

THE ROLE OF PSYCHOSOCIAL FACTORS IN HEALTHCARE TRANSITION FOR
ADOLESCENTS AND YOUNG ADULTS WITH CHRONIC KIDNEY DISEASE

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ABSTRACT

Sarah E. Cohen: The Role of Psychosocial Factors in Healthcare Transition for Adolescents and Young Adults with Chronic Kidney Disease
(Under the direction of Eileen Burkner)

The number of children and adolescents with chronic health conditions surviving into adulthood has dramatically increased over the last half-century. Individuals with Chronic Kidney Disease (CKD) are one population that has seen some of the biggest increases in children surviving into adulthood. Becoming an adult is a critical period of time, such that an improper transition may lead to poor health outcomes. The purpose of this study was to evaluate the relationship between psychosocial factors and healthcare transition for adolescents and young adults with CKD. In this IRB-approved study, validated transition measures and psychosocial scales were administered in pediatric and adult nephrology clinics at UNC Hospitals to patients with CKD. Family functioning and social support were the main psychosocial factors that influenced transition readiness. These findings can be used to guide interventions to improve transition readiness and self-management for adolescents and young adults with CKD.

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LIST OF ABBREVIATIONS

CES-D	Center for Epidemiologic Studies Depression
CF	Cystic Fibrosis
CKD	Chronic Kidney Disease
DKA	Diabetic Ketoacidosis
ESRD	End-Stage Renal Disease
FRI	Family Relationship Index
GFR	Glomerular Filtration Rate
IBD	Inflammatory Bowel Disease
NVS	Newest Vital Sign
SSQSR	Social Support Questionnaire Short-Form Revised

CHAPTER 1: INTRODUCTION

Fifty years ago youth with chronic health conditions did not survive into adulthood. Through research and technology developments, children with chronic health conditions now not only survive, but also thrive in society (DeBaun & Telfair, 2012; McDonald & Craig, 2004). One health condition that has seen some of the most dramatic improvements in childhood survival rates is Chronic Kidney Disease (CKD). This creates large numbers of pediatric nephrology patients transferring to adult services. This transfer to adult services usually occurs at a crucial period of time for the patient. For the first time they may be self-managing their disease, living independently, or starting a job. Conditions such as cystic fibrosis (CF) (Capelli, MacDonald, & McGrath, 1989; Conway, 1998; Hink & Schellhase, 2006; Nasr, Campbell, & Howatt, 1992) and congenital heart disease (Sommerville, 1997) have been the focus of transition research for many years, but the same national attention is still lacking for nephrology patients. Previous research identifies patient, provider, and institutional barriers for transitioning youth with chronic health conditions to adult services (Viner, 2003). However, one important factor less frequently examined is the psychosocial barriers to transitioning to the adult world. Specifically, the psychosocial factors related to transition for patients with CKD has yet to be explored. Thus, this thesis aims to examine the role of psychosocial factors in the healthcare transition process for adolescents and young adults with CKD.

Chronic Kidney Disease

CKD encompasses a number of different conditions (e.g. congenital kidney and urinary tract anomalies, polycystic kidney disease, glomerular diseases, and hypertension) that damage

the kidneys and prevent them from functioning at a normal level (National Kidney Foundation, 2013). CKD is classified from stage 1 to 5, depending on the severity of the condition, with stage 5 being the most severe (Warady & Chadha, 2007). Each stage is determined by an individual's Glomerular Filtration Rate (GFR), which estimates how the kidneys filter blood (Warady & Chadha, 2007). Normal levels of GFR are dependent on an individual's age, gender, and body size (Warady & Chadha, 2007). The lower an individual's GFR, the more severe their stage of CKD (Warady & Chadha, 2007). A GFR above 90 signifies normal kidney functioning. If the disease progresses, the kidneys gradually lose their function over time, which may eventually lead to kidney failure (National Kidney Foundation, 2013). Individuals experiencing kidney failure must undergo dialysis or a transplant to maintain life (National Kidney Foundation, 2013).

Prevalence estimates vary, but in North America it is estimated that 11% of the population (19 million) have CKD (Warady & Chadha, 2007). At the end of 2009 it was estimated that over 871,000 people were diagnosed with the most severe stage (CKD 5), or End-Stage Renal Disease (ESRD) (National Kidney and Urologic Diseases Information Clearinghouse, 2012). Prevalence estimates for the pediatric population are much lower overall, only accounting for 2% of those diagnosed with ESRD in North America (Warady & Chadha, 2007).

A number of factors impact the prevalence rates of CKD in adolescents and young adults. Incidence rates in the U.S. are affected by racial and ethnic distribution, type of prevalent renal disease, and quality of medical care (Warady & Chadha, 2007). Typically, prevalence rates are higher for boys than girls and in North America the rates are two to three times higher for black children compared to white children (Warady & Chadha, 2007).

The etiology of CKD is different for childhood and adult diagnoses. The main causes for developing CKD as an adult are diabetes and hypertension (Warady & Chadha, 2007). For children, congenital causes account for the greatest percentage of cases (Warady & Chadha, 2007). Other possible risk factors for developing CKD as a child include family history or genetics, small birth weight, diabetes mellitus, and developing other kidney conditions such as renal dysplasia or acute kidney failure (Hogg et al., 2003).

The development of better dialysis techniques, and optimization of transplant-related medication drastically increased survival rates for this population (Gortmaker & Sappenfield, 1984). On average, dialysis patients live an extra 16 years and kidney transplant patients live an extra 40 years, compared to when these procedures did not exist (Ferris, Gipson, Kimmel, & Eggers, 2006). A pediatric diagnosis poses a unique challenge to healthcare professionals as the disorder also affects other areas of growth and development (Warady & Chadha, 2007). The 10-year survival rate for adolescents with ESRD has increased from 77% to 81% since 1978 (Ferris et al., 2006) and more recent data from Canada suggests that survival rate has increased to 86% (Samuel et al., 2011). Therefore, more than 80% of patients with ESRD will transition from pediatric to adult care. However, the mortality rate for children who reach ESRD and receive dialysis is between 30 to 150 times that of the general pediatric population (Ferris et. al 2006; McDonald & Craig, 2004). It is important to note that the mortality rate is still around 20%, which remains unchanged since the 1980s (Ferris et al., 2006; McDonald & Craig, 2004; Samuel et al., 2011). Thus, a critical examination of the care for adolescents with CKD and ESRD is still needed.

Transition from Pediatric to Adult Care

Transitioning from pediatric to adult care is one of many transitions that adolescents and young adults experience. Adolescents transitioning to adulthood may also be living independently for the first time, entering post-secondary education or the workforce, and developing adult relationships. Individuals with chronic health conditions face a unique situation, in that they must also learn to care for their condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). A successful and coordinated transition is crucial to maintain positive health outcomes (Watson, 2005).

It is important to distinguish the difference between a medical transition and a medical transfer. A medical transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems” (Blum et al., 1993, p. 570). Ideally, this transition should be comprehensive and provide developmentally appropriate healthcare in a coordinated and uninterrupted manner (Callahan, Todd, Winitzer, & Keenan, 2001). A medical transfer is the movement to a new healthcare setting, provider, or both (Callahan et al., 2001). Transfer is only a part of the medical transition (Ansell & Chamberlain, 1998; Conway, 1998). The medical transition may encompass several domains of an individual’s life including vocational and psychosocial (Watson, 2005).

Experts in the healthcare transition field are still currently debating what constitutes a proper transition. Currently, there is no formalized transition process or model. Each chronic health condition is different, so the transition process needs to be catered to each individual and their diagnosis. Understanding the factors that impact the transition process is needed in order to create interventions that are tailored to each individual.

What Impacts the Transition Process?

Barriers to Transition. Barriers to transition can originate from the patient and family, the health providers and clinic itself, and from structural and administrative obstacles (Viner, 2003). It is important to understand these barriers so that interventions can be tailored to address these needs.

Patients may feel intimidated by the environment of adult clinics (Viner, 2003). While pediatric healthcare providers may seem more caring and compassionate, adult providers take more of an individual approach to their patients and use less of a family-centered model (Viner, 2003). Typical adult clinics do not expect patients to bring their family, which can intimidate young patients who may have always attended their appointments with their parents or other family members (Viner, 2003).

Parents of children with chronic health conditions may be overprotective because they have helped their child manage their illness from a young age. This prevents children from learning how to self-manage their condition and creates a dependency on their parents, which is not as accepted in adult-focused clinics (Bell, 2007). Youth with chronic health conditions must learn how to manage their illness on their own so that they are prepared to enter the adult world and be successful. Proper self-management and transition preparation provides patients with the necessary skills to interact with adult providers.

Barriers to transition also arise from pediatric and adult providers. Many pediatric providers may have cared for their patients since birth or early childhood, and may have trouble letting go of these patients (Bronheim et al., 1988; Reiss, Gibson, & Walker, 2005). Providers that care for patients with conditions of a pediatric-onset may also not trust adult providers to provide the proper care for their patients (Bronheim et al., 1988; Reiss et al., 2005). Pediatric

providers have the expertise and training to care for a patient with a condition that is purely childhood-onset and adult providers may not have sufficient training. Adult providers may be reluctant to take on patients with pediatric conditions (Bronheim et al., 1988). Adult providers may also view adolescents and young adults as immature, and not ready to handle an adult clinic (Bell, 2007). Furthermore, coordination between pediatric and adult services is uncommon in institutions throughout the United States and the world (Blum, 2002; Harris, Freeman, & Duke, 2011). Without institutional support, developing effective transition services will be difficult.

Unfortunately, there is little to no funding available for transition programs at the majority of hospitals or university-affiliated medical centers (Scal, Evans, Blozis, Okinow, & Blum, 1999). At many medical institutions there is also a shortage of adult healthcare specialists who are familiar with uncommon pediatric-onset conditions (Scal, 2002; Scal et al., 1999). Other institutional barriers to transition include lack of support, insurance coverage, and lack of time to provide transition preparation services (Scal, 2002). These administrative barriers further complicate the healthcare transition process.

All of these barriers, including those related to the patient and family, the health providers and clinics, and structural and administrative may prevent successful transition of adolescents and young adults with chronic health conditions. These factors are only part of the picture for understanding the healthcare transition process. Research on other chronic conditions provides insight into important factors for the transition process.

Transition for Other Chronic Conditions. Knowing less about their health condition and poor self-management skills can prevent adolescents and young adults from properly transitioning. For example, Bell (2007) found that many patients do not know how to refill their prescriptions or make doctor's appointments on their own without their parents. A survey of

patients with physical disabilities found that many adolescents are not able to describe their disability or explain why they are taking their medications (Whitehouse & Paone, 1998). These factors are crucial for success in the adult clinic world.

Transition programs for patients with CF (Nasr et al., 1992) and diabetes (Holmes-Walker, Llewellyn, & Farrell, 2007) have resulted in better health outcomes and quality of life. Patients with CF found the transition to adult care much less intimidating and there was increased follow-up in adult clinic visits after involvement in a transition program including guidance by a social worker and coordination between the pediatric and adult clinics (Nasr et al., 1992). In a transition program for youth with diabetes, a transition coordinator and diabetes educator helped coordinate appointments and provided after-hours phone support for sick day management (Holmes-Walker et al., 2007). Participants in the program showed increased attendance in appointments, improvement in diabetes control, and reduced hospital admission rates due to diabetic ketoacidosis (DKA) (Holmes-Walker et al., 2007).

Interestingly, transition programs for renal patients have not yielded the same results. A study by Remorino and Taylor (2006) found no improvements in medication adherence for kidney transplant recipients participating in transition services. These services involved appointments in the pediatric clinic without parents present, a joint transition clinic with the adult and pediatric medical and nursing staff, and information about expectations during the transition (Remorino & Taylor, 2006). Bell (2007) also found that after surveying a variety of centers with transition programs, renal patients' sense of independence did not increase when they transitioned to adult care. Many patients were still not able to fill their own prescriptions or make their own appointments (Bell, 2007). The factors contributing to these conflicting transition outcomes between youth with chronic conditions need to be elucidated. One area that has been

minimally studied in individuals with CKD is the impact of psychosocial factors on transition. This may provide new insight into a more comprehensive model for transition.

Psychosocial Factors

Psychosocial factors can significantly impact the outcomes of an individual with a chronic illness or disability (Falvo, 2014). Both psychological factors, such as co-occurring mental health conditions, and social factors, such as family and friend support, need to be taken into consideration. Numerous research studies highlight the impact of psychosocial factors for all different types of chronic health conditions (Schneiderman, 2004).

For youth with CF, parent-youth strains, physical strains, and activity limitations can have significant effects on pulmonary functioning (Patterson, Wall, Berge, & Milla, 2009). Individuals with congenital heart disease need constant medical monitoring and may experience repeated hospitalizations, which results in excessive absences from school (Sable et al., 2011). This can affect self-image, lower self-esteem, and delay completion of normal developmental tasks (Sable et al., 2011). Youth with chronic health conditions are also at risk for depression, increased dependency, and poor emotional and social adjustment (Sable et al., 2011). Qualitative research reveals that many feel “different” and set apart from their healthy peers (Sable et al., 2011, p. 1457). Health-related quality of life is one domain that is significantly impacted for adolescents and young adults with chronic health conditions (Sable et al., 2011). They are at risk for an overall lower perceived quality of life, including physical, psychosocial, and school functioning (Sable et al., 2011). Overall, these negative psychosocial outcomes for adolescents and young adults are fairly consistent across a number of health conditions.

While less researched, psychosocial factors in relation to health outcomes in youth with CKD, yield similar results. Mongeau et al. (1997) found that better psychological functioning,

including intellectual, psychomotor, emotional, and social development, helps children keep their transplants longer. A well-adjusted and supportive family may serve as a buffer for children with CKD (Ferris & Mahan, 2009). Lower internalizing symptoms are seen in children with families that are cohesive and expressive, and also families that are better adjusted to having a child with CKD (Ferris & Mahan, 2009). On the other hand, factors such as altered physical appearance, sexuality issues, stress, anxiety, and guilt complicate life after receiving a transplant, and put the youth at risk for poorer health outcomes (Muehrer & Becker, 2005). These and many other psychosocial factors can impact the experience of youth with CKD. However, these factors have yet to be critically examined for adolescents and young adults with CKD in relation to healthcare transition.

Livneh and Antonak's Conceptual Framework

An adaptation to chronic illness model may be the best way to depict the relationship between psychosocial factors and healthcare transition for adolescents and young adults with CKD. Livneh and Antonak (2001) suggest that psychosocial adaptation can be divided into three levels for individuals with chronic illnesses or disabilities (Figure 1). The macroanalytic level focuses on intrapersonal, interpersonal, and extrapersonal domains (Livneh, 2001; Livneh & Antonak, 1997). The intermediate level divides each of those domains into specific content areas (Livneh, 2001; Livneh & Antonak, 1997). The intrapersonal domain is divided into health (biomedical) and psychological (subjective) well-being (Livneh, 2001; Livneh & Antonak, 1997). The interpersonal domain is divided into family and marital life and peer and social relations (Livneh, 2001; Livneh & Antonak, 1997). Lastly, the extrapersonal domain is divided into work activities, housing or living environments, recreational activities, and learning or schooling activities (Livneh, 2001; Livneh & Antonak, 1997). This framework provides a

holistic view of the experience of someone with a chronic illness or disability (Parker & Patterson, 2012). With this model in mind, interventions should be comprehensive and target the intrapersonal, interpersonal, and extrapersonal domains for a person with a chronic illness or disability.

This framework may help explain the experience of an adolescent or young adult with CKD, and help provide for effective interventions for transition readiness and self-management. This model has yet to be applied to the field of healthcare transition. If these factors are all pertinent to a successful healthcare transition, then future interventions can target these specific domains. In order to fully understand what is needed for a patient to complete a successful healthcare transition, Livneh and Antonak's model needs to be investigated. Examining this model will provide insight into the psychosocial domains that affect healthcare transition and provide a guiding model for future healthcare transition interventions for adolescents and young adults with CKD.

Aims of the Study

This study examined how psychosocial adaption affects healthcare transition readiness and self-management for adolescents and young adults with CKD. The overall hypothesis was, the more psychosocially adapted adolescents or young adults are, the more prepared they will be for healthcare transition and to self-manage their condition. That is, the higher an individual's intrapersonal, interpersonal, and extrapersonal functioning, the higher their transition readiness and self-management skills. Utilizing Livneh and Antonak's framework the following hypotheses were investigated:

- 1) Intrapersonal Functional Domain
 - a. Health and Biomedical Area

- i. Because adolescents with IBD with greater perceived regimen complexity, and objective reports of regimen complexity have been found to be less adherent to their disease regimen (Hommel, Greenley, Maddux, Gray, & Mackner, 2013) it is hypothesized that individuals with greater disease severity (higher CKD stage) will have lower transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x Questionnaire).

- b. Psychological Area

- i. Because depression has been identified as a risk factor for nonadherence and poor self-management in a variety of chronic health conditions across all ages (DiMatteo, Lepper, & Croghan, 2000), and more depressive symptoms were correlated with nonadherence in youth with IBD (Gray, Denson, Baldassano, & Hommel, 2012) it is hypothesized that individuals with more depressive symptoms (higher scores on the CES-D) will have lower transition readiness/self-management (lower scores on the UNC TR_xANSITION scale and STAR_x Questionnaire).

2) Interpersonal Functional Domain

- a. Family and Marital Area

- i. Because family cohesiveness is positively correlated with adherence to treatment regimen in individuals of all ages with medical conditions (DiMatteo, 2004) and previous research in pediatric patients with IBD showed a relationship between higher levels of family dysfunction and nonadherence (Mackner & Crandall, 2005) it is hypothesized that individuals with better

family functioning (higher scores on the Family Relationship Index) will have higher transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x Questionnaire).

b. Peer and Social Relations Area

- i. Because various kinds of social support are associated with adherence to treatment regimens and self-management in individuals with chronic illnesses (DiMatteo, 2004), and in kidney disease, social support has been linked to increased survival (Cohen et al., 2007), it is hypothesized that individuals with more social support (higher scores on the Social Support Questionnaire) will have higher transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x questionnaire).

3) Extrapersonal Functional Domain

a. School Area

- i. Because adolescents and young adults with CKD are at risk for poor academic functioning (Duquette, Hooper, Wetherington, Icard, & Gipson, 2007) and it has been noted that knowledge and organizational skills are related to self-management in pediatric patients with IBD (Hommel et al., 2013), it is hypothesized that individuals with higher academic quality of life (higher scores on the PedsQL school functioning scale) will have higher transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x questionnaire).

b. Recreational Area

- i. Because a significant impact of physical functioning on self-management abilities has been found in patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes (Cramm & Nieboer, 2014) and disease interference with activities can also create a barrier to adherence in adolescents with IBD (Hommel & Baldassano, 2010; Ingerski, Baldassano, Denson, & Hommel, 2010), it is hypothesized that individuals who are able to participate in more leisure activities (higher scores on the PedsQL physical functioning scale) will have higher transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x questionnaire).

4) Overall Model

- a. Based on the literature on psychosocial factors, adolescents and young adults with CKD, and self-management, the following hypothesis was determined for an overall model:
 - i. Because of the literature supporting a strong relationship between both social support (Patel, Peterson, & Kimmel, 2005) and family functioning (Wamboldt & Wamboldt, 2000) with health outcomes and survival in individuals with chronic illness it is hypothesized that more social support (higher scores on the Social Support Questionnaire) and better family functioning (higher scores on the Family Relationship Index) will have the greatest impact on transition readiness/self-management (higher scores on the UNC TR_xANSITION scale and STAR_x questionnaire), after controlling for demographic factors. Social support and family functioning were selected based on their strong relationship with chronic illness and self-management in a variety of health

conditions and ages (Falvo, 2014; Patel et al., 2005; Wamboldt & Wamboldt, 2000).

CHAPTER 2: METHODS

This IRB-approved study utilized data collected at the UNC Kidney Center from 2012-2013. As a research assistant, the author of this thesis helped recruit participants and enter the data into the database. The author was also responsible for obtaining and entering information from the patients' medical records. The author completed all data analysis. The study and subsequent data analysis were funded by grants from the Renal Research Institute from 2012-2015.

Participants

To be eligible for recruitment, patients needed to be of transition-age, ranging from 12 to 29 years old. They must also have been diagnosed with CKD stage 2 and above. CKD stage was determined through a calculation of the estimated Glomerular Filtration Rate (eGFR), using the clinically common Schwartz formula (Schwartz & Work, 2009). Patients with a GFR of 89 and below were eligible for recruitment. Participants must have also had their diagnosis for three or more months. The measures deployed were administered in English, so all participants needed to be able to speak and read English. Patients with intellectual disabilities were not eligible for recruitment.

A power analysis was conducted using the software program G*Power 3.0.10. To obtain a medium effect size, a sample size of 89 was needed. A total of 180 participants were recruited for this study.

Measures

Demographics Questionnaire. This questionnaire included the participant's date of birth, sex, and race (See Appendix 1). The participant's phone number and e-mail were recorded in case there was a need for additional contact. Their address was recorded for the purpose of sending the thank-you gift card. To save time in clinic, additional demographic questions were part of an online Qualtrics survey (See Appendix 2). The online survey included the following questions: age at time of diagnosis, and type of insurance. If the patient did not know what type of health insurance he or she had, this information was collected from the electronic medical record.

Health Literacy. Health literacy was measured through the Newest Vital Sign (NVS) (Weiss et al., 2005) (See Appendix 3). The NVS scale measures both health literacy and numeracy via a food label with questions that are administered orally and scored as "yes" or "no." Scores on the measure range from 0 to 6, with higher scores indicating better health literacy. The average time to administer the scale is approximately 3 minutes. The NVS displays both good internal consistency and criterion validity (Weiss et al., 2005).

Transition Readiness and Self-Management. Two validated scales were used to assess transition readiness and self-management. The UNC TR_xANSITION Scale (Ferris et al., 2012) is a disease non-specific provider-administered scale that assesses the following ten domains: Type of Condition, Medications, Adherence, Nutrition, Self-Management, Issues of Reproduction, Trade/School, Insurance, Ongoing Support, and New Providers (See Appendix 4). These domains were all identified as essential to the transition process. The questionnaire is composed of a total of 32 questions and each item is scored with a 0, 0.5, or 1, with higher scores indicating greater transition readiness and self-management. All of the domains are totaled to determine an

overall transition readiness or self-management score. Participants still in pediatric care received the adolescent and young adult version, which measures transition readiness, while participants in adult clinics received the adult version, which measures self-management. The inter-rater reliability of the scale has a weighted kappa statistic of 0.71 (Ferris et al., 2012). The measure also has good internal consistency, with all of the items on the scale correlating with their subscale in a moderate to strong fashion ($r > 0.42$) (Ferris et al., 2012). The total score of the TR_xANSITION scale increases with age, which indicates good test-retest reliability (Ferris et al. 2012). For this study, an abbreviated version of the TR_xANSITION scale was used to include only domains that were rated by the provider, as some of the items are more self-report in nature, such as those in the adherence and ongoing support domains.

The STAR_x questionnaire is a self-report transition readiness and self-management measure (See Appendix 5). The questionnaire is a total of 18 items that assesses six domains of transition including medication management, provider communication, engagement during appointments, disease knowledge, adult health responsibilities, and resource utilization. All of the domains are totaled to determine an overall self-reported transition readiness or self-management score.

Disease Severity. Disease severity was determined by an individual's CKD stage. CKD stage was determined through a calculation of estimated GFR using the Schwartz formula (Schwartz & Work, 2009). For participants that did not have available labs to calculate GFR, a trained research assistant reviewed the participant's electronic medical record to determine their CKD stage through clinic and inpatient notes.

Depressive Symptoms. Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (*CES-D* Scale) (Radloff, 1977) (See Appendix 6). The

CES-D is an 11-item self-report scale that measures depressive symptomatology in the general population (Radloff, 1977). Internal consistency is high for the scale, with correlations between items at .85 for the general population, and .90 for patient populations (Radloff, 1977). The correlations for test-retest reliability range from .45 to .70 (Radloff, 1977). The *CES-D* scale also correlates with clinical scales for depression (Radloff, 1977). The scale shows discriminant validity, by strongly correlating with other depression scales such as the Bradburn Negative Affect and Bradburn Balance measures (Radloff, 1977). A factor analysis of the *CES-D* scale reveals four domains that the scale can determine including, depressed affect, positive affect, somatic and retarded activity, and interpersonal (Radloff, 1977). A cut-off score of 11 is indicative of significant or mild depressive symptomatology (Radloff, 1977).

Family Functioning. Family functioning was measured using the Family Relationship Index (FRI) (Holahan & Moos, 1983) (See Appendix 7). This index measures the quality of family relationships by assessing cohesiveness, expressiveness, and conflict (Holahan & Moos, 1983). The FRI displays high reliability and good concurrent and construct validity (Holahan & Moos, 1983). The FRI is negatively related to physical and psychological symptoms, and has a moderate positive relationship with traditional measures of social support (Holahan & Moos, 1983). Scores on the scale range from 0 to 9, with higher scores indicating better family functioning.

Social Support. Social support was measured using the Social Support Questionnaire Short-Form Revised (SSQSR) (Sarason, Sarason, Shearin, & Pierce, 1987) (See Appendix 8). This questionnaire assesses who participants can count on when they need help, who they can count on to care about them, and how satisfied they are with the overall support. The internal reliability is marginal, but acceptable because the scale has only a few items (Sarason et al.,

1987). The test-rest reliability and correlations with other personality scales are acceptable (Sarason et al., 1987).

School Functioning. School functioning was measured using the PedsQL scale (Varni, Seid, & Rode, 1999) (See Appendix 9). This measure is a five-point Likert Scale that asks questions about school behavior, with answers ranging from 0 (never) to 4 (almost always). The scores are then transformed to 0 to 100 as follows: 0=100, 1=75, 2=50, 3=25, and 4=0. The total score is computed by taking an average of scores on each item in the scale. Higher scores on the scale indicate better quality of life. The scale assesses how hard it is for participants to pay attention in class, how easily they forget things, how much trouble they have keeping up with schoolwork, how much school they miss because of not feeling well, and how much school they miss to go to the doctor or hospital. Item-internal consistency is adequate for the PedsQL scale, with correlations above the .40 standard (Varni et al., 1999). Internal consistency reliability is high, as 92% of correlations meet the .40 standard (Varni et al., 1999). The PedsQL shows clinical validity, as it is able to discriminate between patients that are on and off treatment (Varni et al., 1999).

Leisure Activities. Participants' ability to participate in leisure activities was assessed using another portion of the PedsQL scale (Varni et al., 1999) (See Appendix 9). The items from this part of the scale assess questions such as how hard it is for participants to do sport activities or exercise, how hard it is to run, and whether they have low energy. The physical functioning scale has the same psychometric properties and scoring as the school functioning scale (Varni et al., 1999). The physical functioning scale shows construct validity by correlated with school days missed in the past six months, and does not correlate with emotional distress, perceived competence, and social functioning (Varni et al., 1999).

Procedure

Participants were recruited both over the phone and in pediatric and adult nephrology clinics at UNC Hospitals.

Clinic Recruitment. Patient eligibility was determined by a review of electronic medical records via UNC Webcis. Each week a research assistant reviewed the adult and pediatric nephrology clinic schedules and created a password-protected list of eligible patients for recruitment. Research assistants approached eligible patients in the waiting room at their clinic appointment. The research assistant provided an overview of the study's IRB-approved protocol to the patient. If the patient agreed, he or she first signed the IRB consent forms (See Appendix 10). Participants older than 18 consented to the IRB form and a HIPPA form. Participants under 18 signed an IRB assent form and their parent signed an IRB parental permission form and a HIPPA form as their personal representative. After the participant and the research assistant signed the consent forms, the demographics questionnaire was administered orally. The research assistant then administered the TRxANSITION Scale. If the participant had time in clinic he or she completed the rest of the questionnaires via the online Qualtrics survey. A laptop was provided to each participant to complete the survey. If a participant had difficulty reading the questions, then the research assistant read the questions out-loud to the participant. If the participant did not have time to complete the survey in clinic, they were e-mailed the survey to complete at home. After the participant completed both the orally administered scales and online survey they were mailed a \$20 gift card as a thank you.

Phone Recruitment. The procedure for phone recruitment followed the same protocol as clinic recruitment. After the research assistant read the IRB-approved protocol over the phone and the participant agreed, the research assistant signed the consent form as "consented over the

phone.” All participants recruited over the phone had the link to the online survey e-mailed to them.

Data Analysis

Data were analyzed using the statistics program SPSS (Statistical Packages for the Social Sciences, PASW Statistics 18, 2009). Participant demographics were calculated using frequencies and descriptive statistics. The relationship between each demographic factor, psychosocial factor, and the outcome variables (UNC TR_xANSITION scale scores and STAR_x Questionnaire scores) was determined. Pearson correlations were used to evaluate the relationship between continuous variables, and t-tests were used to evaluate the relationship between the dichotomous variables (e.g. gender) and outcomes. ANOVAs were used to evaluate the relationship between categorical variables (e.g. race) and the outcomes. Chi-square tests were used to evaluate the relationship between dichotomous and categorical variables (e.g. gender and race). The regression model was built using variables that had a significant relationship with the outcome variable. To examine the overall relationship between psychosocial factors and transition readiness/self-management, the variables that had significant relationships with the outcome variables were entered into a hierarchical multiple regression. Additional demographic factors were added to the model if they were supported by previous literature as control variables, even if no significant relationship was found with the outcome variable. Two hierarchical multiple regressions were conducted, one with the UNC TR_xANSITION scale as the outcome measuring provider-assessed transition readiness/self-management and one with the STAR_x Questionnaire as the outcome measuring self-reported transition readiness/self-management. For each regression model, demographic factors that were significantly associated with transition readiness/self-management were entered first as controls. Then, the psychosocial

factors that were significantly correlated with the outcome were entered into the model, with the factors that showed the strongest correlation entered in first.

CHAPTER 3: RESULTS

Participant Characteristics

After removing all participants that did not have complete data from the sample, 143 participants were included in the final sample (Table 1). There were 57 males (39.9%) and 86 females (60.1%); 42.7% of the sample was Caucasian, 41.3% was African American, and 11.9% was Hispanic. Insurance was used as a proxy for the socioeconomic status of the participants; 37.1% had private insurance and 47.6% had public insurance. Diagnoses of the participants included glomerular disease, non-glomerular disease, systemic lupus erythematosus (SLE), kidney transplant, and dialysis. The most prevalent diagnoses in this sample were post-kidney transplant (34.3%), glomerular disease (30.1%), and SLE (15.4%). The mean age of the sample was 20.57 years (± 5.46 years) and mean age at diagnosis was 11.05 years (± 8.17 years). The age of participants ranged from 12 to 31 years and age at diagnosis ranged from 0 to 28 years. For CKD stage, 22.4% of participants were classified as stage 2, 20.3% stage 3, 9.8% stage 4, and 47.6% stage 5.

Frequencies and Descriptives of Psychosocial Factors and Outcomes

The frequencies and mean scores of the psychosocial predictors used in analysis are presented in Table 2. Scores on the CES-D ranged from 0 to 27, with a mean of 7.43 (± 5.60). In the sample, 36 participants (25.2%) had scores above 11, indicating significant or mild depressive symptomatology. The mean score on the Family Functioning Index was 7.62 (± 1.57), with scores ranging from 2 to 9. Two scores were calculated from the Social Support Questionnaire. The SSQ Number Score represents the quantity of individual's social support.

SSQ Number Scores ranged from 0 to 9, with a mean of 5.32 (± 2.52). The SSQ Satisfaction Score represents the quality of an individual's social support. SSQ Satisfaction Scores ranged from 1 to 7, with a mean of 6.09 (± 1.53). For the PedsQL, the physical functioning scores ranged from 6.25 to 100, with a mean 73.47 (± 21.28), and the school functioning scores ranged from 0 to 100, with a mean of 64.65 (± 20.27).

Mean scores were also determined for the outcomes used in the analysis (Table 2). The mean score on the UNC TR_xANSITION scale was 4.97 (± 1.33), with a range of 1.63 to 6.88, indicating overall high rates of provider-assessed transition readiness. Scores on the STAR_x Questionnaire ranged from 24 to 73, with a mean of 57.15 (± 10.11), which is typical of the mean score for 75th percentile on the scale for this age group, indicating that this sample had high rates of self-reported transition readiness (Cohen et al., under review). The correlations between psychosocial factors and outcomes can be found in Table 3.

Intrapersonal Functional Domain

Greater disease severity was not associated with lower transition readiness/self-management. Thus, in the Health and Biomedical Area of the model, there was no relationship between CKD stage and transition readiness/self-management.

For the Psychological Area of this domain, a significant positive correlation was found between depressive symptoms and transition readiness/self-management assessed by the UNC TR_xANSITION scale. Interestingly, it was found that more depressive symptoms correlated with higher transition readiness/self-management ($r=.210$, $p=.012$).

Interpersonal Functional Domain

For the Family and Marital Area, a significant positive correlation was found between family functioning and transition readiness/self-management. Higher scores on the Family

Relationship Index correlated with higher scores on the STAR_x Questionnaire ($r=.296$, $p=.000$). Thus, better family functioning correlated with higher transition readiness/self-management.

Significant positive correlations were found in the Peer and Social Relations Area between social support and transition readiness/self-management. Higher SSQ Number scores correlated with higher scores on the UNC TR_xANSITION scale ($r=.234$, $p=.005$). This indicates that higher quantities of social support correlate with better transition readiness/self-management. SSQ Satisfaction scores correlated with the STAR_x Questionnaire, such that better quality social support correlated with higher transition readiness/self-management ($r=.178$, $p=.034$).

Extrapersonal Functional Domain

No significant relationships were found between the School Area and transition readiness/self-management. However, it is important to note there was a trend towards significance for higher academic quality of life correlating with higher transition readiness/self-management, as measured by the STAR_x Questionnaire ($r=.158$, $p=.061$).

For the Recreational Area of this domain, no significant relationships were found; no significant correlations were found between participation in leisure activities and transition readiness/self-management.

Overall Model

Two regression models were evaluated based on the demographic variables and psychosocial variables that displayed significant relationships with each measure of transition readiness/self-management. The regression models were built using variables that had a significant relationship with the outcome variables and demographic factors that were supported by previous studies as control variables.

Provider-Assessed Transition Readiness/Self-Management. Significant relationships between the total TR_xANSITION scale score and demographic variables were found including age ($r=.578$, $p=.000$), age at diagnosis ($r=.264$, $p=.001$), and health literacy ($r=.457$, $p=.000$). Females ($M = 4.60$, $SD = 1.42$) also scored higher than males ($M = 5.21$, $SD = 1.22$), $t(141)=-2.746$, $p=.007$). Though insurance did not display a significant relationship with the UNC TR_xANSITION scale, this variable was added to the model to serve as a control for socioeconomic status. Previous studies indicate health and transition outcome disparities as a result of socioeconomic status or insurance in individuals with CKD (Andreoni et al., 2013; Javalkar, Fenton, Cohen, & Ferris, 2014). Thus, the aforementioned demographic variables, along with depressive symptoms and quantitative social support were included in the hierarchical multiple regression.

Results of the final model for provider-assessed transition readiness/self-management are presented in Table 4. In step 1, demographic variables accounted for 44.2% of the variance in TR_xANSITION scores ($p=.006$). In step 2, social support accounted for an additional 0.8% of the variance ($p=.012$). In step 3, depressive symptoms accounted for an additional 0.8% of the variance ($p=.002$). All together, age, sex, age at diagnosis, health literacy, insurance, quantitative social support, and depressive symptoms explained 45.9% of the variance in UNC TR_xANSITION scale scores ($p=.002$). The conceptual model for this outcome can be found in Figure 2.

Self-Reported Transition Readiness/Self-Management. Age and health literacy correlated with the STAR_x total score, such that older age ($r=.281$, $p=.001$) and better health literacy ($r=.168$, $p=.045$) correlated with higher transition readiness. Additional control variables of sex, age at diagnosis, and insurance were added to the hierarchical regression in order to keep

the same controls as the provider-assessed model. Thus, age, healthy literacy, sex, age at diagnosis, insurance, along with qualitative social support and family functioning were included in the regression for self-reported transition readiness/self-management.

Results of the final model for self-reported transition readiness/self-management are reported in Table 5. In step 1, the demographic variables accounted for 11.1% of the variance ($p=.000$). In step 2, family functioning accounted for an additional 5.7% of the variance ($p=.000$). In step 3, qualitative social support accounted for an additional 0.6% of the variance. All together, age, sex, age at diagnosis, health literacy, insurance, family functioning, and qualitative social support accounted for 17.3% of the variance in scores on the STAR_x Questionnaire ($p=.000$). The conceptual model for this outcome can be found in Figure 3.

CHAPTER 4: DISCUSSION

This study examined the role of psychosocial factors in healthcare transition for adolescents and young adults with CKD. Overall, the results highlight the importance of family functioning and social support to transition readiness and self-management. When examining transition readiness/self-management as assessed by a provider, both more depressive symptoms and social support, along with the demographic characteristics of older age, being female, older age at diagnosis, and higher health literacy play a role in how prepared an adolescent or young adult with CKD is to transition to adult healthcare and self-manage their condition. For transition readiness/self-management that is self-reported, better family functioning, higher quality social support, older age, and higher health literacy play a role.

Intrapersonal Functional Domain

Though studies in other populations of youth with chronic illnesses suggest that disease severity plays a role in self-management, in the present study, disease severity was not associated with transition readiness/self-management. A similar study that specifically examined socioecologic factors in relation to transition readiness in youth with CKD also found that disease severity did not play a role (Javalkar et al., 2014). In a smaller sample of adolescents and young adults with CKD, neither percentage of life with disease or the total number of prescribed medicines was related to transition readiness or disease self-management (Javalkar et al., 2014). These findings from Javalkar and colleagues (2014), along with the present study's findings contrast the available literature that complex care regimens negatively impact self-management (Sevick et al., 2007). Specifically for CKD, as the disease progresses, there is typically an

increase in medications, diet restrictions, and complexity of the healthcare regimen. One explanation for the present study's finding is that these measures of disease severity were objective rather than subjective. It has been noted in other youth with chronic illnesses that greater perceived regimen complexity decreases self-management and adherence (Schurman, Cushing, Carpenter, & Christenson, 2011). Thus, for adolescents and young adults with CKD it may be more important to have an understanding of their perception of their disease severity and healthcare regimen when assessing transition readiness and self-management. Even if patients are in CKD stage 5, if they do not perceive their treatment regimen as complex, then they may be able to better self-manage their disease and be more prepared for transition. This factor of perception of disease severity should be collected and evaluated in future studies for adolescents and young adults with CKD.

It was interesting to note that more depressive symptoms were significantly associated with better transition readiness and self-management when rated by a provider. This finding was opposite of the initial proposed hypothesis that more depressive symptoms would correlate with lower transition readiness/self-management. These results contrast the available literature on the relationship between depression and self-management for individuals with chronic illness. For example, Gonzalez and colleagues (2007) found that individuals with diabetes and depression had worse self-care and medication adherence. However, one available study on psychological distress and adherence in adolescent renal transplant recipients parallels the present study's results. In a small cohort of adolescents with renal transplants, no relationship was found between depression and risk for nonadherence with medication (Penkower et al., 2003). Rather than depressive symptoms influencing nonadherence, Penkower and colleagues (2003) found that adolescents with anger were more likely to be nonadherent. Thus, for adolescents and young

adults with CKD, it may be that anger is the key psychological factor in creating a barrier to adherence and self-management, rather than depression. Patients who are angry may be more resistant to accepting their condition and learning to self-manage. No measures of anger were included in the present study, so in future research it would be important to include this construct to compare to measures of depression.

Nonetheless, investigation of the positive relationship between depression and self-management in this cohort is still warranted because very few studies on psychological functioning in individuals with and without chronic health conditions correlate depression with positive outcomes. One possible explanation for this finding may be that individuals with depression may be able to cope with life difficulties in the long-term after recovery (Spijker, 2004). Findings from The Netherlands Mental Health Survey and Incidence Study (NEMESIS) suggest that after symptomatic recovery, there can be improvements in daily activities and work, especially as recovery time increases (Spijker, 2004). While this does not account for the participants in this study that were still reporting a high number of depressive symptoms, this may suggest that the patients in this study with co-occurring depression were starting to experience resiliency. Resiliency can strengthen adaptation to chronic illness (Kralik, Van Loon, & Visentin, 2006). Individuals who are able to reflect and interpret their experience with chronic illness are more likely to be resilient and develop a stronger sense of self-worth (Kralik, 2006). Thus, it is possible that participants in this study reporting higher amounts of depressive symptoms had the opportunity to discuss this experience with a mental health professional if they were receiving treatment. In future studies it would be helpful to collect information on engagement in mental health treatment and resiliency, to determine if these may mediate the existing relationship between depression and transition readiness/self-management.

Further investigation into this study's finding also revealed that the highest scoring items on the CES-D were those related to physical symptoms (Figure 4). On the CES-D scale (Appendix 6), item 2, "I felt that everything I did was an effort," item 4, "My sleep was restless," and item 11 "I could not get "going"" had the highest average scores. These items tap into the physiological symptoms of depression that are also the symptoms associated with kidney disease. Thus, because these items are related to physical symptoms and patients with CKD typically experience many physical symptoms, it might be that participants were rating these items higher not because they were depressed, but because they have kidney disease. Patients that have better self-management skills might be more attuned to the physical symptoms of their disease, which may have caused them to rate these items higher, thus accounting for the overall trend that patients with more depressive symptoms have better transition readiness/self-management skills. In future studies more objective measures of psychological functioning should be used, such as diagnoses given by a mental health provider, or measures that do not include physical symptoms, in order to further examine this finding.

Interpersonal Functional Domain

Overall it seems that the interpersonal domain of adaptation to chronic illness (Livneh, 2001) plays a critical role in how adolescents and young adults with CKD are prepared to transition to adult care or self-manage their disease. Both hypotheses in this domain were supported, such that individuals with better family functioning and higher quality social support had higher self-reported transition readiness/self-management, and those with higher quantities of social support had higher transition readiness/self-management as assessed by the provider.

The hypothesis that individuals with better family functioning would have higher transition readiness/self-management was supported by the STAR_x Questionnaire, which

measures the outcome by self-report. This finding adds to the existing literature on the importance of family functioning and family environment on adaptation to chronic illness. More importantly, this strengthens the available literature on the role of family functioning in self-management. This is the first study to investigate the role of family functioning in preparation for transition readiness and self-management in youth with CKD. Healthcare professionals should take this factor into consideration when working with adolescents and young adults with CKD, as it may play a critical role in the health outcomes of their patients. If a patient is at risk for poor family functioning, it is important for the healthcare provider to make referrals to mental health professionals or provide interventions and additional support during the transition process to ensure these patients are prepared. If family functioning is not addressed and there is a poor transition to adult healthcare and lack of self-management skills, then patients are at risk for negative health outcomes, as documented by previous research (Watson, 2005).

It was also found that participants with more social support had higher transition readiness as assessed by both the UNC TR_xANSITION scale and STAR_x Questionnaire. Patients with higher levels of social support had higher provider-assessed transition readiness/self-management. Similarly, patients with higher-rated quality of social support had higher self-reported transition readiness/self-management. DiMatteo (2004) highlights how different forms of social support play a role in adherence to medical treatment. Practical social support is consistently associated with greater medication adherence (DiMatteo, 2004; Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012). Though emotional support has also been found to play a role in adherence to treatment, the results are not as compelling as for practical support (DiMatteo, 2004; Scheurer et al., 2012). Thus, while both types of social support in this study seemed to play a role in transition readiness/self-management, it may be more important to take into

consideration a patient's available practical support. Nonetheless, healthcare providers should also examine their patients' social support network in order to provide appropriate interventions or extra support with patients who are at risk for poor transition readiness/self-management.

Extrapersonal Functional Domain

Neither of the factors from the extrapersonal domain (academic and physical quality of life) were related to either measure of transition readiness/self-management in adolescents and young adults with CKD. It may be that the selected measures did not accurately represent the constructs as described by Livneh (2001). In future studies the relationship of overall quality of life should be examined, as that has been identified as one of the most impaired outcomes for adolescents and young adults with chronic illness. Furthermore, it may be that rather than academic and physical quality of life impacting transition readiness/self-management, that transition readiness/self-management impacts academic and physical quality of life. Youth with CKD are at risk for poor school functioning because of the complexities of medical care and frequency of medical visits that may interfere with school attendance, and possible impairments in attention or cognitive functioning that develop as kidney function deteriorates (Gerson et al., 2010). Additionally as the disease progresses, physical functioning and quality of life decline (Gerson et al., 2010). Adolescents and young adults who are able to properly self-manage their condition may be able to help prevent a decline in their health status, and subsequently maintain more optimal school and physical quality of life. Though these factors did not predict better transition readiness/self-management in this cohort, it is still important to assess for these factors with youth with CKD. Even though other factors were identified as significantly related to the outcomes, it is important to take a holistic approach and consider all of the intrapersonal, interpersonal, and extrapersonal factors for each individual.

Overall Model

Two models for the role of psychosocial factors in transition readiness/self-management were identified in this study. When providers are assessing transition readiness/self-management, older age, being a female, older age at diagnosis, more depressive symptoms, and more social support may all play a role in outcomes for adolescents and young adults with CKD.

Demographic factors played a much larger role in the model for provider assessed-transition readiness when compared to the readiness assessed by self-report. Older patients, females, patients with an older age at diagnosis, and patients with higher health literacy had higher provider-assessed transition readiness and self-management. These findings parallel those found in previous research on the role of socioecologic factors in transition readiness for youth with CKD (Javalkar et al., 2014). These demographic factors, along with more depressive symptoms and higher quantities of social support played a role in transition readiness/self-management assessed by the provider for this cohort. These results identify risk factors for poor transition readiness/self-management in youth with CKD and can help guide interventions to improve these outcomes.

When assessing transition readiness/self-management by self-report, older age, higher health literacy, better family functioning, and higher quality of social support played a role. Age was also an individual predictor of transition readiness in both models. This highlights a natural progression in skills that patients with CKD may experience, as they get older. However, in the future it would be important to understand factors that may impact or inhibit this natural progression. Clearly, family functioning plays a role in this process, as it was both an individual predictor and part of the model that predicted transition readiness/self-management outcomes. The influence of family functioning in this model furthers the literature on the role of this factor

in self-management for youth with chronic conditions. Additionally, this is a novel finding for adolescents and young adults with CKD. Future transition readiness/self-management interventions should target family functioning, as literature in other youth chronic illness populations suggests that optimal family functioning can improve self-management and quality of life (Whittemore, 2014).

It was interesting to note that though scores on both outcome scales were highly correlated, there were different predictors that significantly correlated with each scale. Overall it is clear that there is a natural age progression with transition readiness and self-management skills, because in both scales the scores increased with age. However, differences were noted both for sex and age at diagnosis for the provider-assessed scale. It is possible that there may be a gender bias when providers are rating their patients' transition readiness and self-management scales, as this difference was not found in the self-reported scale. This reflects some available literature on gender bias in treating individuals with chronic illness (Beery, 1995; Chapman, Tashkin, & Pye, 2001). It may be important for providers working with transition-age youth to consider their own personal biases when assisting with building self-management skills and preparing for transition. Age at diagnosis was also only correlated with provider-assessed transition readiness. Patients with an older age of diagnosis may be less dependent on their parents because they have not needed to be cared for their entire life. This may also cause bias within the providers to assume that a patient has better transition readiness and self-management skills if the parents have not been as involved for many years. Age at diagnosis should be taken into consideration when planning interventions and preparing youth with CKD for transition, as to not bias the treatment that is provided.

Though social support was a significant predictor of transition readiness and self-management for both scales, depressive symptoms and family functioning were correlated with only one of the scales. If a provider is assessing transition readiness and self-management, more depressive symptoms are correlated with better preparation and skills. It may be that the provider feels sympathy if the patient is experiencing depressive symptoms, and subsequently rates the patient higher in transition readiness and self-management skills. The provider may also be more motivated to work and improve skills for patients that are having more psychological difficulties associated with their condition. Psychological functioning should be taken into account when working with transition-age youth, but all patients should be supported and provided sufficient education in order to be prepared for transition and fully develop their self-management skills.

Another interesting difference between the two models was that the variables in the model for provider-assessed transition readiness/self-management accounted for a much greater percentage of variance in scores than those in the self-reported model. Demographic factors in the model examining provider-assessed transition readiness accounted for over 40% of the variance, while all of the variables in the self-reported model, both demographic and psychosocial, only added up to 17.3%. This further demonstrates a potential bias within providers when working with adolescents and young adults with CKD. Providers may tend to rate their patients higher if they are older in age, female, were diagnosed at an older age, or have better health literacy. This highlights a need for further examination and future studies to understand the etiology of these discrepancies.

Limitations

Though this study identified key factors that play a role in transition readiness and self-management for adolescents and young adults with CKD, there are several limitations to the

study. Aside from the UNC TR_xANSITION scale, all measures were collected through self-report. While this could promote participants to be more honest with their answers, this could also bias the results because they are subjective. In the future, more objective measures could be utilized to solidify these findings. Furthermore, it is important to collect objective measures of health outcomes, such as lab results, in order to certify the effect poor transition readiness/self-management can have on the health outcomes in adolescents and young adults with CKD. The sample was also collected from one site, which reduces the generalizability of the study. However, the participant characteristics are representative of the population of adolescents and young adults with CKD throughout the United States. Furthermore, the participants resided across all parts of the state of North Carolina. In the future it would be important to collect data from different geographic regions of the country to increase the validity of these novel findings.

Future Directions

Future research on this topic should examine the specific health outcomes related to transition readiness and self-management in adolescents and young adults with CKD. Though many factors were identified as playing a role in this process, it is important to understand what the subsequent health outcomes may be for patients with CKD that have lower transition readiness and self-management. Along with this, experimental and intervention studies are needed to examine the impact of transition preparation and self-management on the skills of youth with CKD. Future studies should also examine the differences between the pediatric and adult population. Though a strength of this study was the ability to generalize across all youth with CKD in the transition age-range, it is important to discern these outcomes within a more specific age-range. Comparing the pediatric and adult populations will provide insight to help create more targeted interventions.

CHAPTER 5: CONCLUSIONS

This study examined the role of psychosocial factors in healthcare transition for adolescents and young adults with CKD. The model of adaptation to chronic illness proposed by Livneh and Antonak (2001) guided the proposed hypotheses. The results showed that social support and family functioning play a significant role in healthcare transition and self-management for adolescents and young adults with CKD. These factors should be assessed with all youth with CKD in order to guide interventions to improve transition readiness/self-management. Improving these psychosocial outcomes may in turn increase transition readiness and self-management, subsequently increasing positive health outcomes.

TABLES

Table 1

<i>Participant Characteristics</i>			
Variable	N	Range	Mean \pm SD
<i>Age</i>	143	12 – 31	20.50 \pm 5.46
<i>Age of Diagnosis</i>	143	0 – 28	11.08 \pm 8.14
Variable	N	Percentage	
<i>Sex</i>			
Male	57	39.9	
Female	86	60.1	
<i>Race</i>			
Caucasian	61	42.7	
African American	59	41.3	
Hispanic	17	11.9	
Other	3	2.1	
Native American	2	1.4	
Asian	1	0.7	
<i>Insurance</i>			
Public	68	47.6	
Private	53	37.1	
Private and Public	13	9.1	
None	9	6.3	
<i>Diagnosis</i>			
Kidney Transplant	49	34.3	
Glomerular Disease	43	30.1	
SLE	22	15.4	
Dialysis	10	7.0	
<i>CKD Stage</i>			
2	32	22.4	
3	29	20.3	
4	14	9.8	
5	68	47.6	

Table 2

Frequencies and Descriptive Statistics of Psychosocial Factors and Outcomes

Variable	N	Range	Mean \pm SD
<i>Depressive Symptoms</i>	143	0 – 27	7.43 \pm 5.60
<i>Family Functioning</i>	143	2 – 9	7.62 \pm 1.57
<i>Social Support Quantity</i>	143	0 – 9	5.32 \pm 2.52
<i>Social Support Quality</i>	143	1 – 7	6.09 \pm 1.53
<i>Academic Quality of Life</i>	143	0 – 100	64.65 \pm 20.27
<i>Physical Quality of Life</i>	143	6.25 – 100	73.47 \pm 21.28
<i>TR_xANSITION Scale Total</i>	143	1.63 – 6.88	4.97 \pm 1.33
<i>STAR_x Questionnaire Total</i>	143	24 – 73	57.15 \pm 10.11

Table 3

Correlations Among Variables

Variable	T-scale	STAR _x	Age	Age at D _x	Depression	Family	SSQN	SSQS	Academic QOL	Physical QOL
T-scale	--									
STAR _x	.371 ^{***}	--								
Age	.578 ^{***}	.281 ^{**}	--							
Age at D _x	.264 ^{**}	.069	.283 ^{**}	--						
Depression	.210 [*]	-.133	.210 [*]	.133	--					
Family	.159	.296 ^{***}	.165 [*]	.123	-.328 ^{***}	--				
SSQN	.234 ^{**}	.111	.142	.115	-.115	.162	--			
SSQS	.037	.178 [*]	-.055	-.107	-.146	.323 ^{***}	.183 [*]	--		
Academic QOL	.000	.158	.098	-.108	-.428 ^{***}	.253 ^{**}	.027	.078	--	
Physical QOL	-.102	.119	-.230 ^{**}	-.083	-.422 ^{***}	.090	.078	.071	.511 ^{***}	--

Notes. T-scale, UNC TR_xANSITION Scale; STAR_x, STAR_x Questionnaire; Age at D_x, Age at Diagnosis; Depression, Depressive Symptoms; Family, Family Functioning; SSQN, Social Support Quantity; SSQS, Social Support Quality; QOL, Quality of Life.

*p < .05, **p < .01, ***p < .001.

Table 4

Hierarchical Multiple Regression Analysis of Provider-Assessed Transition Readiness/Self-Management

Variable	β	p	Cumulative R^2	ΔR^2
Step 1			.442	.442
Age	.438	.000		
Sex	.106	.105		
Age at Diagnosis	.047	.485		
Insurance	-.044	.507		
Health Literacy	.262	.000		
Step 2			.451	.008
Social Support	.110	.102		
Step 3			.459	.008
Depressive Symptoms	.096	.153		

Notes. $F(7,135) = 16.373$, $p = .000$. Social support in this model was defined as the quantity of social support.

Table 5

Hierarchical Multiple Regression Analysis of Self-Reported Transition Readiness/Self-Management

Variable	β	p	Cumulative R^2	ΔR^2
Step 1			.111	.111
Age	.239	.006		
Sex	.073	.365		
Age at Diagnosis	-.032	.702		
Insurance	-.095	.245		
Health Literacy	.044	.613		
Step 2			.167	.057
Family Functioning	.215	.012		
Step 3			.173	.006
Social Support	.086	.323		

Notes. $F(7,135) = 4.042$, $p = .000$. Social support in this model was defined as the quality of social support.

FIGURES AND CAPTIONS

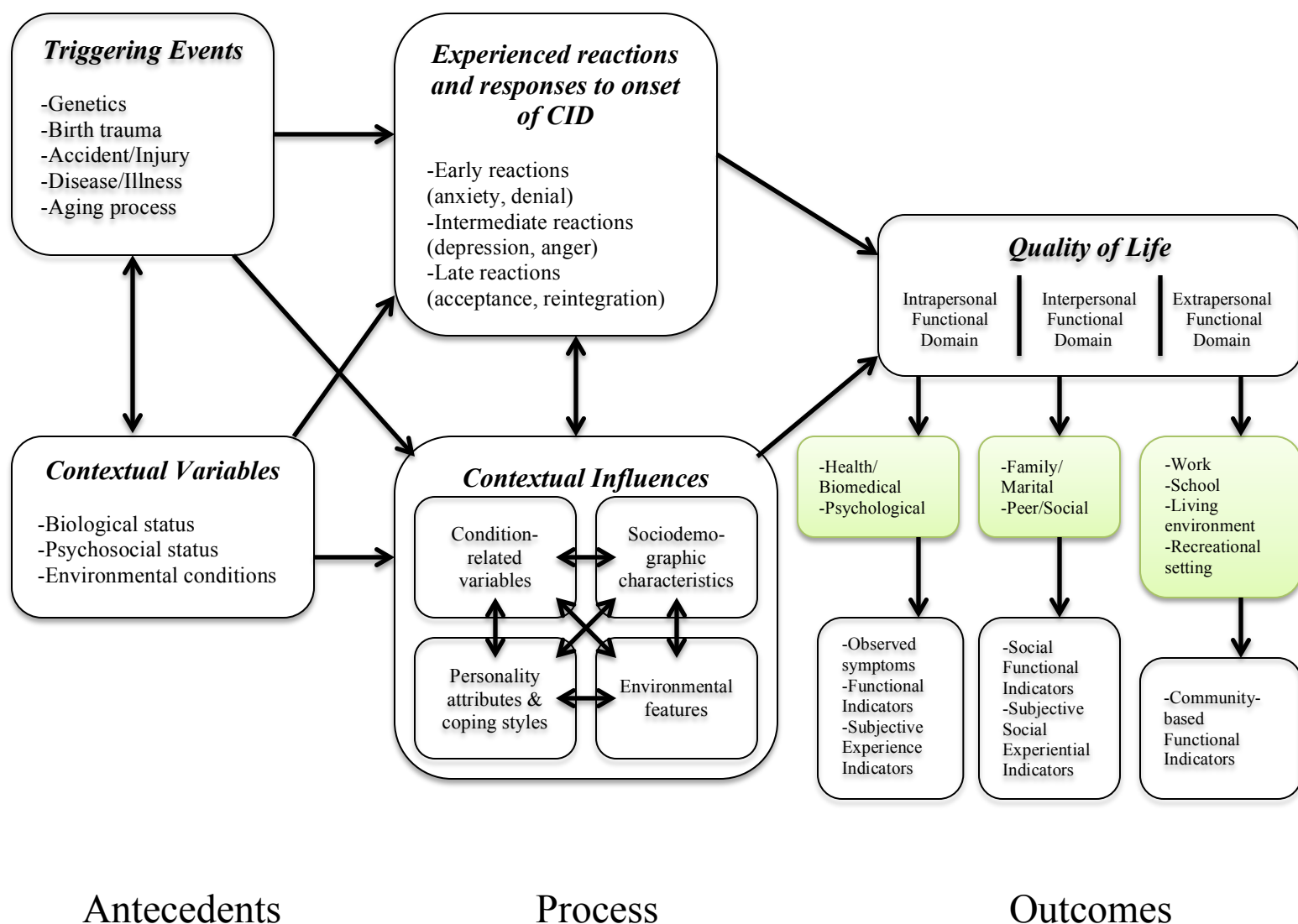


Figure 1. A model depicting the structure, content, and process of psychosocial adaptation to CID (Livneh, 2001).

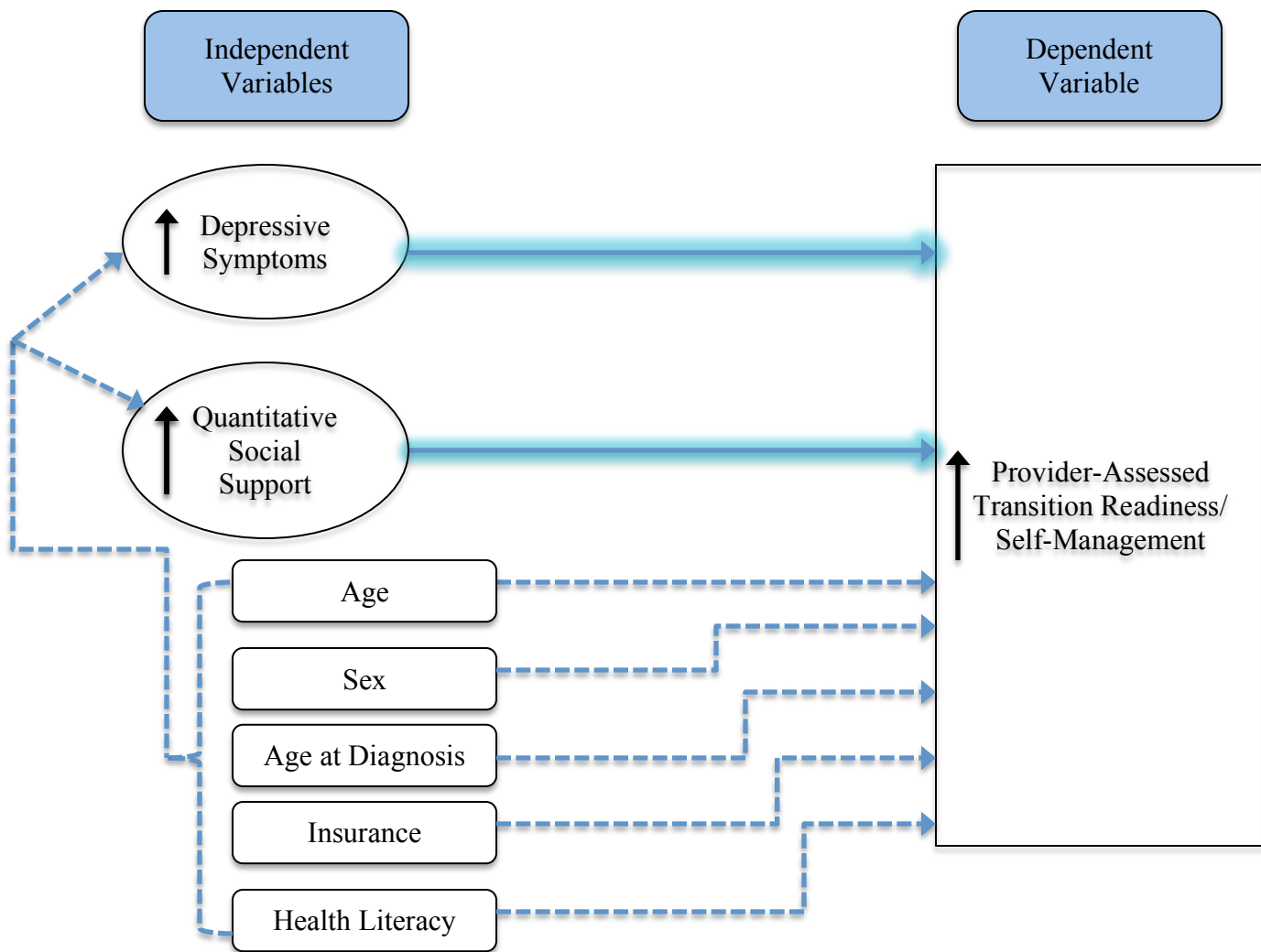


Figure 2. Conceptual model of the relationship between psychosocial factors and provider-assessed transition readiness/self-management.

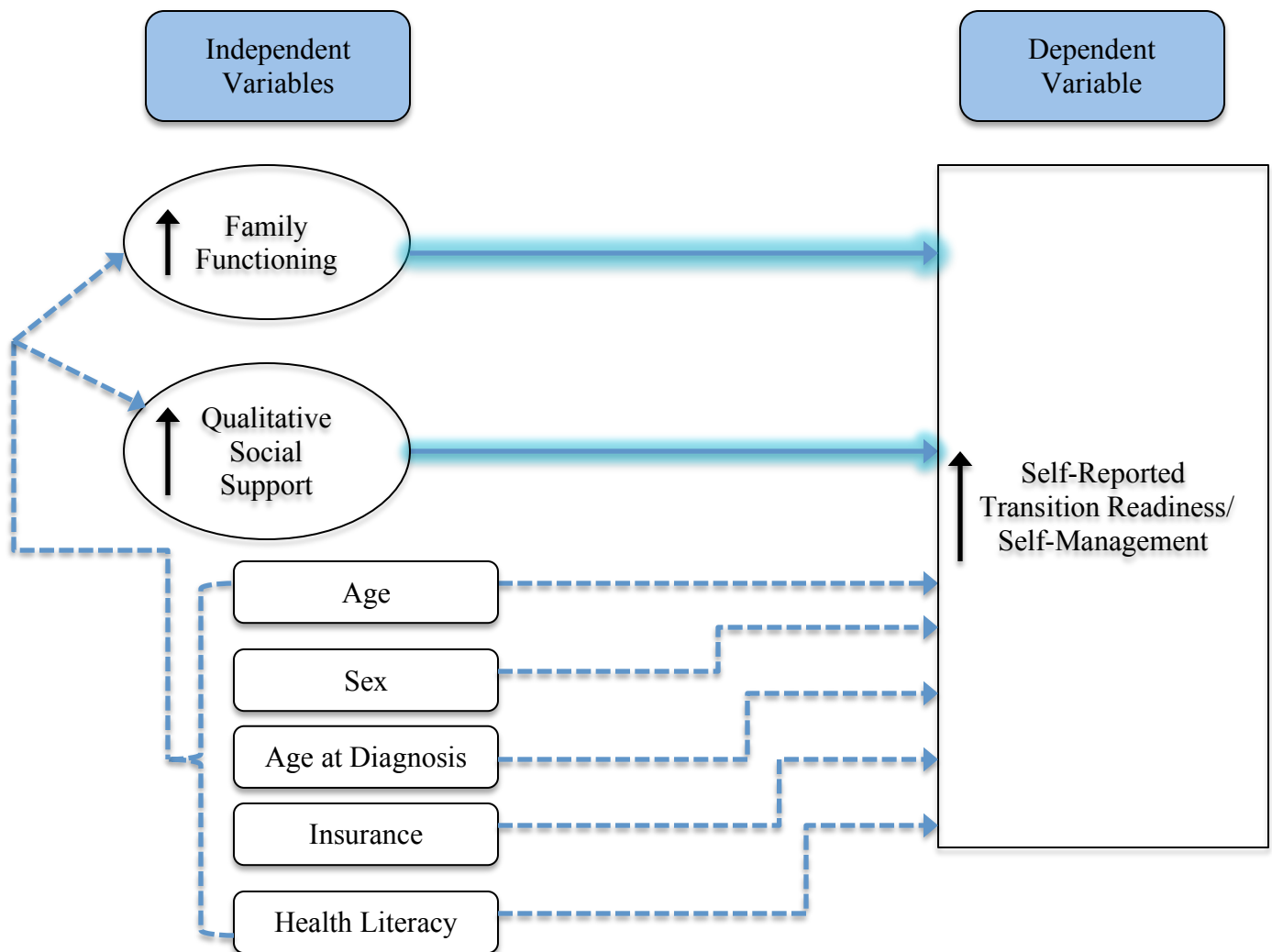


Figure 3. Conceptual model of the relationship between psychosocial factors and self-reported transition readiness/self-management.

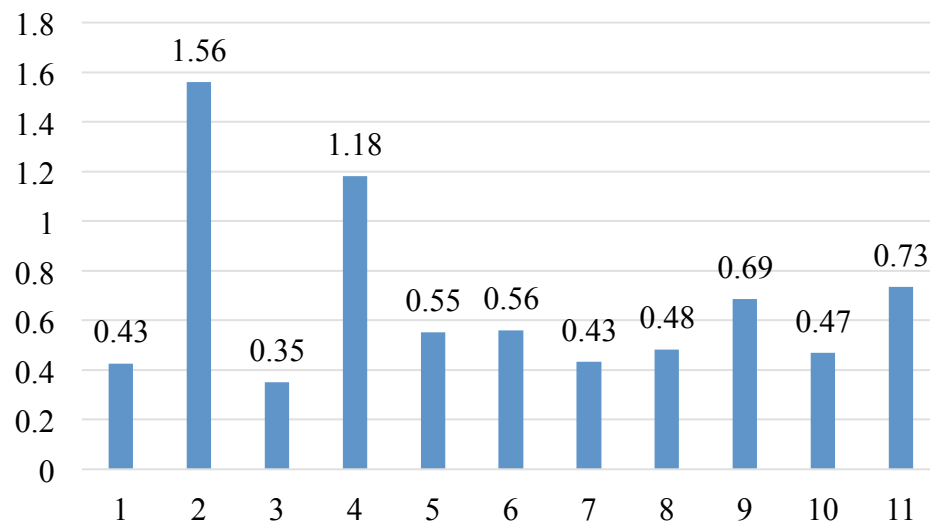


Figure 4. Mean score by item on the CES-D scale.

APPENDIX 1: DEMOGRAPHICS QUESTIONNAIRE

Grant Info sheet

Study ID: _____

Name: _____

DOB (mm/dd/yyyy): _____

Sex: _____

Race: _____

Address: _____

Phone: _____

Email: _____

APPENDIX 2: ONLINE DEMOGRAPHICS QUESTIONS

At what age were you diagnosed with kidney disease?

What type of health insurance do you have?

- ☐ Private (Blue Cross Blue Shield, TriCare, etc.)
- ☐ Public (Medicaid, Medicare, etc.)
- ☐ Private and public
- ☐ Other insurance
- ☐ Self-pay (no insurance)
- ☐ Don't know

APPENDIX 3: THE NEWEST VITAL SIGN



Unified Health Communication:
Addressing Health Literacy, Cultural Competency, and Limited English Proficiency



Job Aid

The Newest Vital Sign Assessment

Nutrition Facts			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
			%DV
Total Fat	13g		20%
Sat Fat	9g		40%
Cholesterol	28mg		12%
Sodium	55mg		2%
Total Carbohydrate	30g		12%
Dietary Fiber	2g		
Sugars	23g		
Protein	4g		8%
*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.			
Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.			

The content for this material was excerpted from *The Newest Vital Sign—A Health Literacy Assessment Tool* website available at: <http://www.newestvitalsign.org/nvs-resources.aspx>

The views expressed in these documents, Web sites, or other products do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

APPENDIX 4: THE 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]?	1.0	0.5	0.0
3	How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
Sum the scores for this section		Subtotal T	____ out of 3	
Divide the subtotal by the number of applicable questions		Proportion T		

R _x : Medications		Can name all	Can name some	Cannot name any	N/A
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	<input type="checkbox"/>
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	<input type="checkbox"/>
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	
Sum the scores for this section		Subtotal R _x	____ out of ____		
Divide the subtotal by the number of applicable questions		Proportion R _x			

This form has been approved by the IRB for use between 02/23/2012 and 02/21/2013

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.
Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09

Adherence

		Yes	Sometimes	No	N/A
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	
Sum the scores for this section		Subtotal A		___ out of ___	
Divide the subtotal by the number of applicable questions		Proportion A			

Nutrition

		Knows definitely	Has an idea	Does not know	
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	[if the patient is on a special diet] 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
Sum the scores for this section		Subtotal N		___ out of ___	
Divide the subtotal by the number of applicable questions		Proportion N			

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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?) <input type="checkbox"/>	1.0	0.5	0.0	
Sum the scores for this section		Subtotal S		____ out of ____	
Divide the subtotal by the number of applicable questions		Proportion S			

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? <i>[If male]</i> get someone pregnant?	1.0	0.5	0.0	
22	<i>[Females only]</i> What are risks you might face if/when you become pregnant because you have [name of health condition]?	1.0	0.5	0.0	N/A
23	<i>[Females only]</i> Do you take any medicines that would be harmful to an unborn baby if you became pregnant? <input type="checkbox"/>	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STD's?	1.0	0.5	0.0	
Sum the scores for this section		Subtotal I			
		Male		____ out of 2	
		Female		____ out of 4	
Divide the subtotal by the number of applicable questions		Proportion I			

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Trade / School

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

Insurance

		Knows definitely	Has an idea	Does not know	
26	What is health insurance and why is it important to have?	1.0	0.5	0.0	
27	What is the name of your current health insurance provider?	1.0	0.5	0.0	
28	[If he/she is currently insured] At what age will your current health insurance coverage end?	1.0	0.5	0.0	N/A
29	How can you get health insurance coverage for yourself when you are an adult?	1.0	0.5	0.0	
Sum the scores for this section		Subtotal I	_____ out of _____		
Divide the subtotal by the number of applicable questions		Proportion I			

Ongoing support

		Self	Parents/friends	Does not know
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 pharmacy, and make doctor appointments?	1.0	0.5	0.0
Sum the scores for this section		Subtotal O	_____ out of 1	

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New health care providers		Knows definitely	Has an idea	Does not know
31	When it comes time for you to switch to an adult doctor, how will you find one?	1.0	0.5	0.0
32	In order to get your medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0
Sum the scores for this section		Subtotal N	_____ out of 2	
Divide the subtotal by the number of applicable questions		Proportion N		

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

<http://unckidneycenter.org/hcprofessionals/transition.html>

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APPENDIX 5: THE STAR_x QUESTIONNAIRE

Site ID: _____
Patient ID: _____
Date: _____

STAR_x Transition Readiness Questionnaire

DIRECTIONS

Patients with chronic health conditions need to have special skills and do special tasks to stay healthy.

On the following pages, please check the box underneath the answers that describe you most.

If you do not understand a question, just ask for help. We're here to help you 😊

Site ID: _____
 Patient ID: _____
 Date: _____

Section 1 :

- **How often have you done the following things?**
- **Please check the box that tells how often you have done each thing in the *PAST 3 MONTHS*.**

In the past 3 months ...	Never	Almost Never	Sometimes	Almost Always	Always	Not Needed for my care
1. How often did you make an effort to understand what your doctor told you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How often did you take your medicines on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How often did you ask your doctor or nurse questions about your illness, medicines or medical care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How often did you make your own appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. How often did you need someone to remind you to take your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How often did you use the internet, books or other guides to find out more about your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. How often did you forget to take your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. How often did you work with your doctor to take care of new health problems that came up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Site ID: _____
Patient ID: _____
Date: _____

Section 2:

- **Some patients know a lot about their health and some patients don't.**
- **How much do you know?**
- **Please check the answer that best describes how much you feel you know *TODAY*.**

	Nothing	Not Much	A little	Some	A Lot	Not Needed for my care
10. How much do you know about your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. How much do you know about taking care of your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. How much do you know about what will happen if you don't take your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Site ID: _____
 Patient ID: _____
 Date: _____

Section 3:

- **Some patients may find it hard to do certain things.**
- **How easy or hard is it for you to do the following things?**
- **Please check the answer that best describes how you feel *TODAY*.**

	Very Hard	Somewhat Hard	Neither Hard nor Easy	Somewhat Easy	Very Easy	Not Needed for my care
13. How easy or hard is it to talk to your doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. How easy or hard is it to make a plan with your doctor to care for your health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. How easy or hard is it to see your doctor by yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. How easy or hard is it to take your medicines like you are supposed to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. How easy or hard is it to take care of yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. How easy or hard do you think it will be to move from pediatric to adult care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 6: CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way **during the past week.**

There are no right or wrong answers.

During the Past Week

	Rarely (less than 1 day)	Some (1-2 days)	Occasionally (3-4 days)	Most (5-7 days)
1. I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I felt that everything I did was an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My sleep was restless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I was happy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I felt lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. People were unfriendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I enjoyed life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I felt that people disliked me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I could not get "going"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX 7: FAMILY RELATIONSHIP INDEX

The following statements are about families. You are to decide which of these statements are true for your family and which are false. You may feel that some statements are true for some family members and false for others. Mark true if the statement is true for most members and false if the statement is false for most members.

1. Family members really help and support one another.

- ☐ True
- ☐ False

2. We often seem to be killing time at home.

- ☐ True
- ☐ False

3. We put a lot of energy into what we do at home.

- ☐ True
- ☐ False

4. There is a feeling of unity and togetherness in our family.

- ☐ True
- ☐ False

5. We rarely volunteer when something has to be done at home.

- ☐ True
- ☐ False

6. Family members really back each other up.

- ☐ True
- ☐ False

7. There is very little group spirit in our family.

- ☐ True
- ☐ False

8. We really get along well together.

- ☐ True
- ☐ False

9. There is plenty of time and attention for everyone in our family.

- ☐ True
- ☐ False

APPENDIX 8: SOCIAL SUPPORT QUESTIONNAIRE SHORT FORM REVISED

The following questions ask about people who provide you with help or support.

Each question has three parts.

- 1) List the initials of all the people you know, excluding yourself, who you can count on for help or support.
- 2) List the person's relationship to you.
- 3) Circle how satisfied you are with the overall support you have.

If you have no support, write in "No one," but still rate your level of satisfaction.

Who can you really count on to be dependable when you need help?

	Initial	Relationship to you
1.	<input type="text"/>	<input type="text"/>
2.	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>
5	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>
8	<input type="text"/>	<input type="text"/>
9	<input type="text"/>	<input type="text"/>

How Satisfied are you with the overall support?

- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Neutral
- ☐ Somewhat Satisfied
- ☐ Satisfied
- ☐ Very Satisfied

Whom can you really count on to care about you, regardless of what is happening to you?

	Initial	Relationship to you
1.	<input type="text"/>	<input type="text"/>
2.	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>
5	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>
8	<input type="text"/>	<input type="text"/>
9	<input type="text"/>	<input type="text"/>

How Satisfied are you with the overall support?

- ☐ Very Dissatisfied
- ☐ Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Neutral
- ☐ Somewhat Satisfied
- ☐ Satisfied
- ☐ Very Satisfied

APPENDIX 9: PEDSQL

ID#

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

APPENDIX 10: IRB APPLICATION

University of North Carolina at Chapel Hill Assent to Participate in a Research Study Minor Subjects (7-14 yrs)

Consent Form Version Date: 1/28/2014

IRB Study # 07-0352

Title of Study: Successful Transition to Adulthood with Therapeutics (STARx)

Person in charge of study: Maria Ferris

Where they work at UNC-Chapel Hill: Unc Kidney Center

Other people working on this study: Kristi Bickford, Nicole Fenton, Sarah Cohen, Karina Javalkar, Alex Phillips, Mia Lassiter, Ali Annaim

The people named above are doing a research study.

These are some things we want you to know about research studies:

Your parent needs to give permission for you to be in this study. You do not have to be in this study if you don't want to, even if your parent has already given permission.

You may stop being in the study at any time. If you decide to stop, no one will be angry or upset with you.

Sometimes good things happen to people who take part in studies, and sometimes things happen that they may not like. We will tell you more about these things below.

Why are they doing this research study?

The reason for doing this research is to learn more about how young people who have health conditions grow up to become healthy adults. We want to find out what young people do and do not know about their health. We also want to find out how having a health condition has affected other parts of your life like your friends, family, and overall happiness. This will help doctors know how to better teach other kids about their health and taking care of themselves.

Why are you being asked to be in this research study?

You are being asked to be in this study because you are a young person who has a health condition and will grow up to be an adult with a health condition one day.

How many people will take part in this study?

If you decide to be in this study, you will be one of about 750 people in this research study.

What will happen during this study?

During this study, you may be asked to answer questions asked by a researcher and/or fill out surveys on your own. These questions and surveys will help us learn how much you know and don't know about your health, medicines, and taking care of yourself. They will also tell us other information that is important in learning how to best help you. You may be asked to complete one or more surveys during your doctor appointments, but you have the option of choosing not to answer any questions that you do not want to. We may ask if it is ok to record your answers to some questions with a digital recorder. You can choose whether or not it is ok to be recorded by checking one of the lines below that best matches your

choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

This study will take place at the UNC Children's Hospital or the Ambulatory Care Clinic (ACC) and will last until you or your parent withdraws consent.

Who will be told the things we learn about you in this study?

The only people who will be told the things we learn about you in this study are your parents, your doctor, and the people listed on the first page of this form.

What are the good things that might happen?

People may have good things happen to them because they are in research studies. These are called "benefits." There is little chance you will benefit from being in this research study.

What are the bad things that might happen?

Sometimes things happen to people in research studies that may make them feel bad. These are called "risks." We do not think any bad things will happen to you if you take part in this study. You should report any problems to the researcher

Will you get any money or gifts for being in this research study?

You will not get any money or gifts for being in this research study.

Who should you ask if you have any questions?

If you have questions you should ask the people listed on the first page of this form. If you have other questions, complaints or concerns about your rights while you are in this research study you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

If you sign your name below, it means that you agree to take part in this research study.

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Date

Print your name here if you want to be in the study

Signature of Research Team Member Obtaining Assent

Date

Printed Name of Research Team Member Obtaining Assent

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