

GETTING READY TO LEAVE: TRANSITION READINESS IN ADOLESCENT KIDNEY
TRANSPLANT RECIPIENTS

by

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(Under the Direction of Ronald Blount)

ABSTRACT

Objective: To develop a measure of transition readiness and use the measure to identify factors associated with perceived readiness for transition from pediatric to adult medical care among patients participating in a multidisciplinary adolescent kidney transplant transition clinic.

Methods: The adolescent and parent completed Readiness for Transition Questionnaire (RTQ-teen; RTQ-parent) was created for use in this study to assess overall transition readiness, adolescent healthcare behavior, and familial involvement in healthcare. Participants consisted of 48 adolescent kidney transplant recipients ages 15 to 21. Thirty-two (66.7%) of the adolescents' caregivers also participated in the study. Adolescents completed the RTQ-teen and self-report measures of adherence and barriers to adherence. Parents completed the RTQ-parent. *Results:* Although highly and positively correlated with one another, there were significant differences between parent and teen report of transition readiness and adolescent responsibility with teens reporting significantly higher scores. In one set of regression models, increased adolescent responsibility and decreased parental involvement predicted significantly greater reported transition readiness. In an additional set of regression models, increased adolescent adherence factors (e.g., fewer barriers to medication taking, increased medication knowledge, calling in refills) also predicted significantly greater transition readiness. *Conclusions:* The preliminary

psychometrics of the RTQ appear to be robust. The components of the RTQ showed strong internal consistency and the construct validity of the components of the RTQ was supported by the significant relationships with other variables assessed in this investigation. As a whole, these data demonstrate that transition readiness involves more than an adolescent's age. Instead, transition readiness involves adolescents taking responsibility for their own healthcare tasks with less ongoing assistance from their parents and caregivers. Further, these data underscore the need for assessing both parent and adolescent report of transition readiness and healthcare responsibility. Additional research should begin to evaluate transitional programming to identify which clinical components are related to improvements in transition readiness, adolescent responsibility, and medical outcomes.

INDEX WORDS: Pediatric transition, Transition readiness, Adolescent transplant, Kidney transplant

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B.S., The University of Georgia, 2003

M.S., The University of Georgia, 2008

A Dissertation Submitted to the Graduate of The University of Georgia in Partial Fulfillment of
the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2010

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July 2010

ACKNOWLEDGEMENTS

I would like to thank my major professor, Dr. Ronald Blount, as well as my committee members, Dr. Cindy Suveg and Dr. Anne Shaffer, for all of their thoughtful ideas, gracious criticism, and enthusiasm for this project.

In addition, I must share my gratitude with Dr. Sandra Amaral and the Transplant Services Division of Children's Healthcare of Atlanta. Thank you so much for allowing me access to your patients and for your financial support of this project.

I would also like to thank the other hands who have helped facilitate this endeavor along the way: Dr. Laura Mee, Megan McCormick, Rochelle Schmidt, and Margo Kamel.

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	iv
LIST OF TABLES.....	vi
CHAPTER	
1 INTRODUCTION	1
Adolescent Healthcare Responsibility.....	2
Parental Involvement.....	4
Measuring Transition Readiness	5
2 METHOD.....	8
Participants and Settings	8
Procedures	9
Instruments	10
3 RESULTS	16
Overview	16
Preliminary Analyses	16
Teen and Parent Between Reporter Analyses	17
Evaluation of the Developmental Transitional Model: RTQ Overall Transition Readiness.....	18
Transition Readiness: Adherence and Psychosocial Analyses.....	19
4 DISCUSSION.....	22
REFERENCES	28

LIST OF TABLES

	Page
Table 1: <i>RTQ Correlates of Teen and Parent Report of Transition Readiness</i>	33
Table 2: <i>Hierarchical Regression of Transition Readiness: Adolescent Responsibility and Parental Involvement</i>	34
Table 3: <i>Healthcare Behavior Correlates of Transition Readiness</i>	35
Table 4: <i>Hierarchical Regression of Teen Report of Transition Readiness: Adherence Behaviors and Teen-Parent Relationship</i>	36
Table 5: <i>Hierarchical Regression of Parent Report of Transition Readiness: Healthcare Adherence Behavior</i>	37

CHAPTER 1

INTRODUCTION

Pediatric transplant recipients are now living longer than in the past due to improved immunosuppression regimens and better allograft survival. As a result, these pediatric patients are surviving into late adolescence and young adulthood. In the past decade, the number of adolescent kidney transplant recipients aged 11-17 years old has increased 35% (Magee, Krishnan, Benfield, Hsu, & Shneider, 2008). The transition of medical care from pediatric to adult care providers is thus a growing area of clinical concern for transplant recipients and healthcare providers. Transition has been defined by the Society of Adolescent Medicine as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al., 1993). Transition has been conceptualized in the literature as both a process and an event (Annunziato et al., 2007; McDonagh, 2005; Rodrigue & Zelikovsky, 2009; While et al., 2004); the process necessitates gradual, increased healthcare responsibility being turned over from the parent to the adolescent, while the event occurs when the patient transfers from a pediatric to an adult healthcare team.

In a systematic review of transitional care programming research, While et al. (2004) propose four theoretical practice models for pediatric transition to adult care. Each of these models show increased adolescent responsibility for healthcare management and decreased parental involvement prior to transfer. The models proposed for empirical testing differ in the focus, timing, and amount of transition service provided. Only the Developmental Transitional Model hypothesizes a trajectory in which teens with chronic illnesses are actively assisted by

clinical transition programming in developing increased healthcare management skills and responsibilities while their parents or caregivers involvement is scaled back accordingly. These increases in teen responsibility and decreases in parental involvement happen on an individualized basis during a longitudinal period of clinical transitional care. Thus, in this model adolescent responsibility develops as a process in both a clinical and familial context and continues to increase as the teen matures. The current investigation seeks to test the Developmental Transitional model by constructing and analyzing a measure of transition readiness for adolescents and young adults participating in transitional readiness training program for kidney transplants.

Adolescent Healthcare Responsibility

Developmental research has historically depicted adolescence as a time of increasing autonomy development for both healthy teens and teens with chronic illnesses (Seiffge-Krenke, 1998; Steinberg, 2001; Steinberg & Silverberg, 1986). In the pediatric literature, adolescent healthcare responsibility and management has been shown to increase with age in both transplant and other pediatric populations (Annunziato et al., 2009; Palmer et al., 2004; Sawicki, Lukens-Bull, Yin, Demars, & Huang, 2009), and low levels of adolescent responsibility for healthcare has been indicated as a barrier to transition (Freyer & Kibrick-Lazear, 2006). The importance of transition readiness to the pediatric healthcare community is indicated in a survey of over 18,000 adolescents ages 12-17 with special health care needs. Over 75% of respondents reported that the adolescent healthcare provider usually encouraged the teen to take responsibility for their own healthcare (Lotstein et al., 2009). For adolescent transplant recipients, healthcare responsibility means taking on a host of health related tasks (e.g., appointment keeping, communicating with medical staff) in addition to adhering to a daily medication schedule.

Adolescent medicine conference reports and position papers have recommended that transitional programs should promote and evaluate teens' responsibility and autonomy related to managing their healthcare (Bell et al., 2008; McDonagh, 2005; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). However, negotiating the appropriate amount of healthcare responsibility to give adolescent transplant recipients is challenging because, although adolescence is a time of growing independence and autonomy, it is also a time of increased risk for non-adherence, allograft dysfunction, and rejection (Horslen, Barr, Christensen, Ettenger, & Magee, 2007; Magee et al., 2008; McDonagh, 2005). Adolescent kidney transplant recipients have the highest rates of acute rejection and rejection related graft loss of any age group (Bell et al., 2008). Additionally, kidney patients who were transplanted during adolescence had the poorest allograft outcomes of any age group except for the elderly at a 5 year follow-up (Horslen et al., 2007). These poorer medical outcomes for adolescents are believed to be related to high rates of medication non-adherence (Dobbels, Damme-Lombaert, Vanhaecke, & De Geest, 2005; Simons et al., 2008). Reported rates of medication non-adherence in adolescent solid organ transplant recipients vary widely due to the use of different assessment methods with reported rates ranging from 9-75% (Rodrigue & Zelikovsky, 2009). A meta-analysis using a variety of different adherence measurement techniques (e.g., self-report, pill count, MEMS caps, chart review, lab assays) found an average of 32% of adolescent kidney transplant recipients were non-adherent (Dobbels et al., 2005). In an investigation of medication adherence amongst adolescent transplant recipients at Children's Healthcare of Atlanta, 63% of participants were classified as non-adherent using parent and adolescent self-report of non-adherence. In this sample, when self-report was combined with serum immunosuppressant indicators, the non-adherence rate rose to 87% (Simons et al., 2008; Simons, McCormick, Mee, & Blount, 2009). In order to

successfully transition to adult care, teens must be adherent to their medication regimen and be able to assume responsibility for managing other aspects of their healthcare.

Parental Involvement

In addition to promoting responsible healthcare behavior by adolescents, parents and caregivers can give valuable support to safeguard against non-compliance throughout the transition process. Parental involvement in their adolescent's healthcare can be a protective factor against non-adherence (Dobbels et al., 2005; Feinstein et al., 2005; Simons & Blount, 2007; Zelikovsky, Schast, Palmer, & Meyers, 2008), but too much involvement or over-protectiveness may impair adolescents' ability to acquire skills necessary to manage their healthcare (McDonagh, 2005). Unfortunately, without standardized intervention or guidance from healthcare providers, families are left to do the best they can and may transition responsibility to children too early or too late. Further, parental involvement is frequently observed to be negatively correlated with age (Graue, Wentzel-Larsen, Hanestad, & Sjøvik, 2005; Palmer et al., 2004), which may or may not be congruent with the adolescents' self-management abilities.

An investigation of pediatric liver transplant recipients reported that the children began taking primary responsibility for medication taking between the ages of 9 and 16 years and that all of the adolescents aged 17 and older took sole responsibility for medication taking (Shemesh et al., 2004). Unfortunately, even though they were assuming responsibility there were no measures of the degree to which these adolescents adhered to medical recommendations. In the only study of its kind with pediatric transplant recipients, a family oriented educational intervention aimed at facilitating transition of responsibility from parents to adolescents showed improved medication adherence among a small sample of adolescent liver transplant recipients

(Annunziato et al., 2008). However, as in the prior study, the investigators did not measure or quantify parent or child healthcare responsibility in taking medication. Taken together, these data suggest that there is a dynamic, individualized balance between adolescent healthcare responsibility and parental involvement during the transition process where teens take increasing amounts of responsibility and parents become less involved over time.

Measuring Transition Readiness

The available literature on healthcare transition is sparse and consists mostly of policy statements, recommendations for practice, and qualitative narratives (Reiss, Gibson, & Walker, 2005). The need for intervention is evident, in that transfer to adult centered care has been associated with 30% allograft loss in kidney transplant patients 15 months post-transfer (Watson, 2000) and with lower serum immunosuppressant levels and increased non-adherence and mortality in liver transplant recipients (Annunziato et al., 2007). A small number of studies assessing transition readiness or adolescents' healthcare responsibility have been conducted in general (Sawicki et al., 2009) and specific pediatric populations such as patients with cystic fibrosis (Cappelli, MacDonald, & McGrath, 1989; Patton, Graham, Varlotta, & Holsclaw Jr, 2003), rheumatic disease (Cappelli et al., 1989), and HIV (Wiener, Battles, Ryder, & Zobel, 2007). In terms of assessment, the Transition Readiness Assessment Questionnaire (TRAQ) was developed to assess self- management and advocacy in a general pediatric population and covers a wide range of important healthcare behavior, yet the TRAQ does not capture parental involvement or autonomy in carrying out these behaviors (Sawicki et al., 2009). The instruments, used with patients with cystic fibrosis and rheumatic disease, are disease/regimen specific and rely heavily on regimen knowledge as opposed to evaluating healthcare behavior. The Transition Readiness Questionnaire that was developed for the study conducted by Wiener et al. (2007)

focuses on important behavior related to proximal planning for transfer of patients with HIV (e.g., made appointment with adult provider). However, it neglects to evaluate the transition of responsibility from parent to teen and does not address the important domain of medication taking behavior. In a consensus report from a conference of the American Society of Transplantation, United Network for Organ Sharing (UNOS), and other international transplant organizations, demonstration of adolescent healthcare responsibility (e.g., calls in refills, makes appointments, communicates independently with healthcare providers, understands insurance coverage) was identified as a critical component of transfer readiness (Bell et al., 2008). To date, there are no instruments which assess these and other important aspects of transition readiness and healthcare responsibility in the pediatric transplant literature.

The dual purpose of the present study is to develop a measure of transition readiness and use the measure to identify factors associated with patients' and parents' perceived readiness for transition among patients participating in a multidisciplinary adolescent kidney transplant transition clinic. This study will examine factors associated with transition readiness that have been identified in the theoretical and empirical literature, such as adolescent responsibility for healthcare (Annunziato et al., 2007; Annunziato et al., 2008; Annunziato et al., 2009; Bell et al., 2008; Rodrigue & Zelikovsky, 2009; While et al., 2004), parental involvement (Dobbels et al., 2005; While et al., 2004), medication adherence and barriers to adherence (Simons et al., 2009; Zelikovsky et al., 2008), and age (Annunziato et al., 2009; McDonagh, 2005; Reiss et al., 2005). Additional patient related factors of interest in this study include medication knowledge, appointment and medication refill adherence, teen-parent relationship quality and demographic factors. These additional factors have been shown to be important in the literature on pediatric medication adherence (La Greca & Mackey, 2009; Simons & Blount, 2007). Older age is

hypothesized to be a strong predictor of transition readiness. Greater teen healthcare responsibility, adherence behavior, medication knowledge, and better familial relationship quality are expected to be positive predictors of transfer readiness. Fewer barriers to adherence and lower levels of parental involvement are also hypothesized to be predictive of increased adolescent transition readiness.

CHAPTER 2

METHOD

Participants and Settings

The participants in this study consisted of 48 adolescent and young adult kidney transplant recipients between the ages of 15 and 21 who were enrolled in Children's Healthcare of Atlanta's Adolescent Kidney Transplant Transition Clinic (AKTTC). Of the 54 patients seen in the AKTTC, 48 patients (88.9%) agreed to participate in this study. Two patients (3.7%) were not present in clinic during the 7 months of data collection. Another two patients were deemed ineligible for the study by the clinic psychologist due to cognitive deficits. One adolescent patient wanted to participate in the study, but was underage and parent could not be reached to provide consent. Only one patient (1.9%) declined participation in the investigation. Thirty-two (66.7%) of the 48 participants' parents and caregivers also participated in the study. Four parents (8.3%) were not eligible for the study as they were non-English speaking. Twelve parents (25%) did not attend their teen's clinic appointment and either could not be reached by phone or did not return their packet after verbally consenting on the phone.

The mean adolescent age of study participants was 18.6 years ($SD=1.64$ years) and 52 percent were male. The ethnic makeup of the sample was 58.3% Caucasian, 29.2% African-American, 10.4% Hispanic, and 2.1% Asian. Twenty-eight mothers (87.5%) and four fathers completed demographic and parent report measures.

The AKTTC was designed to facilitate the transition of adolescent patients to adult care and to improve graft survival outcomes during the transition process. The clinic's programming is intended to encourage patient autonomy and responsibility, build confidence in their ability to

adhere to medication and healthcare regimens, and increase their knowledge that adherence will lead to improved long-term allograft functioning. Patients in the clinic are scheduled to be seen on an outpatient basis every 3 months as per standard of care for patients greater than one year post-kidney transplant. At each clinic visit, the patient has individual interactions with members of a multidisciplinary healthcare team, including a transplant coordinator, social worker, psychologist, pharmacologist and physician.

Procedures

During their transition clinic visit, participants were recruited by research team members and presented with the appropriate informed consent documents prior to their participation in the study. For adolescent participants under age 18, written parental consent, HIPAA release, and adolescent assent were obtained by researchers. Adolescent participants ages 18 and over provided their own written consent and HIPAA release. Parents were recruited by research team members either at their teen's clinic visit or over the phone. Parents who participated in the study and completed parent measures also provided written consent for their own participation in the study.

During their clinic visit, participants completed separate self-report measures assessing adolescent transition readiness, healthcare responsibility, adherence, and barriers to adherence. Parents who attended their teen's clinic visit completed corresponding parent-report measures in clinic. Parents who did not attend their teen's clinic visit were contacted by phone and then mailed consent and self-report forms to return via self-addressed stamped envelope. Per clinic protocol, patients are asked semi-structured interview questions during their encounter with each member of the multidisciplinary team. As a component of the proposed study, data from these encounter interviews were collected from the patients' electronic medical charts along with

medical and demographic information (e.g., age, gender, ethnicity, appointment history). There was a \$10 honorarium in the form of a gift card for adolescent participants and parking vouchers for parent participants. This study was reviewed and approved by University of Georgia and Emory School of Medicine's Institutional Review Boards.

Instruments

Instruments included in the study consisted of questionnaires and semi-structured interview questions that are currently used by the medical team. Adolescents completed self-report measures of perceived transition readiness, frequency of healthcare responsibility behavior, and parental involvement (RTQ-Teen), as well as barriers to adherence (AMBS). Adolescents also engaged in a semi-structured interview with members of the AKTTC team (e.g., psychologist, pharmacist, researcher) during clinic to assess relationship quality with their parents, medication adherence, and medication knowledge (MAM-medication knowledge). Information from these interview encounters was recovered from the teens' medical records. Relevant medical data were collected from the patients' electronic medical records to assess adherence with clinic appointments, and calling in refills. Parents completed self-report measures of demographics, as well as perceived transition readiness, frequency of teen healthcare responsibility behavior, and parental involvement (RTQ-Parent).

Demographic Questionnaire and Medical Record Review. The demographic questionnaire was completed by the parent and assessed adolescent age, ethnicity, and education, as well as parental age, ethnicity, education, income, marital status, and relationship to the child (e.g., mother, father, grandparent, foster parent).

As part of the medical chart review, data were obtained on the teens' clinic appointment adherence, medication refill behavior, and teen-parent relationship quality. The AKTTC protocol

calls for teens to attend quarterly clinic visits. Clinic appointment adherence was calculated as a percentage by dividing the number of clinic visits the teen attended in the past year by 5 (number of possible appointments) and multiplying by 100. Medication refill behavior was coded as a dichotomous variable and assessed by looking at whether the teen was calling in their own medication refills per the results of their interview with the pharmacist. Finally, during their standard clinic encounter with the pediatric psychologist, teens are asked to rate the quality of their relationship with their parents on a 5-point Likert-like scale which includes: “1- poor”, “2- fair”, “3-good”, “4-very good”, and “5- excellent.” The teen-parent relationship quality data from this interaction with the psychologist was recovered from the teens’ medical record.

Readiness for Transition Questionnaire (RTQ- teen; RTQ-parent). The RTQ was created for use in this study to assess overall transition readiness, frequency of responsible adolescent healthcare behavior, and frequency of familial involvement in healthcare. To our knowledge, there are no other assessment tools to gauge transition readiness from patient and parent standpoints (Bell et al., 2008). Adolescents and their parents or caregivers each completed appropriately worded parallel versions the RTQ. The RTQ yields four pieces of information related to transition readiness; these include measures of Overall Transition Readiness, Adolescent Responsibility (AR), Parental Involvement (PI), and adolescent Healthcare Autonomy (HA). The Flesch-Kincaid grade level readability formula estimates the readability of the RTQ to be at the 5th grade level: RTQ-teen: 4.9, RTQ-parent 5.2 (Kincaid, Fishburne, Rogers, & Chissom, 1975).

Adolescents and parents reported on who in the family shares healthcare responsibility (e.g., teen, mother, father, other) and identified one person who is primarily responsible for healthcare. Given that the literature has conceptualized transition as a process as well as an

event, transition readiness on the RTQ is quantified by assessing the adolescent's readiness to assume complete responsibility for their healthcare and their readiness to transfer to adult medical care. Adolescents received a summary score for Transition Readiness (Teen RTQ-Overall, Parent RTQ-Overall) ranging from 2 to 8. Their RTQ-Overall score was obtained by summing scores for the following items: "Overall, how ready do you think you are to assume complete responsibility for your healthcare... 1- not at all ready, 2- somewhat ready, 3- mostly ready, 4- completely ready?" and "Overall, how ready do you think you are to transition from care at Children's Healthcare of Atlanta to adult care... 1- not at all ready, 2- somewhat ready, 3- mostly ready, 4- completely ready?". Thus, a higher Transition Readiness score indicates increased perceived preparedness to transfer both responsibility (from parent to teen) and services (from pediatric to adult care). The correlations between the two items forming the RTQ-Overall score were .652 for the adolescents and .785 for the parents.

In addition to reporting on overall transition readiness, parents and teens also reported on the current frequency of adolescent responsibility and parental involvement with 10 specific healthcare behaviors (e.g., scheduling specialty and primary care appointments, attending medical appointments, calling in refills, taking medication daily, communicating with medical staff in person and via phone, explaining their medical condition to others, getting monthly labs, knowing terms of insurance) identified in the literature and by the multidisciplinary transition-clinic staff as being key for successful transfer to adult care (Annunziato et al., 2008; Bell et al., 2008; Wiener et al., 2007). Frequency of adolescent responsibility (Teen RTQ-AR, Parent RTQ-AR) for each of the 10 healthcare behaviors was rated on a four point Likert-like scale with verbal anchors of "1- not at all responsible" and "4- responsible almost all the time." Frequency of parental involvement in healthcare behavior (Teen RTQ-PI, Parent RTQ-PI) was rated on a

corresponding four point Likert-like scale with verbal anchors of “1- not at all involved” and “4- involved almost all the time.” Hence, the RTQ subscales of responsible adolescent healthcare behavior (RTQ-AR) and frequency of parental involvement in the adolescents’ healthcare (RTQ-PI) each range from 10 to 40 with higher scores denoting increased adolescent responsible behavior and caregiver involvement. Within the current sample, the Adolescent Responsibility subscale had strong internal consistency (Teen RTQ-AR Cronbach’s $\alpha = .857$; Parent RTQ-AR Cronbach’s $\alpha = .846$), as did the Parental Involvement subscale (Teen RTQ-PI Cronbach’s $\alpha = .936$; Parent RTQ-PI Cronbach’s $\alpha = .887$).

Finally, to assess for adolescent autonomy across healthcare behavior (Teen RTQ-HA, Parent RTQ-HA), adolescents and parents each endorsed 10 forced-choice items indicating whether the teen or the parent is primarily responsible for each of the 10 healthcare behaviors. Adolescents scored one point for each behavior they were primarily responsible for, resulting in a range of 0 to 10 with higher scores indicating increased healthcare autonomy. The Healthcare Autonomy subscale had a Cronbach’s α ’s of $.860$ (Teen RTQ-AR) and $.820$ (Parent RTQ-AR).

Adolescent Medication Barriers Scales (AMBS). The AMBS was designed to measure perceived barriers to medication taking and were developed using an adolescent solid organ transplant sample (Simons & Blount, 2007). Items were rated on a 5-point Likert-like scale ranging from “1- strongly disagree” to “5- strongly agree.” The 17 items on the AMBS show strong internal consistency in the current sample (Cronbach’s $\alpha = .907$). The AMBS also demonstrated validity in an adolescent transplant recipient sample where those who were classified as non-adherent had significantly higher barrier scores than those classified as adherent.

Adolescent Report of Medication Adherence and Medication Knowledge (MAM Medication Module-medication adherence; MAM Medication Module- medication knowledge).

The Medical Adherence Measure Medication Module (MAM) is a semi-structured interview used to assess adolescent self-report of medication adherence (Zelikovsky & Schast, 2008). In this study, the pharmacist administered the MAM- medication knowledge to adolescents during their transition clinic visit, while the researchers independently administered the MAM-medication adherence to the adolescents without a healthcare provider present. Adolescents reported on how many doses of medication were missed or taken late over the past week. Percentages of missed and late doses were calculated by dividing the number of missed or late doses by the total number of doses prescribed for the week and multiplying by 100. Similar to a previous investigation of medication adherence, adherence in this sample was examined as a dichotomous variable with teens reporting missing any doses or taking more than 10% of doses late (e.g., non-adherent) coded as 2 and teens reporting missing no doses or taking less than 10% of doses late coded as 1 (Simons et al., 2008).

Medication knowledge was evaluated by asking the adolescents to report: 1) the name of each medication, 2) dosage frequency, 3) dosage amount, and 4) medication indication. Their responses will be compared with the current medication regimen in the medical chart, with a possible total score of 4 for each medication. An overall medication knowledge score was obtained by adding the score from each of the medications, dividing by the number of medications prescribed, and multiplying by 100. For the purposes of data analysis, medication knowledge was examined as a dichotomous variable with teens exhibiting complete medication knowledge (e.g., 100%) coded as 2 versus those exhibiting less than complete medication knowledge coded as 1. Self reported non-adherence on the MAM has been associated with

decreased medication regimen knowledge and increased perceived barriers (Simons & Blount, 2007; Zelikovsky et al., 2008).

CHAPTER 3

RESULTS

Overview

Preliminary correlational and between group analyses assessed the association between demographic factors and measures from the RTQ (Adolescent Responsibility, Parental Involvement, and Overall Transition Readiness). Paired samples t-tests were then conducted to examine differences in adolescent and parent reports of Adolescent Responsibility (AR), Parental Involvement (PI), Healthcare Autonomy (HA) and Overall Transition Readiness from the RTQ. Next, the Developmental Transition Model was tested by evaluating adolescent and parent report hierarchical linear regression models of Overall Transition Readiness using age, Adolescent Responsibility, and Parental Involvement as independent predictors (While et al., 2004). The adolescent Healthcare Autonomy (HA) component of the RTQ was excluded from the regression analyses because it is a forced choice version of the Adolescent Responsibility and the Parental Involvement components, and was seen as too overlapping in scope. Pearson correlational analyses were conducted to evaluate the validity of the RTQ by determining associations between psychosocial and adherence variables and adolescent and parent report of Adolescent Responsibility, Parental Involvement, and Overall Transition Readiness. From the correlation matrix, psychosocial and adherence variables were considered for entry into hierarchical linear regression models predicting adolescent and teen report of Overall Transition Readiness.

Preliminary Analyses

Preliminary analyses were conducted to examine two primary questions. First, were demographic factors (e.g., gender, ethnicity) associated with adolescent and parent reported

outcome variables on the RTQ? Second, were there differences in demographic or outcome variables associated with parental participation in the study? For the adolescent sample as a whole ($N=48$), there were no significant differences in gender or ethnicity on Adolescent Responsibility, Parental Involvement, or Overall Transition Readiness. The gender and ethnicity analyses were re-ran on the 32 adolescents whose parents participated in the study. These analyses also revealed no significant differences in gender or ethnicity on Adolescent Responsibility, Parental Involvement, or Overall Transition Readiness. Age was not included in these preliminary analyses as it is used as a predictor in all regression models.

Finally, an additional set of preliminary analyses were conducted to evaluate differences in demographic factors and the RTQ scales for those adolescents whose parents participated ($N=32$) versus those parents who did not participate ($N=16$). Results indicated that parents who participated in the study were more likely to be the parents of younger adolescents ($t= -3.09$, $p=.004$) and more likely to be Caucasian ($t=2.73$, $p= .01$). Teens whose parents who did not participate in the study reported greater levels of healthcare autonomy (Teen RTQ-HA: $t=4.50$, $p< .001$). The analyses showed no significant differences in the other scores on the Teen RTQ (Overall, AR, PI) between teens whose parents participated versus teen whose parents did not.

Teen and Parent Between-Reporter Analyses

Paired samples t-tests were used to assess for significant differences in parent and teen reporting on teens' Overall Transition Readiness, Adolescent Responsibility, Parental Involvement, and Healthcare Autonomy from the RTQ. There was a statistically significant difference in the teen ($M= 5.96$, $SD= 1.49$) and parent ($M= 4.41$, $SD= 1.86$) report of teens' Overall Transition Readiness ($t(31)= 5.52$, $p<.001$). There also was a statistically significant difference in the teen ($M= 32.96$, $SD= 5.73$) and parent ($M= 25.56$, $SD= 6.88$) reports of

Adolescent Responsibility ($t(31)= 5.44, p<.001$). Additionally, there was a significant difference in the teen ($M= 7.31, SD= 2.50$) and parent ($M= 4.19, SD= 2.91$) reports of adolescent Healthcare Autonomy ($t(31)= 6.06, p<.001$). Finally, there was no significant difference in the teen ($M= 29.15, SD= 8.96$) and parent ($M= 32.38, SD= 7.09$) report of Parental Involvement in healthcare management ($t(31)= -1.87, p=.071$). Table 1 displays the bivariate relationships between the adolescent and parent report of the same RTQ variables. There were significant positive relationships between teen and parent report of Overall Transition Readiness, teen and parent report of Adolescent Responsibility, teen and parent report of Parental Involvement, and teen and parent report of Healthcare Autonomy.

Evaluation of the Developmental Transition Model: RTQ Overall Transition Readiness

The relationships between age, Overall Transition Readiness, Adolescent Responsibility, Parental Involvement, and Healthcare Autonomy from the RTQ were investigated using Pearson product-moment correlation coefficients. Table 1 displays the bivariate relationships between the adolescent and parent report on the RTQ scales and age. Age was significantly related to decreased teen and parent report of Parental Involvement and increased teen and parent report of adolescent Healthcare Autonomy; however, age was not significantly related to teen or parent report of Overall Readiness or Adolescent Responsibility. Teen and parent report of Overall Transition Readiness was significantly related to increased teen and parent report of Adolescent Responsibility, increased teen and parent report of Healthcare Autonomy, and decreased teen and parent report of Parental Involvement. Teen report of Adolescent Responsibility was significantly related to increased teen and parent report of Healthcare Autonomy. Parent report of Adolescent Responsibility was significantly related to increased teen and parent report of Healthcare Autonomy and decreased teen report of Parental

Involvement. Teen and parent reports of Parental Involvement were significantly associated with decreased adolescent and parent report of Healthcare Autonomy.

Separate hierarchical regression analyses were used to predict teen and parent report of Overall Transition Readiness using the Developmental Transition Model as a guide (While et al., 2004). Adolescent age was entered as Block 1 into the Overall Transition Readiness models. Adolescent Responsibility was entered on the second block with Parental Involvement on the third block. Table 2 displays that age alone accounted for a non-significant 6% and 2% of the variance in teen and parent models, respectively. Adolescent Responsibility accounted for a significant 42% and 48% of the variance in teen and parent models, respectively. Decreased Parental Involvement accounted for an additional significant 5% of the variance in the teen model and a non-significant additional 5% in the parent model. Adolescent age, increased Adolescent Responsibility and Decreased Parental Involvement together accounted for 53% of variance in the teen and 55% of the variance in the parent models of Overall Transition Readiness.

Transition Readiness: Adherence and Psychosocial Analyses

The relationships between teen and parent report of Overall Transition Readiness, adherence behavior, and psychosocial variables were investigated using Pearson product-moment correlation coefficients. Table 3 displays the bivariate relationships between teen and parent reports of transition readiness and healthcare behavior predictor variables. There were significant positive relationships between teen report of Overall Transition Readiness and medication knowledge (MAM), calling in refills, and teen-parent relationship quality; additionally, there was a significant negative relationship with between teen report of Overall Transition Readiness and adolescent report of medication barriers (AMBS- Total). There were

significant positive relationships between parent report of Overall Transition Readiness and medication knowledge (MAM) and calling in refills. Adolescent self report of medication adherence (MAM- adherence) was not significantly related to either teen or parent report of Overall Transition Readiness.

Two separate hierarchical regression models were created to evaluate predictors of teen and parent report of Overall Transition Readiness. In both of these models, adolescent age was entered on the first step. On the second step, adherence related variables that were statistically significant at the bivariate level were automatically entered. In addition, in the adolescent model, appointment adherence was also entered on the second step as appointment adherence is particularly salient during the transfer to adult healthcare providers. For the parent model, adolescent report of medication barriers was also entered on the second step. Although it was non-significant at the bivariate level, it was included to parallel the adolescent report model and because the correlation between medication barriers and Overall Transition Readiness was similar across adolescent and parent report. Finally, for the adolescent model, teen parent relationship quality, which was significantly correlated with Overall Transition Readiness, was entered on the third step.

Table 4 displays that age accounted for a non-significant 6% of the variance in teen report of Overall Transition Readiness, with adherence factors and teen-parent relationship quality adding significant 33% and 5% increments, respectively. Age, adherence behavior, and teen-parent relationship quality together accounted for 44% of the variance in teen report of Overall Transition Readiness. Significant predictors in the final adolescent model included decreased adolescent barriers to medication adherence (AMBS), complete knowledge of their medication regimen (MAM-knowledge), and better teen-parent relationship quality.

For the parent report model of Overall Transition Readiness, Table 5 displays that age accounted for a non-significant 2% of the variance in parent report of Overall Transition Readiness, with adherence factors adding a significant 41% increment. Age and adherence factors together accounted for 43% of the variance in parent report of Overall Transition Readiness. Significant predictors in the final parent model included teens showing complete knowledge of their medication regimen (MAM-knowledge) and teens calling in their own medication refills.

CHAPTER 4

DISCUSSION

The current study addresses several significant gaps in the pediatric healthcare transition literature. First, the results of the investigation add empirical data supporting the validity of the Developmental Transition model proposed by While et al. (2004). In addition, the measure of transition readiness developed in this project fills a need established in the transplant literature for a reliable and valid assessment tool to gauge transition readiness from both patient and parent standpoints (Bell et al., 2008). Finally, the study is also novel in its exploration of teen and parent reporter differences in their evaluation of the adolescents' transition readiness.

The results from the first set of regression analyses (Table 2) investigating the associations between age, Adolescent Responsibility, and Parental Involvement strongly support the Developmental Transition model (While et al., 2004). The adolescent model of transition readiness clearly shows strong relationships between increased Adolescent Responsibility and decreased Parental Involvement with Overall Transition Readiness. High adolescent responsibility and correspondingly lower parental involvement represents the goal of both preparing the adolescents to transition to adult healthcare clinics and to successfully manage key aspects of their healthcare needs with less reliance on their parents. The parent model also demonstrates a strong relationship between increased Adolescent Responsibility and Overall Transition Readiness. Although the parent model did not show decreased parental involvement as a significant predictor of transition readiness, this may have been due to lower statistical power in the parent vs. the adolescent model. Interestingly, adolescent age was not a significant predictor in either the teen or the parent model of transition readiness. These findings are

congruent with the transition literature which emphasizes the importance of developmental stage over chronological age as being indicative of transition readiness (Bell et al., 2008; Rodrigue & Zelikovsky, 2009). As a whole, these data demonstrate that transition readiness involves more than an adolescent's age. Instead, transition readiness involves adolescents taking responsibility for their own healthcare tasks with less ongoing assistance from their parents and caregivers.

The development of the RTQ was central to the purpose of this study. Although a few measures of transition readiness exist in the literature (Cappelli et al., 1989; Patton et al., 2003; Sawicki et al., 2009; Wiener et al., 2007), none of these instruments were specifically developed for use with transplant recipients. Also, these prior instruments had not been used to assess both teen and parent report or to assess parental involvement in teens' healthcare activities. Thus, the RTQ addresses these issues and provides a more complete picture of transition readiness including multiple reporters (i.e., teen, parents) detailing both adolescent and parent healthcare behavior. The components of the RTQ (e.g., Overall Readiness, Adolescent Responsibility, and Parental Involvement) were based on important constructs that have been discussed but not measured in the transition literature (Annunziato et al., 2007; McDonagh, 2005; Rodrigue & Zelikovsky, 2009; While et al., 2004). The corresponding specific items on the AR and PI components were selected based on healthcare behaviors described as essential for transfer readiness by the Transition Consensus Conference of seven major transplant organizations including the American Society of Transplantation and the United Network for Organ Sharing (UNOS), as well as based on additional input from the AKTTC healthcare team (Bell et al., 2008). The preliminary psychometrics of the RTQ appear to be robust. The 10 items on each of the Adolescent Responsibility and Parental Involvement components of the RTQ showed strong internal consistency with Cronbach's alphas ranging in the mid .80's to .90's. The construct

validity of the components of the RTQ was supported by the significant relationships with the other variables assessed in this investigation.

This investigation identified several behavioral indices associated with transition readiness. Transition readiness was strongly associated with adolescent adherence factors including fewer barriers to medication adherence, complete knowledge of their medication regimen, and independence with calling in refills. Thus, transition readiness is not only associated with knowing their medication regimen, but having few factors that interfere with that regimen and independently anticipating when refills are needed to continue that regimen. Surprisingly, there were no significant associations between transition readiness and adolescent self-report of medication adherence on the MAM. Perhaps this lack of finding has to do with the short-term nature of the self-report of adherence as assessed by the MAM (e.g., past 7 days) versus the long-term and cumulative process of becoming ready to transition. Finally, better teen-parent relationship quality was also associated with adolescent report of increased transition readiness and fewer barriers to medication adherence. Research on adolescents has documented the importance of the high quality parent-child relationships on autonomy development (Steinberg, 2001). A high quality family relationship may be facilitative of learning, growth, and independence in adolescents, while simultaneously associated with fewer factors such as high adolescent rebellion, emotional distress, and chaotic conditions that would interfere with becoming ready to transition. Further, relationship quality may influence adolescents' reactions to parental efforts to encourage their assumption of greater responsibility for their healthcare, as well as to direct parental interventions to assure adherence to their medical regimen.

An additional set of noteworthy findings include the comparisons between teen and parent report on the RTQ. Although highly correlated with one another, there were significant

discrepancies between parent and teen report of Overall Transition Readiness, Adolescent Responsibility, and Healthcare Autonomy with teens reporting significantly higher scores on these components. It remains unclear if these differences reflect teen overestimation of their abilities, parental undervaluing of their teens abilities and efforts, or whether the truth lies somewhere in the middle. Anecdotally, we have observed some parents who are understandably very reluctant to surrender responsibility for adolescents' adherence and other healthcare behaviors, given the consequences of nonadherence, while other parents yield control before their child appears to be ready for such responsibility. Additionally, we have also encountered some adolescents who report high levels of transition readiness with little demonstration of healthcare management skills or performance. Other teens demonstrate high levels of behavioral competence, but are cautious about their overall evaluation of their abilities and readiness to assume healthcare responsibility or transfer to adult care services. In tandem, these situations underscore the need for assessing both parent and adolescent report, as well as ongoing monitoring of healthcare behaviors and biomarkers by medical staff.

There are several limitations to this project which are important to describe here and address in future studies. Despite efforts to collect data from all parents of teen participants, data were not available from all families. Therefore, the results of the parent models may not be reflective of the AKTTC as a whole given significant adolescent age and ethnic differences found between parental responders versus non-responders. Future studies should make intensive efforts to collect data from all parents and caregivers. Additionally, although this investigation collected data from over 85% of the available patients in the AKTTC, the sample size of 48 limited statistical power. Future research should utilize multi-site recruitment and collection strategies in order to yield a larger sample size. A larger sample of adolescent transplant

recipients would allow for more complete testing of the predictors in the regression models and detection of smaller significant effects. Also, as the literature conceptualizes transition as both a process and an event as patients move from pediatric to adult care. This investigation focused on the process, but not the transition event in that follow-up data were not collected to assess participant progress at the time of the first appointment with the adult care providers or after the transition to adult healthcare services. Future investigations evaluating transition readiness should include follow-up evaluations of readiness, parental involvement, adherence, and post-transfer medical and psychosocial outcomes. Lastly, the measure of transition readiness created for this study was developed in an adolescent and young adult sample of kidney transplant recipients receiving active, transition-focused clinical programming. It is possible that this measure would prove useful with other heart and liver transplant recipients, as well as other pediatric populations, regardless of whether they are participating in formal transition readiness training. Additional research is needed to explore this issue.

In conclusion, this investigation addresses the importance of preparing adolescents and their families for transition to adult care. Factors associated with readiness were identified. Though the empirical transition literature may be sparse, it is clear that the medical and emotional costs of being unprepared for transition can be devastatingly high (Annunziato et al., 2007; Watson, 2000). Additional research should begin to evaluate transitional programming to identify which clinical components are related to improvements in transition readiness, adolescent responsibility, and medical outcomes. Studies of this kind may identify critical components that will refine transition readiness programming. Finally, future investigations should target parents of teens in transition and identify ways to help parents decrease their involvement while simultaneously encouraging adolescent adherence and healthcare

responsibility. With an increased knowledge of effective, family-centered transition programming, we can confidently assist our adolescent patients as they are getting ready to leave pediatrics for the world of adult care.

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Table 1. *RTQ Correlates of Teen and Parent Report of Transition Readiness*

Variable	1	2	3	4	5	6	7	8	9
1. Overall Transition Readiness- Teen report (Teen RTQ- Overall) (N= 48, M= 5.96, SD= 1.487)	--	.68**	.68**	.62**	-.39**	-.39*	.63**	.67**	.25
2. Overall Transition Readiness- Parent report (Parent RTQ- Overall) (N= 32, M= 4.41, SD= 1.864)		--	.65**	.71**	-.49**	-.41*	.47**	.63**	.13
3. Adolescent Responsibility- Teen report (Teen RTQ-AR) (N= 48, M= 32.96, SD= 5.731)			--	.50**	-.21	-.34	.59**	.59**	.20
4. Adolescent Responsibility- Parent report (Parent RTQ-AR) (N= 32, M= 25.56, SD= 6.877)				--	-.47**	-.32	.50**	.55**	.19
5. Parental Involvement- Teen report (Teen RTQ-PI) (N= 48, M= 29.15, SD= 8.956)					--	.58**	-.53**	-.65**	-.53**
6. Parental Involvement - Parent report (Parent RTQ-PI) (N= 32, M= 32.38, SD= 7.088)						--	-.61**	-.79**	-.51**
7. Adolescent Healthcare Autonomy- Teen report (Teen RTQ-HA) (N= 48, M= 7.31, SD= 2.502)							--	.70**	.67**
8. Adolescent Healthcare Autonomy - Parent report (Parent RTQ-HA) (N= 32, M= 4.19, SD= 2.912)								--	.41*
9. Teen Age (N= 48, M=18.60, SD=1.635)									--
<i>Note.</i> * $p \leq .05$, ** $p \leq .01$									

Table 2. *Hierarchical Regression of Transition Readiness: Adolescent Responsibility and Parental Involvement*

	B ^a	SEB ^b	β^c	R ²	ΔR^2	F
Teen Report of Overall Transition Readiness (Teen RTQ; N=48)						
Step 1: Adolescent age (<i>M</i> =18.60, <i>SD</i> =1.635)	.22	.13	.25 [†]	.06	.06 [†]	2.98 [†]
Step 2: Adolescent age	.10	.10	.11			
Adolescent Responsibility (RTQ- Teen AR)	.17	.03	.66 ^{**}	.48	.42 ^{**}	20.78 ^{**}
Step 3: Adolescent age	-.02	.11	-.03			
Adolescent Responsibility (RTQ- Teen AR)	.16	.03	.63 ^{**}			
Parental Involvement (RTQ- Teen PI)	-.05	.02	-.27 [*]	.53	.05 [*]	16.60 ^{**}
Parent Report of Overall Transition Readiness (Parent RTQ; N=32)						
Step 1: Adolescent age (<i>M</i> =18.17, <i>SD</i> =1.682)	.15	.20	.13	.02	.02	.54
Step 2: Adolescent age	.00	.15	.00			
Adolescent Responsibility (RTQ-Parent AR)	.19	.04	.71 ^{**}	.50	.48 ^{**}	14.65 ^{**}
Step 3: Adolescent age	-.14	.16	-.12			
Adolescent Responsibility (RTQ-Parent AR)	.07	.03	.65 ^{**}			
Parental Involvement (RTQ- Parent PI)	-.07	.04	-.27 [†]	.55	.05 [†]	11.49 ^{**}
<i>Note.</i> ^a B, unstandardized coefficients; ^b SEB, standard error of unstandardized coefficients; ^c β , standardized coefficients [*] $p \leq .05$, ^{**} $p \leq .01$, [†] $p \leq .10$						

Table 3. *Healthcare Behavior Correlates of Transition Readiness*

Variable	1	2	3	4	5	6	7	8	9
1. Overall Transition Readiness Teen RTQ- Overall (<i>M</i> = 5.96, <i>SD</i> = 1.487)	--	.68**	.25	-.15	.40*	-.36*	.20	.36*	.30*
2. Overall Transition Readiness Parent RTQ- Overall (<i>M</i> = 4.41, <i>SD</i> = 1.864)		--	.13	-.08	.44*	-.33	.05	.48**	.08
3. Teen Age (<i>M</i> =18.60, <i>SD</i> =1.635)			--	.14	.09	.08	-.07	.50**	-.09
4. Medication Adherence MAM- Adherence (<i>M</i> = 1.38, <i>SD</i> = .489)				--	-.08	.33*	-.06	.12	-.01
5. Medication Knowledge MAM- Knowledge (<i>M</i> = 1.44, <i>SD</i> = .501)					--	-.20	.11	.08	.11
6. Overall Medication Barriers Teen AMBS- Total (<i>M</i> = 32.08, <i>SD</i> = 12.687)						--	.18	-.04	-.32*
7. Appointment Adherence (<i>M</i> =86.67, <i>SD</i> =15.065)							--	.11	-.13
8. Calls in Refills (<i>M</i> =1.77, <i>SD</i> =.425)								--	-.10
9. Teen-Parent Relationship Quality (<i>M</i> =3.62, <i>SD</i> =1.123)									--
<i>Note.</i> * $p \leq .05$, ** $p \leq .01$									

Table 4. *Hierarchical Regression of Teen Report of Transition Readiness: Adherence Behaviors and Teen-Parent Relationship*

	B ^a	SEB ^b	β ^c	R ²	Δ R ²	F
Teen Report of Overall Transition Readiness						
(Teen RTQ; N=48)						
Step 1: Adolescent age (<i>M</i> =18.60, <i>SD</i> =1.635)	.22	.13	.25 [†]	.06	.06 [†]	2.98 [†]
Step 2: Adolescent age	.14	.13	.15			
Barriers to Medication Adherence (AMBS- Total)	-.04	.02	-.35 ^{**}			
Medication Knowledge (MAM- Knowledge)	.79	.37	.27 [*]			
Calls in Medication Refills	.77	.50	.22			
Clinic Appointment Adherence	.02	.01	.22 [†]	.39	.33 ^{**}	5.42 ^{**}
Step 3: Adolescent age	.15	.13	.10			
Barriers to Medication Adherence (AMBS- Total)	-.03	.12	-.28 [*]			
Medication Knowledge (MAM- Knowledge)	.74	.36	.25 [*]			
Calls in Medication Refills	.85	.48	.24 [†]			
Clinic Appointment Adherence	.02	.01	.24 [†]			
Teen-Parent Relationship Quality	.33	.16	.25 [*]	.44	.05 [*]	5.50 ^{**}
<i>Note.</i> ^a B, unstandardized coefficients; ^b SEB, standard error of unstandardized coefficients; ^c β, standardized coefficients						
* $p \leq .05$, ** $p \leq .01$, [†] $p \leq .10$						

Table 5. *Hierarchical Regression of Parent Report of Transition Readiness: Healthcare Adherence Behaviors*

	B ^a	SEB ^b	β ^c	R ²	Δ R ²	F
<i>Parent Report of Overall Transition Readiness</i>						
(Parent RTQ; N=32)						
Step 1: Adolescent age (<i>M</i> =18.17, <i>SD</i> =1.682)	.15	.20	.13	.02	.02	.54
Step 2: Adolescent age	-.15	.19	-.13			
Barriers to Medication Adherence (AMBS- Total)	-.03	.02	-.20			
Medication Knowledge (MAM- Knowledge)	1.30	.56	.35*			
Calls in Medication Refills	1.87	.68	.47**	.43	.41**	5.12**
<i>Note.</i> ^a B, unstandardized coefficients; ^b SEB, standard error of unstandardized coefficients; ^c β, standardized coefficients						
* <i>p</i> ≤ .05, ** <i>p</i> ≤ .01, † <i>p</i> ≤ .10						