Published in final edited form as:

J Clin Psychol Med Settings. 2013 March ; 20(1): 88–96. doi:10.1007/s10880-012-9303-6.

Health-Related Quality of Life and Perceived Need for Mental Health Services in Adolescent Solid Organ Transplant Recipients

Bonney Reed-Knight,

Department of Psychology, University of Georgia, Athens, GA 30602, USA

Kristin A. Loiselle,

Department of Psychology, University of Georgia, Athens, GA 30602, USA

Katie A. Devine,

Department of Radiation Oncology, University of Rochester Medical Center, Rochester, NY, USA

Laura E. Simons,

Division of Pain Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, Children's Hospital Boston, Boston, MA, USA. Department of Psychiatry, Harvard Medical School, Boston, MA, USA

Laura L. Mee, and

Department of Psychiatry, Emory University, Atlanta, GA, USA

Ronald L. Blount

Department of Psychology, University of Georgia, Athens, GA 30602, USA

Bonney Reed-Knight: bonreed@uga.edu

Abstract

The purpose of the current investigation was to assess interest in mental health services among parents of adolescent solid organ transplant recipients and the relationship between parent perceived need for mental health services and patient health-related quality of life (HRQOL). Sixty-three parents rated interest in receiving 10 mental health services, and patient HRQOL ratings were gathered from adolescent transplant recipients and their parents. Ninety-four percent of parents expressed some level of interest in at least one of the proposed services, with over 40 % indicating maximum interest. Parents' perceived need for mental health services was inversely related to adolescent and parent reports of HRQOL on the behavior, mental health, family cohesion, and parental impact-emotional domains. Results suggest that parents of adolescent solid organ transplant recipients are interested in receiving mental health services for their families. Assessment of need for mental health services and HRQOL may inform the medical team of families requiring intervention.

Keywords

Health-related quality of life; Pediatric transplantation; Adolescent; Mental health; Intervention

With advances in biomedical science and patient care, adolescent solid organ transplant recipients are experiencing unprecedented survival rates (Department of Health and Human

Services Health Resources and Services Administration Healthcare Systems Bureau, Division of Transplantation 2009). For patients and their families, however, survival is associated with ongoing chronic illness management including daily immunosuppressant medications, clinic visits, and lab work, as well as stress related to the risk of graft loss and other medical complications. Given the disease management demands following transplantation and their potential impact on daily functioning, health-related quality of life (HRQOL) has become an increasingly salient research and clinical topic. HRQOL is a multidimensional construct including, but not limited to, an individual's perception of his/her physical functioning, mental health, and psychosocial well-being (De Civita et al., 2005). Assessment of HRQOL in pediatric patients is particularly important since poor HRQOL has been shown to be related to adverse medical outcomes including more frequent hospitalizations (Bucuvalas et al., 2003) and rejection episodes (Devine et al., 2011) in transplant recipients and higher rates of anxiety and depression in youth with other chronic conditions (Cruz, Marciel, Quittner, & Schechter, 2009; Hassan, Loar, Anderson, & Heptulla, 2006).

Past research has documented that adolescent solid organ transplant recipients report poorer HRQOL compared to healthy peers, though the specific domains where deficits are noted vary across studies and reporter (Alonso et al., 2010; Fredericks, Lopez, Magee, Shieck, & Oipari-Arrigan, 2007). Consistently, adolescents report lower general health perceptions compared to their peers (Fredericks et al., 2008; Sundaram, Landgraf, Neighbors, Cohn, & Alonso, 2007), and parents observe their adolescents to have poorer physical functioning, worse general health perceptions, greater restrictions on family activities, and a more negative emotional impact on themselves as parents (Bucuvalas et al., 2003; Fredericks et al., 2008; Sundaram et al., 2007). The body of research suggests that adolescent transplant recipients and their parents are at increased risk for needing intervention to address low HRQOL compared to their healthy peers. Unfortunately, recent research has provided evidence that HRQOL demonstrates stability over time (Devine, Reed-Knight, Simons, Mee, & Blount, 2010) and does not improve without targeted mental health intervention.

One mechanism for potentially improving low adolescent HRQOL is through the provision of mental health services. Since HRQOL encompasses mental health and psychosocial well-being in addition to physical health, interventions designed to address mental health needs could result in improvements in HRQOL domains specific to mental health and psychosocial functioning, as well as overall HRQOL. In addition, transplantation affects not only the adolescent's quality of life but also the quality of life of parents and the family system. Emotional distress has been documented among parents of children with chronic illness (Ireys & Silver, 1996; Wallander & Varni, 1998), suggesting that parents may also benefit from intervention. The many demands associated with having an adolescent with a chronic health condition may result in burden on parents trying to manage multiple stressors. Therefore, parents may perceive a need for mental health services for themselves and their families. However, there is currently a lack of research on the relationship between mental health service provision and HRQOL in pediatric chronic illness samples, with no published studies of this kind in pediatric transplant patients.

The current study examines the relationships between parents' perceived need for particular mental health services and both adolescent-reported and parent-proxy reported HRQOL among families of adolescent solid organ transplant recipients. Given that parents ultimately consent for mental health intervention for adolescents and generally bring adolescents to treatment, only parent perceived need for mental health services was examined in the current study. Although HRQOL encompasses several domains, the current study specifically examined adolescent internalizing and externalizing psychological symptoms and family cohesion, as well as the emotional impact that adolescents' transplants had on the parents.

These HRQOL domains were considered the most likely targets of mental health interventions, and they encompass common presenting problems seen by mental health care practitioners. Further, the emotional impact of adolescent's health on parents has consistently been shown to be a facet of HRQOL affected for parents of transplant recipients (Bucuvalas et al., 2003; Devine et al., 2010; Fredericks et al., 2008; Sundaram et al., 2007). The goal of this research was to evaluate parents' perceived need for services and elucidate possible points of intervention related to HRQOL to guide treatment development and clinical service provision for adolescent transplant recipients and their families. We hypothesized that poorer HRQOL across the selected domains would be related to greater parental perceived need for mental health services for their families.

Method

Participants

This investigation included data collected at Time 2 from a larger, prospective investigation with a sample of adolescents who had received a solid organ transplant (kidney, liver, heart, lung) at a single medical institution. At Time 1 data collection, 30 % of parents expressed interest in receiving a referral for mental health services when offered. Given this expressed need, the decision was made to formally assess parents' perceived need for mental health services at Time 2 data collection using the Perceived Need for Mental Health Services questionnaire designed for this study. No data from Time 1 data collection are included in this manuscript. See (Simons et al., 2008) for data regarding HRQOL at Time 1 and (Devine et al., 2010) for data regarding the stability of HRQOL across the two time points, parent-adolescent concordance on ratings of HRQOL, and comparison of parent report of HRQOL to CHQ-PF50 normative data. In brief, those studies indicated that HRQOL was generally stable over 18-months without targeted intervention and that parents reported lower levels of HRQOL relative to parents of healthy peers across several domains.

Parents of 63 adolescent and young adult transplant patients from the original sample (38 kidney, 15 liver, 10 heart) were included in this analysis. Within this sample of 63 parents, 48 adolescents reported their HRQOL. Only parents were interviewed for adolescents with developmental delay ($n = 5$ or 8 % of sample). Additional reasons for missing adolescent data at Time 2 include active refusal to participate ($n = 3$), passive refusal by failing to return recruitment phone calls ($n = 3$), invalid data ($n = 1$), adolescent did not participate at Time 1 ($n = 2$), and reason unknown ($n = 1$). Time since transplant at Time 2 data collection ranged from 1.5 to 18.0 years ($M = 7.18$, $SD = 5.08$, Median = 5.39 years). Demographic characteristics of the sample are provided in Table 1. Parent respondents were 98 % female.

Procedures

Following Institutional Review Board approval, adolescents and parents from the Time 1 study were invited to participate at Time 2. Patients and parents were contacted during clinic appointments or via telephone. New informed consent, assent, and HIPAA release forms were obtained at clinic or via postal mail after initial contact was made with the family. The structured interview with each parent and adolescent consisted of verbal administration of all study measures over the phone conducted by trained research assistants. For the entire research battery, including measures utilized in the current study, parent interview length ranged from 35 to 112 min ($M = 58.6$, $SD = 15.8$) and adolescent interview length ranged from 25 to 60 min ($M = 37.2$, $SD = 7.4$). Twenty-dollar gift cards were provided for participation.

Measures

Demographic Information—Demographic information collected about the adolescent included age, gender, and race. Race was dichotomized as Caucasian or other (coded as 1 or 0, respectively) for all analyses given that over 90 % of the sample was either Caucasian or African American. Demographic information collected about the parent included marital status, educational attainment, and income.

Health-Related Quality of Life

Adolescent Self-Report: The Child Health Questionnaire-Child Form 87 (CHQ-CF87) (Landgraf, Abetz, & Ware, 1999) is an 87-item generic measure of HRQOL for adolescents 12–18 years of age. Although 11 of our participants were outside of this age range at Time 2, we utilized the measure for consistency with Time 1. The CHQ is a well-established measure of HRQOL, with strong evidence of reliability and validity (Palermo et al., 2008). It was chosen for its comprehensive assessment of HRQOL, the availability of adolescent and parent report forms, psychometric properties, and because no condition-specific measures of HRQOL were available for transplant recipients at the initiation of the study. Each item consists of five response choices using a Likert-like rating scale. Higher scores on the CHQ indicate better HRQOL. Although the CHQ-CF87 yields 12 domains, the current study examined three domains of HRQOL that were considered most likely to be a focus for mental health interventions: (1) behavior, a measure of externalizing symptoms and behavior problems, (2) mental health, a measure of internalizing symptoms such as being nervous or upset, and (3) family cohesion, a single item regarding the family's ability to get along. In the present sample, alpha coefficients were .89 for behavior and .85 for mental health.

Parent Report of Adolescent's Quality of Life: The Child Health Questionnaire-Parent Form 50 (CHQ-PF50) (Landgraf et al., 1999) is a validated, 50-item generic HRQOL measure for children ages 5–18 years. Again, 11 of our participants were outside of this age range at Time 2, but we utilized the measure to allow for consistency with Time 1 data. Further, although the CHQ-PF50 yields 14 domains, the three subscales corresponding to those examined for adolescent report were chosen for these analyses: (1) behavior, (2) mental health, and (3) family cohesion. We also examined the parental impact-emotional scale, a measure of the emotional impact of the child's illness on the parent. Each of these HRQOL domains were considered to be likely targets for mental health interventions. Higher scores indicate better functioning. Extensive psychometric data exist for the CHQ-PF50 and it is used frequently in pediatric populations, including adolescent transplant recipients (Fredericks et al., 2008; Sundaram et al., 2007). In the present sample, alpha coefficients were .68 for behavior, .74 mental health, and .76 for parental impact-emotional, which are generally consistent with published estimates of internal consistency for these CHQ-PF50 scales in clinical samples.

Perceived Need for Mental Health Services—Parents completed a measure of perceived need for mental health services which was designed for the current study. Parents rated their interest in 10 common types of mental health services for themselves and their adolescents on a 0–10 scale with 0 = no interest at all and 10 = a tremendous amount of interest. The list was developed based on clinical expertise of psychologists, physicians, and transplant coordinators working with adolescent transplant recipients. The measure was designed to assess need for a variety of mental health services to address common difficulties seen in the adolescent transplant population. The developers sought to create a comprehensive yet parsimonious selection of services that could be offered feasibly in an outpatient setting and considered evidence-based treatments (e.g. parent training) as well as transplant specific treatments applicable to all organ transplant groups (e.g. strategies and

techniques to enhance medication taking) when developing the measure. See Table 2 for the complete list of mental health services proposed. The scale demonstrated good internal consistency with a Cronbach's alpha coefficient of .89 for the current sample.

Data Analyses

Preliminary analyses examined the potential differences in responses to the Perceived Need for Mental Health Services Questionnaire based on demographic and medical variables using Spearman's rho correlations and non-parametric tests for differences between means (i.e. Mann-Whitney test and Kruskal-Wallis test). Spearman's rho correlation coefficient and other non-parametric statistics were utilized because responses to the Perceived Need for Mental Health Services Questionnaire were positively skewed. To analyze the primary research questions, parents' perceived need for mental health services was summarized using frequency counts and measures of central tendency (i.e. mean and median). Next, hypotheses regarding the associations between perceived need for mental health services and HRQOL were examined using Spearman's rho correlations. Given multiple planned comparisons, a p value of less than or equal to .01 was used for all analyses to control for Type I error.

Results

Preliminary Analyses

No significant associations were found between responses to the Perceived Need for Mental Health Services Questionnaire and child gender, race, organ type, time since transplant, or parental education level. In addition, no differences were found for youth older than 18-years-old versus those 18 and younger or for youth with developmental delay compared to typically developing youth. A significant relationship was found between parental income and responses to one questionnaire item, with lower income related to greater interest in (1) training in how to communicate more effectively with your child's health care providers ($r = -.31, p = .01$). To account for this significant relationship, partial correlation analysis was utilized holding parental income constant when examining the relationship between HRQOL and perceived need for training in how to communicate more effectively with health care providers.

Perceived Need for Mental Health Services: Descriptive Statistics

A summary of parental responses to the Perceived Need for Mental Health Services Questionnaire can be found in Fig. 1. Ninety-four percent of parents endorsed some level of interest in at least one of the mental health services offered, with interest being defined as responding with a score of one or higher on the 0–10 scale of interest. A total score for the questionnaire was calculated by taking the mean response across the 10 types of services offered for all participants. The mean total score of interest for the sample was 3.71 ($SD = 2.81$). To further understand patterns of response, we examined parents' highest interest levels across the 10 types of services proposed. Out of 63 participating parents, 27 (43 %) responded with an interest level of 10 on at least one of the proposed services, indicating tremendous interest. In addition, 51 parents (81 %) responded with an interest level of 5 or higher on at least one of the proposed services. Table 2 displays the frequency of responses for the 10 types of mental health services proposed to parents.

Associations between Dimensions of HRQOL and Need for Particular Services

To examine the relationships between HRQOL and perceived need for mental health services, two-tailed Spearman's rho correlations were calculated between both parent and adolescent HRQOL domains and the 10 types of mental health services that were proposed.

These results as well as means and standard deviations for the HRQOL scales are reported in Table 3.

Behavior Scale—Parents' perceived need for the following types of mental health services was correlated with lower parent-reported HRQOL on the behavior Scale: (1) training in better ways for you and your marital partner/spouse to communicate more effectively and support each other, (2) training for you and your adolescent child in how to communicate more effectively with each other, (3) presentations and group discussions on how to help your child become more independent and responsible, (4) presentations and discussions on how to help your non-patient child/children.

Parents' perceived need for the following types of mental health services was correlated with lower adolescent-reported HRQOL on the behavior scale: (1) presentations and group discussions on how to help your child become more independent and responsible, (2) presentations and discussions on how to support your non-patient child/children, (3) support groups for parents, and (4) counseling for emotional or adjustment issues.

Mental Health—Parents' perceived need for the following types of mental health services was correlated with lower parent-reported HRQOL on the mental health scale: (1) training in better ways for you and your marital partner/spouse to communicate more effectively and support each other, and (2) training for you and your adolescent child in how to communicate more effectively with each other.

Parents' perceived need for mental health services was unrelated to adolescent-reported HRQOL on the mental health scale.

Family Cohesion—Parents' perceived need for the following types of mental health services was correlated with lower parent-reported HRQOL of family cohesion: (1) training in better ways for you and your marital partner/spouse to communicate more effectively and support each other, (2) training for you and your adolescent in how to communicate more effectively with each other, (3) training in how to discipline and set limits with your adolescent, (4) presentations and group discussions on how to help your child become more independent and responsible, (5) presentations and discussions on how to support your non-patient child/children, (6) training in ways to manage your own stress more effectively, and (7) counseling for emotional or adjustment issues.

Parents' perceived need for mental health services was not significantly related to adolescent-reported HRQOL on the family cohesion scale.

Parental Impact—Emotional—Parents' perceived need for the following types of mental health services was correlated with lower parent-reported HRQOL on the parental impact—emotional scale: (1) presentations and group discussions on how to help your child become more independent and responsible, (2) training in ways to manage your own stress more effectively, and (3) counseling for emotional or adjustment issues.

Adolescent-report of HRQOL on the CHQ-CF87 does not assess emotional impact on the parent.

Discussion

The present study examined perceived need for mental health services among parents of solid organ transplant recipients. As hypothesized, parents' greater perceived need for mental health services was related to adolescent and parent report of lower HRQOL across

several domains. Although the mean score for the sample across the 10 types of mental health services offered was relatively low, over 40 % responded with the maximum rating (i.e. rating = 10), indicating tremendous interest in receiving at least one of the proposed services. Further, 81 % of parents responded with an interest level of five or higher on at least one of the proposed services. Parents expressed the greatest interest in presentations and group discussions on how to help their adolescents become more independent and responsible, as well as support groups for themselves. Parents expressed relatively lower interest levels in communication training with spouses/partners and their child's health care providers.

In examining the relationships between parents' perceived need for services and patient HRQOL, parents' perceptions of adolescents' behavior was significantly related to higher need for four of the 10 proposed mental health services. Further, adolescents' report of their own behavior difficulties was related to greater parental perceived need for individual counseling, support groups for parents, group discussions on how to help adolescents become more independent and responsible, and for discussions about how to support non-patient children. Similar to their healthy peers, adolescent solid organ transplant recipients who are experiencing difficulties with behavioral functioning may have an increased need for mental health services. Interestingly, parent perception of poorer adolescent behavioral functioning was related to interest in training for parents to communicate more effectively with their spouses. These results suggest that adolescent behavior problems, which may or may not be related to the adolescents' chronic health condition, are related to difficulties within the entire family system. Parent training, an effective intervention for behavior problems, may be a useful mental health intervention for adolescent transplant recipients who display these difficulties.

Parents who perceived poorer mental health functioning in their adolescents expressed higher interest in training to improve communication both with their child and their partner/spouse, suggesting that parents perceived deficits in effective communication within their family as a whole. Adolescent report of their own mental health functioning was unrelated to parents' perceived need for mental health services. These results are surprising given that prior research showed moderate parent-adolescent agreement on the mental health domain of HRQOL (Devine et al., 2010). It is possible that completing the questionnaire about adolescents' mental health functioning prompted parents to consider previously unidentified deficits in functioning. It is also possible that the lack of significant correlations with adolescent-reported mental health, as opposed to adolescent-reported behavioral HRQOL, may be due to the mental health scale assessing less observable internalizing symptoms such as feeling lonely or nervous.

At the family level, poorer parent-reported family cohesion was related to greater perceived need for seven of the 10 mental health services offered, suggesting that low family cohesion may be especially indicative of greater perceived need for mental health services. Lower family cohesion has been associated with other important outcomes for adolescent transplant recipients, including non-adherence (Fredericks et al., 2008). Interventions that increase family cohesion may benefit both HRQOL and other health behaviors.

Parents who reported more difficulties with their own emotional reactions to their adolescent's condition also expressed stronger interest in counseling for emotional or adjustment issues and training in stress management, in addition to discussions about how to help their child become more independent and responsible. Thus, it appears that parents who are the most distressed and in greatest need for intervention are expressing higher interest in receiving intervention. Clinically, this needs assessment questionnaire may be a brief way

for identifying parents and families who may benefit from referral to appropriate mental health services.

Of note, the highest endorsed service was for group discussions regarding how to help adolescents become more independent and responsible. Higher interest in this service was also associated with lower HRQOL. The high interest in services to promote independence and self-management in adolescents may reflect parents' hesitancy to transition responsibility for critical healthcare management tasks to adolescents who may not be demonstrating skill readiness (Bell et al., 2008; Fredericks et al., 2010; Gilleland, Amaral, Mee, & Blount, 2011).

The results from the present study should be considered within the context of several limitations. First, we did not assess whether adolescents or their parents were actually receiving mental health services at the time of participation in the study. Second, the measure used to assess parents' perceived need for mental health services was not previously validated. Also, although parents generally consent for treatment and are responsible for seeking mental health care for adolescents, it is unknown whether adolescents perceived a need for mental health services for themselves, or if they would be willing to assent to the behavioral interventions endorsed by their parents. Although rater variance may contribute to the higher number of correlations for parent-proxy reported HRQOL and need for services, this did not emerge between parent and adolescent behavior HRQOL. Also, the current sample was drawn from a single center, limiting generalizability to other settings. There were also multiple statistical tests performed, which could have inflated Type I error. To control for this, a more conservative p level was used, as were two tailed tests of significance in spite of a priori hypotheses. Further, all significant results were in the hypothesized direction. Lastly, this study assessed parental perception of need for different types of mental health services. However, a clinician's evaluation may identify different types of services needed compared with parent report.

There are several areas that should be addressed in future research in this area. First, periodic routine screening of adolescents' and parents' perceptions of need for mental health services could be implemented for both clinical and research purposes for adolescents who have organ transplants and their families. Given that many transplant centers have limited psychosocial resources, results of screenings could be used to guide referrals for further assessment or treatment. Provision of psychosocial services could be based on families' level of need and adolescents' HRQOL so that limited resources are most appropriately provided (Kazak, 2006). Related to this, future studies should evaluate the economic and logistic feasibility of providing mental health services within pediatric settings, as well as families' follow-through with referrals to providers outside those settings. Future studies may also include an assessment of health care providers' perceptions of psychosocial services that would be beneficial for adolescent solid organ transplant recipients and their families.

In conclusion, the results of this study represent an important initial step forward in assessing the perceived need for mental health interventions for adolescent transplant recipients and their families. As biomedical science continues to advance and pediatric transplant recipients are able to thrive physically, providing appropriate mental health services for recipients and their families will become increasingly important to facilitate optimal psychosocial functioning and transfer to adult-centered care.

Acknowledgments

This study was supported by the Transplant Services Research Fund at Children's Healthcare of Atlanta, Atlanta, GA.

References

- Alonso EM, Limbers CA, Neighbors K, Martz K, Bucuvalas JC, Webb T, et al. Cross-sectional analysis of health-related quality of life in pediatric liver transplant recipients. *Journal of Pediatrics*. 2010; 156:270–276. [PubMed: 19846110]
- Bell LE, Bartosh SM, Davis CL, Dobbels F, Al Uzri A, Lotstein D, et al. Adolescent transition to adult care in solid organ transplantation: A consensus conference report. *American Journal of Transplantation*. 2008; 8:2230–2242. [PubMed: 18822088]
- Bucuvalas JC, Britto M, Krug S, Ryckman FC, Atherton H, Alonso MP, et al. Health related quality of life in pediatric liver transplant recipients: A single center study. *Liver Transplantation*. 2003; 9:62–71. [PubMed: 12514775]
- Cruz I, Marciel KK, Quittner AL, Schechter MS. Anxiety and depression in cystic fibrosis. *Seminars in Respiratory and Critical Care Medicine*. 2009; 30:569–578. [PubMed: 19760544]
- De Civita M, Regier D, Alamgir AH, Anis AH, FitzGerald MJ, Marra CA. Evaluating health-related quality-of-life studies in paediatric populations: Some conceptual, methodological and developmental considerations and recent applications. *Pharmacoeconomics*. 2005; 23:659–685. [PubMed: 15987225]
- Department of Health and Human Services Health Resources and Services Administration Healthcare Systems Bureau, Division of Transplantation. 2009 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: Transplant Data 1994–2006. Rockville, MD: 2009.
- Devine KA, Reed-Knight B, Loiselle KA, Simons LE, Mee LL, Blount RL. Predictors of long-term health-related quality of life in adolescent solid organ transplant recipients. *Journal of Pediatric Psychology*. 2011; 36:891–901. [PubMed: 21343144]
- Devine KA, Reed-Knight B, Simons LE, Mee LL, Blount RL. Prospective comparison of parent and adolescent report of health related quality of life in adolescent solid organ transplant recipients. *Pediatric Transplantation*. 2010; 14:1000–1006. [PubMed: 20846240]
- Fredericks EM, Dore Stites D, Well A, Magee JC, Freed GL, Shieck V, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. *Pediatric Transplantation*. 2010; 14:944–953. [PubMed: 20598086]
- Fredericks EM, Lopez MJ, Magee JC, Shieck V, Opipari-Arrigan L. Psychological functioning, nonadherence and health outcomes after pediatric liver transplantation. *American Journal of Transplantation*. 2007; 7:1974–1983. [PubMed: 17617862]
- Fredericks EM, Magee JC, Opipari Arrigan L, Shieck V, Well A, Lopez MJ. Adherence and health related quality of life in adolescent liver transplant recipients. *Pediatric Transplantation*. 2008; 12:289–299. [PubMed: 18282211]
- Gilleland J, Amaral S, Mee LL, Blount RL. Getting ready to leave: Transition readiness in adolescent kidney recipients. *Journal of Pediatric Psychology*. 2011; 37:85–96. [PubMed: 21878430]
- Hassan K, Loar R, Anderson BJ, Heptulla RA. The role of socioeconomic status, depression, quality of life, and glycemic control in type 1 diabetes mellitus. *Journal of Pediatrics*. 2006; 149:526–531. [PubMed: 17011326]
- Ireys HT, Silver EJ. Perception of the impact of a child's chronic illness: Does it predict maternal mental health? *Journal of Developmental and Behavioral Pediatrics*. 1996; 17:77–83. [PubMed: 8727840]
- Kazak AE. Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, and Health*. 2006; 24:381.
- Landgraf, JM.; Abetz, L.; Ware, JE. The CHQ user's manual. 2. Boston: HealthAct; 1999.
- Palermo TM, Long AC, Lewandowski AS, Drotar D, Quittner AL, Walker LS. Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology. *Journal of Pediatric Psychology*. 2008; 33:983. [PubMed: 18430762]
- Simons LE, Anglin G, Warshaw BL, Mahle WT, Vincent RN, Blount RL. Understanding the pathway between the transplant experience and health related quality of life outcomes in adolescents. *Pediatric Transplantation*. 2008; 12:187–193. [PubMed: 18307667]

- Sundaram SS, Landgraf JM, Neighbors K, Cohn RA, Alonso EM. Adolescent health related quality of life following liver and kidney transplantation. *American Journal of Transplantation*. 2007; 7:982–989. [PubMed: 17391138]
- Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry and Allied Disciplines*. 1998; 39:29–46.

Fig. 1.

Summary of parental responses to the Perceived Need for Mental Health Services Questionnaire. For each of the 10 proposed mental health services, mean and median responses are displayed with standard deviations in parentheses. 95 % confidence intervals are displayed for each bar

Table 1Parent-reported demographic characteristics of the sample ($n = 63$)

Factor	<i>n</i>	%
Adolescent sex		
Male	35	55.6
Female	28	44.4
Adolescent ethnicity		
Caucasian	39	61.9
African-American	19	30.2
Other	5	7.9
Parent ethnicity		
Caucasian	40	63.5
African-American	19	30.2
Other	4	6.3
Parent marital status		
Married/life partner	43	68.3
Single	12	19
Divorced	6	9.5
Separated/widowed	2	3.2
Parent educational background		
Did not complete high school	11	17.5
High school graduate	13	20.6
Some college	13	20.6
College graduate	15	23.8
Professional degree	11	17.5

Table 2

Percent frequency of responses from 0 = “no interest at all” to 10 = “tremendous amount of interest” for ten types of mental health services proposed to parents of adolescent solid organ transplant recipients

Item	0 (%)	1-4 (%)	5-9 (%)	10 (%)	Number of responses
1. Training in better ways for you and your marital partner/spouse to communicate more effectively and support each other?	58	10	24	8	50
2. Training for you and your adolescent child in how to communicate more effectively with each other?	38.7	14.5	30.6	16.1	62
3. Training in how to discipline and set limits with your adolescent?	45.9	16.4	24.6	13.1	61
4. Presentations and group discussions on how to help your child become more independent and responsible?	23.8	15.9	31.7	28.6	63
5. Presentations and discussions on how to support your non-patient child/children?	47.5	13.1	24.6	14.8	61
6. Training in ways to manage your own stress more effectively?	43.5	12.9	27.4	16.1	62
7. Training in how to communicate more effectively with your child's health care providers?	54	11.1	22.2	12.7	63
8. Presentations and discussions on strategies and techniques you and your child can use to enhance your child's medication taking?	39.7	14.3	28.6	17.5	63
9. Support groups for parents?	33.3	17.5	30.2	19	63
10. Counseling for emotional or adjustment issues?	44.4	15.9	27	12.7	63

Responses from 1 to 4 and from 5 to 9 are collapsed for ease of interpretation

Table 3
Spearman's rho correlations between the 10 types of proposed mental health services and parent-report and child-report of HRQOL

Item	Behavior		Mental health		Family cohesion		Emotional impact Parent M = 67.33, SD = 26.53
	Parent (n = 63) M = 78.43, SD = 14.23	Adolescent (n = 48) M = 74.49, SD = 16.07	Parent M = 74.42, SD = 15.54	Adolescent M = 74.97, SD = 13.84	Parent M = 81.83, SD = 21.39	Adolescent M = 74.58, SD = 23.61	
1. Training in better ways for you and your marital partner/ spouse to communicate more effectively and support each other?	-.40*	-.31	-.39*	-.22	-.40*	-.14	-.23
2. Training for you and your adolescent child in how to communicate more effectively with each other?	-.40*	-.33	-.38*	-.19	-.51**	-.16	-.26
3. Training in how to discipline and set limits with your adolescent?	-.28	-.24	-.20	.06	-.41**	-.02	-.22
4. Presentations and group discussions on how to help your child become more independent and responsible?	-.50**	-.47**	-.26	-.16	-.45**	-.28	-.37*
5. Presentations and discussions on how to support your non-patient child/children?	-.32*	-.49**	-.18	-.02	-.31*	.03	-.17
6. Training in ways to manage your own stress more effectively?	-.31	-.31	-.18	-.06	-.32*	-.13	-.31*
7. Training in how to communicate more effectively with your child's health care providers? ^a	-.15	-.29	-.09	.10	-.22	-.01	-.24
8. Presentations and discussions on strategies and techniques you and your child can use to enhance your child's medication taking?	-.29	-.34	-.15	-.08	-.29	-.27	-.05
9. Support groups for parents?	-.19	-.38*	-.08	-.17	-.22	-.18	-.07
10. Counseling for emotional or adjustment issues?	-.28	-.47**	-.26	-.17	-.37*	-.08	-.45**

*
p .01,

**
p .001

^aPartial correlations holding parent income constant are reported given the significant relationship between responses to item number seven and parent income