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Providers' assessment of transition readiness among adolescent and young adult kidney transplant recipients

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Abstract: The Readiness for Transition Questionnaire- provider version (RTQ-Provider) was developed to evaluate adolescent patients' transition readiness and healthcare behaviors from the perspective of the healthcare provider. The RTQ-Provider is a parallel version of the RTQ-Teen and RTQ-Parent completed by patients and parents. This study seeks to evaluate the psychometric properties of the RTQ-Provider and its utility as a clinical transition planning tool. Participants consisted of 49 kidney transplant recipients between the ages of 15 and 21. The RTQ-Provider was completed by the pediatric nephrologist and psychologist from the multidisciplinary healthcare team and compared to RTQ data from teens and parents. The RTQ-Provider demonstrated good-to-excellent internal consistency and interrater reliability. Construct validity was supported through significant predictive relationships between providers' perceptions of transition readiness and older patient age, increased patient healthcare responsibility, and decreased parent involvement in health care. By providing parallel teen, parent, and provider forms, the RTQ has the potential to foster open communication between patients, families, and healthcare team members regarding transition readiness. The study provides initial support for the RTQ-Provider as a clinical tool to assess providers' perceptions of transition readiness; however, future longitudinal research is needed to evaluate predictive validity following patients' transfer to adult care.

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In recent years, attention has increasingly focused on the process of transition to adult health care for pediatric solid organ transplant recipients. The salience of transition-related research and programming is made evident by the growing number of pediatric transplant recipients reaching young adulthood (1) as well as the increased risk of non-adherence and graft loss associated with the transfer to adult care (2–6). Whereas transfer is a discrete event referring to the change from pediatric to adult healthcare providers, transition is a "process that addresses the medical, psychosocial, and educational/vocational needs" of pediatric patients as they enter young adulthood (7).

Regular tracking of transition readiness is an integral component of optimizing health and transition outcomes so that barriers can be identified, treatment planning can be individually tailored, and progress can be monitored (8, 9). Successful evaluation of transition programming depends on assessment of patients' transition readiness using measures with demonstrated reliability and validity (10). Measuring transition readiness from multiple perspectives including

Abbreviations: AKTTC, AYA kidney transplant transition clinic; AYA, adolescent and young adult; EBA, evidence-based assessment; GSE, Generalized Self-Efficacy Scale; ICC, intraclass correlation coefficients; MAM, Medication Adherence Module; RTQ, Readiness for Transition Questionnaire.

patients, families, and healthcare providers is important for determining consensus, gathering potentially unique information, identifying intervention targets, tracking progress, and determining change following intervention (11).

The Readiness for Transition Questionnaire (RTQ) was designed to evaluate transition readiness perceptions, adolescent healthcare behavior, and familial involvement in health care (12). In the initial development of the RTQ, data from AYA kidney transplant recipients and their parents indicated that the RTQ-Teen and RTQ-Parent versions, with corresponding adolescent-report and parent-report measures, had good preliminary reliability and validity. In a recent review of transition readiness measures, the RTQ was one of only 10 assessment measures meeting criteria for "promising" assessment as defined by the American Psychological Association Division 54 EBA Task Force (13). The current investigation builds upon this previous work and evaluates a version of the RTQ for healthcare provider use, the RTQ-Provider. The RTQ-Provider is a parallel-worded version of the RTQ-Teen and RTQ-Parent designed to be completed by healthcare providers. At present, the RTQ is the only one of the 10 measures meeting criteria for a "promising" assessment instrument with a companion provider report version available. As the provision of transition-related services is ultimately dependent upon healthcare providers, assessment of their perceptions of patients' transition readiness is paramount.

The purpose for this study was to test the use of the RTQ-Provider within the original sample of adolescent kidney transplant recipients to evaluate its psychometric properties and utility as a clinical transition planning tool. Theory from the developmental transitional model proposes a trajectory in which AYAs are engaging in clinical transition programming to develop healthcare management skills, while their parents' or caregivers' involvement in their health care is scaled back accordingly. These theorized increases in AYA healthcare responsibility and decreases in parental involvement occur across time with active transition preparation and practice (14). Guided by theory from the developmental transitional model and developmental systems perspectives, we hypothesized that the overall construct validity of the RTQ-Provider would be supported by regression data showing significant relationships between RTQ-Provider overall transition readiness scores and older patient age, greater RTQ adolescent responsibility scores, and decreased RTQ parental involvement scores (14, 15). Concurrent validity was also hypothesized to be confirmed by regression data exhibiting significant relationships between RTQ-Provider overall transition readiness scores and older patient age, increased patient health knowledge and behaviors, and greater adolescent reported self-efficacy. Similar to the RTQ-Teen and RTQ-Parent, the RTQ-Provider version was hypothesized to demonstrate good internal consistency and interrater reliability on the overall transition readiness, adolescent responsibility, and parental involvement components.

Method

Setting and participants

The participants in this study consisted of 49 kidney transplant recipients between the ages of 15 and 21 participating in a multidisciplinary, AKTTC at a large pediatric transplant center. At this transplant center, all kidney transplant patients between the ages of 14 and 21 yr receive their ongoing nephrology care through the AKTTC. Of the 54 patients enrolled in the AKTTC, 49 agreed to participate in this study (90.7%). Adolescents were excluded from study recruitment 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). One patient was not present in clinic during the nine month recruitment period in the AKTTC and was thus not approached. Only one patient (1.9%) declined participation. Thirty-three (67.3%) of the participants' parents and/or caregivers also participated in the study. Parents were excluded if they were non-English speaking (N = 4). Participant demographic and medical characteristics are shown in Table 1. Further description of the clinic setting may be found in Gilleland et al. (12). Previously collected RTQ data from the original measure development cohort of teens (N = 48) and parents (N = 32) were used in this new investigation to evaluate the RTQ-Provider. Following analyses of our previous dataset, we had an additional family enroll in this RTQ-Provider study for a total of 49 AYA participants and 33 parent participants.

Procedures

During their AKTTC visit, participants were recruited and consented by research team members. Patients (N = 49) completed the RTQ-Teen and a self-report measure of self-efficacy. Parents (N = 33) completed the RTQ-Parent. Patients were also asked semi-structured interview questions during their visit. As part of their typical encounter with patients in the AKTTC, the pharmacist assessed medication knowledge and patients' reported responsibility for calling in refills. Medication adherence was also assessed through structured interview with a member of the research team. Relevant medical data were collected from the patients' electronic medical records to characterize patient medical history. A $10 honorarium in the form of a gift card was offered to participants, and free parking vouchers were offered to parent participants.

Following the patients' visits, the pediatric nephrologist (S.A.) and the pediatric psychologist (L.M.) from the multidisciplinary AKTTC team completed the provider version of the RTQ. The providers saw these AYA patients regu-

Table 1. Participant characteristics

Participants N = 49	M (s.d.) or N (%)
Age and time	
Current age	18.6 yr (±1.62)
Age at transplant	12.8 yr (±3.96)
Time since transplant	5.8 yr (±3.91)
Number of visits to transition clinic (AKTTC)	6.4 visits (±2.54)
Gender	
Male	26 (53.1%)
Female	23 (46.9%)
Ethnicity/Race	
Caucasian	28 (57.1%)
African American	15 (30.6%)
Hispanic	5 (10.2%)
Other	1 (2.0%)
Diagnosis	
Cystic/hereditary/congenital diseases	21 (42.9%)
Glomerulonephritis (GN)	19 (38.8%)
Secondary GN/vasculitis	3 (6.1%)
Other	3 (6.1%)
Missing	3 (6.1%)
Donor type	
Living	19 (38.8%)
Deceased	30 (61.2%)
MAM	
% of missed doses in past week	3.4% (±13.12%)
% of late doses in past week	4.7% (±7.12%)
% medication knowledge (e.g., name, dose, indication)	88.8% (±16.32%)
Medication refill responsibility	
Teen calls in own refills	37 (75.5%)
Parent calls in refills	11 (22.5%)
Missing	1 (2.0%)
GSE	
Teen self-report	33.8 (±5.27)

The GSE is scored on a four-point Likert-type scale rating from 1— "not at all true" to 4— "exactly true" and scores range from 10 to 40.

larly as part of the AKTTC, completed RTQ-Provider ratings independently of one another, and were unaware of study data results completed by participants and their parents. Both the pediatric nephrologist and the pediatric psychologist completed the RTQ-Provider questionnaire for each AYA participant. This research study was approved by the governing Institutional Review Boards.

Instruments

Demographic Questionnaire and Medical Record Review

Parents and/or patients completed a demographic questionnaire which included the AYA's age, gender, ethnicity, and education. Medical chart review was used to recover data on participants' medical history (e.g., diagnosis, time since transplant, donor type, number of visits to the AKTTC). Medication refill responsibility was coded as a dichotomous variable (i.e., "teen calls in own refills" or "parent calls in refills") and was assessed via medical record review of their clinical encounter with the pharmacist at the time of study.

Readiness for Transition Questionnaire (RTQ) (RTQ-Teen, RTQ-Parent, RTQ-Provider)

The RTQ was created to assess perceptions of transition readiness, responsible adolescent healthcare behavior, and family involvement in health care, with information on the original development of the RTQ constructs, items, and complete data available in Gilleland et al. (12). Central to the goal of this investigation, the RTQ-Provider was adapted to be a parallel version of the RTQ-Teen and the RTQ-Parent which captures healthcare providers' perceptions of their patients' overall transition readiness (RTQ-Provider overall readiness), frequency of responsible adolescent healthcare behavior (RTQ-Provider AR), and the frequency of familial involvement in patients' health care (RTQ-Provider PI). Adolescents and their caregivers completed appropriate versions of the RTQ as part of the original measure development study.

The RTQ-Provider overall readiness scores range from 2 to 8 and were obtained by summing scores for the following items: "Overall, how ready do you think the patient is to assume complete responsibility for their healthcare?" and "Overall, how ready do you think the patient is to transfer 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." For the RTQ-Provider AR scale, providers rated the frequency of adolescent responsibility for 10 healthcare behaviors on a four-point Likert-type scale with verbal anchors of "1 — not at all responsible" and "4 — responsible almost all the time." Similarly, for the RTQ-Providers PI component, providers rated the frequency of parental involvement in each of the 10 healthcare behaviors on a four-point Likert-type scale with verbal anchors of "1 — not at all involved" and "4 — involved almost all the time." The RTQ-Provider AR and RTQ-Provider PI components each range from 10 to 40 with higher scores denoting increased adolescent responsibility or caregiver involvement. The RTQ-Provider AR and PI items were identical to the original RTQ and focused on assessing adherence to laboratories, scheduling medical appointments, taking daily medications, communicating with medical staff, and other salient health self-management behaviors. The RTQ-Provider, RTQ-Teen, and RTQ-Parent versions each take approximately five min or less to complete.

Medical Adherence Measure—MAM

The Medical Adherence Measure, the MAM, is a semi-structured interview used to evaluate self-reported medication adherence and knowledge (16). The pharmacist administered the medication knowledge portion of the MAM as part of their standard AKTTC encounter with patients. For the purposes of this study, researchers administered the medication adherence portion of the MAM at the end of each patient's AKTTC visit. Medication knowledge was evaluated by asking AYAs to recall their medication names, dosages, frequencies, and indications. Participant responses were scored against their prescribed medications listed in their medical record, with a possible total score of 4 for each correct answer for each medication. An overall medication knowledge percentage score was created by adding the score from each of the medications, dividing by four times the number of medications prescribed, and multiplying by 100. Participants also reported on how many doses of their medication that they missed taking and how many doses they took "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.

GSE Scale

The AYA participants completed the GSE to assess for perceived self-competency to successfully deal with a variety of

life challenges (17). Each of the 10 items is scored on a four-point Likert-type scale rating from 1 — "not at all true" to 4 — "exactly true." The GSE had an internal consistency of 0.94 in this sample and has demonstrated acceptable reliability and construct validity in numerous worldwide populations (18, 19). The GSE contains items such as "I can always manage to solve difficult problems if I try hard enough" and "I am confident that I could deal efficiently with unexpected events" (17).

Statistical approach

Physician and psychologist RTQ component ratings for N = 49 AYA patients were averaged to create RTQ-Provider adolescent responsibility, RTQ-Provider parental involvement, and RTQ-Provider overall transition readiness scores for the purposes of demographic and regression analyses. Preliminary correlational and between-group analyses were used to assess relationships between demographic factors and RTQ-Provider scores. To establish initial reliability for the RTQ-Provider, internal consistencies for the physician and psychologist completed RTQ scales and interrater reliability were evaluated. Hierarchical linear regression modeling was employed to test our hypotheses that the overall construct validity of the RTQ-Provider would be supported by significant relationships between RTQ-Provider overall transition readiness scores and older patient age, greater RTQ adolescent responsibility scores, and decreased RTQ parental involvement scores (12, 14). Hierarchical linear regression analyses were also conducted to investigate the concurrent validity of the RTQ-Provider by determining associations between provider report of overall transition readiness and AYA age, self-efficacy, and medication knowledge and medication refill responsibility. Paired t-tests were conducted to evaluate differences between providers' and teens' perceptions of transition readiness. Given that the RTQ overall readiness component is comprised of the sum of two ordinal scores, we utilized nonparametric tests to evaluate these scores. For participants with parent data (N = 33), Friedman tests and follow-up pairwise comparison Wilcoxon tests were conducted to evaluate differences between providers', teens', and parents' perceptions of transition readiness. Holm–Bonferroni sequential corrections were employed to control for Type I errors among the follow-up pairwise comparisons. All statistical analyses were conducted with IBM SPSS® Statistics V21.0 (IBM Corp., Armonk, NY, USA).

Results

Descriptive demographic, medical, and self-reported patient data are shown in Table 1, while multiple reporters' RTQ descriptive data are shown in Table 2. Of note, those participants whose parents participated in the original study and provided RTQ-Parent data (N = 33, *mean age* = 18.25, s.d. = 1.71) were significantly younger than participants whose parents did not participate (N = 16, *mean age* = 19.37, s.d. = 1.12; p = 0.009, 95% CI: 0.30, 1.94). There were no significant differences in gender (p = 0.29–0.84), ethnicity/race (p = 0.13–0.56), age at transplant (p = 0.09–0.17), time since transplant (p = 0.67–0.92), diagnosis type (p = 0.20–0.30), donor type (p = 0.21–0.98), number of visits to the AKTTC (p = 0.11–0.19), or self-reported medication adherence (p = 0.49–0.98) on any of the component scores of the RTQ-Provider (e.g., adolescent responsibility, parental involvement, overall transition readiness). Age was not included in these preliminary analyses as it is used as a predictor in all regression analyses. Scores on the RTQ-Provider overall transition readiness component were significantly correlated with medication knowledge scores on the MAM (r = 0.41, p = 0.003) and medication refill responsibility, namely AYA report of calling in

Table 2. Descriptive data and reliability analyses for the RTQ-Provider

RTQ-provider component descriptive data—*M* (s.d.)	Physician (1)	Psychologist (2)	Provider (1 and 2 Average)	Teen*	Parent*
RTQ overall readiness	5.33 (±2.21)	5.84 (±1.83)	5.58 (±1.81)	5.96 (±1.47)	4.45 (±1.86)
RTQ adolescent responsibility	29.92 (±6.78)	33.76 (±4.89)	31.84 (±5.37)	32.92 (±5.68)	25.55 (±6.77)
RTQ parent involvement	24.76 (±8.91)	20.22 (±7.42)	22.48 (±7.53)	29.00 (±8.92)	32.18 (±7.06)

Internal consistency: Cronbach's alpha	Physician	Psychologist	Teen*	Parent*
RTQ overall readiness	0.96	0.99	0.79	0.88
RTQ adolescent responsibility	0.93	0.92	0.85	0.84
RTQ parent involvement	0.96	0.95	0.94	0.89

Interrater Reliability: ICCs (95% CI)	Physician and Psychologist *k* = 2, N = 49	Physician, Psychologist, Teen, and Parent *k* = 4, N = 33	Physician, Psychologist, and Teen *k* = 3, N = 49
RTQ overall readiness	0.73 (0.52–0.85)	0.79 (0.63–0.89)	0.72 (0.55–0.83)
RTQ adolescent responsibility	0.70 (0.23–0.86)	0.73 (0.48–0.86)	0.75 (0.57–0.86)
RTQ parent involvement	0.75 (0.37–0.88)	0.78 (0.55–0.89)	0.70 (0.41–0.84)

*Data for N = 48 of these teens and N = 32 of these parents were included in the sample analyzed in the manuscript by Gilleland et al. (12).

their own refills ($r = 0.63$, $p < 0.001$). In addition, the RTQ-Provider overall transition score was modestly associated with AYA self-reported self-efficacy scores on the GSE ($r = 0.26$, $p = 0.07$).

Reliability analyses

Table 2 displays the internal consistency and interrater reliability data for the RTQ-Provider scores. Data for the RTQ-Teen and RTQ-Parents are provided for comparison. The descriptive classifications of the RTQ's internal consistency and interrater reliability are based upon the guidelines set forth by Cicchetti (20). All of the components of the RTQ-Provider demonstrated excellent internal consistency with Cronbach's alphas ranging from 0.92 to 0.99 for physician and psychologist ratings. Interrater reliability was evaluated using a two-way mixed, absolute, average-measures ICCs to assess the degree that providers, teens, and parents provided consistency in their ratings on the RTQ overall, RTQ AR, and RTQ PI components. Three sets of ICCs were conducted, the first including physician and psychologist RTQ scores ($k = 2$) for all $N = 49$ AYA participants, a second including physician, psychologist, and teen RTQ scores ($k = 3$) for all $N = 49$ AYA participants, and the third that included parent RTQ scores ($k = 4$) along with the other RTQs for the $N = 33$ participants with parent data. The ICCs ranged from 0.70 to 0.79 indicating good-to-excellent interrater agreement between providers, teens, and parents on all RTQ components.

Validity analyses

As in the initial assessment of the RTQ, hierarchal regression analyses were used to evaluate the construct and concurrent validity of the RTQ-Provider (12). Physician and Psychologist ratings on the RTQ-Provider components were averaged for the purposes of all of the validity analyses. To determine the construct validity of the RTQ-Provider components, the individual and collective contributions of participant age, adolescent responsibility, and parental involvement were used to predict RTQ-Provider overall transition readiness scores (Table 3). Two models were built to evaluate RTQ-Provider construct validity, with Model 1 using RTQ AR and RTQ PI data from providers and Model 2 using RTQ AR and RTQ PI data from teens. Model 1 using solely provider data demonstrated that age, RTQ-Provider AR, and RTQ-Provider PI scores together predicted a large portion of the variance in provider perceptions of transition readiness ($R^2 = 0.81$, $F(3, 45) = 65.12$, $p < 0.001$, Cohen's $f^2 = 4.26$). Model 2 using a combination of provider and teen report also demonstrated that age, RTQ-Teen AR, and RTQ-Teen PI scores together predicted a large portion of the variance in provider perceptions of transition readiness ($R^2 = 0.59$, $F(3, 45) = 21.93$, $p < 0.001$, Cohen's $f^2 = 1.44$). Table 3 displays that age alone accounted for a significant 38% of the variance in the models. Adolescent responsibility accounted for a significant 40% and 17% increment to the variance in models 1 and 2, respectively. Decreased parental involvement accounted for an additional significant 3% of the variance in Model 1 and 5% in Model 2. Adolescent age, increased Adolescent responsibility, and decreased parental involvement were all significant predictors in the final models and together accounted for 81% and 59% of

Table 3. Construct validity analyses for the RTQ-provider

	B	SEB	β	R^2	ΔR^2	F
Model 1. Provider report of overall transition readiness						
Step 1: Adolescent age	0.69	0.13	0.62**	0.38	0.38**	29.20**
Step 2: Adolescent age	0.30	0.09	0.27**	0.78	0.40**	84.23**
Adolescent responsibility (RTQ-Provider AR)	0.24	0.03	0.72**			
Step 3: Adolescent age	0.20	0.09	0.18*	0.81	0.03*	65.12**
Adolescent responsibility (RTQ-Provider AR)	0.18	0.04	0.53**			
Parental involvement (RTQ-Provider PI)	−0.07	0.03	−0.30*			
Model 2. Provider report of overall transition readiness						
Step 1: Adolescent age	0.69	0.13	0.62**	0.38	0.38**	29.20**
Step 2: Adolescent age	0.60	0.11	0.54**	0.55	0.17**	27.68**
Adolescent responsibility (RTQ-Teen AR)	0.13	0.03	0.41**			
Step 3: Adolescent age	0.45	0.13	0.40**	0.59	0.05*	21.93**
Adolescent responsibility (RTQ-Teen AR)	0.12	0.03	0.39**			
Parental involvement (RTQ-Teen PI)	−0.05	0.02	−0.26*			

B, unstandardized coefficients; SEB, standard error of unstandardized coefficients; β, standardized coefficients.
*$p \leq 0.05$, **$p \leq 0.01$.

Table 4. Concurrent validity analyses for the RTQ-provider

	B	SEB	β	R^2	Δ R^2	*F*
Provider report of overall transition readiness: concurrent validity						
Step 1: Adolescent age	0.69	0.13	0.62**	0.38	0.38**	28.77**
Step 2: Adolescent age	0.51	0.12	0.46**	0.60	0.22**	22.21**
Medication knowledge (MAM knowledge %)	1.10	0.53	0.26*			
AYA medication refill responsibility (Yes vs. No)	0.04	0.01	0.32**			
Step 3: Adolescent age	0.52	0.11	0.47**	0.67	0.07**	22.06**
Medication knowledge (MAM knowledge %)	1.23	0.49	0.29*			
AYA medication refill responsibility (Yes vs. No)	0.03	0.01	0.27*			
GSE	0.09	0.03	0.27**			

B, unstandardized coefficients; SEB, standard error of unstandardized coefficients; β, standardized coefficients.
*$p \leq 0.05$, **$p \leq 0.01$.

the variance in the models of provider perceptions of overall transition readiness.

To evaluate our hypothesis that the RTQ-Provider's concurrent validity would be supported, a hierarchical regression model was created to evaluate the individual contributions of patients' health knowledge, medication adherence, and self-efficacy in relation to RTQ-Provider overall transition readiness scores. Adolescent age was entered on the first step. Adolescent medication knowledge and medication refill responsibility were entered on the second step. Finally, adolescent-reported GSE was entered on the third step. Table 4 shows that age, medication knowledge, medication refill responsibility, and self-efficacy together predicted a large portion of the variance in RTQ-Provider overall transition readiness scores (R^2 = 0.67, F(4, 43) = 22.06, $p < 0.001$, Cohen's $f^2 = 2.03$). Age accounted for a significant 38% of the variance in provider report of overall transition readiness, with medication factors and self-efficacy adding significant 22% and 7% increments, respectively. Age, medication knowledge, medication refill responsibility, and self-efficacy scores were all significant predictors in the final regression model and together accounted for 67% of the variance in provider report of overall transition readiness.

Perceptions of transition readiness

Transition readiness perceptions were evaluated for all participants (N = 49), as well as for the subset of participants with available parent data (N = 33). AYAs reported greater readiness to assume complete responsibility for health care than their providers (p = 0.025, 95% CI: 0.04, 0.59). No differences were found between AYA and provider perceptions of readiness to transfer to adult care. For participants with parent data, a significant difference was found for providers', AYAs', and parents' perceptions of readiness to assume responsibility for health care (χ^2 (2, N = 33)= 20.85, $p < 0.001$, Kendall's W = 0.32). Follow-up pairwise comparisons indicated that AYAs reported significantly greater readiness to assume responsibility than did their parents ($p < 0.001$) and providers (p = 0.046) and that providers reported greater readiness for responsibility than did parents (p = 0.034). A significant difference was also found between reporters' perceptions of readiness to transfer to adult care (χ^2 (2, N = 33) = 15.02, p = 0.001, Kendall's W = 0.23). Follow-up pairwise comparisons indicated that AYAs reported significantly greater readiness to transfer than did their parents (p = 0.003). No statistical differences were found between AYA and provider reports or parent and provider reports of readiness to transfer.

Discussion

With the development of a provider-report assessment, the RTQ provides clinicians with an option for capturing a more complete picture of patients' health self-management abilities through the inclusion of data from multiple reporters that details providers', teens', and parents' perceptions about overall transition readiness, adolescent healthcare responsibility, and parent involvement in health care. Although several measures of transition readiness have been published in the literature (13), the RTQ is unique in that it can be used to assess provider, teen, and parent report. In their Clinical Report on Health Care Transition, the joint committee of the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommended that healthcare providers conduct ongoing assessments of patients' transition readiness and use

these assessments to discuss transition planning with patients and their families (8). The RTQ has the potential to be utilized by healthcare teams to screen for transition readiness using patients', parents', and providers' perspectives and to facilitate patient–family–provider communication around transition planning.

Similar to the teen and parent versions of the RTQ, the preliminary psychometrics of the RTQ-Provider appear to be robust (12). The RTQ-Provider components demonstrated good-to-excellent internal consistency and interrater reliability. Construct validity was supported through significant predictive relationships between providers' perceptions of transition readiness and older patient age, increased patient healthcare responsibility (RTQ AR), and decreased parent involvement in health care (RTQ PI). These relationships followed the patterns expected based on developmental systems theory and the developmental transitional model (15). Interestingly, older patient age remained a significant predictor of providers' perceptions of transition readiness (Table 3), despite not serving as a significant predictor of teen or parent perception of transition readiness (12). Findings suggest that providers rely to a greater extent on chronological age to determine transition readiness than do patients and families, perhaps because providers are often urged to attend to institutional policies and resource constraints which may require transfer by a set chronological age as opposed to developmental maturity.

In addition, the construct validity models were significant using both provider report of individual patients' AR and PI (Table 3; Model 1) and teen report of their own AR and PI (Table 3; Model 2). Predicting provider's perception of transition readiness using teen report of their own AR and PI avoids the potential for same-reporter variance bias present when using only one reporter and offers stronger evidence of construct validity. Concurrent validity was also supported by significant predictive relationships between providers' perceptions of transition readiness and patients' demonstration of medication knowledge, responsibility for refills, and increased general self-efficacy. By demonstrating knowledge and skill attainment, AYAs are exhibiting behaviors showing providers that they are more ready to manage their health care and transfer to adult care. Medication adherence was not associated with provider's perception of transition readiness, which may be indicative of adherence being a challenge across the life course for transplant recipients and not necessarily a practical requirement for transition (21).

Although there was general concordance between reporters and good interrater reliability on the RTQ, there were some differences in AYAs', parents', and providers' perceptions of transition readiness which are important to highlight. In general, AYAs reported significantly greater transition readiness than did their parents. Providers' and parents' ratings of readiness to transfer were similar, yet providers reported significantly greater AYA readiness to assume responsibility for health care than did parents. In the same way, providers' and AYAs' ratings of readiness to transfer were similar, yet AYAs reported greater readiness to assume complete responsibility for health care than was reported by providers. It remains unclear whether these differences reflect teen overestimation of their abilities and 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 non-adherence. In contrast, 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. Taken together, these data underscore that the process of transition of healthcare responsibility and transfer to adult care are not synonymous and also emphasize the importance of assessing transition readiness from multiple perspectives.

This study offers an important contribution to the body of literature on the assessment of transition readiness for pediatric transplantation patients; however, limitations and suggestions for future research should be considered. First, replication of study findings with a larger sample and a greater number of providers is necessary to provide evidence as to generalizability. This measure was tested in a multidisciplinary clinic setting in which multiple providers were focused on assessing and preparing patients for transition readiness. Thus, this setting may have lent itself to more concordant measures between the psychologist and nephrologist. Utilization of the RTQ by multiple providers in a non-multidisciplinary, less collaborative clinic might result in higher discordance and, in turn, highlight areas

where the healthcare team, patient, and parent might need to work together to improve transition readiness. In addition, the RTQ-Provider should be evaluated with healthcare providers from additional disciplines involved in the care of pediatric transplant patients such as nursing, pharmacy, and social work. As with any study utilizing self-report data, there is always a possibility of biased reporting; thus, the self-report data from the AYAs and parents may be limited by individual biases or social desirability. At present, the RTQ is available in English only. Although we had only English-speaking or bilingual AYA participants, the current study is limited by the exclusion of Spanish-speaking parents (N = 4). While we did not find a relationship between self-reported medication adherence and RTQ-Provider scores, future studies may also consider evaluating RTQ scores along with participants' immunosuppressant lab values to further explore the relationships between transition readiness and adherence. The current study offers promising initial psychometrics for the RTQ-Provider, although longitudinal data are needed to evaluate predictive validity through patients' post-transfer medical and psychosocial outcomes as well as the measure's sensitivity to change. Results of these longitudinal studies across the transition period can be used to develop clinical cutoff scores to guide treatment planning and decision-making. At the time of this study's development, there were no other published measures of transition readiness; thus, future studies using the RTQ may wish to evaluate convergent validity via testing the RTQ alongside other currently available measures of transition readiness. To assess generalizability beyond use with AYA kidney transplant recipients, the RTQ-Provider should also be evaluated in other organ transplant recipients and pediatric chronic illness groups.

In conclusion, the current study provides initial support for the RTQ-Provider as a clinical tool to assess for provider's perceptions of transition readiness. Based on the findings of this investigation, it is expected that the RTQ-Provider will have clinical utility both for assessment with individual patients during their transition processes and at the group level to evaluate transitional programming. By providing parallel teen, parent, and provider forms, the RTQ has the potential to foster open communication between patients, families, and healthcare team members regarding transition readiness and the factors that determine perceptions of readiness. If any stakeholder in this process identifies deficits in self-management, discrepancies can be openly discussed and addressed prior to transfer to adult care to maximize the likelihood of successful transition.

Authors' contributions

Jordan Gilleland Marchak: Participated in concept/design, data analysis/interpretation, drafting article, critical revision of article, approval of article, statistics, and data collection; Bonney Reed-Knight: Participated in concept/design, data analysis/interpretation, drafting article, critical revision of article, approval of article; Sandra Amaral: Participated in concept/design, data analysis/interpretation, critical revision of article, approval of article, and data collection; Laura Mee: Participated in concept/design, critical revision of article, approval of article, and data collection; and Ronald Blount: Participated in concept/design, data analysis/interpretation, critical revision of article, and approval of article.

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References

1. Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR). OPTN/SRTR 2012 Annual Data Report Rockville, MD2014.
2. Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA, Shemesh E. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. Pediatr Transplant 2007: 11: 608–614.
3. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. Pediatr Nephrol 2000: 14: 469–472.
4. Foster BJ, Platt RW, Dahhou M, Zhang X, Bell LE, Hanley JA. The impact of age at transfer from pediatric to adult-oriented care on renal allograft survival. Pediatr Transplant 2011: 15: 750–759.
5. Samuel SM, Nettel-Aguirre A, Soo A, Hemmelgarn B, Tonelli M, Foster B. Avoidable hospitalizations in youth with kidney failure after transfer to or with only adult care. Pediatrics 2014: 133: e993–e1000.
6. Foster B. Heightened graft failure risk during emerging adulthood and transition to adult care. Pediatr Nephrol 2015: 30: 567–576.
7. Fredericks EM, Dore Stites D, Well A, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. Pediatr Transplant 2010: 14: 944–953.
8. American Academy of Pediatrics AAoFP, American College of Physicians TCRAG. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2011: 128: 182–200.
9. Pai ALH, Ingerski LM, Perazzo L, Ramey C, Bonner M, Goebel J. Preparing for transition? The allocation of oral medication regimen tasks in adolescents with renal transplants. Pediatr Transplant 2011: 15: 9–16.
10. Schwartz L, Tuchman L, Hobbie W, Ginsberg J. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. Child Care Health Dev 2011: 37: 883–895.
11. Schwartz LA, Daniel LC, Brumley LD, Barakat LP, Wesley KM, Tuchman LK. Measures of readiness to transition to

adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. J Pediatr Psychol 2014: 39: 588–601.
12. Gilleland J, Amaral S, Mee LL, Blount RL. Getting ready to leave: Transition readiness in adolescent kidney recipients. J Pediatr Psychol 2012: 37: 85–96.
13. Schwartz LA, Daniel LC, Brumley LD, Barakat LP, Wesley KM, Tuchman LK. Measures of readiness to transition to adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. J Pediatr Psychol 2014: 39: 588–601.
14. While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care: Synthesis of the evidence. Child Care Health Dev 2004: 30: 439–452.
15. Reed Knight B, Blount RL, Gilleland J. The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. Fam Syst Health 2014: 32: 219–234.
16. Zelikovsky N, Schast AP. Eliciting accurate reports of adherence in a clinical interview: Development of the Medical Adherence Measure. Pediatr Nurs 2008: 34: 141–146.
17. Schwarzer R, Jerusalem M. Generalized Self-Efficacy Scale. In: Johnston M, Wright S, Weinman J, eds. Measures in Health Psychology: A User's Portfolio. Windsor, UK: Nfer-Nelson, 1995.
18. Luszczynska A, Scholz U, Schwarzer R. The general self-efficacy scale: Multicultural validation studies. J Psychol 2005: 139: 439–457.
19. Scholz U, Doña BG, Sud S, Schwarzer R. Is general self-efficacy a universal construct? Psychometric findings from 25 countries. Eur J Psychol Assess 2002: 18: 242–251.
20. Cicchetti DV. Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. Psychol Assess 1994: 6: 284–290.
21. Russell CL, Ashbaugh C, Peace L, et al. Time-in-a-bottle (TIAB): A longitudinal, correlational study of patterns, potential predictors, and outcomes of immunosuppressive medication adherence in adult kidney transplant recipients. Clin Transplant 2013: 27: E580–E590.