Getting Ready to Leave: Transition Readiness in Adolescent Kidney Transplant Recipients

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Objective To develop a measure of transition readiness and assess factors associated with perceived readiness for transition of healthcare responsibility and transfer among adolescent kidney transplant recipients. **Methods** The Readiness for Transition Questionnaire (RTQ-teen; RTQ-parent) was created to assess overall transition readiness, adolescent healthcare behavior, and familial involvement in healthcare. Participants were 48 adolescent kidney transplant recipients ages 15–21 years. Thirty-two (66.7%) of the adolescents' caregivers also participated. Adolescents completed the RTQ-teen, as well as self-reported measures of adherence and barriers to adherence. Parents completed the RTQ-parent. **Results** The RTQ showed good internal consistency, inter rater reliability, and demonstrated construct validity. Increased adolescent responsibility and decreased parental involvement predicted higher transition readiness. Additionally, greater adolescent adherence factors predicted greater transition readiness. **Conclusions** The preliminary psychometrics of the RTQ appear to be supported. Additional research should evaluate healthcare transition programming to identify clinical components related to improved transition readiness, adolescent responsibility, and medical outcomes.

Key words adolescent; healthcare responsibility; transition; transplant.

Introduction

Pediatric transplant recipients are living longer due to improved immunosuppression regimens and better allograft survival, with many of these patients surviving well into adulthood. In the past decade, the number of adolescent kidney transplants has increased 35% (Magee, Krishnan, Benfield, Hsu, & Shneider, 2008). The transition from pediatric to adult medical care is thus a growing area of clinical concern for transplant recipients and healthcare providers. Transition has been conceptualized as both a process and an event (Annunziato et al., 2007; Rodrigue & Zelikovsky, 2009). The process (i.e., transition) necessitates gradual, increased healthcare responsibility being turned over from the parent to the adolescent, while the event (i.e., transfer) occurs when the patient transfers from a pediatric to an adult healthcare team. Although transition is a prominent issue in healthcare, the available literature on healthcare transition is in its infancy, and the need for empirical and intervention research in this area is crucial. Transfer to adult centered care has been associated with a 30% allograft loss in kidney transplant patients 15-months posttransfer (Watson, 2000) and with increased nonadherence, lower serum immunosuppressant levels, and increased mortality in liver transplant recipients (Annunziato et al., 2007). Progress in transition research has been limited, in part, due to the lack of psychometrically valid measures. The current investigation addresses this deficit by evaluating a measure of transition readiness that assesses shifts in healthcare responsibility from parents to adolescent participants in a transitional program for adolescent kidney transplant recipients.

In a systematic review of transitional care research, While et al. (2004) proposed 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 programming provided. Only the Developmental Transitional Model hypothesizes a trajectory in which teens with chronic illnesses are actively assisted. In this model, adolescents are trained in healthcare management skills so that they may assume increased responsibilities and their parents or caregivers are encouraged to decrease their involvement accordingly. These increases in teen responsibility and decreases in parental involvement happen on an individualized basis during an extended period of clinical transition-focused care. Thus, increased adolescent responsibility develops as a process, in both a clinical and familial context, as the teen matures. The current investigation seeks to construct and analyze a measure of transition readiness for adolescents and young adults with kidney transplants based on the tenants of the Developmental Transitional model.

In some of the few empirical studies that have been conducted in this area, adolescent healthcare responsibility increased with age in both transplant and other pediatric populations (Annunziato et al., 2009; Fredericks et al., 2010; Pai et al., 2010; Palmer et al., 2004; Sawicki, Lukens-Bull, Yin, Demars, & Huang, 2009). Also, low levels of adolescent healthcare responsibility have been found to be a barrier to transfer (Freyer & Kibrick-Lazear, 2006). The importance of the transition process is indicated in a survey of over 18,000 adolescents with healthcare needs. Over 75% of the adolescents reported that their pediatric healthcare provider ''usually encouraged'' them to take responsibility for their own healthcare (Lotstein et al., 2009). 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 nonadherence, allograft dysfunction, and rejection (Horslen, Barr, Christensen, Ettenger, & Magee, 2007; Magee et al., 2008). Adolescent kidney transplant recipients have the highest rates of acute rejection and rejection-related graft loss of any age group (Bell et al., 2008). These adverse outcomes are believed to be related to high rates of medication nonadherence (Dobbels et al., 2010; Simons et al., 2008). Reported rates of medication nonadherence in adolescent solid organ transplant recipients vary widely due to the use of different assessment methods with reported rates ranging from 9% to 75% (Rodrigue & Zelikovsky, 2009). A meta-analysis of studies that used a variety of adherence measurement techniques found an average of 32% of adolescent kidney transplant recipients were nonadherent (Dobbels et al., 2010). In order to successfully transfer to adult care, teens must be adherent with medication regimens and able to assume responsibility for managing other aspects of their healthcare (e.g., call in refills, communicate with healthcare team).

In addition to encouraging responsible healthcare behavior by adolescents, parents and caregivers can give valuable support to safeguard against nonadherence throughout the transition process. Parental involvement in supervision or management of their adolescent's healthcare tasks can be a protective factor against nonadherence (Dobbels et al., 2010; Fredericks et al., 2010; Pai et al., 2010; Simons & Blount, 2007; Zelikovsky, Schast, Palmer, & Meyers, 2008). Further, although parental involvement is frequently lessened for older adolescents (Fredericks et al., 2010; Graue, Wentzel-Larsen, Hanestad, & Søvik, 2005; Naar-King et al., 2009; Palmer et al., 2004), age should not be seen as equivalent to adolescents' greater self-management ability or reliable performance of healthcare behaviors. Taken together, these data suggest that there is a dynamic, individualized balance between adolescent healthcare responsibility and parental involvement during the transition process, with the goal of teens taking increasing amounts of responsibility and parents becoming less involved over time, without compromising adherence.

A small number of studies assessing transition readiness or adolescents' healthcare responsibility have been conducted in other pediatric populations (Sawicki et al., 2009), including patients with cystic fibrosis (Patton, Graham, Varlotta, & Holsclaw, 2003) and HIV (Wiener, Battles, Ryder, & Zobel, 2007). However, none of these measures of transfer readiness assess parental involvement or adolescent autonomy in healthcare management, nor do they evaluate the amount of responsibility that parents and adolescents assume in carrying out these behaviors. Conversely, there are established and promising adolescent and parent report measures of allocation of treatment responsibility and medical self-management in the areas of diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990), HIV (Naar-King et al., 2009) and transplant (Fredericks et al., 2010; Pai et al., 2010), yet these measures do not assess adolescent and parent perceptions of transition or transfer readiness.

In preparation for the development of the Readiness for Transition Questionnaire (RTQ), an extensive review of the transition literature, adolescent medicine policy statements and position papers, and existing transition measures was conducted. Given that the literature has

conceptualized transition as a process as well as an event, Overall Transition Readiness on the RTQ was operationally quantified by assessing the adolescent's readiness to assume complete responsibility for their healthcare (e.g., process) and their readiness to transfer to adult medical care (e.g., event). The components of the RTQ (e.g., Adolescent Responsibility and parental involvement) were developed based on important constructs that had been discussed, but not measured, in association with transition readiness (Annunziato et al., 2007; McDonagh, 2005; Rodrigue & Zelikovsky, 2009; While et al., 2004). The specific items on the Adolescent Responsibility and parental involvement components were selected based on the 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 (Bell et al., 2008). The RTQ was written at a fifth-grade level to optimize readability, and the wording and content of items from the RTQ were then reviewed and approved by the multidisciplinary healthcare providers who designed an Adolescent Kidney Transplant Transition Clinic (AKTTC) at a large pediatric transplant center.

The purpose for the present study was to evaluate the RTQ, a novel measure of patients' and parents' perceived transition readiness for adolescent kidney transplant recipients. This study examined factors associated with transition readiness that have been identified in the theoretical and empirical literature, such as age, adolescent responsibility for healthcare, parental involvement, medication adherence, and barriers to adherence (Annunziato et al., 2009; Dobbels et al., 2010; Rodrigue & Zelikovsky, 2009; While et al., 2004; Zelikovsky et al., 2008). Additional factors of interest, which have been shown to be important in the literature on pediatric medication adherence were considered, including medication knowledge, appointment adherence, refill behavior, teen–parent relationship quality, and demographic factors (La Greca & Mackey, 2009). The RTQ scales are expected to display good internal consistency and inter rater reliability on teen and parent reports of each of the components (e.g., Overall Transition Readiness, Adolescent Responsibility, and parental involvement). Initial construct validity was expected to be supported by significant positive correlations between Overall Transition Readiness and Adolescent Responsibility on the RTQ, while parental involvement was expected to be negatively correlated with Adolescent Responsibility and Overall Transition Readiness. Initial criterion validity was expected to be supported by positive relationships between Overall Transition Readiness and greater teen healthcare responsibility, adherence, medication knowledge, self-refill behavior, older age, and greater familial relationship quality. Fewer adolescent-perceived barriers to adherence and lower parental involvement were hypothesized to also be predictive of higher RTQ Overall Transition Readiness.

Method
Participants and Setting

The participants in this study consisted of 48 adolescent and young adult kidney transplant recipients between the ages of 15 and 21 years who were enrolled in an AKTTC at a large pediatric transplant center. Of the 54 patients enrolled at the AKTTC, 48 agreed to participate in this study (88.9%). Adolescents were excluded from the study if they were a minor and a legal guardian could not be reached to provide consent ($N = 1$) or if they were deemed by the clinic psychologist to have significant cognitive impairments ($N = 2$). An additional two patients were not present in clinic during data collection. Only one patient (1.9%) declined participation. Thirty-two (66.7%) of the 48 adolescents' parents and caregivers also participated in the study. Parents were excluded if they were non-English speaking ($N = 4$). Twelve parents did not attend their teen's clinic appointment and either could not be reached by phone or did not return their packet after providing verbal consent by phone. The mean age of study participants was 18.6 years ($SD = 1.64$ years) with an average time since transplant of 5.73 years ($SD = 3.87$ years). Fifty-two percent of the sample was 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 the demographic and parent report measures.

The AKTTC was designed to facilitate the transfer of adolescent patients to adult care and to improve graft survival outcomes during the transition of healthcare responsibility process. AKTTC programming was intended to encourage patient autonomy and responsibility and improve adherence to medication and healthcare regimens by providing extensive, individually tailored behavioral and educational support to patients. Within the AKTTC, the patients have individual interactions with members of a multidisciplinary healthcare team, including a transplant coordinator, social worker, psychologist, clinical pharmacist, and pediatric nephrologist. At each clinic visit, the multidisciplinary healthcare team assesses and encourages medication adherence and knowledge, healthcare responsibility, psychosocial adjustment, and avoidance of risk behaviors.

Procedures

During their transition clinic visit, participants were recruited by research team members and presented with the appropriate informed consent, assent, and HIPAA documents prior to their participation in the study. Participants completed separate self-report measures assessing adolescent transition readiness, adherence, and barriers to adherence. Parents who attended their teen's clinic visit completed a demographics measure and a parent-report measure of adolescent transition readiness. 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 were asked semi-structured interview questions during their encounter with each member of the multidisciplinary team. Data from these encounter interviews assessing medication knowledge and relationship quality with parents were collected from the patients' electronic medical charts. In addition, relevant medical data were also collected from the patients' electronic medical records to assess adherence with clinic appointments and reported responsibility for calling in refills. Medication adherence was assessed through structured interview with the researcher at the end of the clinic visit. There was a $10 honorarium in the form of a gift card for adolescent participants and parking vouchers for parent participants. This study was approved by the governing Institutional Review Boards.

Instruments

Demographic Questionnaire and Medical Record Review

Parents completed a demographic questionnaire that included the adolescent age, ethnicity, and education, as well as the reporting caregiver's age, ethnicity, education, income, marital status, and relationship to the child. Medical chart review was used to assess the teens' clinic appointment adherence, and medication refill behavior, as well as teen–parent relationship quality. The AKTTC protocol calls for all teens to attend quarterly multidisciplinary clinic visits, thus clinic appointment adherence was calculated as a percentage by dividing the number of clinic visits the teen attended in the past year by five (number of possible appointments including their present visit) and multiplying by 100. Medication refill behavior was coded as a dichotomous variable and assessed by looking at whether the teen reported calling in their own medication refills per the results of their interview with the AKTTC pharmacist. Finally, during their standard clinic encounter with the pediatric psychologist, teens were asked to rate the quality of their relationship with their parents on a 5-point Likert-type 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; Adolescent Responsibility (AR), or the frequency of responsible adolescent healthcare behavior; and parental involvement, the frequency of familial involvement in their teen's healthcare. Adolescents and their caregivers completed parallel versions of the RTQ. Items from the RTQ-teen are listed in Table I. Adolescents' Overall Transition Readiness (Teen RTQ-Overall, Parent RTQ-Overall) scores could range from 2 to 8. The RTQ-Overall score was obtained by summing scores for the following items: ''Overall, how ready do you think you are (or your teen is) to assume complete responsibility for your healthcare?'' and ''Overall, how ready do you think you are (or your teen is) to transition from care at (specific name for this pediatric hospital) to adult care? 1-not at all ready, 2-somewhat ready, 3-mostly ready, 4-completely ready.'' Thus, higher Overall Transition Readiness scores indicate greater perceived readiness for healthcare responsibility as well as greater perceived readiness to transfer to adult care.

In addition to reporting on overall transition readiness, parents and teens also reported on the current frequency of adolescent responsibility and parental involvement for 10 specific healthcare behaviors (e.g., scheduling specialty care appointments, scheduling primary care appointments, attending medical appointments, calling in refills, taking medication daily, communicating with medical staff in person, communicating with medical staff via phone, explaining their medical condition to others, getting monthly labs, and knowing terms of insurance) identified in the literature as being key for successful transition to adult care (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-type scale with verbal anchors of ''1-not at all responsible'' and ''4-responsible almost all the time.'' Parents and teens also rated the frequency of parental involvement in each of the 10 healthcare behaviors (Teen RTQ-PI, Parent RTQ-PI) on a four point Likert-type scale with verbal anchors of ''1-not at all involved'' and ''4-involved almost all the time.'' Hence, the RTQ components of responsible adolescent healthcare

Table I. *Readiness for Transition Questionnaire-Teen (RTQ-teen)*

Please rate **YOUR RESPONSIBILITY** for the following healthcare behaviors...	1-Not responsible at all 2-Sometimes responsible 3-Often responsible 4-Almost always responsible			
Getting monthly labs	1	2	3	4
Taking medication daily as prescribed	1	2	3	4
Scheduling specialty care appointments (e.g., transition clinic)	1	2	3	4
Scheduling primary care appointments	1	2	3	4
Calling in or ordering refills	1	2	3	4
Explaining your medical condition to others	1	2	3	4
Knowing details about your insurance coverage (e.g., plan, copays, eligibility)	1	2	3	4
Attending medical appointments	1	2	3	4
Communicating with medical staff in person	1	2	3	4
Communicating with medical staff over the phone	1	2	3	4
Please rate **PARENT INVOLVEMENT** for the following healthcare behaviors...	1-Not involved at all 2-Sometimes involved 3-Often involved 4-Almost always involved			
Getting monthly labs	1	2	3	4
Taking medication daily as prescribed	1	2	3	4
Scheduling specialty care appointments (e.g., transition clinic)	1	2	3	4
Scheduling primary care appointments	1	2	3	4
Calling in or ordering refills	1	2	3	4
Explaining your medical condition to others	1	2	3	4
Knowing details about your insurance coverage (e.g., plan, copays, eligibility)	1	2	3	4
Attending medical appointments	1	2	3	4
Communicating with medical staff in person	1	2	3	4
Communicating with medical staff over the phone	1	2	3	4
Overall, how ready do you think you are...	1-Not at all ready 2-Somewhat ready 3-Mostly ready 4-Completely ready			
Assume complete responsibility for your healthcare?	1	2	3	4
Transfer from care at a children's hospital to adult care?	1	2	3	4

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behavior (RTQ-AR) and frequency of parental involvement in their teen's healthcare (RTQ-PI) each range from 10 to 40 with higher scores denoting increased adolescent responsibility or caregiver involvement.

Adolescent Medication Barriers Scale

The adolescent medication barriers scale (AMBS) was designed to measure perceived barriers to medication taking and was developed using an adolescent solid organ transplant sample (Simons & Blount, 2007). Items were rated on a 5-point Likert-type scale ranging from "1-strongly disagree" to "5-strongly agree." The 17 items on the AMBS showed strong internal consistency in the current sample (Cronbach's $\alpha = .907$).

Adolescent Report of Medication Adherence and Medication Knowledge

The Medical Adherence Measure, the Medication Adherence 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 Medication Knowledge portion of the MAM as part of the standard clinic encounter, and researchers administered the Medication Adherence portion of the MAM for study purposes at the end of the clinic visit. 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 multiplied by

100. Similar to a previous investigation, adherence in this sample was examined as a dichotomous variable with teens who reported missing any doses or taking more than 10% of doses late coded as nonadherent and teens who reported missing no doses and taking less than 10% of doses late coded as adherent (Simons et al., 2008). Medication knowledge was evaluated by asking the adolescents to recall the medication name, dosage, frequency, and indication. Responses were compared with the medical chart with a possible total score of 4 for each correct answer for each medication. An overall medication knowledge score was obtained by adding the score from each of the medications, dividing by four times the number of medications prescribed, and multiplying by 100. For data analysis, medication knowledge was examined as a dichotomous variable with teens exhibiting complete medication knowledge (e.g., 100%) versus less than complete medication knowledge.

Results
Overview of Analyses
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). Next, to establish initial reliability for the RTQ, correlations between teen and parent report on the RTQ components were calculated along with subscale internal consistencies. The overall construct validity of the measure was assessed by evaluating hierarchical linear regression models of Overall Transition Readiness using age, Adolescent Responsibility, and parental involvement as independent predictors (While et al., 2004). Pearson correlational analyses were conducted to investigate the criterion 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 parent reports of Overall Transition Readiness.

Preliminary Analyses
Preliminary analyses were conducted to examine relationships between demographic factors, parental participation, and outcome variables. For the adolescent sample as a whole ($N = 48$), there were no significant differences in gender, ethnicity, or time since transplant on Adolescent Responsibility, parental involvement, or Overall Transition

Readiness from the RTQ. The gender and ethnicity analyses were rerun on the subset of the 32 adolescents whose parents participated in the study, and no significant differences were found for gender or ethnicity for these RTQ variables. Age was not included in these preliminary analyses as it is used as a predictor in all validity analyses. Additional preliminary analyses were conducted to evaluate differences in demographic factors and the RTQ scales for adolescents whose parents participated ($N = 32$) versus those whose parents did not participate ($N = 16$). Results indicated that adolescents whose parents participated in the study were more likely to be younger adolescents (Participating: $M = 18.25$ years, $SD = 1.71$ years, nonparticipating: $M = 19.38$ years, $SD = 1.16$ years, $t = -3.09$, $p = .004$) and Caucasian ($t = 3.24$, $p = .003$). Analyses showed no significant differences on the Teen RTQ between teens whose parents participated versus teens whose parents did not.

Reliability Analyses
The relationships among the Teen RTQ and Parent RTQ variables were examined using Pearson product-moment correlation coefficients. Teen and parent reports of overall transition readiness (RTQ-Overall $r = .68$, $p \leq .01$), adolescent responsibility (RTQ-AR $r = .50$, $p \leq .01$), and parental involvement (RTQ-PI $r = .58$, $p \leq .01$) were significantly correlated across informants. In addition, all of the components of the RTQ demonstrated strong internal consistencies, including the two item Overall Transition Readiness component (Teen RTQ-Overall Cronbach's $\alpha = .79$; Parent RTQ-Overall Cronbach's $\alpha = .88$), the 10 item Adolescent Responsibility component (Teen RTQ-AR Cronbach's $\alpha = .86$; Parent RTQ-AR Cronbach's $\alpha = .85$) and the 10 item parental involvement component (Teen RTQ-PI Cronbach's $\alpha = .94$; Parent RTQ-PI Cronbach's $\alpha = .89$).

Validity Analyses
In order to provide initial validity data for the RTQ, Pearson correlational analyses were conducted to investigate the associations between psychosocial and adherence variables and adolescent and parent report of Adolescent Responsibility, parental involvement, and Overall Transition Readiness. Table II displays the bivariate relationships between the adolescent and parent report on the RTQ scales and age with specific indicators of transition readiness. Age was correlated with decreased teen and parent reports of parental involvement with older patients having less parental involvement. Age was not correlated with teen or parent report of Overall

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

Variable	1 Teen age	2 Teen RTQ- overall	3 Parent RTQ- overall
1. Teen age	–	.25	.13
($N = 48$, $M = 18.60$, $SD = 1.635$)			
2 Overall transition readiness-Teen report (teen RTQ-Overall)	.25	–	.68**
($N = 48$, $M = 5.96$, $SD = 1.487$)			
3. Overall transition readiness-Parent report (parent RTQ-Overall)	.13	.68**	–
($N = 32$, $M = 4.41$, $SD = 1.864$)			
4. Adolescent responsibility-Teen report (teen RTQ-AR)	.20	.68**	.65**
($N = 48$, $M = 32.96$, $SD = 5.731$)			
5. Adolescent responsibility-Parent report (parent RTQ-AR)	.19	.62**	.71**
($N = 32$, $M = 25.56$, $SD = 6.877$)			
6. Parental involvement-Teen report (teen RTQ-PI)	−.53**	−.39**	−.49**
($N = 48$, $M = 29.15$, $SD = 8.956$)			
7. Parental involvement-Parent report (parent RTQ-PI)	−.51**	−.39*	−.41*
($N = 32$, $M = 32.38$, $SD = 7.088$)			
8. Medication adherence (MAM)	.14	−.15	−.08
($M = 0.38$, $SD = 0.489$) Dichotomous classification			
($M = 3.51\%$, $SD = 13.27\%$) Doses missed			
9. Medication knowledge (MAM)	.09	.40*	.44*
($M = 0.44$, $SD = 0.501$) Dichotomous classification			
($M = 88.57\%$, $SD = 16.41\%$) Percent correct			
10. Overall medication barriers (AMBS)	.08	−.36*	−.33
($M = 32.08$, $SD = 12.687$)			
11. Appointment adherence	−.07	.20	.05
($M = 86.67$, $SD = 15.065$)			
12. Calls in refills	.50**	.36*	.48**
($M = 1.77$, $SD = 0.425$)			
13. Teen–parent relationship quality	−.09	.30*	.08
($M = 3.62$, $SD = 1.123$)			

Note. *$p \leq .05$, **$p \leq .01$.

Transition Readiness or Adolescent Responsibility. Teen and parent reports of Overall Transition Readiness were positively correlated with teen and parent reports of Adolescent Responsibility and negatively correlated with reports of parental involvement, such that patients who were deemed more transition ready also reportedly had more responsibility in their healthcare and less parental involvement. Additionally, parent report of Adolescent Responsibility was negatively correlated with teen report of parental involvement, showing that teens who were deemed to have more responsibility also reported less parental involvement.

Further correlational analyses were conducted to assess the degree to which scores on the RTQ were associated with healthcare and family variables (Table II). There were significant positive relationships between teen report of Overall Transition Readiness and adolescent medication knowledge, adolescent report of calling in refills, and teen–parent relationship quality; additionally,

there was a significant negative relationship between teen report of Overall Transition Readiness and adolescent report of medication barriers. There were significant positive relationships between parent report of Overall Transition Readiness and adolescent medication knowledge and adolescent report of calling in refills. Adolescent medication adherence was not significantly related to teen or parent report of Overall Transition Readiness.

To support the construct validity of the RTQ, two separate regression analyses were used to predict teen and parent report of Overall Transition Readiness. Hierarchical regression analyses were conducted so that the individual contributions of each related construct could be evaluated. 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. Both the adolescent [$R^2 = .53$, $F(3, 44) = 16.60$, $p < .001$,

Table III. *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 ($M = 18.60$, $SD = 1.635$)	.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 ($M = 18.17$, $SD = 1.682$)	.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**

Note. [a]B, unstandardized coefficients.
[b]SEB, standard error of unstandardized coefficients.
[c]β, standardized coefficients.
$*p \leq .05$, $**p \leq .01$, [†]$p \leq .10$.

Cohen's $f^2 = 1.13$] and parent models [$R^2 = .55$, $F(3, 28) = 11.49$, $p < .001$, Cohen's $f^2 = 1.22$] predicted a large portion of the variance in Overall Transition Readiness scores. Table III displays that age alone accounted for a nonsignificant 6% and 2% of the variance in teen and parent models, respectively. Adolescent responsibility accounted for a significant 42% and 48% increment to the variance accounted for in the teen and parent models, respectively. Decreased parental involvement accounted for an additional significant 5% of the variance in the teen model and a nonsignificant additional 5% in the parent model. Adolescent age, increased Adolescent Responsibility, and decreased parental involvement together accounted for 53% and 55% of the variance in the teen and parent models of Overall Transition Readiness, respectively.

To evaluate our hypotheses about adherence, health behavior, and familial relationship quality, two separate regression models were created to evaluate predictors of teen and parent report of Overall Transition Readiness on the RTQ. Again, hierarchical regression analyses were conducted so that the individual contributions of each related construct could be evaluated. In these models, adolescent age was entered on the first step. On the second step, all adherence-related variables that were statistically significant at the bivariate level were entered. In addition to these statistically significant variables, appointment adherence was also entered on the second step in the adolescent model for exploratory purposes, as appointment adherence is particularly important during transfer

to adult healthcare providers. For the parent model, adolescent report of medication barriers was also entered on the second step to parallel the adolescent model and because the correlation value 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. The adolescent model [$R^2 = .44$, $F(6, 41) = 5.50$, $p < .001$, Cohen's $f^2 = .786$] and parent model [$R^2 = .43$, $F(4, 27) = 5.12$, $p = .003$, Cohen's $f^2 = .754$] each predicted large portions of the variance in Overall Transition Readiness scores. Table IV displays that age accounted for a nonsignificant 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, clinic appointment attendance, 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, complete knowledge of their medication regimen, and better teen–parent relationship quality. For the parent report model of Overall Transition Readiness, Table IV displays that age accounted for a nonsignificant 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

Table IV. *Hierarchical Regression of Transition Readiness, Adherence Behaviors, and Teen–Parent Relationship*

	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 (M = 18.60, SD = 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	.5	.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**
Parent report of overall transition readiness (Parent RTQ; N = 32)						
Step 1: Adolescent age (M = 18.17, SD = 1.682)	.15	.2	.13	.02	.02	.54
Step 2: Adolescent age	−.15	.19	−.13			
Barriers to medication adherence (AMBS- total)	−.03	.02	−.20			
Medication knowledge (MAM- knowledge)	1.3	.56	.35*			
Calls in medication refills	1.87	.68	.47**	.43	.41**	5.12**

Note. [a]B, unstandardized coefficients.
[b]SEB, standard error of unstandardized coefficients.
[c]β, standardized coefficients.
*$p \leq .05$, **$p \leq .01$, [†]$p \leq .10$.

report of Overall Transition Readiness. Significant predictors in the final parent model included teens showing complete knowledge of their medication regimen and teens calling in their medication refills.

Discussion

The current study addresses a gap in the pediatric healthcare transition literature. Although a few measures of transition readiness exist in the literature (Patton et al., 2003; Sawicki et al., 2009; Wiener et al., 2007), none of these instruments were specifically developed for use with transplant recipients, assess both teen and parent report, and assess parental involvement in teens' healthcare activities. Thus, the RTQ provides a more complete picture by including multiple reporters and by detailing perceptions about overall transition readiness and adolescent and parent healthcare behavior. 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 α's ranging in the mid-.80s to low-.90s. Correlations across informants among the teen and parent completed scales were significantly large and in the expected direction. Also,

the construct validity of the components of the RTQ was further supported by the significant relationships with the other variables assessed in this investigation. The RTQ has the potential to be utilized by healthcare providers to quickly screen both patients' and parents' perceptions about transition readiness and identify potential deficits in healthcare responsibility and self-management prior to transfer to adult care. On the whole, the RTQ appears to be an easily administered, readable, and psychometrically supported measure which could be used clinically to assess transition readiness from parent and teen perspectives.

Similar to what has been hypothesized in position papers in the literature, our adolescent model of Overall Transition Readiness shows strong relationships with increased Adolescent Responsibility and decreased parental involvement (While et al., 2004). High adolescent responsibility and correspondingly lower parental involvement represent the goal of both preparing the adolescents to transfer to adult healthcare and for the successful management of 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 overall

transition readiness, it did account for 5% of the variance in both models. Thus, lack of significance may have been due to lower statistical power in the parent versus 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 particularly important in that increasing age was associated with both adolescent and parent reports of less parental involvement. Therefore, as the safety net of parental involvement decreases, assuring adolescents are equipped to assume responsibility for their own healthcare is critical. These findings are congruent with the transition literature which emphasizes the importance of adolescents' reliable performance of healthcare behaviors over chronological age as being indicative of transition and transfer readiness (Bell et al., 2008; Rodrigue & Zelikovsky, 2009).

This investigation identified several behavioral indices associated with perceived transition readiness. Transition readiness was 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 also having fewer factors that interfere with that regimen and independently acting 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 nonsignificant finding has to do with patients underreporting nonadherence to please healthcare providers or 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 has documented the importance of the high-quality parent–child relationships on adolescents' autonomy development (Steinberg, 2001). A high-quality family relationship may be facilitative of learning, growth, and independence in adolescents, while simultaneously being 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 their receptiveness to direct parental interventions such as prompting to ensure medication adherence.

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 caregivers. Therefore, the results of the parent models may not be reflective of the AKTTC as a whole, given adolescent age and ethnic differences found between parental responders versus nonresponders. Future studies should make intensive efforts to collect data from all parents and caregivers. Additionally, our information about family-relationship quality was based on Likert ratings by the teens during interviews with the clinic psychologist. Given that this one exploratory item was significant in the teen model, future studies should employ an evidence-based family functioning measure to assess both parent and teen opinions of relationship quality. Although this investigation collected data from over 85% of patients in the AKTTC affiliated with a large pediatric transplant center, only 48 adolescents participated. Future research should utilize multisite recruitment 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, as well as determine if these findings generalize to other pediatric kidney transplant recipients. Also, the literature conceptualizes transition as both a process and an event as patients move from pediatric to adult care. This investigation developed a measure with promising initial psychometrics, but longitudinal data to assess both sensitivity to change over time and participants' responsibility posttransfer were not collected. These should be included in future validation studies. Our ability to evaluate those end points awaits a sufficient number of patients graduating from this relatively new transition clinic. Future investigations utilizing the RTQ should evaluate its predictive validity by including follow-up of posttransfer 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. Additional research is needed to explore the potential clinical utility of using the RTQ to screen for transition readiness in other organ transplant recipients and pediatric populations, regardless of whether they are participating in formal transition readiness training.

In conclusion, this investigation addresses the importance of preparing adolescents and their families for transfer to adult care. Factors associated with readiness were identified. Though the empirical transition of healthcare responsibility literature may be sparse, it is clear that the medical and emotional costs of being

unprepared for transfer to adult services can be devastatingly high, with possible consequences including allograft loss and death (Annunziato et al., 2007; Watson, 2000). Additional research should evaluate transitional programming to identify which training components are related to improvements in transition readiness, adolescent responsibility, and medical outcomes. The RTQ could be utilized in studies of this kind and may help identify critical components that could refine transition readiness programming. Finally, future investigations should target parents of teens in transition and identify ways to assist parents in decreasing their involvement while simultaneously encouraging adolescent adherence and healthcare responsibility. With an increased knowledge of effective, family-centered transition programming, we can more confidently assist adolescent patients as they are getting ready to leave pediatrics for the world of adult care.

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