT is complex and demanding. Sudden changes in provider aspects and health care system processes may be disorientating to pediatric patients accustomed to intense and involved care all of their lives (Samuel et al., 2014). This, along with the increase in survival to adulthood, increases the need to have systematic processes in place to successfully transition these youth to adult care services.

Purpose: The purpose of this scholarly project was to develop a structured HCT preparation program for adolescents with CKD while maintaining their trust and assuring continued medical care.

Methods: This quality improvement project, completed in a large Mid-Atlantic urban outpatient nephrology clinic, aimed to successfully transition adolescent CKD patients to adult health care and involved four steps. The first was recruitment of participants, with specific criteria including English speaking, ages 15-23 and no hospitalizations in the past 3 months. The second phase was evaluation of ability to participate with the use of a readiness assessment; a formal validated scale, created by the National Alliance to Advance Adolescent Health (NAAAH, 2016) and development of an individualized, interprofessional treatment plan. Lastly, application of the

transition plan and patient evaluation involved the use of a formal, published teaching tool, called TRxANSITION (Ferris, 2012) which includes 7 domains of care. The UNC TRxANSITION Scale™ inter-rater reliability is strong ($r= 0.71$) and item-total correlation scores were moderate to high (Ferris et al, 2012). BUN and creatinine levels were also monitored during the program change to assure stability. Success was noted by full transition from pediatric to adult care, indicated by keeping the first independent appointment with the adult provider.

Results: Nineteen participants were enrolled; ages between 16 and 27 years; 54% females; 75% with CKD and 26% were renal transplant recipients. Patient responses to the TRxANSITION Scale variables were evaluated using the Pearson Correlation coefficient. Sub-scales that had the highest correlation coefficients with the total score and with a strong positive relationship to their domain were self- management ($N=19, r=0.91, p<0.01$, two-tailed), insurance ($N=19, r=0.83, p<0.01$, two-tailed) and school ($N=19, r= 0.82, p<0.01$, two-tailed). During the program development process, four participants successfully transitioned from pediatric to adult nephrology services without incident, while others continued with preparation for transition.

Conclusion: Purposeful HCT preparation provides youth with ongoing access to subspecialist care, promotes competence in disease management, fosters independence, social, and emotional development through teaching self-advocacy and communication skills, and allows for a sense of security for support of long-term health care planning and life goals.

Background of the Problem

Increasing numbers of children with chronic illness are surviving into adulthood, including those with Chronic Kidney Disease (CKD) (Watson, 2012; Ferris 2016). CKD is the presence of either kidney damage or a glomerular filtration rate (GFR) of less than 60 mL per minute per 1.73 m² for three months or longer, that is further classified in five stages based on GFR, which is the level of kidney function (National Kidney Foundation, 2002) with stage 5 being the worst level requiring renal replacement therapy (dialysis or transplant). The exact prevalence of CKD in children is unknown, but it is estimated at 82 cases per million per year (Massengil and Ferris, 2014). A diagnosis of CKD also includes many comorbidities in a vulnerable population. This, along with the increase in survival to adulthood over the last decade, supports the need to have systematic processes in place for successful HCT preparation of these youth to adult-focused health care services.

Transitioning from pediatric to adult care is complex and demanding. Sudden changes in provider aspects and health care system processes may be disorientating to pediatric patients accustomed to intense and involved care all of their lives (Samuel et al., 2014). HCT has been described as, “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al., 1993, p. 570). The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) (2015) coauthored a clinical report attesting that the aim of a planned health care transition is to magnify life expectancy and quality for all youth, including those with or without chronic illness. Despite this clinical report, there are many barriers in coordinating care for children with chronic illness.

One major barrier to HCT is the lack of insurance coverage. For emerging adults with chronic conditions, the normative demands and stressors corresponding to their age and illness occur within the context of decreasing support from the medical system and frequently fall outside the focus of the current health care system (Weissburg - Benchell, et al, 2007). Many federal and state programs often discontinue service after patients become 18 years of age, or the nature of the service becomes different from that provided for the younger chronically ill patient. Additionally, insurance companies may place time and service limits on medical care. These limitations reduce the likelihood that these children will receive preventive medical care; thus leading to increased long-term system costs.

Another major barrier to HCT is breaking the bond between pediatric specialty providers, the chronically ill patient and the caregiver. Caregivers develop close personal ties and have shared a common goal over many years with the pediatric specialty provider. This bond may inhibit discontinuation of services. Furthermore, caregivers may be unnerved by an abrupt cessation of their role following transition and may unknowingly sabotage transition by conveying lack of confidence in the adult care team (Harris, et. al 2011). They may elude that the adult care team is not trustworthy which will impede adolescent and young adult interest in transition.

According to the 2010 National Survey of Children with Special Health Care Needs, patients report that many providers and/or health care systems may be ill-prepared to assist children with chronic health conditions during the transition from pediatric to adult care (Waldman et al., 2013). Contributing to the problem, pediatric and adult care providers rarely coordinate HCT, nor do pediatric providers always adequately prepare the patient or caregiver for HCT. There is a lack of adult provider availability and those that are available rarely adjust

service provision to accommodate the developmental needs of the pediatric patient with chronic illness. The adult medicine culture may be less attuned to the developmental and behavioral struggles of young patients as compared to the pediatric care culture. Furthermore, they may require separate appointments as part of their multidisciplinary approach, as opposed to an integrated interdisciplinary care team, like that in the case of pediatric healthcare. Much progress needs to be made in addressing these barriers to transition for children with chronic illness to adult health services.

The literature findings support the importance of structured HCT to improve patient health outcomes and decrease morbidity (Chu et al., 2015). Up to 35% of young adults with chronic renal failure lose successful kidney transplants and are lost to follow up within three years when there is inadequate or lack of health care transition (Harden et al., 2012). Nonadherence to Post-transplant medication regimens is believed to contribute to adverse outcomes, such as failed allografts and kidney rejection (Dobbels et al., 2010). Without a structured approach, poorly or insufficiently managed transition can be fatal.

Currently in a large, metropolitan, academic medical center, chronically ill children with CKD, have no structured HCT in place. HCT occurs with simply a written medical summary and a new appointment scheduled with the adult provider. Many of these adult-focused providers are not familiar with the patients' congenital diagnoses and have not had a verbal hand-off with the pediatric provider prior to the patient's visit. Many patients are not comfortable with their adult providers and fear they are not being cared for adequately, often leading to missed appointments, poor medication adherence and frequent hospital admissions.

A more recent intervention that contributes to positive outcomes for these patients is a structured transition program. The National Alliance to Advance Adolescent Health (2016) has

outlined six core elements necessary for successful approach to transition: (1) “transition policy, (2) transition tracking/ monitoring, (3) transition readiness, (4) transition planning/ integration, (5) transfer to adult approach to care and (6) transfer completion/ ongoing care” (para 2). These six core elements are congruent with the consensus by the AAP, AAFP and ACP (2011), in that, transition involves multidisciplinary collaboration to cultivate independence.

Purpose

The purpose of this scholarly project is to develop a structured program for adolescents with CKD to undergo HCT to adult services while maintaining their trust and assuring continued medical care. It is anticipated that this project will increase adherence to appointments and medications, as indicated by stable blood urea nitrogen and creatinine levels. This project is also aimed at fostering independence and self-care management for patients and their families to successfully achieve HCT.

Theoretical Framework

The theoretical framework used to guide this scholarly project is the Middle Range Transition Theory (MRT). MRT is an emerging theory developed by Meleis et al., (2000) that highlights the role of the nurse in aiding healthy individual role adequacy. The major role of the nurse is to prepare the patient for appropriate coping with developmental, situational, and health transitions (Meleis et al., 2000).

There are many components of the HCT framework: types and patterns of transition, properties of transition experiences, transition conditions, process indicators, outcome indicators and nursing therapeutics (Meleis et al., 2000). Types and patterns indicate that transitions are developmental, situational, and health-illness related, meaning they are the development of life

changes in relationships, health, and environments. Transition leads to the advancement of a new role. Knowledge of specific transition properties aids the nurse in developing effective strategies to benefit the patient in adapting to a change. If the conditions of transition are personal, societal and shared by all, the patient and their family will discover positive patterns of response.

The Middle Range Transition Theory comprises the following assumptions: 1) “Transitions are complex and multidimensional and have patterns of multiplicity and complexity” (Alligood and Toomey, 2006, p. 423) 2) “All transitions are characterized by flow and movement over time” (Alligood & Toomey, 2006, p. 423)., 3) “Transition causes changes in identities, roles, relationships, abilities, and patterns of behavior” (Alligood & Toomey, 2006, p. 423) and 4) “Transitions involve a process of movement and changes in fundamental life patterns, which are manifested in all individuals” (Alligood & Toomey, 2006, p. 423). These assumptions can be used to guide all disciplines related to health.

Modifications to individuals’ health status can offer the chance to improve one’s well-being or display increased risks to health disturbances. Transition should result in the following: improved health outcomes, improved collaboration with pediatric and adult providers, decreased health care costs, self-confidence and self-empowerment. Bridging the gap between pediatric and adult care services for children with chronic illness will not simply occur by increasing these patients’ knowledge of their disease process management, but also by maintaining their health status during illness and wellness.

MRT can be used to provide clinicians with the understanding that transitions can occur simultaneously. For example, adolescents can experience transition in their development, while experiencing transition to adult care. The MRT considers diversity and culture in healthcare and can be useful to evoke positive role unification in individual, family, organization or community.

This theory can be operationalized using care coordination with a transition coordinator to address knowledge and readiness of the patient and care giver. MRT was used to guide this project with an interdisciplinary team approach. It is anticipated that reducing complications and hospitalization so, a cost saving will occur.

Literature Review

HCT program development is essential to the process of transitioning adolescents/ young adults from pediatric to adult-focused care because it prepares the child with chronic illness and caregiver in an organized manner (Hallowell, 2014). HCT Programs should be individualized based on the youth with chronic illness' readiness and should be developmentally appropriate throughout this gradual process (ZHANG, Ho & Kennedy, 2014; AAP, AAFP & AAC, 2011). Developing a structured HCT program for children with chronic illness, with an emphasis on failure of renal allograft, is the focus of the reviewing evidence this literature. This review began with the evidence supporting allograft survival in a formal HCT program. The discussion is followed by review of studies on HCT involving other chronic illnesses due to the paucity of research on interventions for transitioning young adults with CKD. This included outcomes such as, patient satisfaction, patient perception and medication adherence. Characteristics of a structured transition program were another focus of this review. Finally, the review concludes with current evidence to support use of adapting item questionnaires and scale development to measure the HCT and self-management skills by youth with chronic illnesses.

A plausible question to investigate is whether the formal transition of youth and young adults with CKD to adult care has any effect on healthcare outcomes. A recent study designed to answer this question is a retrospective comparison of two cohorts of kidney transplant patients in London pediatric centers that transitioned to six different adult nephrology centers in Oxford.

The younger group ($N=9$) were involved in the use of a transition clinic, and an older group ($N=12$) transferred before the transition clinic had been implemented (Harden et al., 2012). Out of a total of 21 patients, six of the twelve who transitioned before implementation of the transition program had kidney transplant failure compared with no transplant failures in the group that was transitioned after implementation of the transition program (Harden et al., 2012).

In another retrospective comparison study of transitioning kidney transplant patients that took place in Germany, 59 patients were transitioned to three different adult care settings: an adult nephrologist, a structured transition clinic and a general post-transplant clinic (Pape et al., 2013). There were three renal allograft losses, but there was 100% survival of the transition group. There were no statistical differences between the three settings with regards to graft survival or function. This study is limited by patients lost to follow-up. Patient satisfaction was highest in the structured HCT clinic compared to nephrologist or general post-transplant clinic ($p<0.05$) (Pape et al., 2013).

The development of a structured HCT program may be applicable to other young adult populations with chronic illness transitioning to adult healthcare services (Chaudry, Keaton & Samya, 2013; Hankins et al., 2012; Annunziato et al., 2013). A retrospective study, using a questionnaire to evaluate the experiences and opinions of patients with cystic fibrosis (CF) who went through a formal transition ($N=45$) program was compared to a population who did not ($N=46$) patients with formal transition had increased satisfaction, increased perception of health status, and increased independence; no difference in level of anxiety for transitioning to adult CF program (Chaudry, Keaton & Samya, 2013). When comparing patients who went through the structured HCT process and those who did not, there was a statistically significant difference between satisfaction of the pediatric program before transition was developed ($P=0.001$) and

after the transition implementation process ($P=0.006$); justifying the need for a structured transition program and its importance to patient satisfaction (Chaudry, Keaton & Samya, 2013).

A pre-test, post-test pilot study for adolescents with sickle cell disease (SCD) also investigated patient satisfaction, looking at helpfulness and first visit fulfillment (Hankins et al, 2012). All of the participants deemed the program as either helpful or very helpful. Seventy-four percent of the participants in the pilot transition program attended their first visit to an adult provider within three months, whereas, only 33% of non-participants completed this visit (Hankins et al, 2012). Limitations of this study included lack of randomization, which poses a threat to its validity; but the study proposes a probable benefit for young adults with SCD who engage in a structured transition program. The effectiveness of a transition coordinator in a formal transition program was tested in a prospective study of children with liver transplants ($N=34$), evaluating medication adherence and psychosocial outcomes (Annunziato et al., 2013). After transition, transplant medication levels were sustained; Tacrolimus $SD= 1.88$ ($SD 1.57$), but elevated compared to comparison group; Tacrolimus $SD= 4.36$ ($SD=0.99$) and psychosocial outcomes were sustained during the transition (Annunziato et al., 2013). The involvement of a transition coordinator may improve the transition process.

A systematic review of five studies investigating the current evidence of the effect of HCT interventions on distinct health services was published by Chu et al., (2015). Four of the studies were retrospective and one was a randomized control trial pilot study. Sample sizes ranged from 26 to 165 participants (Cadario et al, 2009; Hankins et al., 2012; Johnston, Bell, Tennet & Carson , 2006; Steinbeck, Harvey, Shrewsbury, Donaghue, & Woodhead, 2014; Van Wallegem, MacDonald, & Dean, 2008). In three of the five studies, patients in the transition program had higher success rates for transfer and / or higher rates of visits to adult clinics than

those who did not participate in the transition program (Cadario et al, 2009; Hankins et al., 2012; Van Wallegghem, MacDonald, & Dean, 2008). Consensus of this systematic review indicates that formal transition programs can positively effect health outcomes of patients with chronic illness.

The characteristics of a structured HCT program are defined in the consensus statement of the AAP, AAFP, ACP (2011). This statement identifies six steps to transition. The first step is that the child with chronic illness (CCI) must have a professional who can assist with identifying an adult provider in order for there to be comprehensive and accessible continuity of care upon completion of transition. The next step is that providers are given instruction on how to educate the child on knowledge and skills needed for transition. The third step is that each CCI must have an up to date medical summary. Step four notes that, beginning at age 14, there should be an initiation of a plan for transition to adult care that should be reviewed annually. The plan should include resources needed for transition, who will provide these resources and who will fund these resources. The fifth step involves utilizing standard guidelines for preventive care. Finally, the last step demonstrates the need for continuous, affordable health insurance coverage that includes compensation for transition and care coordination.

The “TR_xANSITION,” a tool with strong inter-rater reliability ($r=0.71$) and proven validity in English and Spanish was used to measure healthcare transition and self-management skills by youth with chronic health conditions (Ferris et al., 2012; Cantu, 2015). This tool was piloted on 185 young adults in interview format with review of medical records for validation. The TR_xANSITION Scale has the potential to measure healthcare skill mastery and knowledge in a multifaceted mode (Ferris et al., 2012).

The manner of transition of youth and young adults to adult care does have effects on healthcare outcomes, but it is important to note that the primary study designs in the literature were retrospective and included the use of questionnaires and surveys to evaluate the transition process (Chaudry, Keaton & Samya; Hankins et al, 2012; Harden et al., 2012; Pape et al., 2013); while only the (UNC) TR_xANSITION was proven to be reliable and valid (Ferris et al., 2012). Most of the literature linked each transition program with a specific chronic illness (Chu et al., 2015; Annunziato et al., 2013; Chaudry, Keaton & Samya, 2013; Hankins et al., 2012), thus there were limited studies to consider for CKD (Pape et al., 2013; Ferris et al., 2012; Harden et al., 2012). The common denominators for all studies demonstrate an increase in patient satisfaction, patient perspective, and medication adherence after implementing a formal transition program. Therefore, appropriate and reliable transition programs are essential to decreasing poor healthcare outcomes during transition; thus credible tools are needed for evaluation.

Methodology

Design, Sample, Setting

The design of this scholarly project is a quality improvement which involves program development, application and evaluation. The project takes place in the Pediatric Nephrology Outpatient specialty clinic in a large academic medical center in the Mid-Atlantic region. Nineteen participants were enrolled with purposeful sampling, but participation was voluntary. The participants gave verbal agreement for enrollment and signed a copy of the Pediatric Nephrology Transition Policy. They were given a signed copy of this policy. Inclusion criteria included English speaking participants ages 15-23 with a diagnosis of CKD stage ≥ 3 or status post renal transplant, established baseline creatinine and no hospitalizations within the last three

months. There was electronic record review for monitoring of Blood Urea Nitrogen (BUN) and Creatinine levels during this project. The exclusion criteria are non-English speaking, younger than age 15 and cognitive impairment as deemed by their providers.

Data Collection/ Procedures

The project was developed in four phases. Phase one was carried out during weeks one through three and involved meeting with the pediatric nephrology providers, the adult nephrology providers, the HCT coordinator and the social worker to discuss and explain the tools used to develop the transition program and to recruit patients. Participants were selected by viewing an electronic report that contained their age, diagnosis, last follow up visit and hospitalizations. The selected participants were scheduled for a follow up clinic appointments to discuss the program and their interest in participating.

Phase two was initially designed to be implemented during weeks four and five, but extended through week twenty-four as recruitment processes were slow and additional participants were still needed. During this phase, the participants were given copies of the transition policy and received a self-administered transition readiness questionnaire, adapted from The National Alliance to Advance Adolescent Health (NAAAH, 2006). This questionnaire took approximately 10 minutes to complete. (See Appendices E and F for the Transition Policy and Transition Readiness Questionnaire). The purpose of this questionnaire was to help track and determine the HCT status in regards to the participant's readiness to move from pediatric to adult-focused care and to identify educational needs. Parents were allowed to be present during the visit but were not allowed to answer the questionnaire. The HCT coordinator and advanced practice nurse provided teaching materials for medication refills, developing independent skills, and lab or test visit scheduling. The HCT coordinator's role is an outpatient care specialist and

includes medication teaching as part of her skill set. The social worker and HCT coordinator provided teaching about health insurance, social support and assessment of transportation needs to and from the clinic.

Phase three occurred during week six. During this phase, the participants met with the transition coordinator or advanced practice nurse to establish a treatment plan based upon their transition readiness questionnaire and adapted from the NAAAH (2016). The treatment plan establishes priorities and a course of action that integrates health and personal goals.

Phase four occurred over weeks seven through twenty-four. This phase involved administering the TRxANSITION Scale™ Educational Handouts. These are single sheet educational handouts that correspond with the different subdomains of the TRxANSITION Scale™ 1) type of illness, 2) Rx= medications, 3) adherence, 4) nutrition, 5) self-management, 6) informed-reproduction, 7) trade/ school, 8) insurance, 9) ongoing support and 10) new healthcare provider. A guide to healthy renal specific meals that were low on phosphorous, potassium and sodium was provided during the review of the nutrition handouts session. The dietician provided low sodium seasonings to go along with managing blood pressure. She discussed how a diet high with salt intake causes increased blood pressure and volume overload. Participants were required to demonstrate their ability to call the pharmacy to request a medication refill during this phase. They were allowed to use the telephone during a clinic visit to make medication refill requests. The participants were instructed to bring their medications to the next clinic visit to check for accuracy. Participants were also scheduled an appointment with an adult nephrology provider during this clinic visit. Participants with TRxANSITION scores greater than 85% were given a medical passport. The medical passport is a wallet-

sized, laminated card that included the following: (1) name, (2) date of birth, (3) pediatric nephrology contact numbers, (4) insurance carrier, (5) transition ID number, (6) diagnosis/ transplant, (7) allergies, (8) emergency contacts, and (9) medications.

Participants were able to present their medical passport if they presented to the emergency department or to use during visits with their other adult providers. The medical passport serves as a snapshot of the participant's health record.

Participants had successfully achieved transition if they were capable of completing their first appointment to the adult nephrologist. Blood Urea Nitrogen and Creatinine levels were continued to be monitored as part of routine care throughout the four phases of the project. The advanced practice nurse, HCT coordinator and social worker met one to two times per week in the clinic or via teleconference to monitor and discuss the progress of the patients and the program.

Program Evaluation

The program was evaluated using the University of North Carolina (UNC) TRxANSITION Scale™. Permission was granted by Dr. Maria Ferris to use this tool for this project. The UNC TRxANSITION Scale™ is health care provider-administered, disease-neutral questionnaire that verifies and measures the healthcare transition and self-management skills in youth and young adults with chronic illness (Ferris et al., 2012). The inter-rater reliability was reported to be strong ($r= 0.71$) and item-total correlation scores were moderate to high. Construct and content validity were reported as satisfactory. The univariate linear regression yielded a beta coefficient of 1.08 ($p<0.0001$), indicating total scores increase with the patient's age. This scale includes ten comprehensive areas (sub-scales): 1) type of illness, 2) Rx= medications, 3) adherence, 4) nutrition, 5) self-management, 6) informed-reproduction, 7) trade/

school, 8)insurance, 9)ongoing support and 10) new healthcare provider. This 10-domain, 32-item questionnaire is administered in approximately 7-8 minutes. Each response is scored individually as either 1 (adequate knowledge/skill mastery), 0.5 (some knowledge/skill attainment), and 0 (no knowledge/skill attainment) for a maximum score of 10. The T-Scale Answer Guide: Kidney provides criteria for scoring responses to each question. (See Appendices J and K for the TRxANSITION Scale™ and the T-Scale Answer Guide Kidney).

Human Subjects Protection

There were great benefits along with minimal risks for participants in the development of this project. The benefits were to provide ongoing access to adult care and to insure gaps in healthcare are excluded. The minimal risks included: 1) privacy and confidentiality, 2) some questions may have been uncomfortable to answer, and 3) non-adherence to medication may have been exposed, which may have questioned the participant's integrity. To maintain confidentiality, there were no patient identifiers. To protect the participant's anonymity, participants were assigned a transition identification sequential number for tracking purposes that was disclosed only to the principal investigator (advanced practice nurse). Paper data collected from the surveys was stored in a locked cabinet in the principal investigator's locked office and later transcribed on a password-protected computer to an excel spread file for data analysis.

A query was submitted to the University of Maryland Baltimore (UMB) Institutional Review Board (IRB) for a Non-Human Subjects Research (NHSR) determination. Submission to the IRB was deemed as a quality improvement initiative and did not constitute human subject research; was considered to be exempt. The participants were made verbally aware that the results may be published, using only aggregate, anonymous data.

The results of this project are not intended for generalizable knowledge, but are aimed at fostering continued adult healthcare services within this organization for a specific pediatric population. It is anticipated that the findings will also be disseminated via public forums, conferences, professional meetings, peer review publications and didactic presentations (in-person and online), with prior granted permission.

Data Analysis

Descriptive statistics were used to present demographic characteristics of the participants; specifically, mean age, gender, CKD diagnosis and renal transplant diagnosis. Descriptive statistics were used to describe the mean score for transition. Patient responses to the TRxANSITION Scale™ variables were evaluated the Pearson Correlation coefficient. Internal consistency was evaluated using the data collected from TRxANSITION Scale™. Pearson Correlations were conducted to examine the relationship of each of the items with their respective domain score and to examine the relationship of each of the items with the overall total score. Differences were considered significant when the *p* values were < 0.01. These differences indicate if there is a relationship between the participant's transition readiness with respect to each domain and over transition readiness score; provides a measure of how much transition preparation is necessary to move successfully through the transition program. Lab trends for BUN and creatinine testing were evaluated at the start and end of the transition program development to look for variations.

Results

Table 1 summarizes the count and the corresponding percentage of all the demographic variables for a sample of 19 individuals who participated in the pediatric transition program. Twelve out of nineteen of the participants were between the ages of 16 and 27. The average age of the participant was 20 years old. In this sample there were 54% females and 47% males. About 75% had a diagnosis of CKD with 26% characterized as Renal Transplants. There was 36% parent involvement for the participants enrolled in the HCT program.

In general, the items on the TRxANSITION Scale™ had a good internal consistency with respective sub-scale score and each sub-scale total with the overall score. (Tables 2 and 3). The sub-scales that had the highest correlation coefficients with the total score were found to be statistically significant with strong positive relationships to their domains: Self- Management ($N=19$, $r=0.914$, $p<0.01$, two-tailed), Insurance ($N=19$, $r=.830$, $p<0.01$, two-tailed) and School ($N=19$, $r= 0.818$, $p<0.01$, two-tailed). The sub-scale with the lowest correlation coefficients was Type Chronic Condition ($r= 0.298$). This finding was not statistically significant, ($p=0.216$).

The BUN and Creatinine levels were monitored at the start and end of the HCT program. Table 4 depicts the means and standard deviations of BUN and Creatinine levels, indicating that levels decreased over the course of the HCT program. Kidney function remained stable and improved slightly throughout the program. It is suspected that these results correlated to the engagement of the participants in the program and their understanding of medications from the TRxANSITION Scale™.

Four participants successfully transitioned to adult nephrology services without incident or health compromise. The other fifteen participants remained enrolled in the program. They are

continuing through the transition process at a much slower paced determined by their TRxANSITION Scale™ scores.

Discussion

Utilization of a structured HCT program is essential to successful transition and contributes to positive patient outcomes. Poor HCT or lack of preparation can lead to poor healthcare outcomes or even worse, increased morbidity/ mortality. The structured HCT program allowed for a continuous process to prepare the participants to move on to adult care services. The quality improvement project fostered independence and self-care management to patients and their families to successfully achieve HCT.

Participation was greater than anticipated with a projected sample size of 10 participants, but an actual sample size of 19 participants. Participants had positive attitudes towards learning about HCT with meaningful participation and feedback on the program. Some of the comments from the participants varied around, “I’m glad someone is helping me to move on and not just letting me go”. Participants were very appreciative of the teaching sessions as evidenced by statements: “I like that you have provided healthy lunches to go along with the teaching sessions for nutrition” and “I didn’t know healthy food could be so much fun”.

Even though the results of the project were positive, there still remained challenges. One of the major challenges to HCT that patients commented on was, “I cannot afford to pay for parking with these extra visits” and “It’s easier for me if we discuss HCT the same day as my health care follow up appointment”. Patients’ parking was not compensated for HCT visits.

Although some participants did successfully move on to adult-focused care, some pediatric providers faced their own challenges with HCT. Anecdotal comments included providers’ worry if adult-focused providers would continue to manage comorbidities of CKD

just as they had or if the patient would be lost to follow up. Some felt compelled to remain the patient's provider given the strong personal relationships they had developed over the years and their ingrained awareness of their patients' specific health issues and needs. Some gave reasons to continue the pediatric setting, stating, "The patient will be lost to follow up if we transition them now". Although some patients scored greater than 8-10 on the TRxANSITION Scale™, there remained contentions- "This patient still needs a lot of work before we can transition".

Limitations

Although the project reached its aims, there were some limitations. First, the challenges for HCT rest as much with the healthcare providers as with the patients and their families. The outlook on HCT and the relationship between the pediatric and adult clinics are central to the success of the program. Many of the pediatric providers at this institution continue to find it hard to let go of children they have looked after for so long; claiming they are just not comfortable with the care provided by the adult providers. However, holding on to pediatric patients who could benefit from the expertise of an adult service causes as many problems as pretending HCT transition is simply a clerical task or just a matter of paperwork.

Secondly, this patient population of teens and young adults with CKD has a large no-show rate for follow up appointments. Since there is a cost for parking, patients with a limited amount of funds find it difficult to return for health care visits. Because patients did not return for visits, this contributed to the delay in HCT preparation.

Lastly, because of limited time, manpower and budget, this project includes results for only six months. It would be ideal to begin transition at age 15 and continue the process until approximately age 21 to see if this gradual transition would yield higher results. This would also

allow for patients whose HCT to adult care was placed “on pause”, due to acute illness, to recover and move forward with a successful transition.

Plans for Translation

At the institutional level, the long-term success of the HCT program is contingent upon a successful sustainability plan. For continued offerings of the teaching sessions the HCT coordinator and Doctor of Nursing Practice must share the findings to other specialty divisions within the organization for sustainability. A step by step learning packet of the teaching handouts was created, assembled, and bound for the participants for easy reference. Continued collaboration with the adult and med-peds providers was helpful to the creation of this program and will ensure its success in the future. Planned meetings between pediatrics and adult specialties can also benefit patients with increased communication and better provider acceptance.

The Doctor of Nursing Practice (DNP) serves as the clinical expert/ leader and can improve the scientific underpinning for practice by using systematic thinking and participating in interprofessional collaboration to improve patient healthcare outcomes (Chism, 2013). It is essential that the DNP disseminate quality improvement results through local, national and international conferences, poster presentations, abstracts and publications. This dissemination of information allows for other leaders to benefit by developing structured transition programs at their institutions of medicine. This dissemination also allows the DNP to collaborate with other experts to improve patient and population health outcomes. The collaboration with UNC has provided further opportunity to participate in the development and implementation of practice models, standards of care, and other scholarly projects.

Implications for Future Practice

The development of a transition program has the potential to influence frequency and quality of transition for the Division of Pediatric Nephrology at this Mid-Atlantic institution as well as other pediatric sub-specialty divisions. In Pediatric Nephrology 70% of patients are between the ages of 14-21 and 30% percent are over the age of 21. Including HCT preparation as a part of routine clinic visits and comprehensive evaluations would promote self-management skills that will be valuable for the life-long HCT process in other facets of transition for young adults. Self-care behaviors developed from well-executed HCT programs may also be useful during other periods of transition, such as changes in residence, insurance, and personal preference.

Using this model of HCT for a pediatric population with chronic illness other than CKD is another opportunity for the future. It is often difficult for primary care providers to assist the transition of aging children to adult care, but much harder to transition children with significant chronic illnesses such as diabetes, hematologic problems, neurologic or neurodevelopmental issues, among many others, to adult subspecialty programs. A published model that has been documented as successful offers other providers an outline to apply to their patient populations.

Conclusions

Purposeful HCT preparation provides youth with ongoing access to subspecialist care, promotes competence in disease management, fosters independence, social, and emotional development through teaching self-advocacy and communication skills, and allows for a sense of security for support of long-term health care planning and life goals. Transfer of care to an adult provider, as a component of HCT, provides the benefit of access to targeted care for issues related to adulthood and aging. Continued efforts for developing a HCT program for this

population of patients will aid in tracking the decrease in hospital readmissions, decrease in morbidities and the decrease in hospital costs.

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APPENDIX A: Tables

Table 1. Demographics of Participants

Demographics (N=19)

Characteristics	n	%	Range	Mean (SD)
Age in years			15 – 27	20.15 (2.93)
15-18	7	36%		
19-21	6	32%		
21 +	6	32%		
Gender				
Male	9	47%		
Female	10	53%		
Diagnosis				
CKD	14	74%		
Renal Transplant	5	26%		

Table 2. Correlation of TRxANSITION Scale™ Items with Domain Scores

Chronic Condition/ Type of Illness		SCORE
Can you tell me the name of your health condition?	Pearson	.584.
	Correlation	
	Sig. (2-tailed)	0.062
	N	19
Can you describe symptoms of your health condition?	Pearson	.911**
	Correlation	
	Sig. (2-tailed)	.000
	N	19
Can you tell me how this condition may affect your health in the future?	Pearson	.965**
	Correlation	
	Sig. (2-tailed)	.000
	N	19
SCORE	Pearson	1
	Correlation	
	Sig. (2-tailed)	
	N	19

Correlation is significant at the 0.01 level (2-tailed).

Medications		SCORE
Can you tell me the names of your medications, vitamins, and/ or supplements you are supposed to be taking?	Pearson Correlation	.651**
	Sig. (2-tailed)	.003
	N	19
Can you tell me when you take your medicines?	Pearson Correlation	.727**
	Sig. (2-tailed)	.000
	N	19
Can you tell me why you are taking each of your medicines?	Pearson Correlation	.882**
	Sig. (2-tailed)	.000
	N	19
Can you tell me what would happen if you stopped taking them?	Pearson Correlation	.935**
	Sig. (2-tailed)	.000
	N	19
SCORE	Pearson Correlation	1
	Sig. (2-tailed)	
	N	19

** . Correlation is significant at the 0.01 level (2-tailed).

Adherence		SCORE
Do you miss a full day of medicine during the week, either because you forgot to take it or didn't want to take it?	Pearson Correlation Sig. (2-tailed) N	.884** .000 19
Do you usually have trouble remembering to take your medicines everyday?	Pearson Correlation Sig. (2-tailed) N	.891** .000 19
Do you usually come to your doctor's appointments when they are scheduled?	Pearson Correlation Sig. (2-tailed) N	.632** .004 19
SCORE	Pearson Correlation Sig. (2-tailed) N	1 19

** . Correlation is significant at the 0.01 level (2-tailed).

Nutrition		SC ORE
When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	Pearson Correlation Sig. (2-tailed) N	.940** .000 19
Do you know if there is any special diet you are supposed to follow because of your health condition?	Pearson Correlation Sig. (2-tailed) N	.926** .000 19
Do you know specific examples of the food or drinks that you cannot eat or drink?	Pearson Correlation Sig. (2-tailed) N	.944** .000 19
SC ORE	Pearson Correlation Sig. (2-tailed) N	1 19

** . Correlation is significant at the 0.01 level (2-tailed)

Self Management		SCORE
Do you usually remember to take your medicines on your own?	Pearson Correlation Sig. (2-tailed) N	.823** .000 19
Does someone usually have to remind you to take your medicines?	Pearson Correlation Sig. (2-tailed) N	.715** .001 19
Do you usually call in your prescription refills yourself?	Pearson Correlation Sig. (2-tailed) N	.842** .000 19
Do you usually pick-up refills from the pharmacy yourself?	Pearson Correlation Sig. (2-tailed) N	.898** .000 19
Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	Pearson Correlation Sig. (2-tailed) N	.893** .000 19
Do you usually make your own doctor's appointment?	Pearson Correlation Sig. (2-tailed) N	.923** .000 19
(if the pt has medical procedures performed) Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc.)	Pearson Correlation Sig. (2-tailed) N	.798** .000 16
SCORE	Pearson Correlation Sig. (2-tailed) N	1 19

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Issues of Reproduction		SCORE
Would your health condition likely affect your ability to: (if female) become pregnant?	Pearson Correlation Sig. (2-tailed) N	.921** .000 19
(Females only) What are the risks you might face if/when you become pregnant because you have (name of health condition)?	Pearson Correlation Sig. (2-tailed) N	.593 .092 9
(females only) Do you take any medicines that would be harmful to an unwanted baby if you became pregnant?	Pearson Correlation Sig. (2-tailed) N	.841** .004 9
Can you tell me ways sexually active people help protect themselves from pregnancy or STDs?	Pearson Correlation Sig. (2-tailed) N	.659** .002 19
SCORE	Pearson Correlation Sig. (2-tailed) N	1 19

** . Correlation is significant at the 0.01 level (2-tailed).

Trade/ School		SCORE
What are your future plans in regards to school and /or a job?	Pearson Correlation Sig. (2-tailed) N	1.000** .000 19
SCORE	Pearson Correlation Sig. (2-tailed) N	1 19

** . Correlation is significant at the 0.01 level(2-tailed)

Insurance		SCORE
(If he/she is currently insured) At what age will your current health insurance expire?	Pearson Correlation	.812**
	Sig. (2-tailed)	.000
	N	19
How can you get health insurance coverage for yourself when you are an adult?	Pearson Correlation	.784**
	Sig. (2-tailed)	.000
	N	19
What is health insurance and why is it important to have?	Pearson Correlation	.909**
	Sig. (2-tailed)	.000
	N	19
What is the name of your current health insurance provider?	Pearson Correlation	.863**
	Sig. (2-tailed)	.000
	N	19
SCORE	Pearson Correlation	1
	Sig. (2-tailed)	
	N	19

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Ongoing Support

		SCORE
When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy?	Pearson Correlation	1.000**
	Sig. (2-tailed)	.000
	N	19
SCORE	Pearson Correlation	1
	Sig. (2-tailed)	
	N	19

** . Correlation is significant at the 0.01 level (2-tailed).

New Health Care Providers

		SCORE
When it comes time for you to switch to an adult doctor, how will you find one?	Pearson Correlation	.899**
	Sig. (2-tailed)	.000
	N	19
In order to get your medical records transferred to another doctor, do you know how and what is required to make this happen?	Pearson Correlation	.901**
	Sig. (2-tailed)	.000
	N	19
SCORE	Pearson Correlation	1
	Sig. (2-tailed)	
	N	19

** . Correlation is significant at the 0.01 level (2-tailed).

Table 3. Correlation of TRxANSITION Scale™ scores of Each Item with Overall Total Scores

		OVERALL TRANSITION Score
Chronic Cond. SCORE	Pearson Correlation	.298
	Sig. (2-tailed)	.216
	N	19
Medications SCORE	Pearson Correlation	.790**
	Sig. (2-tailed)	.000
	N	19
Adherence SCORE	Pearson Correlation	.610**
	Sig. (2-tailed)	.006
	N	19
Nutrition SC ORE	Pearson Correlation	.594**
	Sig. (2-tailed)	.007
	N	19
Self Manage SCORE	Pearson Correlation	.914**
	Sig. (2-tailed)	.000
	N	19
Reproduction SCORE	Pearson Correlation	.671**
	Sig. (2-tailed)	.002
	N	19
School SCORE	Pearson Correlation	.818**
	Sig. (2-tailed)	.000

	N	19
Insurance SCORE	Pearson Correlation	.830 ^{**}
	Sig. (2-tailed)	.000
	N	19
Support SCORE	Pearson Correlation	.448
	Sig. (2-tailed)	.054
	N	19
Health Care SCORE	Pearson Correlation	.726 ^{**}
	Sig. (2-tailed)	.000
	N	19
TRANSITION Score	Pearson Correlation	1
	Sig. (2-tailed)	
	N	19

^{**}. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 4. Pre and Post BUN/Creatinine Levels

N= 19	Pre BUN	Pre Creatinine	Post BUN	Post Creatinine
Mean	15.5	1.12	14.3	1.05
StDev	7.63	0.55	7.69	0.52

APPENDIX B. Literature Review

Evidence RATING Table

Author, year	Study objective/intervention or exposures compared	Design	Sample (N)	Outcomes studied (how measured)	Results	*Level and Quality Rating
Annunziato, et al., 2013	To compare the impact of a transition coordinator in a formal transition program on outcomes for pediatric liver transplant recipients versus a historical comparison group	Prospective evaluation using historical comparators Interviews, questionnaires	Patients in liver transplant program (n= 20) Historical cohort (n=14)	Medication adherence measured with patient report and lab values; psychosocial outcomes: developmental skills and acceptability of the transition process	Medication adherence was significantly better for patients who had access to the transition coordinator compared to the cohort patients who did not.	3C
Chaudry, Keaton & Samya, 2013	To evaluate the experiences and opinions of patients in adult cystic fibrosis center who went through a formal transition program versus those who did not; in an attempt to evaluate overall process and to identify means for improvement	Retrospective Survey (questionnaire)	45 participants went through structured program 46 participants with no structured program (n=91)	These were studied before and after transition of the 44 participants: Anxiety Satisfaction Perceived Health status Independence	Participants with formal transition had higher satisfaction with both programs, perceived health status, and independence; no difference in level of anxiety for transitioning to adult CF program	3A

Chu, Maslow, Von Isenburg & Chun, 2015	To examine the current evidence regarding the effect of transition interventions on care transfer	Systematic Review	Four studies were retrospective observational studies, and one was a pilot randomized controlled trial. (n=5)	Transfer as defined as the proportion of patients in transition programs that transferred from pediatric to adult health care settings; lab values, hospitalizations, patient satisfaction	In three of the five studies, patients in transition programs had higher rates of successful transition than those who did not. There was no statistical difference in the remaining two studies in transfer rates between transition and control groups. Three of the four diabetic transition programs showed glycemic control after transitioning to adult services, measuring Hemoglobin A1C.	1B
Ferris et al, 2012	To describe the development of the University of North Carolina (UNC) TR _x ANSITION Scale that measures the health-care transition and self-management skills by youth with chronic health conditions	Item and Scale Development	Adolescents and emerging adults with different chronic illnesses (n= 185)	Type of illness Medications Adherence Nutrition Self-Management Informed Reproduction Trade/ School Insurance Ongoing Support New health Providers	The UNC TR _x ANSITION Scale is a disease-neutral tool that can be used in the clinical setting. Initial findings suggest it is a reliable and valid tool that has potential to measure health-care transition skill mastery and knowledge in a multidimensional fashion.	2A
Hankins et al., 2012	To improve the success of transitioning adolescents with SCD, prepare	Survey (questionnaires) Pre- Post Pilot Study	Adolescent patients with sickle cell disease ages 17 to 19 years of age	Rate the impression of the transition pilot program during the first 18	All participants of the program and their parents rated the program as either helpful or very helpful. Overall fulfillment of a first	3B

	adolescents for the transition process and establish a relationship with the adult care provider	18 months preceding start of transition program and 18 months after start of transition program	(n=83)	months; rate of fulfillment of first appointments with adult hematologists.	appointment with adult provider was 49%.	
Harden et al., 2012	To reduce the rate of late rejection of kidney transplants and improve renal allograft survival.	Retrospective comparison of two cohorts- a younger group who had used transition clinic, and an older group that had transferred before the transition clinic had been implemented	Young adult kidney transplant patients (n=21); before 2006 (n=9); between 2006 and 2010 (n=12)	Rates of acute organ rejection with medication non-adherence, looking at morbidity and hospital admissions	6 of 9 (67%) patients who transitioned before implementation of transition program had kidney transplant failure compared with no transplant failures in the group that was transitioned after implementation of the transition program	3A
Pape et al., 2013	To determine whether a transfer in a specialized adolescent clinic is associated with better future GFR and a higher rate of patient satisfaction	Retrospective comparison, using questionnaires of pediatric kidney transplant patients in three different settings	Specialized transition clinic (n=15); general post-transplant clinic (n=25); adult nephrologist (n=19)	Use of questionnaires and surveys to evaluate the transition process	Immunosuppressive medication levels were stable in the specialized transition clinic compared to the others; Patient satisfaction was highest in the specialized transition clinic compared to the other settings (100% vs 64% and 78%, p <0.05); specialized transition clinic was associated with fewer changes in therapy	3A

*Rating system for the hierarchy of evidence (Melnyk & Fineout-Overholt, 2011)

*Rating quality of study (Newhouse et al., 2007)

Evidence Review Appraisal for QUALITY (Strengths and Weaknesses Table)

Author, year	Study objective/intervention or exposures compared	Strengths	Weaknesses	Quality Rating
Annunziato, et al., 2013	To compare the impact of a transition coordinator in a formal transition program on outcomes for pediatric liver transplant recipients versus a historical comparison group	Low generalizability Clearly presented results in text and table Conceptualization was well developed Operational definition of transition coordinator	Small sample size (strong likelihood of Type II error Use of a historical comparison group No perspectives from parents Non-randomized	C
Chaudry, Keaton & Samya, 2013	To evaluate the experiences and opinions of patients in adult cystic fibrosis center who went through a formal transition program versus those who did not; in an	Clearly presented results in text and table Clearly defined inclusion/exclusion criteria Study protocol was clearly articulated. Several open-ended questions used to establish feedback and suggestions for improving the transition process Phases and description of the method are clearly defined	Retrospective Self-Reported data	A

	attempt to evaluate overall process and to identify means for improvement			
Chu, Maslow, Von Isenburg & Chun, 2015	To examine the current evidence regarding the effect of transition interventions on care transfer	Clearly defined inclusion/exclusion criteria Diagrams clearly describe results Intervention characteristics are clearly described; Large data bases reviewed	Only five studies fit inclusion/exclusion criteria Only one of the five studies was RCT Variability in defining transfer Narrow focus on transfer as the central outcome; Many excellent transition interventions used to measure transfer were not mentioned in these studies; All five of the studies reviewed were from different countries	B
Ferris et al, 2012	To describe the development of the University of North Carolina (UNC) TR _x ANSITION Scale that measures the health-care transition and self-management skills by youth with chronic health conditions	Large sample size (less likelihood for Type II error); Use of instruments with established reliability and validity; Moderate to high correlations; Concepts/ Domains clearly defined; Clearly presented results in text and table; Scoring of the tool is standardized according to chronological age and simple, 0-10 scoring; Does not rely totally on patient self-report, but verifies information from the medical record; The scale is disease neutral; allowing for generalizability	Convenience samples were self-selected; Patients may have been influenced by parents since they were allowed to be present during the interviews; Scale cannot be used in non-English speaking patients, or cognitively impaired patients;	A
Hankins et al., 2012	To improve the success of transitioning	Clearly presented results in text Study protocol was clearly articulated Clearly defined inclusion/exclusion	Low participation in the first 18 months; 40% Non-randomized; self-selected with selection bias favoring more motivated patient and	B

	adolescents with SCD, prepare adolescents for the transition process and establish a relationship with the adult care provider	criteria Conceptualization was well developed	families	
Harden et al., 2012 and 2013	To reduce the rate of late rejection of kidney transplants and improve renal allograft survival.	Generalizability; can be adapted for use with other chronic illnesses; Patients seen alone to promote autonomy; Patients are seen jointly by two teams from the age of 5-18; Clearly presented results in text and tables; Study protocol was clearly articulated; Use of texts, email and social media to promote interactions between patients and the healthcare team	Small sample size Non-randomization	B
Lewis and Slobodov, 2015	To identify and systematically review the published evidence focused on transitional care for adolescents and young adults with chronic	Clearly defined inclusion/exclusion criteria Diagrams clearly describe results Intervention characteristics are clearly described; Large data bases reviewed	Majority of articles focused on spina bifida; Small number of studies after inclusion/exclusion applied	A

	illness to adult health care setting			
Pape et al., 2013	To determine whether a transfer in a specialized adolescent clinic is associated with better future GFR and a higher rate of patient satisfaction	Clearly presented results in text and tables Clearly defined inclusion/exclusion criteria Study protocol was clearly articulated. Did not rely solely on self report	Retrospective study The Edlich Erwachsen scale had never been piloted in other studies before 1/3 of patients were lost to follow up, thus small sample size	A

*Rating system for the hierarchy of evidence (Melnik & Fineout-Overholt, 2011)

*Rating quality of study (Newhouse et al., 2007)

Rating system for the hierarchy of evidence (Melnik & Fineout-Overholt, 2011)

Level of the Evidence Type of the Evidence

I (1) Evidence from systematic review, meta-analysis of all relevant randomized controlled trails (RCTs), or practice-guidelines based on systematic review of RCTs.

II (2) Evidence obtained from well-designed RCT

III (3) Evidence obtained from well-designed controlled trials without randomization

IV (4) Evidence from well-designed case-control and cohort studies

V (5) Evidence from systematic reviews of descriptive and qualitative studies

VI (6) Evidence from a single descriptive or qualitative study

VII (7) Evidence from the opinion of authorities and/or reports of expert committees

Quality Rating Scheme (Newhouse et al, 2007) Rating quality of study (from Newhouse et al., 2007) Newhouse, R.P. (2006). Examining the support for evidence-based nursing practice. *Journal of Nursing Administration*, 36(7-8), 337-40.

A: High – consistent results with sufficient sample, adequate control, and definitive conclusions; consistent recommendations based on extensive literature review that includes thoughtful reference to scientific literature

B: Good – reasonably consistent results; sufficient sample, some control, with fairly definitive conclusions; reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence

C: Low/major flaw – Little evidence with inconsistent results; insufficient sample size; conclusions cannot be drawn

Summary Evidence Rating Table

Evidence Based Practice Question (PICO): Do youth and young adults with CKD transitioning to adult healthcare settings have better outcomes with a formal/ structured transition program?			
Level of Evidence	Number of Studies	Summary of Findings	Overall Quality (you may expand further)
1	1	Overall, evaluation of transfer appears to be hindered by methodological challenges. Establishing clearer definitions and metrics of transfer and creating the infrastructure needed to monitor the transfer of patients more consistently are important goals.	B- Limitations of the small amount of studies in the review; however excellent interventions were evaluated
2	1	The UNC TR _x ANSITION Scale is a disease-neutral tool that can be used in the clinical setting. Initial findings suggest it is a reliable and valid tool that has potential to measure health-care transition skill mastery and knowledge in a multidimensional fashion.	A
3	5	Common denominators of these studies after formal transition program were increased patient satisfaction, medication adherence and patient perception.	B

*Rating system for the hierarchy of evidence (Melnyk & Fineout-Overholt, 2011)

*Rating quality of study (Newhouse et al., 2007)

APPENDIX C.

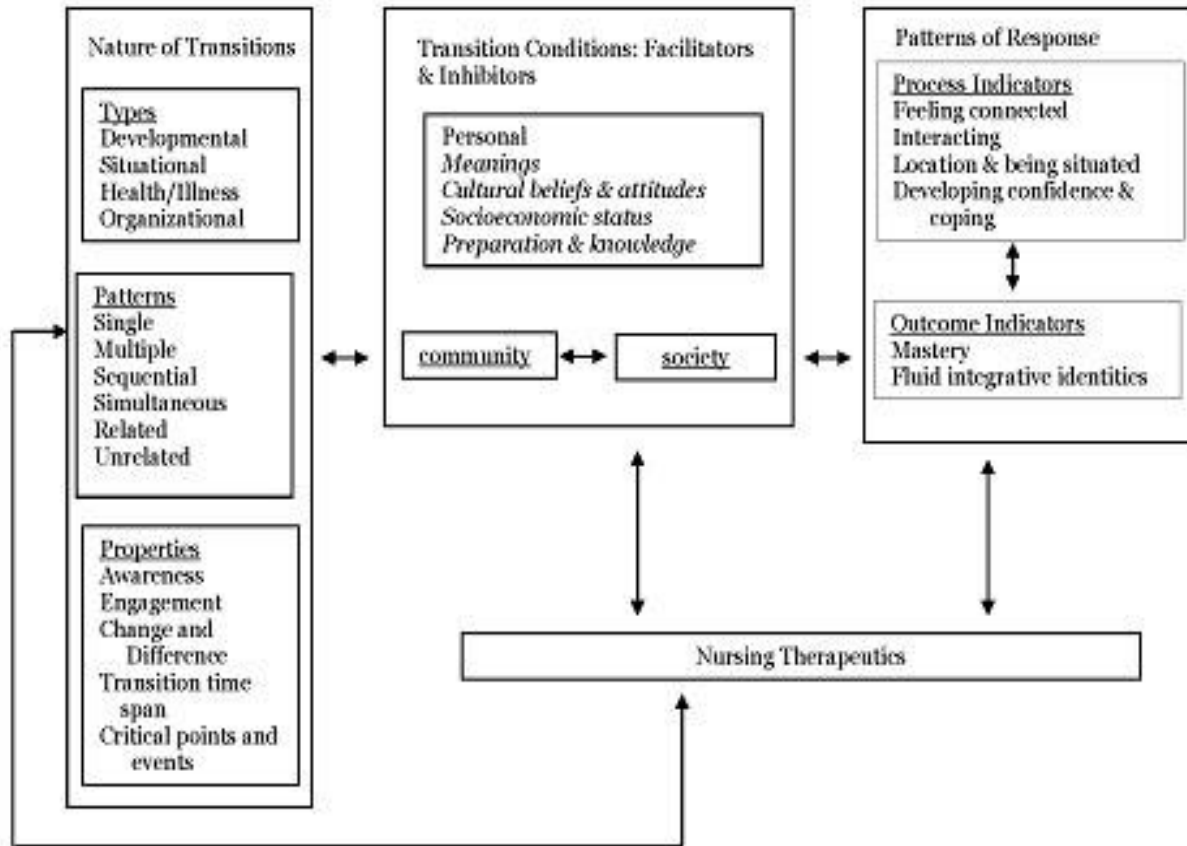


Figure 1. Middle Range Transition Theory

Meleis, A.I., Sawyer, L., Im, E., Schumacher, K., and Messias D. (2000). Experiencing transitions: An emerging middle range theory. *Advances in Nursing Science*, 23(1), 12-28

APPENDIX D: Project Timeline

Submit Proposal to committee members by May 2016

Present Proposal to committee members by May 2016

Submit project proposal to UMB and hospital Institutional Review Boards (IRBs) by May 2016

Implement project from September 2016 to February 2017

Analyze, synthesize and evaluate data by end of February 2017

Submit final scholarly project manuscript to committee for review by early March 2017

Present final scholarly project report to Committee by early March 2017

APPENDIX E: Transition Policy

Sample Transition Policy

Six Core Elements of Health Care Transition 2.0

[*Pediatric Practice Name*] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

APPENDIX F: Transition Readiness Questionnaire



Sample 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.

Date:

Name:

Date of Birth:

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
---------	---	---	---	---	---	---	---	---	---

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
---------	---	---	---	---	---	---	---	---	---

My Health	<i>Please check the box that applies to you right now.</i>	Yes, I know this	I need to learn	Someone needs to do this... Who?
I know my medical needs.	<input type="checkbox"/>	<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"/>	<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"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what each medication is for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how and when to take each medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how I will get to my appointments.	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, and medical summary).	<input type="checkbox"/>	<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"/>	<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"/>	<input type="checkbox"/>

Using Health Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>
<hr/>			
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"/>
I know who to talk to regarding my sexual health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX G: Treatment Plan



Six Core Elements of Health Care Transition 2.0

Instructions: This sample plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Name: _____

Date of Birth: _____

Primary Diagnosis: _____

Secondary Diagnosis: _____



What matters most to you as you become an adult? How can learning more about your health condition and how to use health care support your goals?

Prioritized Goals	Issues or Concerns	Actions	Person Responsible	Target Date	Date Complete
-------------------	--------------------	---------	--------------------	-------------	---------------

--	--	--	--	--	--

Initial Date of Plan: _____

Last Updated: _____

Parent/Caregiver Signature: _____

APPENDIX H: TRxANSITION Scale™ Educational Handouts

Self-Management

What is self-management?

What a person with a chronic disease does to control their illness and stay healthy.

Examples of Self-Management

1. Getting medication refills.
2. Always taking your medicines - on your own!
3. Setting up doctor appointments.
4. Asking questions about your condition.

All of these things, and more, make up self management!

Things you should know about your medicines:

- What medicines do you take?
- How many medicines do you take each day?
- Why do you take them?
 - What do they do?
- Which other medicines "do not mix" with yours?
- When and how do you take them?



You can read the medicine label to find out many of these things!

Here are some tips for refilling you prescriptions:

- Refill your prescription either by phone or online 2 weeks before you run out.
- Read the label to see how many refills you have left before you need to ask your doctor for a new prescription.
- Ask about getting a 90-day refills to make it easier to always have your medication.
- Ask your parents about how your medicines are refilled.

Appointments

Appointments are a time for your doctor to check on your health. They are also a chance for you to ask questions about your care. It is very important for you to always go to your appointments. If you cannot make it, be sure to cancel on time, and always call ahead to reschedule!

It's always good to have questions for your doctor, take this space to write down questions for your next appointment!



- 1.
- 2.

Communicating with Your Doctor

You do not have to wait until your appointment to ask your doctor a question. You can email or call them, and they will be happy to help you!

Get their email or phone number to contact them if you have questions about your medications, diet, symptoms, etc.



fill out your doctors' contact information here

Make sure you know the name of your doctor! If you call the main hospital number you will need to tell them this.

If you get put on hold, be patient! Your doctor will get to you as soon as they can.

Have your questions ready on a piece of paper. Write down the answers your doctor gives you.

If you have an emergency, hang up and call 911!



Here are some examples of questions that you can ask your doctor to help you talk about things that might be worrying you...



Questions About Medications

Questions About Tests & Treatments



Questions About an Illness or Symptom

What is wrong with me?
Can you draw me a picture or show me what's wrong?
What causes this type of problem?
Is this serious?
Will there be any long-term effects of this problem?
Can I give this illness to someone else, and if so, for how long?
Are there any activities or foods I should avoid until I'm better?
When can I return to school or work?
How can I prevent this from happening again?

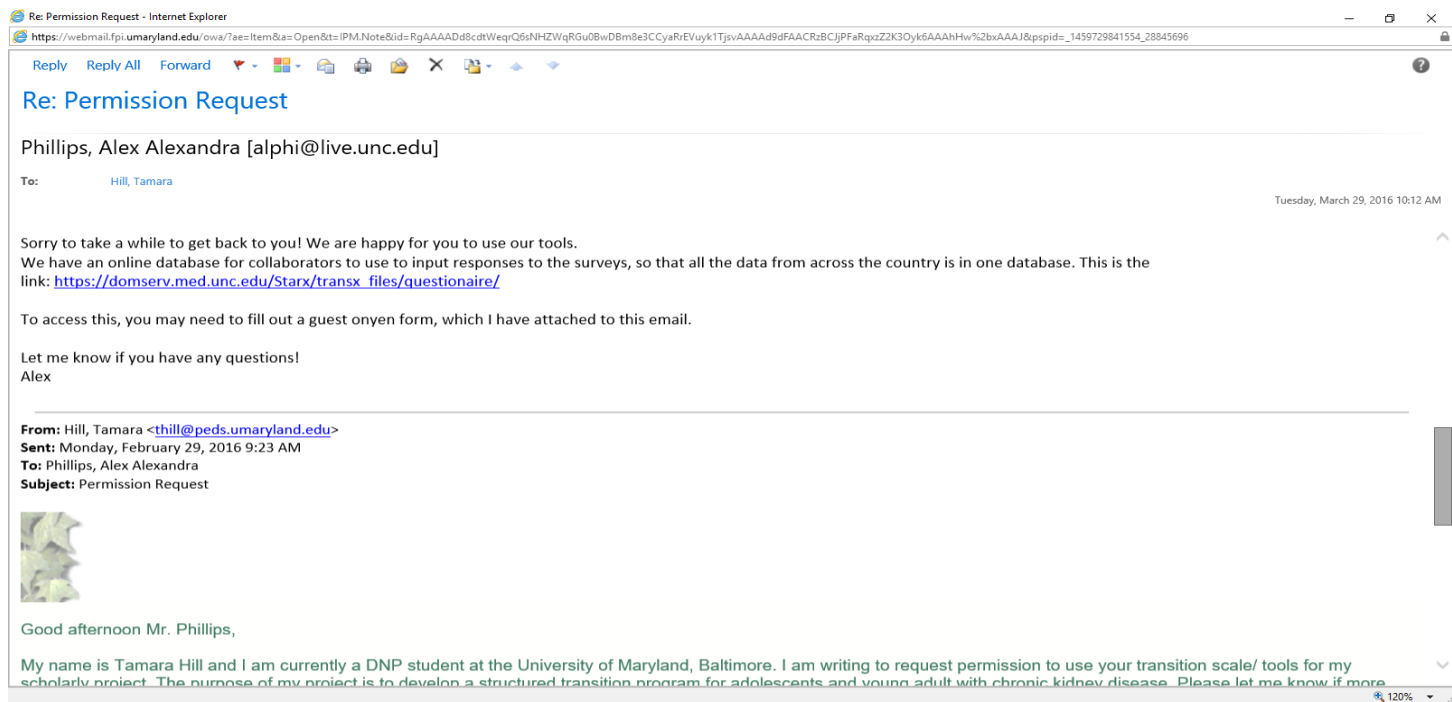
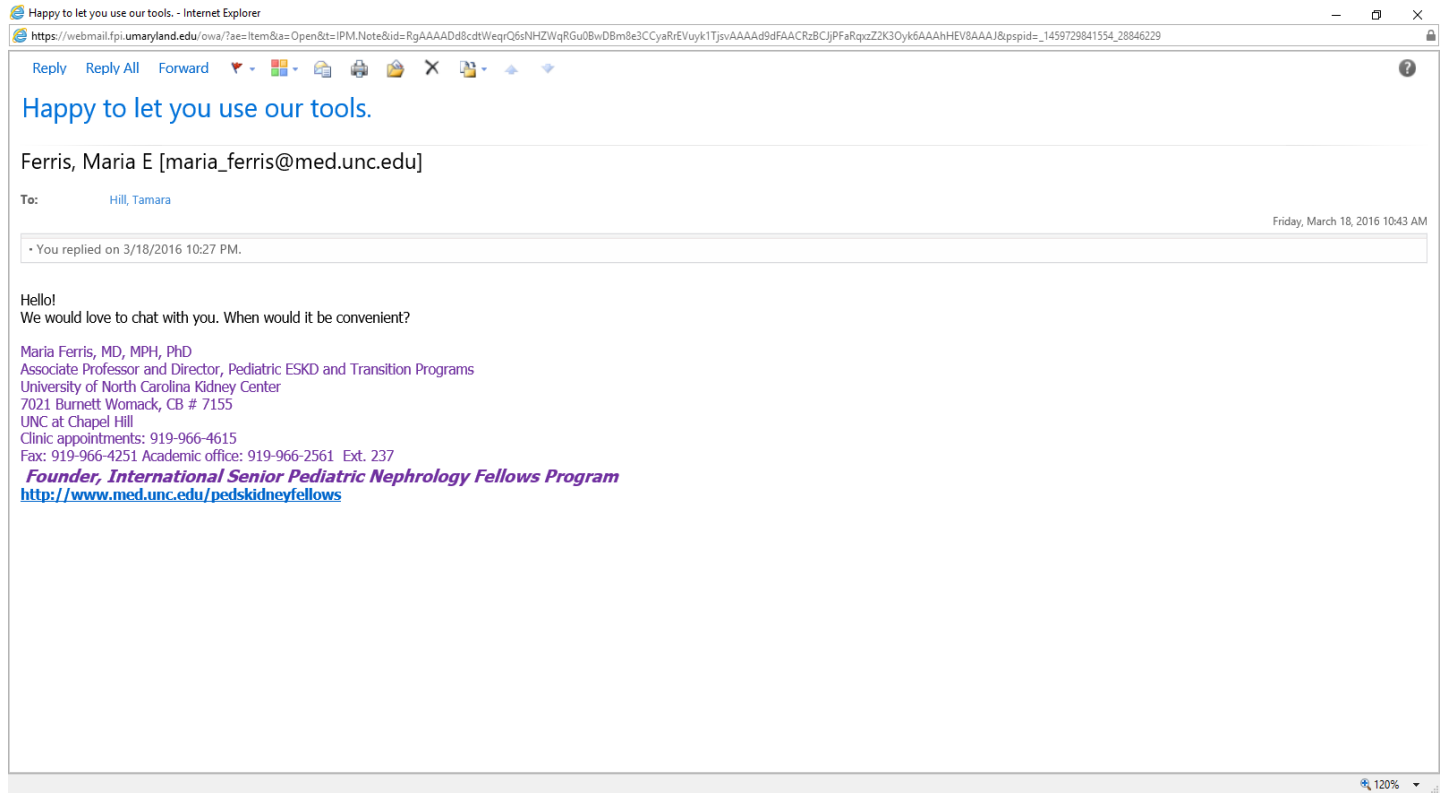


SUMMARY

The more questions you ask, the more you will discover about your body. When you know what is going on with your body, you can take better control of your own health - today and in the future!

1. Self-management is learning to manage your disease as you get older so that your parents do not have to help you.
2. You will need to learn about your medicines, like which ones you take, why, when, and how you take them.
3. You will need to learn to make your own doctor appointments and refill your medications.
4. Asking your doctor questions is important to keep up with your disease. You can ask questions related to: communication with your doctor, your illness or symptoms, medications, tests and treatments, or anything else you can think of!

APPENDIX I: Email Permission



Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.

APPENDIX J: UNC TR_xANSITION Scale

Patient Name			Date	
Medical Record #		Transition ID	Institution	

UNC TR_xANSITION Scale™ for Adolescents and Young Adults:

Instructions: Read the question to the patient, and circle the choice on the right that best describes the patient’s response. Sum the scores for each section in the “Subtotal” row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the “Proportion”.

Type of chronic health condition		Correct	Non-specific	Does not know
1	What is the name of your health condition?	1.0	0.5	0.0
2	What physical symptoms do you experience because you have [name of health condition]?		0.5	0.0
3	How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
<i>Sum the scores for this section</i>				
<i>Divide the subtotal by the number of applicable questions</i>				

R_x: Medications

Can name all	Can name some	Cannot name any	
--------------	---------------	-----------------	--

4	What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition?	1.0	0.5	0.0	
5	When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
6	What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0	
7	What could happen if you do not take [name each medication, vitamin, and supplement patient should be taking] like your doctor has asked you to?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>		Subtotal R _x	___ out of ___		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion R _x			

Adherence

	Yes	Sometimes	No	N/
8 In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or didn't want to take it?	0.0	0.5	1.0	
9 Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0	
10 Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				
<i>Divide the subtotal by the number of applicable questions</i>				

Nutrition

	Knows definitely	Has an idea	Does not	
11 When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	1.0	0.5	0.0	
12 Are you supposed to follow any special diet because you have [name of health condition]?	1.0	0.5	0.0	
13 <i>[if the patient is on a special diet]</i> What are examples of the foods and/or drinks that you should have more or less of?	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>				
<i>Divide the subtotal by the number of applicable questions</i>				
Subtotal N				
Proportion N				

Self-management skills

	Yes	Sometimes	No	N/A
14 Do you usually remember to take your medicines on your own?	1.0	0.5	0.0	
15 Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0	
16 Do you usually call in your prescription refills yourself?	1.0	0.5	0.0	
17 Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18 Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19 Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20 <i>[if the patient has medical procedures to perform]</i> Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				
<i>Divide the subtotal by the number of applicable questions</i>				

Note: Some patients may be too young for the following questions to be appropriate. Score these patients as 0's, as these are important skills not yet obtained.

Issues of reproduction

	Knows definitely	Has an idea	Does not know	
21 Would your health condition likely affect your ability to: <i>[if female]</i> become pregnant?	1.0	0.5	0.0	N/A
22 <i>[Females only]</i> What are risks you might face if/when you become pregnant because you have <i>[name of health condition]</i> ?	1.0	0.5	0.0	N/A
23 <i>[Females only]</i> Do you take any medicines that would be harmful to an unwanted baby if you became pregnant?	1.0	0.5	0.0	
24 Can you tell me ways sexually active people help protect themselves from pregnancy or STD's?	Subtotal I Male _____ out of 2 Female _____ out of 4			
Proportion I				

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.

Trade / School

		Knows definitely	Has an idea	Does not
25	What are your future plans in regards to school and/or a job?	1.0	0.5	0.0
<i>Sum the scores for this section</i>		Subtotal T _____ out of 1		
<i>Divide the subtotal by the number of applicable questions</i>		Proportion T		

Insurance

		Knows definitely	Has an idea	Does not know	
26	<i>[If he/she is currently insured]</i> At what age will your current health insurance	1.0	0.5	0.0	N/A
27	How can you get health insurance coverage for yourself when you are an adult?	1.0	0.5	0.0	
28	What is health insurance and why is it important to have?	1.0	0.5	0.0	
29	What is the name of your current health insurance provider?	1.0	0.5	0.0	

Sum the scores for this section Subtotal 0

Divide the subtotal by the number of applicable questions

Ongoing support

30 When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from

Self	Parents/ friends	Does not know
_____		out of 1

Subtotal 0

New health care providers

31 When it comes time for you to switch to an adult doctor, how will you find one?

32 In order to get your medical records transferred to another doctor has it is required
Will you do to make this happen?

Knows definitely	Has an idea	Does not
1.0	0.5	0.
1.0	0.5	0.

Sum the scores for this section

Subtotal N _____ out of

Divide the subtotal by the number of applicable questions

Proportion N

Raw total score	<i>Sum all section subtotals here (max 32)</i>	
T.R.xA.N.S.I.T.I.O.N Score™	<i>Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)</i>	

APPENDIX K: TR_xANSITION Scale Answer Guide for Kidney Patients

Question	Knows a lot = 1	Knows a little = 0.5	Doesn't know = 0	N/A
1.	They say they have CKD (chronic kidney disease) or kidney failure (ESRD) and/or they can name specific cause of kidney disease: i.e., FSGS (focal segmental glomeruloclerosis), Diabetes, HIV, Hypertension, etc.	They give a general answer like "Something is wrong w/ my kidneys" or "My kidneys don't work like they're supposed to".	They have no idea	
2.	They can name physical symptoms that they experience directly related to or caused by their health condition. They may also be able to name symptoms that others may experience but they do not. Examples: Nephrotic Syndrome or FSGS patients – swelling, fluid retention, spill protein in their urine; Lupus – skin rash, joint pain/swelling. Dialysis patients – swelling, headache, high blood pressure. Peritoneal dialysis – Belly pain if they have an infection. Transplant patients have few or no symptoms.	They name generic symptoms (i.e., tired, less energy, don't feel good, flare) but they are not specific.	They do not know any symptoms or they name symptoms that are unrelated to their health condition.	
3.	They are able to name more than one way their health condition may affect their future health and they are specific. They may say "I won't be able to play football in college bc I have a kidney transplant" and "I may eventually have to go on dialysis as my kidney function gets worse".	They can only name one way how their health condition may affect their future health OR they give a general response such as "I can do more/less of what I want to do or like to do".	They are unable to report or do not know how their future health may be affected.	
4.	They are able to name all of the medicines they take for their health condition.	They are able to name some of the medicines they take for their health condition.	They do not know any of the meds they take for their health condition.	They do not have any prescribed meds for their health condition.
5.	They know when they take each of their medicines. For example, "I take lisinopril once a day in the morning and Cellcept two times a day (once in the a.m. and once in the p.m.)".	They know when they are supposed to take some of their medicines, but not all of them.	They do not know when they are supposed to take any of their meds.	They do not have any prescribed meds for their health condition.
6.	They know why they take each of their medicines. For transplant patients, most important ones are anti-rejection meds: Prograf, Cellcept, Cyclosporin, Gengraf, Prednisone. For CKD or Dialysis patients, most important ones are: phosphorus binders (e.g. calcium carbonate, renagel), Bicarbonate supplements, Iron (ferrous sulfate), Epogen or Aranesp.	They know why they take some of their medicines, but not all of them.	They don't know why they take any of their medicines.	They do not have any prescribed meds for their health condition.

7.	They are able to list consequence for each medicine. Transplant: Loss of kidney or rejection, end up in hospital, could die, etc. CKD or Dialysis: swelling, blood pressure will go up, have to go on dialysis.	They are able to identify general consequences for not taking their meds, but cannot give specific consequence for each med.	They do not know what could happen if they don't take their meds.	They do not have any prescribed meds for their health condition.
8.	They do not ever miss a full day of medicine.	They miss a full day every now and then but not regularly.	They miss a full day at least once/week.	They do not have any prescribed meds for their health condition.
9.	They do not have difficulty remembering to take their meds every day.	They sometimes have difficulty remembering to take their meds every day.	They always have difficulty remembering to take their meds every day.	They do not have any prescribed meds for their health condition.
10.	They come to their appts as scheduled or they cancel/reschedule ahead of time.	They sometimes forget when their appts are scheduled and show up late or don't show up at all.	They usually don't attend their appts when scheduled.	
11.	Yes, they read nutrition labels on foods/drinks.	They sometimes read nutrition labels.	They never read nutrition labels.	
12.	They can name the diet their dr has asked them to follow: i.e., CKD or Dialysis low sodium/salt, low phosphorous, low potassium. Transplant patients do not have a diet unless they have high blood pressure which would be low sodium/salt. Obese patients: low calorie diet.	They know they aren't supposed to eat/drink certain things but they don't know why (can't name specific diet).	They don't know if they are supposed to follow a diet or not.	
13.	They are able to name at least 3 specific foods/drinks they are supposed to have more or less of such as fried foods, processed foods, dark sodas, chocolate, water, etc. Potassium diet – Avoid bananas, potatoes, tomatoes, oranges. If they are on cyclosporine, no grapefruit.	They can name less than 3 examples of foods/drinks they are supposed to have more or less of.	They do not know examples of any foods/drinks they are supposed to have more or less of.	They do not have a diet.
14.	They usually remember to take their meds on their own w/out requiring a reminder.	They sometimes remember to take their meds on their own, but they also sometimes need a reminder.	They do not remember to take their meds on their own and rely on someone to remind them.	They do not have any prescribed meds for their health condition.
15.	They do not need someone to remind them to take their meds.	They sometimes need someone to remind them to take their meds.	They always need someone to remind them to take their meds.	They do not have any prescribed meds for their health condition.

16.	They always call in rx refills themselves or manage them via the internet.	They sometimes call in refills themselves or manage them via the internet.	They never call in refills themselves or manage them via the internet.	They do not have any prescribed meds for their health condition.
17.	They always pick their refills up from the pharmacy. If they do not have a driver's license, they at least ride w/ someone and are responsible for going inside to pick up their meds.	They may go w/ someone to pick up their refills, but they don't do it on their own.	They never pick their refills up on their own.	Their meds are sent via mail.
18.	They contact their health providers on their own via email or phone without help from their parent.	They sometimes contact their health providers on their own, but mostly tell their parents and let them make contact.	They never contact their health providers on their own.	They have never had to contact a provider
19.	They are usually responsible for checking out after an appt and scheduling a f/u appt as necessary or they make their medical appts on their own via phone, email, etc, and coordinate it w/ their schedule	They sometimes schedule appts for themselves, but mostly their parents or health providers do it for them	They never schedule dr appts on their own.	
20.	They always perform their own medical procedures	They sometimes perform their own medical procedures, but someone else does it for them most of the time.	They rely on someone else to perform their medical procedures.	They do not have any medical procedures to perform on their own.
21.	They know their health condition will or will not affect their ability to have children. In most cases, CKD will not affect fertility. Female dialysis patients often have a difficult time getting pregnant, but it is possible. Lupus carries higher risk for infertility in females. Fertility can be	They don't think they will have a problem getting pregnant	They do not know	
22.	They know specific risks associated w/ having their health condition and becoming/being pregnant. CKD IV-V – very low risk of losing pregnancy/miscarriage. Dialysis patients – may lose the baby early on particularly if they have Lupus. Transplant patients – run risk of rejecting their	They are aware that risks may exist but they are unable to name them. They say there may be some problems but they are not specific	They do not know if their health condition will cause risks associated w/ pregnancy.	Males
23.	They are able to name medicines they are currently taking that would be harmful to an unborn baby. CKD and Dialysis – ACE inhibitors (“prils” - lisinopril, enalapril, etc) or ARBs (“-artans”, losartan, valsartan, etc). These blood pressure meds can possibly cause an unborn fetus	They are aware that they are on medicine that would be harmful to an unborn baby but they cannot specify which meds they are.	They do not know if any of their meds would be harmful to an unborn baby	Males
24.	They report both condoms AND birth control	They report either condoms OR birth control.	They cannot name protective methods.	

Question	Knows a lot = 1	Knows a little = 0.5	Doesn't know = 0	N/A
25.	They have a specific plan post-high school or college. They know they will be attending college, entering the workforce, or joining the military. They have an idea of what they would like to be or do.	They do not have a specific plan or idea. If they are in high school, they "think" they might go to college, but they haven't decided. If they are in college, they have not declared a major or identified a field of study or post-college employment.	They have no post-high school/college plans or they don't know.	
26.	They are able to report that health insurance helps pay for (or reduce the cost of) meds, dr visits, hospital stays, labs, etc, things that are medically necessary.	They know it helps pay for "stuff" but they are not specific.	They don't know.	
27.	They are able to name their primary insurance provider.	They know they have insurance but they don't know the name.	They don't know if they have insurance and don't know the name.	They do not have insurance coverage. They are self-pay patients.
28.	For patients covered by their parent's insurance , they know that they are eligible to be covered until age 26, no matter if they are married, not living in their parent's home, or in school. For patients covered by Medicaid , they know that they can receive coverage under MIC (Medicaid for infants and children) until they turn 19yo. Once they turn 19, they will have to reapply as an adult. For Transplant patients, they know their Medicare coverage ends 3 years post-transplant. <i>**Most important knowledge is that their insurance status changes and they need to be aware of how/when this happens and who to seek information from.</i>	They have an idea that it may end at a certain age, but they are unsure what age specifically.	They do not know when it will end.	They do not have insurance coverage. They are self-pay patients.
29.	They know they can get health insurance coverage through their job. If their job does not offer coverage, they can buy it on their own, or they may qualify for government assistance depending on their financial status.	They say they can get coverage by looking in the phone book or internet or going to social services. They do NOT identify employment as a way to get health insurance coverage.	They do not know how to get coverage.	
30.	They report that they will be primarily responsible for taking care of their health needs. They may recognize that others can help and provide support.	They will depend on someone else to primarily take care of their own health needs.	They don't know who will take care of their health needs.	
31.	They report asking their medical provider for a recommendation/referral.	They say they will look in the phone book, on the internet, ask a family member/friend, etc. They do NOT mention asking their current medical provider.	They don't know.	
32.	They know they must sign a consent to release form in order to transfer their medical records.	They say they'll call and ask their dr to fax/send it to their new provider but they do NOT mention signing a consent form.	They don't know what they need to do or what is needed from them.	

