Pediatr Transplantation 2013: 17: 307–314

Pediatric Transplantation
DOI: 10.1111/petr.12064

Measuring family management of transplant tasks: The transplant responsibility questionnaire

Kullgren KA, Hmiel SP, Gevers A. Measuring family management of transplant tasks: The transplant responsibility questionnaire.

Abstract: Little is known about how parents and youth perceive their roles in post-transplant management and how this relates to post-transplant adherence. The goals of this study are to (1) describe a new measure, the TRQ, (2) to describe parent and child performance on the TRQ, and to (3) determine the relationship between the TRQ and adherence. We hypothesized that older youth would describe higher post-transplant self-care behaviors, parents would underestimate youth self-care, and greater parent involvement would be associated with better adherence. Participants included 59 parent–child dyads. Inclusion criteria included: (i) youth aged 7–18 yr and (ii) at least three months post-kidney or post-liver transplant. Parents and youth completed the TRQ, and adherence was measured by s.d. of sequential immunosuppressant blood levels. Youth perceived greater levels of self-care than their parents perceived. Older youth reportedly engaged in more self-care than younger youth. Less than 25% of the sample was non-adherent, and non-adherence was unrelated to performance on the TRQ. The TRQ may have utility as a clinical tool to address areas for improvement in youth self-care. The high degree of parental involvement likely explains the high degree of adherence in this sample.

Kristin A. Kullgren[1], S. Paul Hmiel[2] and Anik Gevers[3]

[1]Department of Pediatrics & Communicable Diseases, University of Michigan, Ann Arbor, MI, USA, [2]Department of Pediatrics, St. Louis Children's Hospital, Washington University School of Medicine, St. Louis, MO, USA, [3]Gender and Health Research Unit, Medical Research Council, Cape Town, South Africa

Key words: organ transplant – pediatric – adherence – responsibility

Kristin A. Kullgren, Division of Child Behavioral Health, University of Michigan Health System, 1924 Taubman Center, SPC 5318, 1500 East Medical Center Drive, Ann Arbor, MI 48109-5318, USA
Tel.: 734-936-7967
Fax: 734-936-6897
E-mail: kullgren@med.umich.edu

Accepted for publication 24 January 2013

Youth receiving a solid organ transplant in adolescence tend to have poorer five-yr graft outcomes than any other pediatric age-group (1). In kidney transplant, for example, the five-yr graft survival of teens 11–17 yr old is worse than any other age-group with the exception of adults older than 65 yr (1). Non-adherence with the complex post-transplant medical regimen is common and is considered the likely primary contributor to graft failure in pediatrics (2). Depending on the measurement strategy and source, reported levels of non-adherence following pediatric solid organ transplant range from about 25 to 63% (3–8). These data highlight the need for a better understanding of the factors that impact post-transplant management within families so that intervention strategies can be developed to improve adherence and thereby improve graft outcomes.

One factor that may impact post-transplant adherence is the parent's, child's, and medical team's changing expectations of illness task management, that is, they assume that the child will take on higher levels of self-care for his or her chronic illness as he or she gets older (9). Following liver transplant, for example, this transition of increased child responsibility has been found to begin as early as age nine yr, with the average family allocating responsibility to the child for medication taking around age 12 yr (2). This shift in responsibility often means that youth are responsible for remembering to take their medications on their own, without parental supervision or reminders. Studies have shown that older youth tend to display more non-adherence behaviors than younger patients following transplant (10). In fact, rates of non-adherence following renal and liver transplant are highest in those youth responsible for their own medications (7, 11). Having some parental involvement,

---

Abbreviations: CTRQ, child transplant responsibility questionnaire; HSD, honestly significant difference; PTRQ, parent transplant responsibility questionnaire; TRQ, transplant responsibility questionnaire.

whether full or partial, may explain better post-transplant medication adherence (11). Maintaining parental involvement is challenging in light of youths' growing need for autonomy, as well as increased demands from the medical team for youth to become more independent with their health care. Given that family factors such as poor parent–child communication (8) and reduced family cohesion (4) are related to poorer adherence following pediatric transplant, it is conceivable that when parents and youth have difficulty working together, transplant tasks do not get done or they are not done consistently. However, little is known about how family and youth division of post-transplant task responsibility relates to adherence outcomes.

In other pediatric chronic illness populations, measures have been developed to assess how parents and youth work together to manage the complex medical regimens. Such measures exist in the asthma (Asthma Responsibility Questionnaire) (9), diabetes (Diabetes Family Responsibility Questionnaire) (12), and cystic fibrosis literatures (Cystic Fibrosis Family Responsibility Questionnaire) (13). Several relevant themes have emerged from studies of these measures. First, it is common for parents to underestimate the amount of responsibility that children perceive they are assuming in their own self-care. This discordance in parent and child reports, while common, can be especially problematic when a caregiver overestimates the child's perceived level of responsibility (14). This type of disagreement leaves open the possibility that no one is managing the child's illness tasks, resulting in poorer adherence (12). Second, while adolescents usually become more involved in their own care as they get older, it is typical for their caregivers to continue to be very involved in their care; few teens assume total responsibility of their illness care (13, 15).

Research in the area of allocation of responsibility in pediatric transplant is in its infancy, with a few recent studies looking at treatment responsibility in renal (16, 17) and liver transplant populations (18). These studies are limited in their population scope, only focusing on specific organ groups rather than across groups of youth following organ transplant. The ability to have a measure that could be used across different organ transplant groups would allow for continuity of care for youth who have multi-organ transplants and in hospital settings where there is consistent staff across organ groups. This is especially important with many institutions moving toward integrated transplant centers. An additional limitation of previous studies is that with the exception of Pai et al. (16), the focus has been on allocation of responsibility in adolescents following transplant. It remains important to study the roots of allocation of responsibility in childhood given data suggesting that youth begin acquiring self-care skills at a very early age (2) and the suggestion that the process of preparation for transfer to adult care should begin in childhood (19).

In light of the gaps in the research, there are three aims to the current study. The first (aim 1) is to describe the TRQ, a new measure developed to assess parent and child perceptions of their management of post-transplant tasks. The second aim (aim 2) is to describe and compare performance on the TRQ from parent and youth perspectives. The third goal (aim 3) is to determine the relationship between the TRQ and immunosuppressant medication adherence. Based on the previous literature on pediatric chronic illness task responsibility, it was hypothesized that: (i) older children would perceive relatively higher rates of personal responsibility for post-transplant self-care behaviors, (ii) parents would underestimate youth self-reported self-care, and (iii) greater parent involvement would be associated with better post-transplant immunosuppressant adherence.

Materials and methods

Participants

Participants were recruited from a large pediatric transplant center in the Midwest United States. Inclusion criteria included: (i) patients aged 7–18 yr and (ii) at least three months post-kidney or post-liver transplant. Families were excluded from the study if they did not have sufficient English literacy to complete study measures or if the child had significant developmental delay.

Eligible participants were identified through the transplant coordinators of the hospital's pediatric kidney and liver transplant programs. Sixty-three families agreed to participate (Table 1). Of these families, four parents consented to their child's participation, but they were either unwilling (i.e., refused) or unable (i.e., had to leave clinic, did not have their glasses) to complete the parent component at the time of their child's clinic appointment. Therefore, the analyses with child-only information include 63 youth and analyses with parents only or the parent–child dyad include 59 participants. There were no significant differences in any of the demographic, medical or outcome variables between the liver and kidney transplant groups.

Procedure

These data were gathered as part of two larger studies (20, 21), both approved by the Human Research Protection Office of Washington University School of Medicine. Recruitment letters were sent to eligible families describing the study and inviting them to participate during their scheduled upcoming transplant follow-up clinic

Table 1. Participant demographic and medical data (n = 63)

	Mean (s.d.)	Percent	n
Age	13.5 (3.3)		
Female		44.4%	28
Caucasian American		81.0%	51
Monthly family income	\$4922.3 (\$3757.1)		
Parent marital status			
Married		77.4%	41/53
Parent education			
Some college or more		66.0%	31/50
Organ transplanted			
Kidney		50.8%	32
Liver		49.2%	31
Time since transplant (months)	65.8 (53.6)		
Age at transplant (yr)	8.5 (5.7)		
Immunosuppressant medication			
Tacrolimus		87.3%	55
Cyclosporine		7.9%	3
Sirolimus		4.8%	5

n = 63 unless noted.

appointment. Families were then approached during a routine transplant clinic visit by a trained psychology graduate or undergraduate research assistant who administered informed consent/assent and a brief demographic interview and provided the study measures. Additional measures were completed at the time of this visit as part of the larger studies in which this study was embedded. Embedding this study in the other studies limited the variables measured, particularly those that could provide external validation for the TRQ.

Caregivers and youth independently completed the study measures before, during, or after their clinic appointment. Demographic (i.e., ethnicity, child and caregiver educational status, occupation, family income, marital status, etc.) and medical data (i.e., organ transplanted, date of transplant, donor source, medications, etc.) were obtained from a questionnaire completed by the caregiver and review of the youth's medical record.

Measures

Immunosuppressant levels

Immunosuppressant trough blood levels are drawn at every clinic visit and at prescribed intervals as part of the child's standard post-transplant care. For the purpose of our study, up to six (min = 3, mode = 6, mean = 5.76, s.d. = 0.66) outpatient blood draws no >12 months prior to and including the study clinic visit were obtained. These data were extracted from the child's medical record. For youth with more than six data points over the prior year, only the six most recent were used. Blood levels obtained at sick visits and inpatient admissions were excluded from the analysis.

Standard deviation (s.d.) of consecutive blood levels of immunosuppressant medication was used to quantify non-adherence to the immunosuppressant regimen. Higher s.d. reflects increased variability in immunosuppressant blood levels and potentially more erratic medication taking. For the purposes of this study, a s.d. of 2.5 was used to quantify the cutoff for optimal adherence. This cutoff was chosen as Stuber et al. (22) found that liver transplant recipients with a s.d. of ≥ 2.5 had about eight times greater odds of a rejection episode than those below that cutoff. It is important to note that this cutoff has only been validated in the pediatric liver transplant population; therefore, use of this cutoff for kidney transplant recipients is exploratory. However, there are a growing number of studies using tacrolimus s.d. as a measure of adherence in kidney transplant (23, 24). Youth prescribed either cyclosporine or sirolimus for immunosuppression were excluded from all adherence analyses. Based on this criterion, 22.4% of participants prescribed tacrolimus were classified as non-adherent.

Transplant responsibility questionnaire

The TRQ was developed for this study based on similar responsibility questionnaires in the asthma (Asthma Responsibility Questionnaire) (14), diabetes (Diabetes Family Responsibility Questionnaire) (12), and cystic fibrosis (Cystic Fibrosis Family Responsibility Questionnaire) (13) literature. As with the previous chronic illness responsibility questionnaires, the items of the TRQ were developed in collaboration with experts in pediatric transplant care including transplant physicians, nurse coordinators, social workers, dieticians, child life workers, pediatric psychologists, and families. It should be noted that with the exception of the hepatologists and nephrologists, the staff of our center's liver and kidney transplant clinics overlapped. The goal was to develop a measure to accurately and concisely reflect the common components of the complex post-transplant regimen for both the liver and kidney transplant recipients.

TRQ items were developed in the following manner: (i) items from existing responsibility measures were reviewed for relevance to the pediatric post-transplant regimen; (ii) stems of relevant items were reworded to match transplant-specific language and tasks; (iii) irrelevant items were excluded; and (iv) additional items unique to solid organ transplant were added. The questionnaire was then reviewed by transplant experts and families to determine whether the list of tasks accurately reflected the pediatric post-transplant regimen demands. This process resulted in a 14-item questionnaire. Child (CTRQ) and parent (PTRQ) versions were developed differing only in that the language on the CTRQ was simplified and presented in the first person. The measures are presented in Appendices A and B.

Parents and children independently complete the 14-item TRQ. Responses on the questionnaire are rated on the following 5-point scale: 1 = parent does (the task) all the time, 2 = parent most of the time, 3 = child and parent equally, 4 = child most of the time, and 5 = child does (the task) all the time. An average score (range 1–5) is calculated to reflect the overall amount of responsibility shared by the caregiver and child. Lower item and overall scores suggest the perception that the parent is primarily managing most tasks, and higher scores indicate the perception that the child is managing most tasks.

Data analysis plan

All analyses were conducted using SPSS version 16.0 statistical package (IBM, Armonk, NY, USA). Data were scored and entered into a database by trained undergraduate or graduate students in psychology. Aim 1 (TRQ description): Measures of internal consistency were used to examine the TRQ's reliability. Aim 2 (performance on the TRQ): Average TRQ scores were tabulated, and t-tests were used to compare parent and child report. One-way ANOVAs and Tukey's HSD were used to assess differences on the TRQ by age-group. Aim

3 (association between TRQ and adherence): Bivariate correlations were calculated between TRQ average scores, caregiver–child TRQ discrepancy scores, and adherence. One-way ANOVAs were used to assess differences between adherent and non-adherent groups on the TRQ. All adherence analyses were conducted only with the youth prescribed tacrolimus ($n = 55$).

Results

Aim 1: TRQ description

The 14-item TRQ took approximately five min to complete. There were no complaints of misunderstanding items. The following items were omitted by participants (total combined parent and child respondents $n = 122$): item #7 $n = 1$, #8 $n = 2$, #9 $n = 1$, #10 $n = 2$, #11 $n = 1$, #12 $n = 3$, #14 $n = 1$. All items were kept in the final analyses as no item had a substantial number of omissions. Pairwise deletion was used when analyzing any items with missing data.

Reliability analysis

Cronbach's alpha was calculated as a measure of internal consistency. The PTRQ yielded an alpha of 0.895, while the CTRQ yielded an alpha of 0.900 indicating strong internal consistency for both measures. For both the parent and child versions of the TRQ, no individual item's alpha was low enough that deletion would improve the reliability of the questionnaire, with all alpha coefficients on both versions ranging from 0.878 to 0.900. Therefore, the entire 14-item questionnaire was retained for the remainder of the analyses.

Aim 2: parent and child performance on the TRQ

Fig. 1 shows TRQ scores by age-group (7–9, 10–12, 13–15, and 16–18 yr old) chosen to roughly correspond with the developmental phases of school age, tweens, younger adolescence, and older adolescence. As hypothesized, child task responsibility as reported by both parent and child increased with age. One-way ANOVA was conducted to determine differences in TRQ report by age-group. The overall equations were significant (PTRQ $F = 10.39$, $p < 0.000$; CTRQ $F = 9.51$, $p < 000$). Analyses comparing the four age-groups were conducted using Tukey's HSD. These comparisons revealed that the youngest age-group (7–9 yr old) had significantly lower scores than youth aged 13–15 (PTRQ mean difference = -0.67, $p < 0.05$; CTRQ mean difference = -0.86; $p < 0.05$) and 16–18 (PTRQ mean difference = -1.0; $p < 0.001$; CTRQ mean difference = -1.44; $p < 0.001$). Scores for youth aged 10–12 were significantly different only from the oldest group of youth aged 16–18 (PTRQ mean difference = -0.65; $p < 0.05$; CTRQ mean difference = -0.67; $p < 0.05$). There were no significant differences between the oldest groups of youth aged 13–15 and 16–18.

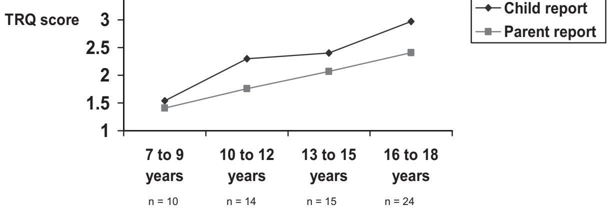

Fig. 1. Average TRQ scores by age-group. Scores range from 1 to 5 with higher numbers indicating more youth responsibility. A score of 3 indicates shared responsibility.

To quantify parent–child agreement, discrepancy scores were calculated by subtracting PTRQ individual item scores from CTRQ individual item scores for each parent–child dyad (9). Positive scores indicate that caregivers underestimate the extent of child perceived responsibility (youth report doing more than the caregiver perceives they are doing), while a negative score indicates the caregiver overestimates the level of perceived responsibility being assumed by their child relative to child's report. All discrepancy scores were in the direction of the child perceiving more responsibility than the parent perceives, with the exception of item #11 (getting medications refilled at the pharmacy) where parents reported more responsibility than the youth reported. Paired *t*-tests revealed significant differences between parent and child report for all items with the exception of items #1, 4, 11, and 13 (Table 2).

Aim 3: TRQ and adherence

Bivariate correlations were made between adherence, average scores for the PTRQ and CTRQ, and difference scores. There were no significant correlations found between the TRQ and adherence.

Participants were then separated into two groups based on whether they were adherent (s.d. < 2.5) or non-adherent (s.d. ≥ 2.5). There were no significant group differences on the TRQ average scores or difference scores when one-way ANOVAs were conducted.

Discussion

The primary goal of the current study was to describe the development of a new measure, the

Table 2. Difference scores for CTRQ and PTRQ

Item	Mean difference	Paired *t*-test	Significance
Avoiding sick people	0.133	1.59	0.117
Noticing signs rejection	0.267	2.46	0.017*
Knowing medications	0.200	2.05	0.045*
Following other MD recommendations	0.267	1.76	0.084
Telling teachers	0.542	2.96	0.004*
Noticing signs infection	0.767	3.87	0.000*
Taking other medications	0.475	2.36	0.022*
Taking antirejection medications	0.441	2.27	0.027*
Getting to appointments	0.373	2.10	0.040*
Scheduling appointments	0.448	2.55	0.014*
Getting blood draws	−0.085	−0.78	0.440
Getting meds refilled	0.621	3.09	0.003*
Noticing meds run out	0.400	1.67	0.101
Calling coordinator	0.356	2.07	0.043*
Total average score	0.368	4.29	0.000*

Difference score is parent score subtracted from child score. Positive difference scores indicate greater child vs. parent responsibility.
$^*p < 0.05$.

TRQ, which assessed how families perceive their allocation of responsibility for the multitude of tasks required following solid organ transplant. We developed a 14-item scale that has preliminary evidence for internal validity and the potential to have both clinical and research utility in the pediatric transplant setting.

We had several hypotheses regarding how youth and their parents would perform on the TRQ. As expected (and similar to literature from other chronic illnesses), we found that parents generally underestimated the youth's perception of their own self-care. Another potential explanation, however, is that youth overreport their self-care. This pattern is consistent with previous studies in pediatrics examining the allocation of chronic illness management within families (9) and in recent studies looking at allocation of responsibility in transplant (16). Several factors may account for the parent–youth discrepancy in perceived responsibility, including the difficulty for parents to know older youth's internal states (i.e., noticing signs of infection or rejection) or self-management behaviors (i.e., telling teachers about their transplant). It may also be that parents are doing more to manage their child's transplant care than the youth are aware of, as many things like scheduling appointments or calling the nurse coordinator might occur outside of the child's awareness (i.e., while they are at school). We identified no parent–child pairs where discrepancy scores suggested no one was taking responsibility, which has been reported in other studies (9, 12).

One of the strengths of this study is the focus on the management of transplant tasks across children and adolescents. Based on the previous literature (13, 14), we expected that older youth would self-report and be perceived as more involved in their care than younger youth, regardless of the informant. While we did see the predicted trend toward significantly greater self-care in the older youth reported by themselves and their parents, we were surprised to see that the levels of self-care did not approach levels of primary responsibility in the older youth. In fact, even the oldest youth (ages 16–18) were at best sharing care with their parents. This finding is in contrast to other studies that have found youth assuming primary responsibility for their care in their teens (2, 25). However, recent research from the pediatric liver transplant literature also found shared responsibility to be the norm (18); perhaps, this finding is unique to transplant given the significant consequences of non-adherence. The strategy of sharing care into the teen years may explain the relatively high levels of adherence (about 75%) found in our sample and is consistent with the literature describing better adherence with more parent involvement (7, 10). This collaborative relationship may be the key to effective illness management when there is a complex regimen to manage (25). Also, important to note is that while younger children are not assuming significant responsibility in their care, they are beginning to become more active in their care in the teen years.

Although shared responsibility may be a helpful strategy in families following transplant, it conflicts with the significant emphasis for youth to move toward independent self-care as they prepare for the transition to more independent living and adult transplant centers. In fact, increased adolescent responsibility along with decreased parental involvement has been found to be a significant predictor of the readiness to transition to adult care (17). According to Annunziato (26), the primary goal for the transition to adult care is the shift of task management from parent to patient. In our sample of older youth, this transfer of task management does not appear to be occurring at the level the adult transplant centers might expect or at the level necessary for youth to function independently as they go to college or leave home. It has been suggested that the gap between what the youth are doing relative to the expectations of the adult center may explain the poorer adherence often seen after transition (27). In fact, several different sources have reported lower immunosuppressant levels and high rates of graft failure after the transition from pediatric to adult care (27, 28).

This trend of adverse events post-transition presents a significant challenge for medical providers preparing teens for the transition to adult care, knowing that while teens are expected to take on more responsibility and become more independent in their illness management, this increase in self-care can, in fact, be associated with poorer health outcomes. Continued efforts toward scaffolding those skills via transition interventions are warranted, and many centers are beginning to study such interventions (26).

An additional goal of the study was to determine the relationship between responses on the TRQ and post-transplant adherence. Although we had hypothesized that we would see poorer adherence (higher immunosuppressant s.d.) in families where the youth was more in charge of their own care, we found no such relationship. We also did not see a trend toward greater non-adherence in our older youth as expected. There are several possible reasons for the lack of significant adherence findings. First, we had very few youth (<25%) who were classified as non-adherent. The lack of variability in the sample's adherence may have hindered our ability to detect differences on the TRQ. Second, we had very little variability in the TRQ responses, with consistent reports of no more than shared responsibility regardless of age. This also may have limited our ability to find significant results. Third, the TRQ's 14 items cover a range of tasks that one must be responsible for following transplant, but only a few of these tasks have direct links to immunosuppressant blood levels. As a result, it is possible that the overall measure may be too broad to detect immunosuppressant variability. Finally, our sample has a high proportion of intact families, which may be a marker for greater family cohesion that is known to positively impact adherence (4).

Description of study limitations

The results of this study should be interpreted with the following limitations in mind. The sample was limited in size and came from a single Midwestern United States transplant program, which may limit generalizability across other settings. The study includes only kidney and liver transplant recipients; therefore, it is hard to know whether we would see similar results in other pediatric solid organ transplant populations. While the use of two organ groups allowed for a larger sample of youth with abdominal organ transplants, we also acknowledge the risk in using two different organ transplant groups for this data analysis and note that unmeasured differences in these groups could have impacted study outcomes. The use of an immunosuppressant s.d. cutoff that has not been validated for kidney transplant recipients may have also impacted results. The study used a single measure of adherence (immunosuppressant s.d.), which only provides a snapshot of the previous days' adherence to immunosuppressant medication. It is possible that there is non-adherence occurring outside of the window prior to the clinic appointment when many patients improve their adherence in anticipation of their upcoming laboratory tests. In addition, further iterations of the TRQ may require modifications as the scaling may have a bias toward shared responses and some questions may need reworking (i.e., #14 has several tasks within one item). Finally, as the development of the TRQ limited our ability to add additional measures for validation beyond age, further research is needed to validate this measure.

Clinical implications

Given the importance of an individualized and planned transition process (26), the TRQ may be a useful tool to help clinic staff assist youth and their families as they prepare for the transition to adult care. Tracking an individual's progress over time could provide the opportunity to set measurable goals for improvement in self-care in between clinic appointments. For example, noticing that a teen has the developmental potential to begin scheduling her or his own appointments but is not, use of the TRQ could allow the medical team the opportunity to address that skill. Additionally, it can be used to identify gaps in the perception of who is managing certain tasks as well as developmentally inappropriate expectations for self-care. Once areas for growth are identified on the TRQ, clinical staff should work to identify goals that are easiest and most in line with the youth's developmental skill set (25). Using this measure at the time of transfer to adult care could also allow for better communication between the pediatric and adult centers regarding ongoing opportunities to improve self-care into adulthood.

Future research

There are several future directions for research with the TRQ. First, further validation studies of the TRQ are necessary in order for consumers of the measure to be able to use it with confidence. Second, it will be important to look at developmental factors that might impact the shifts in responsibility over time, such as autonomy and pubertal status. These factors have been found to be important moderating factors of responsibility allocation for families managing diabetes (29). It is possible that such factors may be impacting acquisition of skills in our sample. Finally, because this study was cross-sectional in nature, it will be important to study families over time to see whether expected developmental shifts in responsibility occur, especially through the transfer of care to adult transplant settings.

Authors' contributions

Dr. Kullgren was involved in the development of the study, data analysis/interpretation, and drafting the article. Dr. Hmiel was involved in the development of the study, provision of access to participants, and review of the article. Ms. Gevers was involved in coordination and recruitment of participants, data analysis, and article review in her role as a graduate psychology research assistant.

References

1. 2007 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1996–2005. Rockville, MD: Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation; Richmond, VA: United Network for Organ Sharing; Ann Arbor, MI: Arbor Research Collaborative for Health.
2. Shemesh E, Shneider BL, Savitzky JK, et al. Medication adherence in pediatric and adolescent liver transplant recipients. Pediatrics 2004: 113: 825–832.
3. Simons LE, Blount RL. Identifying barriers to medication adherence in adolescent transplant recipients. Pediatr Psychol 2007: 32: 831–844.
4. Fredericks EM, Lopez MJ, Magee JC, Shieck V, Opipari-Arrigan L. Psychological functioning, nonadherence and health outcomes after pediatric liver transplantation. Am J Transplant 2007: 7: 1974–1983.
5. Berquist RK, Berquist WE, Esquivel CO, Cox KL, Wayman KI, Littl F. Adolescent non-adherence: Prevalence and consequences in liver transplant recipients. Pediatr Transplant 2006: 10: 304–310.
6. Gerson AC, Furth SL, Neu AM, Fivush BA. Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. Pediatr Transplant 2004: 8: 543–550.
7. Feinstein S, Keich R, Becker-Cohen R, Rinat C, Schwartz SB, Frishberg Y. Is noncompliance among adolescent renal transplant recipients inevitable? Pediatrics 2005: 115: 969–973.
8. Dobbels F, Van Damme-Lombaert R, Vanhaecke J, De Geest S. Growing pains: Non-adherence with the immunosuppressive regiment in adolescent transplant recipients. Pediatr Transplant 2005: 9: 381–390.
9. Mcquaid EL, Penza-Clyve S, Nassau JH, Fritz GK, Klein R, O'Connor S. Sharing family responsibility for asthma management tasks. Child Health Care 2001: 30: 183–199.
10. Kahana SY, Frazier TW, Drotar D. Preliminary quantitative investigation of predictors of treatment non-adherence in pediatric transplantation: A brief report. Pediatr Transplant 2008: 12: 656–660.
11. Zelikovsky N, Schast AP, Palmer J, Meyers KE. Perceived barriers to adherence among adolescent renal transplant candidates. Pediatr Transplant 2008: 12: 300–308.
12. Anderson BJ, Auslander WF, Jung KC, Miller JP, Santiago JV. Assessing family sharing of diabetes responsibilities. J Pediatr Psychol 1990: 15: 477–492.
13. Drotor D, Ivers C. Age differences in parent and child responsibilities for management of cystic fibrosis and insulin-dependent diabetes mellitus. J Dev Behav Pediatr 1994: 15: 265–272.
14. Walders N, Drotar D, Kercsmar C. The allocation of family responsibility for asthma management tasks in African-American adolescents. J Asthma 2000: 37: 89–99.
15. Shemesh E, Lurie S, Stuber ML, et al. A pilot study of posttraumatic stress and nonadherence in pediatric liver transplant recipients. Pediatrics 2000: 105: E29.
16. Pai ALH, Gray E, Kurivial K, Ross J, Schoborg D, Goebel J. The allocation of treatment responsibility scale: A novel tool for assessing patient and caregiver management of pediatric medical treatments. Pediatr Transplant 2010: 14: 993–999.
17. Gilleland J, Amaral S, Mee L, Blount R. Getting ready to leave: Readiness in adolescent kidney transplant recipients. J Pediatr Psychol 2011: 37: 1–12.
18. Fredericks EF, 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.
19. Bell LE, Barthosh SM, Davis CL, et al; on behalf of the conference attendees. Adolescent transition to adult care in solid organ transplantation: A consensus conference report. Am J Transplant 2008: 8: 2230–2242.
20. Maikranz JM, Steele RG, Dreyer ML, Stratman AC, Bovaird JA. The relationship of hope and illness-related uncertainty to emotional adjustment and adherence among pediatric renal and liver transplant recipients. Pediatr Psychol 2007: 32: 571–581. Epub 2006 Dec 4.
21. Wu YP, Aylward BS, Steele RG, Maikranz JM, Dreyer ML. Psychosocial functioning of pediatric renal and liver transplant recipients. Pediatr Transplant 2008: 12: 582–587. Epub 2008 Jan 14.
22. Stuber ML, Shemesh E, Seacord D, Washington J III, Hellemann G, McDiarmid S. Evaluating non-adherence to immunosuppressant medications in pediatric liver transplant recipients. Pediatr Transplant 2008: 12: 284–288.
23. Ratcliff MB, Blount RL, Mee LL. The relationship between adolescent renal transplant recipients' perceived adversity, coping, and medical adherence. J Clin Psychol Med Settings 2010: 17: 116–124.
24. Griva K, Davenport A, Harrison M, Newman SP. Non-adherence to immunosuppressive medications in kidney transplantation: Intent vs. forgetfulness and clinical markers of medication intake. Ann Behav Med 2012: 44: 85–93.
25. Modi AC, Marciel KK, Slater SK, Drotar D, Quittner AL. The influence of parental supervision on medical adherence in adolescents with cystic fibrosis: Developmental shifts from pre- to late adolescence. Child Health Care 2008: 37: 79–92.
26. Annunziato RA, Emre S, Shneider BL, et al. Transitioning health care responsibility from caregivers to patient: A pilot study aiming to facilitate medication adherence during this process. Pediatr Transplant 2008: 12: 309–315.
27. Annunziato RA, Emre S, Shneider BL, 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.
28. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. Pediatr Nephrol 2000: 14: 469–472.
29. Palmer DL, Berg CA, Butler J, et al. Mothers', fathers', and children's perceptions of parental diabetes responsibility in adolescence: Examining the roles of age, pubertal status, and efficacy. J Pediatr Psychol 2009: 34: 195–204.

Appendix A

Transplant Responsibility Questionnaire (Child)

This is a list of things that have to be done to care for your transplant. Please pick who usually does each of these things by using these numbers:

1 Your parent(s) do it all of the time
2 Your parent(s) do it most of the time
3 Your parent(s) and you share doing it about the same
4 You do it yourself most of the time
5 You do it yourself all of the time

1. Calling your transplant nurse coordinator with questions or concerns	1	2	3	4	5
2. Scheduling doctor's appointments or medical tests	1	2	3	4	5
3. Getting to scheduled clinic appointments	1	2	3	4	5
4. Getting scheduled blood draws at the lab	1	2	3	4	5
5. Noticing signs & symptoms of rejection	1	2	3	4	5
6. Noticing signs of infection (i.e., fever, cough, vomiting)	1	2	3	4	5
7. Avoiding sick people or infections	1	2	3	4	5
8. Telling teachers about your transplant (letting them know that you have had a transplant, explaining about the symptoms of rejection, etc.)	1	2	3	4	5
9. Knowing the names of your medications and when to take them	1	2	3	4	5
10. Noticing when medications are beginning to run out	1	2	3	4	5
11. Getting medications refilled at the pharmacy	1	2	3	4	5
12. Taking regular anti-rejection medication (i.e., cyclosporine, tacrolimus, rapamune, prednisone, etc.)	1	2	3	4	5
13. Taking other prescribed medications	1	2	3	4	5
14. Remembering to follow exercise, diet, and/or fluid intake recommendations	1	2	3	4	5

Note. Please contact the primary author for use permission.

Appendix B

Transplant responsibility questionnaire (Parent)

Below are different things that must be done to care for your child's transplant. Please rate who usually does each of these tasks by using the following scale:

1 Parent(s) take responsibility all of the time
2 Parent(s) take responsibility most of the time
3 Parent(s) and child share responsibility about the same
4 Child takes responsibility most of the time
5 Child takes responsibility all of the time

1. Calling your child's transplant nurse coordinator with questions or concerns	1	2	3	4	5
2. Scheduling doctor's appointments or medical tests	1	2	3	4	5
3. Getting to scheduled clinic appointments	1	2	3	4	5
4. Getting scheduled blood draws at the lab	1	2	3	4	5
5. Noticing signs & symptoms of rejection	1	2	3	4	5
6. Noticing signs of infection (i.e., fever, cough, vomiting)	1	2	3	4	5
7. Avoiding sick people or infections	1	2	3	4	5
8. Telling teachers about your child's transplant (letting them know that your child has had a transplant, explaining about the symptoms of rejection, etc.)	1	2	3	4	5
9. Knowing the names of your child's medications and when to take them	1	2	3	4	5
10. Noticing when medications are beginning to run out	1	2	3	4	5
11. Getting medications refilled at the pharmacy	1	2	3	4	5
12. Taking regular anti-rejection medication (i.e., cyclosporine, tacrolimus, rapamune, prednisone, etc.)	1	2	3	4	5
13. Taking other prescribed medications	1	2	3	4	5
14. Remembering to follow exercise, diet, and/or fluid intake recommendations	1	2	3	4	5

Note. Please contact the primary author for use permission.