

Prospective comparison of parent and adolescent report of health-related quality of life in adolescent solid organ transplant recipients

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Abstract: This 18-month prospective investigation sought to examine changes in HRQOL over time for adolescent solid organ transplant recipients. Additionally, this study examined the relationship between adolescent and parent report of HRQOL and compared parent report of HRQOL to published normative data. Forty-eight adolescent–parent dyads completed the CHQ, a measure of HRQOL, at two time periods. Parent and adolescent reports of HRQOL were stable over time. ICCs between parent and adolescent reports were significant and moderate across most domains of HRQOL, with the exception of family cohesion, physical functioning, and bodily pain. However, mean differences indicated that parents perceived significantly worse self-esteem and general health perceptions compared to their adolescents. Compared to normative data, parents reported significantly lower HRQOL across several domains, including adolescents' physical functioning and the emotional impact of their adolescent's condition on themselves. However, parents also reported higher levels of family cohesion. Results indicate that assessment of HRQOL for transplant recipients should include multiple reporters and that HRQOL as reported by adolescents and parents is generally stable over time without intervention. Further research is needed to understand factors related to differential HRQOL outcomes.

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Survival rates for pediatric transplant recipients have dramatically improved in the last few decades, in large part owing to advancements in surgical techniques and the effectiveness of immunosuppressant medications (1–3). With improved survival rates, greater attention has been given to adolescents' post-transplant HRQOL. HRQOL is a multidimensional construct including, but not limited to, an individual's perception of his/her physical func-

tioning, mental health, and psychosocial well-being (4, 5). HRQOL is particularly important to examine in adolescents because the normative developmental tasks of becoming independent from parents, establishing an identity, and fitting in with a peer group become more complicated with the challenges associated with a medical condition.

In the study of HRQOL in pediatric patients, parents often serve as proxy raters. While the validity of parental reports may be higher than that of very young children, both parents and adolescents are able to offer their unique and valid perspectives on adolescents' HRQOL (4–6). The relation between parent and adolescent reports of HRQOL has been evaluated through

Abbreviations: CHQ, Child Health Questionnaire; CHQ-CF87, Child Health Questionnaire-Child Form 87; CHQ-PF50, Child Health Questionnaire-Parent Form 50; HRQOL, health-related quality of life; ICCs, intraclass correlation.

different methods, including mean comparisons, comparisons of each reporter's information to data from healthy adolescents, and correlational methods. While there is general support for low to moderate relations between parent and adolescent reporters in the pediatric literature at large (4, 7), conclusions from research in pediatric transplantation are complicated because of mixed findings and because many samples have included both children and adolescents. The present study aimed at replicating prior findings of moderate relations between parent and adolescent report of HRQOL with a focus on adolescent transplant recipients, as well as expanding this literature by evaluating change in adolescent and parent reports of HRQOL over an 18-month period. To our knowledge, change in HRQOL over time has not been addressed for adolescent transplant recipients and their families.

Few studies have directly compared parent and adolescent reports of HRQOL for solid organ transplant recipients. Sundaram et al. (8) found significant, moderate-to-large ICCs between parent and adolescent reports for most HRQOL scales for adolescent kidney and liver transplant recipients. A study with pediatric renal and liver transplant recipients that examined psychosocial functioning, one aspect of HRQOL, found that parents reported that their adolescents experienced higher levels of somatization symptoms than were reported by adolescents themselves (higher parent-reported symptoms of anxiety and depression were also noted for their mixed sample of children and adolescents; 9). In our report of Time 1 results with the current sample of adolescent kidney, liver, and heart transplant recipients, we found moderate Pearson correlations for most HRQOL domains, but parents reported lower general health perceptions and lower self-esteem for their adolescents when compared to adolescents' own reports (10).

Rather than assessing parent-adolescent differences directly, the majority of studies in this area have focused on how parent and adolescent reports of HRQOL for transplant recipients compare to reports of HRQOL for healthy peers. With few exceptions (see 8, 11), these investigations have mostly included mixed samples of adolescents and children. Results indicate lower HRQOL for transplant recipients relative to healthy normative samples, although the specific domains identified vary across studies and reporter (8, 12-14). For example, while some studies have indicated similar adolescent self-reported HRQOL across most domains except general health perceptions for liver and kidney transplant recipients compared to a healthy

sample (8, 11), another study indicated poorer functioning across most domains compared to a healthy sample (15). As opposed to adolescent self-reports, parent reports of adolescents' HRQOL compared to normative samples have shown consistency across investigations for some domains. Specifically, parents generally report lower physical functioning, poorer general health perceptions, more limitations on family activities, and a more negative emotional impact on themselves as parents (8, 12, 13, 15). However, there has been less consistency regarding the specific *psychosocial* domains in which deficits exist. Different studies indicate that parents report lower self-esteem (13), poorer mental health (15), greater internalizing problems (9), more problem behavior (13, 15), and worse overall psychosocial functioning (13, 15) for adolescent transplant recipients compared to normative samples.

In this investigation, we aimed at building upon the current literature by examining parents' and adolescents' reports of HRQOL over an 18-month period. Because there is little literature to guide hypotheses regarding changes in HRQOL and we were not systematically implementing any interventions with this group, we did not propose specific hypotheses regarding longitudinal changes in HRQOL. Second, we sought to evaluate the association between parent and adolescent reports of HRQOL in two ways, using mean comparisons and ICCs. We expected that adolescents would report higher levels of HRQOL relative to their parent's report, but that reporters' evaluations of most domains of HRQOL would be positively correlated. Finally, we hypothesized that parent report of adolescents' HRQOL would be lower than normative data for healthy adolescents, particularly on physical domains. Normative data from a demographically comparable sample were not available for the adolescent report measure of HRQOL used in this study; therefore, comparisons of these adolescents' scores to healthy adolescents' norms were not conducted.

Method

Participants

This 18-month longitudinal single-center investigation included adolescent transplant recipients and their parents. Our initial sample (10) involved 68 (56% male) dyads consisting of solid organ transplant recipients (39 kidney, 17 liver, and 12 heart) and their parent/guardian. This sample represented 92% of families who were approached for participation. Forty-eight of these adolescent-parent dyads (71% of original sample; 56% female, 28 kidney, 13 liver, and seven heart) participated in 18-month follow-up assessments. From the initial sample of dyads, four

adolescents (6%) died prior to follow-up interviews. Nine adolescents or parents (13%) individually participated, barring dyad comparisons; therefore, their data were excluded from these analyses. Lastly, seven (12%) families were unable to be contacted for follow-up (two were no longer followed at this medical institution, four passively declined after repeated contacts, and one was unable to be contacted owing to incorrect phone numbers and address). Excluding adolescents lost as a result of mortality, our participation rate was 77% of the original sample. There were no systematic differences between dyads who were re-enrolled and those who could not be enrolled in terms of demographic information, with the exception that girls were more likely to be re-enrolled ($\chi^2 = 9.74, p < 0.01$).

In the current sample, participants were predominantly Caucasian (60%) or African American (29%). Participants' ages ranged from 12.5 to 22.4 yr ($M = 17.1, s.d. = 2.4, median = 16.9$ yr). Time since transplant ranged from 1.5 to 17.9 yr ($M = 7.2, s.d. = 5.1, median = 5.4$ yr). Follow-up interviews were conducted an average of 17.0 months after the initial interview ($s.d. = 1.5, range = 12\text{--}20$ months). Inclusion criteria for the initial study were having received a solid organ transplant at least four months prior to the study (based on recommendation of transplant coordinators as a minimal time sufficient to allow for adjusting to the transplant and establishing greater stability of medical care), age of at least 11 yr, living at home with parent(s)/guardian(s), and being English-speaking. Exclusion criteria included being diagnosed with a developmental delay, as only parents were initially interviewed in these cases. All transplant recipients at Time 2 continued to live with their parent(s).

Procedures

This investigation was approved by the university and hospital institutional review boards. Potential participants from the initial study were recruited for the longitudinal aspect of the study via: (i) telephone; (ii) outpatient clinic appointments; and/or (iii) mail. Given our success with phone administration of measures during the initial assessment and the ease of phone participation for patients, we conducted phone interviews with participants to complete all measures. Written consent and assent were obtained via mail, and verbal consent and assent were obtained via telephone prior to starting the interview. Each interview was conducted by trained research assistants. Parent interview length ranged from 35 to 100 min ($M = 58.5, s.d. = 15.4$), and adolescent interview length ranged from 25 to 60 min ($M = 36.9, s.d. = 7.5$).

Measures

Demographic and transplant information

Demographic and transplant information collected about the adolescent included: (i) age, (ii) gender, (iii) race, (iv) type of transplant, (v) time since transplant, and (vi) medical events including hospitalization, rejection episodes, graft loss, and death. Demographic information collected about the parent included: (i) marital status, (ii) educational attainment, (iii) race, and (iv) income.

HRQOL: adolescent self-report

The CHQ-CF87 (16) is an 87-item scale assessing HRQOL in adolescents 12–18 yr of age. This is a generic measure of HRQOL, chosen for its comprehensive assessment of

HRQOL, the availability of adolescent and parent report forms, and because no condition-specific measures were available for transplant recipients. Although eight of our participants were outside of this age range at Time 2, we utilized the measure to allow for comparison with Time 1 data. Each item consists of five response choices using a Likert-like rating scale. Eight subscales were administered, including: physical functioning, bodily pain, general behavior, mental health, self-esteem, general health perceptions, family activities, and family cohesion. Higher scores indicate better functioning. Promising reliability data exist for this measure; however, published normative data have been limited to item means and not subscale means. In the present sample, alpha coefficients ranged from 0.73 to 0.90 for Time 2 data, with the exception of Time 2 physical functioning ($\alpha = 0.59$).

Parent report of adolescent's quality of life

The CHQ-PF50 (16) is a 50-item scale assessing HRQOL in children ages 5–18. Again, eight of our participants were outside of this age range at Time 2, but we utilized the measure to allow for comparison with Time 1 data. Parents completed the same eight subscales as their adolescents did (physical functioning, bodily pain, general behavior, mental health, self-esteem, general health perceptions, family activities, and family cohesion), plus two additional scales measuring role/social limitations owing to physical problems and role/social limitations owing to emotional/behavioral problems. Additionally, parents completed two subscales assessing the impact of the adolescent's condition on the parent's time and emotional functioning: parental impact – emotional and parental impact – time. The CHQ-PF50 also yields two summary scales, the physical summary and the psychosocial summary. Higher scores indicate better functioning.

Extensive reliability and validity data exist for the CHQ-PF50, and it is used frequently in pediatric populations, including adolescent transplant recipients (8, 10, 11, 15). In the present sample, alpha coefficients ranged from 0.74 to 0.90 for Time 2 data, with the exception of Time 2 general health perceptions ($\alpha = 0.62$). Cronbach's alphas for the summary scales were good at 0.86 for both scales.

Data analyses

Domains of HRQOL were the main variables of interest. Preliminary analyses examined the potential associations between demographic and transplant (i.e., type of transplant, time since transplant) variables and HRQOL at Time 2 using Pearson product-moment correlations and ANOVAS. First, changes in HRQOL over time were examined for both adolescents and parents using paired samples *t*-tests, and stability over time was evaluated using Pearson correlations. Next, to examine hypotheses regarding parent-adolescent discrepancies, the relations between adolescent and parent report of HRQOL at Time 2 were measured via ICCs and paired samples *t*-tests. Pearson correlations provide information about the covariation among scores, but not absolute agreement. ICCs, conversely, provide a ratio between subject variability and total variability, thus attending to both covariation and agreement (17, 18). Whereas Pearson correlation is acceptable for examining stability within adolescent or parent reports over time, examining agreement between parent and adolescent using ICCs in addition to mean differences has been recommended as a more rigorous and comprehensive approach

for research in this area (4, 19). Finally, comparison of parent report with normative data was assessed via independent samples *t*-tests. Given multiple planned comparisons, a *p* value of 0.01 was used for all analyses.

Results

Descriptives and preliminary analyses examining demographics, transplant variables, and HRQOL

During the follow-up interval, no participant suffered a graft loss. Ten participants (20.8%) had a documented rejection episode, and 14 participants (29.2%) were hospitalized (for those who were hospitalized, mode number of hospitalizations = 1). Table 1 shows the mean scores and standard deviations for adolescents and parents for each organ group on each domain of HRQOL at Time 2. There were no significant (*p* < 0.01) differences across domains of HRQOL among organ groups; therefore, all participants were grouped together for the remainder of the analyses. Additionally, there were no significant correlations between adolescent age, time since transplant, parent income, or parent educational attainment and HRQOL domains at Time 2. There were also no differences in HRQOL domains by gender, race, or parent marital status (married vs. not married).

Changes in HRQOL from Time 1 to Time 2

Adolescent report

There were no significant (*p* < 0.01) mean differences in adolescent report of HRQOL from Time 1 to Time 2. Additionally, Pearson correlations between the Time 1 and Time 2 levels of each domain were significant for all domains except family cohesion and behavior. Most

domains showed moderate to high correlations, *r*s = 0.38–0.70, *p* < 0.01 (see Table 2). The greatest stability (*r* > 0.60) was found for the domains of self-esteem and general health perceptions.

Parent report

Similar to adolescents, there were no significant (*p* < 0.01) mean differences in parent report of HRQOL from Time 1 to Time 2. Additionally, Pearson correlations between the Time 1 and Time 2 levels of each domain were significant and moderate to high for most domains, *r*s = 0.45–0.71, *p* < 0.01 (see Table 2). The greatest stability was found for the domains of general health

Table 2. Stability of HRQOL from Time 1 to Time 2, 18 months later

| HRQOL domain | Adolescent report | Parent report |
|------------------------------------|-----------------------------------|-----------------------------------|
| | Time 1–Time 2 Pearson <i>r</i> | Time 1–Time 2 Pearson <i>r</i> |
| Physical functioning | 0.45** | 0.52*** |
| Bodily pain | 0.49** | 0.25 |
| Behavior | 0.36 | 0.64*** |
| Mental health | 0.56*** | 0.60*** |
| Self-esteem | 0.70*** | 0.53*** |
| General health perceptions | 0.61*** | 0.71*** |
| Family activities | 0.38** | 0.11 |
| Family cohesion | 0.15 | 0.60*** |
| Role/social – physical | – | 0.03 |
| Role/social – emotional/behavioral | – | 0.17 |
| Parental impact – emotional | – | 0.34 |
| Parental impact – time | – | 0.55*** |
| Physical summary | – | 0.45** |
| Psychosocial summary | – | 0.67*** |

p* < 0.01, *p* < 0.001.

Table 1. Time 2 means and standard deviations of parent and adolescent reports of HRQOL by organ group

| HRQOL domain | Adolescent | | | Parent | | |
|------------------------------------|-----------------|----------------|---------------|-----------------|----------------|---------------|
| | Kidney (n = 28) | Liver (n = 13) | Heart (n = 7) | Kidney (n = 28) | Liver (n = 13) | Heart (n = 7) |
| Physical functioning | 92.6 ± 11.0 | 92.9 ± 7.6 | 95.2 ± 8.2 | 82.5 ± 25.2 | 86.3 ± 18.9 | 96.0 ± 8.3 |
| Bodily pain | 80.3 ± 21.5 | 70.0 ± 25.2 | 81.4 ± 19.5 | 71.8 ± 27.6 | 78.5 ± 25.8 | 91.4 ± 10.7 |
| Behavior | 74.8 ± 17.4 | 71.8 ± 16.5 | 78.5 ± 8.7 | 77.3 ± 14.9 | 79.7 ± 16.8 | 82.9 ± 12.9 |
| Mental health | 75.9 ± 13.1 | 68.4 ± 15.8 | 83.3 ± 6.9 | 70.8 ± 17.4 | 77.7 ± 16.8 | 80.7 ± 16.2 |
| Self-esteem | 83.6 ± 12.3 | 78.8 ± 14.9 | 88.8 ± 6.7 | 69.2 ± 23.1 | 79.4 ± 19.2 | 82.7 ± 13.1 |
| General health perceptions | 55.8 ± 16.0 | 50.3 ± 11.9 | 64.9 ± 10.8 | 44.2 ± 18.2 | 50.2 ± 17.4 | 47.5 ± 13.9 |
| Family activities | 74.4 ± 18.5 | 81.1 ± 19.4 | 87.5 ± 7.6 | 76.5 ± 21.0 | 82.4 ± 14.4 | 94.0 ± 9.3 |
| Family cohesion | 76.8 ± 22.9 | 70.4 ± 27.2 | 73.6 ± 21.4 | 84.3 ± 16.9 | 78.8 ± 25.5 | 81.4 ± 36.6 |
| Role/social – physical | – | – | – | 83.3 ± 29.7 | 83.3 ± 19.2 | 100.0 ± 0 |
| Role/social – emotional/behavioral | – | – | – | 92.9 ± 19.4 | 94.9 ± 12.5 | 100.0 ± 0 |
| Parental impact – emotional | – | – | – | 64.0 ± 25.9 | 76.3 ± 27.2 | 77.4 ± 15.7 |
| Parental impact – time | – | – | – | 90.1 ± 16.0 | 84.5 ± 27.6 | 100.0 ± 0 |
| Physical summary | – | – | – | 42.8 ± 12.7 | 44.4 ± 10.1 | 51.1 ± 3.6 |
| Psychosocial summary | – | – | – | 49.7 ± 9.5 | 53.1 ± 9.3 | 55.1 ± 7.1 |

There were no statistically significant (*p* < 0.01) differences in HRQOL across organ groups for either adolescent or parent reports of HRQOL.

Table 3. Time 2 adolescent versus parent report of HRQOL

| HRQOL domain | Adolescent mean (s.d.) | Parent mean (s.d.) | Mean difference (95% CI) | <i>t</i> | Effect size <i>r</i> | ICC |
|----------------------------|------------------------|--------------------|--------------------------|----------|----------------------|---------|
| Physical functioning | 93.06 (9.68) | 85.53 (22.04) | 7.52 (1.44 to 13.61) | 2.49 | 0.34 | 0.22 |
| Bodily pain | 77.71 (22.34) | 76.46 (25.89) | 1.25 (−7.44 to 9.94) | 0.29 | 0.04 | 0.24 |
| Behavior | 74.49 (16.07) | 78.73 (15.01) | −4.24 (−9.47 to 0.99) | −1.63 | 0.23 | 0.32** |
| Mental health | 74.97 (13.84) | 74.14 (17.18) | 0.83 (−3.54 to 5.19) | 0.38 | 0.06 | 0.54*** |
| Self-esteem | 83.05 (12.64) | 73.92 (21.37) | 9.13 (3.38 to 14.88) | 3.19** | 0.42 | 0.33** |
| General health perceptions | 55.63 (14.77) | 46.32 (17.30) | 9.31 (3.95 to 14.68) | 3.49*** | 0.45 | 0.30** |
| Family activities | 78.13 (17.98) | 80.64 (18.88) | −2.52 (−8.59 to 3.55) | −0.83 | 0.12 | 0.36** |
| Family cohesion | 74.58 (23.61) | 82.40 (22.50) | −7.81 (−16.33 to 0.70) | −1.85 | 0.26 | 0.18 |

p* < 0.01, *p* < 0.001.

perceptions, behavior, and family cohesion, as well as the psychosocial summary composite scale. There were some exceptions in which insignificant correlations were found: parental negative emotional impact on self, bodily pain, family activities, role/social limitations owing to physical problems, and role/social limitations owing to emotional/behavioral problems.

Parent–adolescent discrepancies

The agreement between Time 2 adolescent and parent report was first examined via ICCs. As can be seen in Table 3, significant (*p* < 0.01) ICCs between adolescent and parent report were found for all HRQOL domains at Time 2 except physical functioning, bodily pain, and family cohesion. The ICCs for family cohesion, physical functioning, and bodily pain were small (from 0.18 to 0.24); the ICCs for behavior, self-esteem, general health perceptions, and family activities were moderate (0.30–0.36); and the ICC for mental health was large (0.54).

For each domain, adolescents' and parents' mean scores were compared using paired samples

t-tests. At Time 2, adolescents reported significantly higher functioning in the domains of self-esteem and general health perceptions compared to their parents. These results supported our hypothesis that adolescents would report higher levels of HRQOL compared to parents.

Parent report compared to CHQ-PF50 norms

Table 4 shows parent report of HRQOL domains at Time 2 relative to the published normative data for the CHQ-PF50. Results indicated that parents reported significantly lower functioning for their adolescents on several domains of HRQOL, including physical functioning, general health perceptions, family activities, and physical summary. These differences demonstrated medium to large effect sizes (*r* ranged from 0.30 to 0.83). Additionally, parents reported significantly higher family cohesion relative to norms. Parents also reported significantly worse emotional impact on themselves owing to their adolescent's health relative to norms. These results supported our final hypothesis.

Table 4. Time 2 parent report of HRQOL versus CHQ-PF50 norms

| HRQOL domain | Parent mean | CHQ-PF50 norms | Mean difference (95% CI) | <i>t</i> | Effect size <i>r</i> |
|------------------------------------|-------------|----------------|---------------------------|-----------|----------------------|
| Physical functioning | 85.53 | 96.1 | −10.57 (−16.97 to −4.17) | −3.32** | 0.44 |
| Bodily pain | 76.46 | 81.7 | −5.24 (−12.75 to 2.28) | −1.40 | 0.20 |
| Behavior | 78.73 | 75.6 | 3.13 (−1.23 to 7.49) | 1.45 | 0.21 |
| Mental health | 74.14 | 78.5 | −4.36 (−9.35 to 0.63) | −1.76 | 0.25 |
| Self-esteem | 73.92 | 79.8 | −5.88 (−12.08 to 0.33) | −1.91 | 0.27 |
| General health perceptions | 46.32 | 73.0 | −26.68 (−31.70 to −21.66) | −10.69*** | 0.84 |
| Family activities | 80.64 | 89.7 | −9.06 (−14.54 to −3.58) | −3.32** | 0.44 |
| Family cohesion | 82.40 | 72.3 | 10.10 (3.56 to 16.63) | 3.11** | 0.41 |
| Role/social – physical | 85.76 | 92.5 | −6.74 (−14.07 to 0.60) | −1.85 | 0.26 |
| Role/social – emotional/behavioral | 94.44 | 93.6 | 0.84 (−3.86 to 5.55) | 0.36 | 0.05 |
| Parental impact – emotional | 69.27 | 80.3 | −11.03 (−18.40 to −3.66) | −3.01** | 0.40 |
| Parental impact – time | 90.03 | 87.8 | 2.23 (−3.31 to 7.78) | 0.81 | 0.12 |
| Physical summary | 44.46 | 53.0 | −8.54 (−11.83 to −5.24) | −5.21*** | 0.61 |
| Psychosocial summary | 51.40 | 51.2 | 0.20 (−2.48 to 2.87) | 0.15 | 0.02 |

p* < 0.01, *p* < 0.001.

Discussion

The present study examined stability in HRQOL over an 18-month period, agreement in parent and adolescent report of HRQOL, and differences between parental report of HRQOL and normative data for adolescent solid organ transplant recipients. Results indicated that parent and adolescent reports of HRQOL were generally stable across an 18-month period. At follow-up, parent and adolescent reports were generally consistent, as evidenced by significant moderate ICCs for most HRQOL domains. The magnitudes of ICCs found in our sample are similar or slightly lower than those found in sample of adolescents with liver and kidney transplants using the same HRQOL measure (8). Interestingly, in contrast to a review article of HRQOL in pediatric populations that suggested parent-adolescent reports would be most consistent for "observable" physical domains (7), the largest ICC was for mental health, which assesses internal emotions that are not necessarily observable except as manifested through the adolescents' behavior and verbalizations. Other studies with adolescent transplant recipients have also found moderate ICCs for psychosocial domains (8, 14).

Despite moderate ICCs in most domains, mean differences in parent versus adolescent reports of HRQOL suggested that adolescents tended to perceive their HRQOL as higher than their parents perceived it, particularly for self-esteem and general health perceptions. This finding was consistent with our hypotheses and previous studies, including the analyses of Time 1 data collected from this sample (8, 10). In regard to general health perceptions, it is interesting that parents and adolescents reported similar levels of physical HRQOL but significant differences in general health perceptions. The items from the general health perceptions subscale ask adolescents and parents to compare the adolescent's health to peers and to consider future health. Differences in parent-adolescent report may be attributable to developmental factors, as adolescents may not have fully developed abstract reasoning abilities to think realistically about the future. Further, parents and adolescents may compare adolescents' health using different points of reference. For example, comparing oneself to a time pretransplant when the adolescent's health was significantly worse could result in more positive scores, while comparing one's child to healthy siblings or same-aged peers could result in more negative scores. Regardless of the reasons for

the differences in adolescent- and parent-reported HRQOL found in this study and others, such discrepancies emphasize the need for researchers and clinicians alike to gather both adolescent and parent report when conducting a valid assessment of HRQOL (8).

Parent report of adolescents' HRQOL compared to the healthy normative sample for the CHQ-PF50 indicated lower physical functioning, worse general health perceptions, and more restrictions on family activities owing to the adolescents' health, consistent with our hypotheses and previous studies (8, 12). The parent-reported differences in HRQOL that are consistent across studies appear to be for domains that are owing to physical health limitations and associated restrictions in activities, rather than the adolescents' psychosocial problems, although some previous studies have indicated poorer adolescent psychosocial functioning (13, 15).

It is notable that the parent report of their own emotional functioning was lower than that of the normative sample, consistent with other reports (8, 11–13, 15). It will be important in research and clinical service to attend to the parents of transplant recipients as well as the adolescents themselves, as the functioning of the family is critically impacted by the mental and physical health of the parents. On a positive note, parents reported significantly higher family cohesion compared to norms. Although parent and adolescent reports of family cohesion were not significantly correlated, parental report above the norm suggests a possible resiliency factor for these families. These parents may try to increase family closeness in an attempt to monitor the adolescents' status and be maximally attentive to their needs.

There were several limitations to this study. Despite relatively high re-enrollment for the follow-up period, the sample size was small, which precluded any examination of patterns of association within organ group (although no mean differences between groups were found). Moreover, during the follow-up period, only a small percentage of the sample experienced medical events, such as hospitalization and rejection, which precluded examination of the potential impact of medical events on HRQOL over time. Additionally, there were limitations in use of the CHQ. The CHQ-87 does not have a representative, US-based population normative sample, which limits interpretation of these scores. Further, the CHQ-50 was used for some adolescents who were older than the age range for which there are normative parent-reported data. However, the use of the measure at both

time periods allowed for longitudinal comparisons, and because all adolescents continued to live at home with their parents, it was believed that parents could serve as proxy raters. Generalizability of the findings may be limited owing to the eight individuals who continued to live at home after age 18, although there are little data regarding rates of achievement of young adulthood milestones, such as leaving home, for transplant recipients. Another limitation is the variability within this sample regarding length of time since transplant. However, there were no significant correlations between time since transplant and HRQOL domains. Finally, the findings in this study represent one transplant center, and we recognize that results may vary at another site owing to differing treatment parameters and demographic characteristics. A multisite study of adolescent transplant recipients (such as the Studies of Pediatric Liver Transplantation Registry, 14) would allow for the examination of potential site-specific factors that could influence HRQOL outcomes.

Clinically, our results suggest that it is important to assess adolescents' HRQOL via multiple reporters as part of clinical care. Because patients' HRQOL does not seem to improve over the course of time with only standard medical care, adolescents who are identified as having low HRQOL by self- or parent report warrant intervention to attempt to improve HRQOL. Repeated assessment of HRQOL can serve to evaluate the impact of interventions. Given the length of the CHQ, its use in routine clinical care may be limited; however, its inclusion of scales related to parental functioning in the parent report form may have clinical value and serve to identify the targets of intervention (i.e., patient and/or family). There are likely multiple points of intervention depending on the targeted domain of HRQOL, such as problem solving to overcome restrictions in the family's ability to carry out expected activities. Various health and psychosocial factors, such as hospitalizations and family functioning, likely influence HRQOL over time. Identification of such predictors of HRQOL is a next important step that can inform specific interventions to improve HRQOL.

References

- BURDELSKI M, NOLKEMPER D, GANSCHOW R, et al. Liver transplantation in children: Long-term outcome and quality of life. *Eur J Pediatr* 1999; 158(Suppl 2): S34-S42.
- GUMMERT JF, IKONEN T, MORRIS RE. Newer immunosuppressive drugs: A review. *J Am Soc Nephrol* 1999; 10: 1366-1380.
- 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: 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: University Renal Research and Education Association. Available at: <http://optn.transplant.hrsa.gov/data/annualReport.asp> (accessed August 6, 2009).
- 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.
- EISER C, MORSE R. A review of measures of quality of life for children with chronic illness. *Arch Dis Child* 2001; 84: 205-211.
- TAYLOR R, FRANCK LS, GIBSON F, et al. A critical review of the health-related quality of life of children and adolescents after liver transplantation. *Liver Transpl* 2005; 11: 51-60.
- EISER C, MORSE R. Can parents rate their child's health-related quality of life? Results of a systematic review. *Qual Life Res* 2001; 10: 347-357.
- SUNDARAM SS, LANDGRAF JM, NEIGHBORS K, COHN RA, ALONSO EM. Adolescent health-related quality of life following liver and kidney transplantation. *Am J Transplant* 2007; 7: 982-989.
- 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.
- 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. *Pediatr Transplant* 2008; 12: 187-193.
- FREDERICKS EM, MAGEE JC, OPIPARI-ARRIGAN L, et al. Adherence and health-related quality of life in adolescent liver transplant recipients. *Pediatr Transplant* 2008; 12: 289-299.
- ALONSO EM, NEIGHBORS K, MATTSON C, et al. Functional outcomes of pediatric liver transplantation. *J Pediatr Gastroenterol Nutr* 2003; 37: 155-160.
- BUCUVALAS JC, BRITTO M, KRUG S, et al. Health-related quality of life in pediatric liver transplant recipients: A single-center study. *Liver Transpl* 2003; 9: 62-71.
- ALONSO EM, LIMBERS CA, NEIGHBORS K, et al. Cross-sectional analysis of health-related quality of life in pediatric liver transplant recipients. *J Pediatr* 2010; 156: 270-276.
- 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.
- LANDGRAF JM, ABETZ L, WARE JE. *The CHQ User's Manual*. Boston, MA: HealthAct, 1999.
- MCGRAW KO, WONG SP. Forming inferences about some intraclass correlation coefficients. *Psychol Methods* 1996; 1: 30-46.
- SHROUT PE, FLEISS JL. Intraclass correlations: Uses in assessing rater reliability. *Psychol Bull* 1979; 86: 420-428.
- CREMEENS J, EISER C, BLADES M. Factors influencing agreement between child self-report and parent proxy-reports on the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health Qual Life Outcomes* 2006; 4: 58.