

The Relationship Between Adolescent Renal Transplant Recipients' Perceived Adversity, Coping, and Medical Adherence

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Abstract The aim of the present study was to assess adolescent renal transplant recipients' perceived adversity (PA) for various aspects of living with a transplant, including its association with coping and medication non-adherence, from a theoretical perspective. Thirty-three adolescent renal transplant recipients were interviewed using structured questionnaires and medical record reviews. Health care provider ratings of adversity were also collected. Participants reported moderate levels of PA, with those who received a transplant at an older age reporting more adversity on several domains and girls reporting more adversity for missing school. Ratings of adversity for specific aspects of living with a transplant differed depending on age and medical factors and were related to specific coping strategies and measures of non-adherence. Consistent with the Self-Regulation Model, perceived consequences (represented as PA) appears to be related to coping and illness outcomes. Assessing PA and teaching appropriate coping strategies may yield better medical outcomes among this at-risk population.

Keywords Perceived adversity · Coping · Adherence · Renal transplant · Adolescent

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End Stage Renal Disease (ESRD) is a serious, chronic condition affecting over 7,000 children and adolescents in the United States (United States Renal Data System, 2007). It is commonly defined as the final stage of kidney failure, with less than 15% functioning in both kidneys. The incidence rate for 10–14 and 15–19 year old adolescents with ESRD in the United States increased from 9.5 and 20.1 adolescents per million population in 1980 to 14.7 and 27.2 adolescents per million population in 2005, respectively (United States Renal Data System, 2007). Of these patients, approximately two-thirds will eventually receive a kidney transplant, which is considered the optimal form of treatment in terms of reduced mortality, morbidity, and better psychosocial functioning.

As the number of adolescent renal transplant recipients increases, so too does the recognition of challenges faced by this population. The ongoing demands of ensuring graft survival are considerable, especially for adolescents who may be taking increasing responsibility for their own health while negotiating the transition to adulthood. Care for the new graft requires daily medications and routine outpatient clinic visits for serum assays and medical follow-up. In addition, ongoing monitoring is necessary to assess for health conditions that may have emerged secondary to treatment such as anemia, urinary tract infection, hypercholesterolemia, hyperlipidemia, acute rejection, reduced bone mass, and cytomegalovirus (Berber et al., 2006). These health care requirements often conflict with other essential adolescent demands, including development of autonomy, identity, and romantic relationships. Adolescents' ability to cope with the various treatment-related stressors, superimposed on typical developmental issues, is no doubt related to the notoriously high rates of treatment non-adherence among adolescents, which is estimated to be as high as 70% (Shaw, Palmer, Blasey, & Sarwal, 2003;

Wolff, Strecker, Vester, Latta, & Ehrich, 1998). These rates are notably higher than among adults (up to fourfold), and are associated with higher rates of graft failure (Cecka, Gjertson, & Terasaki, 1997).

Objective measures potentially indicative of poor illness management (e.g., rejection episodes, number of hospitalizations), once regarded as the primary predictors of adjustment to illness, have been increasingly recognized as only one of many factors associated with adolescents' psychosocial adjustment (Casey & Brown, 1993). In addition to illness severity, child and parent coping, social support, adaptive functioning, and treatment adherence are regarded as influential in predicting overall biopsychosocial functioning. With the exception of biometric indices of treatment adherence, these factors are all more personal and subjective in nature and are influenced in no small part by individuals' perceptions of their situations. For instance, Simons and Blount (2007) found that barriers to medication adherence among adolescent transplant recipients clustered into 3 distinct factors (Disease frustration/adolescent issues, Ingestion issues, and Regimen adaptation/cognitive issues) that included such items as medications getting in the way of activities, affecting appearance, and being tired of taking medication.

A number of theoretical models have emerged in recent years that take into account patients' perceptions of the management and consequences of their illness, the most influential of which may be Leventhal, Nerenz, and Steele's Self-Regulation Model (Leventhal, Nerenz, & Steele, 1984). This model (referred to in the literature by various names including the Common-Sense Model [Hale, Treharne, & Kitas, 2007], the Illness Perceptions Model [Leventhal et al., 1997], the Illness Representations Model [Leventhal, Brissette, & Leventhal, 2003], and the Parallel Process Model [Leventhal, Meyer, & Nerenz, 1980]) proposes that individual cognitive representations of illness threat (i.e., illness representations) influence the type of coping strategies selected and their actual implementation, which in turn influences outcome appraisals and actual illness outcomes (Leventhal et al., 1980). According to the Self-Regulation Model, illness representations are comprised of a number of components including identity (label for and symptoms associated with an illness), cause (beliefs about factors responsible for the onset of an illness), timeline (perceptions about duration of illness), cure control (perception of individual's ability to control or recover from an illness), and consequences of a particular illness, the latter of which will be emphasized in this study.

Consequence refers to the individual's perception of the perceived adversity or severity of the illness and the degree to which it interferes with physical, social, and psychological functioning (e.g., I will never be able to play contact sports). Consequence is often evaluated comparatively,

with pre-illness functioning serving as a baseline (Hagger & Orbell, 2003). For example, adolescents managing pre-existing health conditions or who were diagnosed with ESRD at an earlier age are predicted to perceive less consequence associated with a transplant than those who were previously healthy or for whom the transplant was a more acute necessity. The perceived consequences of living with a chronic medical condition (such as a renal transplant) likely affect adherence and psychological outcomes.

To date, research on the consequences component of the Self-Regulation Model has primarily involved adults. Among investigations with adults with a chronic illness, more severe perceived consequences have been found to be associated with greater use of avoidance coping strategies (Kemp, Morley, & Anderson, 1999), denial, and behavioral disengagement (Moss-Morris, Petrie, & Weinman, 1996). Similarly, a meta-analysis (Hagger & Orbell, 2003) revealed that belief in severe consequences and a strong identification with their medical condition were associated with maladaptive coping (e.g., avoidance/denial) and adverse illness outcome (e.g., psychological distress).

There has been a paucity of research applying the consequences component of the Self-Regulation Model to adolescents with chronic illness, with most of these studies restricted to the area of diabetes. In one of these investigations involving adolescents with Type I diabetes, Skinner and Hampson (2001) found that sense of control was associated with better adherence to dietary recommendations whereas greater perceived consequences was associated with more anxiety symptoms. In a subsequent study, Edgar and Skinner (2003) found that the perceived impact of diabetes on day-to-day life was associated with both depressive and anxiety symptoms. In addition, Griva, Myers, and Newman (2000) found that 31% of the variance in metabolic control in adolescents and young adults with Type I diabetes was explained by participants' diabetes-specific self-efficacy, perceived consequences, and identity. Using a self-report instrument developed for the study, perceived severity of illness also was examined by Leung et al. (1997) in adolescents with cystic fibrosis or Type I diabetes. Results indicated that, perceived severity was associated with objective clinical indices of disease severity among adolescents with cystic fibrosis but not among adolescents with Type I diabetes. For both samples, perceived severity was associated with depression and low self-image. Interestingly, physicians' estimates of the severity of adolescents' condition were not correlated with adolescents' self-reported perceptions of severity.

The little research that has been done on perceived adversity (PA) of medical illness among adolescents has more often involved those who have experienced traumas such as rape and abuse. These studies used open-ended

questions such as “think about one or more distressing or disturbing events in your life and describe that feeling as you remember it, including thoughts, feelings, and perceptions of how you got through the experience” (Hunter, 2001, p. 174). Among pediatric patients, one study conducted among adolescents recently diagnosed with cancer used a structured interview and identified “worry about not getting well,” “mucositis,” “nausea,” “pain from procedures and treatments,” and “worry about missing school” as the overall worst aspects of dealing with cancer (Hedstrom, Ljungman, & von Essen, 2005). Thus, research on PA in adolescents remains largely neglected and has not yet been extended to adolescents living with renal transplant. Better understanding of the factors found to be most aversive to renal transplant recipients may provide insight as to the interventions most likely to improve outcomes such as adherence to medical regimens.

The purpose of this study was to explore consequences among adolescent renal transplant recipients, with particular emphasis on understanding which aspects of living with a transplant are perceived to be most aversive. A novel PA scale was developed to assess this previously neglected area in the research, utilization of which will allow for a more systematic study and interpretation of this construct than would be possible with a more qualitative approach such as open-ended questions. Differences in PA were examined for demographic (e.g., sex) and medical (e.g., age at transplant) factors and the association between PA and coping was analyzed. Greater PA was expected to be associated with later age for kidney transplant, more medical procedures in the last year, and larger number of medications taken. Adolescents and transplant coordinators’ ratings of the adolescents’ adversity were expected to be positively associated. Adolescents’ PA was expected to be associated with their use of a greater number of strategies to cope. Finally, PA was expected to be inversely associated with medical adherence to immunosuppressant medication.

Method

Participants

Eleven to 20-year olds (hereafter referred to as “adolescents”) who received a renal transplant were recruited from an outpatient clinic affiliated with a large pediatric hospital in the southeastern United States. Patients who were English speaking, had no known cognitive deficits (per parental and/or transplant coordinator report), and were at least 2 weeks post-transplant were eligible to participate. Of the 42 patients who were eligible for the study, 2 declined to participate and 7 initially consented/assented

but did not respond to multiple follow-up attempts, resulting in a 79% response rate. The final sample consisted of 33 adolescents. Participants did not differ significantly from recruited non-participants in terms of age, gender, race, or transplant type (living or deceased donor). The demographic and medical background of the sample was roughly representative of the institutional population, with slight under-representation of people of Hispanic ethnicity.

The mean age was 15.9 years ($SD = 2.5$), and the sample was 61% male. Fifty-four percent of the participants classified themselves as Caucasians, 43% as African-American, and 3% as Hispanic. Nine percent of families were classified as living below the poverty threshold based on family income and number of persons in the household (Federal Register, January 24, 2007). The majority of the participants received deceased donor kidneys (70%), with 24 and 6% receiving living related and living non-related donor kidneys, respectively. The majority of participants received transplants more than 12 months prior to data collection (73%, $n = 24$), with 27% ($n = 9$) of participants receiving transplants within the past 12 months (range = 1–186 months, median = 24 months). Sixty-four percent of participants were attending public or private school, 18% received homebound schooling, 9% had graduated high school, 6% were attending college or technical school, and 3% were not currently in school.

Measures

Demographic Factors and Medical Record Review

Participants were asked to provide basic demographic information including: age, sex, race/ethnicity, highest grade completed, estimated family income, and current household composition. An electronic medical record review, conducted by the principal investigator, included: (a) medical diagnosis, (b) frequency and days of hospitalizations within the past 12 months (not including any hospital admissions prior to or including transplant surgery, if relevant), (c) current medications, (d) immunosuppressant tacrolimus/sirolimus/cyclosporine lab values, (e) postsurgical medical complications or rejection episodes within the past 12 months, and (f) co-morbid conditions.

Perceived Adversity (PA)

A 10-item PA scale was created specifically for the purposes of this study. Items were based on the authors’ clinical experience working with adolescents with ESRD and talking to them about their illness management difficulties, as well as careful review of qualitative studies that asked pediatric patients to identify most difficult aspects of

living with an illness (e.g., Hedstrom et al., 2005). The scale was piloted among healthcare staff who worked with transplant recipients for clarity and utility before implementation. Participants were asked to consider their experiences both pre- and post-transplant and rate “How hard has it been...” to encounter various aspects of medical treatment and other consequences of living with a renal transplant. Each item was rated using a 10-point Likert scale from 1 (*not at all hard to deal with*) to 10 (*very hard to deal with*). Ratings for individual items and a Total Perceived Adversity score (composite score of all individual items) were used for analyses, with higher scores indicating higher levels of perceived adversity. The scale evidenced good internal consistency as indicated by $\alpha = .84$. Individual questions are displayed in Table 1.

Coping

The A-Cope (Patterson & McCubbin, 1987) is a 54-item theoretically-derived measure of adolescent coping behavior. It consists of 12 factors: Ventilating Feelings, Seeking Diversions, Developing Self-Reliance and Optimism, Seeking Social Support, Solving Family Problems, Avoiding Problems, Seeking Spiritual Support, Investing in Close Friends, Seeking Professional Support, Engaging in Demanding Activity, Being Humorous, and Relaxing. As indicated by the authors, maladaptive coping items (i.e., Avoiding Problems and Ventilating Feelings) were reverse scored and summed with the other subscales to create a Total coping score. Participants were asked to indicate how often they utilized a particular coping strategy when feeling tense or facing a problem or difficulty using a 5-point Likert response format from 1 (*never*) to 5 (*most of the time*). As indicated in the literature, the subscales of the A-Cope have fair to good internal consistency, ranging from $\alpha = .50$ to $\alpha = .75$. Internal consistency was low in this

study for 5 of the 12 subscales with $\alpha < .60$. These individual subscales (Avoidance, Investing in Close Friends, Seeking Professional Support, Engaging in Demanding Activities, and Relaxing) were dropped from further subscale analyses. Overall internal consistency reliability for the remaining scales as indicated by Cronbach’s alpha was $\alpha = .85$ for this study. Therefore, the individual subscales with good internal consistency and the Total coping score were included in the analyses. The A-Cope has been shown to have fair to good predictive validity.

Adherence: Adolescent Reports

The Medical Adherence Measure (MAM; Zelikovsky & Schast, 2008) is a semi-structured clinical interview that includes a comprehensive assessment of participant-reported medication adherence. The MAM has demonstrated adequate convergent validity ($r = .40, p < .05$) and predictive validity ($r = .62, p < .001$; Zelikovsky, Schast, Palmer, & Meyers, 2008). The 23-item module was completed via interview format. For this study, the proportion of self-reported immunosuppressant doses missed or taken late (i.e., ≥ 1 h) were analyzed.

Adherence: Serum Immunosuppressant Drug Assay Levels

Serum levels of tacrolimus, a common immunosuppressant drug prescribed to pediatric nephrology patients, were obtained through medical record review for a period up to 12 months prior to data collection (available serum levels since transplantation were used for participants transplanted within the year). Sirolimus and/or cyclosporine immunosuppressant levels were obtained when tacrolimus was not prescribed. Only outpatient serum levels were utilized to prevent possible confounding associated with

Table 1 Perceived adversity item means, standard deviations, and range of scores

Scale item	Mean (SD)	Range
How hard has it been		
1. to take medications?	3.03(2.05)	1–7
2. to deal with medical procedures like getting shots or going to the hospital?	2.82(2.35)	1–10
3. having to do other treatment things like not eat certain foods or exercising?	3.73(2.78)	1–10
4. missing school for treatment or because you are in the hospital or don’t feel well?	3.70(2.93)	1–10
5. not feeling well?	4.79(3.18)	1–10
6. feeling scared about what might happen?	4.30(2.70)	1–10
7. worrying about the future?	4.30(2.52)	1–10
8. talking with others about what you have gone through?	2.85(2.28)	1–9
9. feeling different from your peers (i.e., classmates, friends)?	3.42(2.51)	1–10
10. not being able to do what other adolescents are doing?	5.00(2.51)	1–10
Total	32.87(17.53)	10–70

inpatient hospital stays (e.g., variability in absorption rates due to acute illness, altered medication regimen, more aggressive treatment). Serum level standard deviations (*SD*) were calculated based on the serum assays of tacrolimus. Higher standard deviations for tacrolimus have been associated with nonadherence and adverse clinical outcomes, including biopsy-proven rejection (Shemesh et al., 2004). Blood levels of cyclosporine (outside of 150–400 ng/ml) or tacrolimus (outside of 5–17 ng/ml) that were outside the therapeutic range were also considered as indicative of poor adherence (Chisholm, Lance, Williamson, & Mulloy, 2005). Blood levels of sirolimus outside of 9–17 ng/ml were considered indicative of poor adherence, as indicated in *Drug Facts and Comparisons: Pocket Version* (2008 Edition) and confirmed by expert consensus by the treating renal physicians.

Health Care Provider (HCP) Estimation of Adversity

Two renal transplant nurses (RN's) who have worked in the clinic for a minimum of 5 years were asked to rate each participant on both the physical and psychosocial adversity the participant had experienced since diagnosis, relative to other patients seen in the clinic. Ratings were made using a 10-point Likert scale ranging from 1 (much less adversity) to 10 (much more adversity). HCP estimation of physical and psychosocial adversity were highly correlated ($r = .84, p < .001$).

Procedure

The study was approved by both participating university and hospital Institutional Review Boards. Informed consent and assent were obtained according to institutional guidelines. Eligible participants meeting criteria for inclusion were identified via an outpatient clinic roster and confirmed by a renal transplant nurse. The lead author approached potential participants when they arrived for their clinic appointment to describe the study and obtain written consent from those who were willing to participate. If the parent/guardian was not present for adolescents under the age of 18, a letter describing the study, parent/guardian informed consent form, and HIPAA authorization form were sent home with the adolescent with instructions to return the forms at the next clinic visit. The lead author then called the parent/guardian to solicit willingness to participate and answer any study-related questions. Participants age 18 and older were not required to have parental consent to participate.

Adolescents were asked to complete a one-time assessment administered orally over the phone by the lead author at the participants' convenience. The assessment took approximately 40–60 min to complete. Additionally,

participants' medical records were reviewed to obtain serum assay values and information on rejection episodes and hospitalizations. The two renal transplant nurses rated each participant on their perception of the psychosocial and treatment-related adversity each participant experienced. Data collection lasted approximately 6 months.

Statistical Analysis

General descriptive statistics were performed to identify means, standard deviations, and ranges for the variables of interest. Multivariate analyses were performed to assess the relationship between demographic/medical variables and PA. Analysis of variance was used to assess differences based on gender, race/ethnicity (0 = white; 1 = non-white), age at transplant (younger than 16, 16 and older), type of transplant (i.e., living related donor, non-living related donor, deceased donor), number of rejection episodes in the chart (0, 1 or more), and hospitalization days (6 or fewer days, 7 or more days). Age sixteen is an important developmental time when adolescent independence increases with the attainment of drivers' licenses and was thus selected as a logical age at which to dichotomize. Roughly two-thirds of adolescents were hospitalized for less than seven days over the past year, with a range of 0–58 days and a mode of two. Conducting multiple analyses potentiates the possibility of detecting an effect where none exists (Type I error). However, altering statistical significance using adjustments such as the Bonferroni method creates the inverse risk of not finding a true effect where one exists (Type II error). Numerous researchers have argued that the Bonferroni correction may be inappropriate and too conservative, especially for studies that are more exploratory in nature (Perneger, 1998; Rothman, 1990). Consequently, it was decided to reject the more conservative p -value and adopt the significance level of $p = .05$. Pearson product-moment correlations were calculated between the PA measure and coping subscales, Total coping, and adherence measures. Alpha was set at .05 using 2-tailed tests of significance. All statistical analyses were performed using SPSS for Windows (version 15.0) software.

Results

Descriptive Statistics and Preliminary Analyses

The consequences deemed most adverse to adolescent renal transplant recipients, as determined by mean score of each item on the PA Scale, were Not Being Able to Do What Others are Doing, Not Feeling Well, Feeling Scared About What Might Happen, and Worrying About the Future (see Table 1). The consequences deemed least

adverse were, Medical Procedures (e.g., getting shots and going to the hospital) and Talking With Others About What You Have Gone Through. The Total PA score revealed that, overall, consequences of renal transplantation were deemed moderately adverse.

Adolescent renal transplant recipients reported engaging in higher levels of coping than the normative sample of healthy adolescents reported by Patterson and McCubbin (1987) ($M = 188$ vs. $M = 163$). The most common coping strategies included using humor ($M = 3.9$, $SD = 1.25$), investing in friends ($M = 3.8$, $SD = 0.94$), and optimism ($M = 3.7$, $SD = 0.68$), with the least used coping strategies including engaging in avoidance activities ($M = 1.7$, $SD = 0.52$) and seeking professional support ($M = 1.8$, $SD = 0.52$).

The average number of medications participants were taking per day, as indicated by their medical charts, was 7.3 ($SD = 2.5$), with a minimum of 3 and a maximum of 14. The number of doses of medication participants reported taking over the course of a week ranged from 14 to 105 ($M = 58.5$, $SD = 22.4$). Across the entire sample, 27% of participants reported missing their immunosuppressant medication at least once within the last week and 76% of participants reported taking their immunosuppressant medicine at least 60 min late at least once within the last week. Of those who reported taking immunosuppressant doses late, the percentage of late doses ranged from 6 to 60% ($M = 21.1$, $SD = 15.3$).

There was no statistically significant difference in outcome data between participants who received their transplant within the last 4 weeks versus those who received the transplant 5+ weeks prior to study participation, with the exception of self-reported medication adherence. More specifically, those who received their transplant within 4 weeks of study participation were less likely to report

missing [$t(27) = 3.4$, $p < .01$] or late [$t(31) = 2.4$, $p < .05$] dosing of their rejection medication ($M_{\text{missing}} = 0 \pm 0$ vs. $M_{\text{missing}} = 3.5 \pm 5.5$ and $M_{\text{late}} = 1.2 \pm 2.7$ vs. $M_{\text{late}} = 18.6 \pm 16.1$, respectively).

Relationship of Perceived Adversity (PA) to Demographic and Medical Variables

One or more of the PA scores differed as a function of gender, age at most recent transplant, and total number of days hospitalized within the past year (see Table 2). More specifically, there was a significant difference between PA for Missing School based on gender, whereby females reported higher levels of PA for missing school than males $F(32) = 4.73$, $p < .05$. Adolescents who received their transplant at an older age (i.e., age 16 or above) reported more PA for a number of illness-related consequences than younger transplant recipients. These included PA towards Medical Procedures, $F(32) = 7.24$, $p \leq .01$; Missing School, $F(32) = 5.24$, $p < .05$; Feeling Scared About What Might Happen, $F(32) = 5.01$, $p < .05$; Not Being Able to Do What Others Are Doing, $F(32) = 4.66$, $p < .05$; and Total Adversity, $F(32) = 5.84$, $p < .05$. Also, adolescents who were hospitalized for 7 or more days during the past year reported more perceived adversity for Medical Procedures, $F(32) = -1.99$, $p < .05$. PA scores did not differ as a function of race/ethnicity, type of transplant donor, and number of rejection episodes indicated in the chart.

The total number of medications adolescents were prescribed (as indicated in the medical chart) was associated with PA for Medical Procedures ($r = .60$, $p < .01$), Missing School ($r = .46$, $p < .01$), Feeling Scared About What Might Happen ($r = .41$, $p < .05$), and Total PA ($r = .42$, $p \leq .01$).

Table 2 Relationship of perceived adversity (PA) to demographic and medical variables

	Gender			Age at Tx			# Hospitalizations		
	Male <i>M (SD)</i>	Female <i>M (SD)</i>	<i>CI</i>	<16 <i>M (SD)</i>	16+ years <i>M (SD)</i>	<i>CI</i>	<7 days <i>M (SD)</i>	7+ days <i>M (SD)</i>	<i>CI</i>
Taking medications	2.65(2.1)	3.62(2.0)	2.3, 3.8	2.82(1.9)	4.25(2.3)	2.4, 4.0	2.87(2.0)	3.40(2.2)	2.3, 3.8
Medical procedures	2.70(2.4)	3.00(2.3)	2.0, 3.7	2.32(1.8)	4.75(3.0)	2.1, 3.9	2.30(1.8)	4.00(3.1)	2.0, 3.7
Other treatment	3.20(2.8)	4.54(2.6)	2.7, 4.7	3.18(2.6)	4.88(3.0)	2.6, 4.7	3.74(2.7)	3.70(3.2)	2.7, 4.7
Missing school	2.85(2.6)	5.00(3.1)	2.7, 4.7	2.82(2.7)	5.38(2.8)	2.4, 4.6	3.35(2.5)	4.50(3.7)	2.7, 4.7
Not feeling wel	4.35(3.3)	5.46(3.0)	3.7, 5.9	4.23(3.1)	6.25(3.1)	3.6, 6.0	4.57(3.3)	5.30(3.0)	3.7, 5.9
Feeling scared	4.15(3.2)	4.54(1.8)	3.4, 5.3	3.68(2.5)	6.13(3.0)	3.3, 5.4	4.09(2.7)	4.80(2.9)	3.4, 5.3
Worrying about future	3.70(2.5)	5.23(2.4)	3.4, 5.2	4.32(2.6)	4.13(2.6)	3.3, 5.2	4.39(2.5)	4.10(2.7)	3.4, 5.2
Talking with others	2.45(2.1)	3.46(2.5)	2.0, 3.7	2.86(2.5)	3.00(2.3)	2.0, 3.8	3.26(2.5)	1.90(1.1)	2.0, 3.7
Feeling different	2.95(2.7)	4.15(2.1)	2.5, 4.3	3.27(2.4)	3.88(2.8)	2.5, 4.4	3.65(2.5)	2.90(2.7)	2.5, 4.3
Not able to do	4.75(3.4)	5.38(3.0)	3.9, 6.1	4.41(3.1)	7.13(2.6)	3.9, 6.3	5.22(3.2)	4.50(3.2)	3.9, 6.1
Total	33.75(16.7)	45.23(17.0)	32.1, 44.5	33.91(15.0)	49.75(18.3)	31.7, 44.5	37.91(16.3)	39.10(21.1)	32.1, 44.5

Relationship of PA to Coping

The coping subscales that were found to be significantly associated with specific adversities include Seeking Social Support, which was associated with PA for Feeling Different from Peers ($r = .44, p < .01$). Greater Total coping scores also were associated with PA for Feeling Different from Peers ($r = .45, p < .01$). There was a significant association between Seeking Diversions and PA for Not Feeling Well ($r = .35, p < .05$) and between Family Support and PA for Feeling Different from Peers ($r = .35, p < .05$). There was also a significant associations between Seeking Spiritual Support and PA for Medical Procedures ($r = .41, p < .05$), Missing School ($r = .38, p < .05$), Not Feeling Well ($r = .40, p < .05$), and Feeling Scared About What Might Happen ($r = .35, p < .05$).

Relationship of PA to Medication Non-Adherence

There were no significant correlations between Total PA and self-reported missed immunosuppressant doses. There was a trend towards significance between PA for Taking Medication and self-reported immunosuppressant doses late, with those reporting higher levels of adversity also reporting taking a higher proportion of immunosuppressant doses late ($r = .30, p < .07$). Also trending towards significance was the association between self-reported immunosuppressant doses late and PA for Talking with Others ($r = .33, p < .06$).

The total number of immunosuppressant levels above the recommended range, as one index of non-adherence, was significantly associated with PA for Medical Procedures ($r = .41, p < .01$), with a trend towards significance for Missing School ($r = .32, p < .07$) and Feeling Scared about What Might Happen ($r = .30, p < .09$). Immunosuppressant standard deviation (*SD*) was significantly associated with PA for Not Being Able to Do What Others Are Doing ($r = .36, p < .04$), with a trend towards significance for Diet and Exercise ($r = .29, p < .10$).

Relationship of PA to Health Care Provider (HCP) Estimation of Adversity

The only PA score associated with HCP estimation of adversity was participants' PA for Taking Medication. Both HCP perception of physical adversity ($r = .46, p < .01$) and psychosocial adversity ($r = .52, p < .01$) were correlated with participants' self-reported adversity for taking medication. There was no association between HCP estimation of adversity and adolescent self-report of coping and medication non-adherence.

Discussion

One of the primary aims of this study was to determine whether the consequences component of the Self-Regulation Model was theoretically and conceptually related to illness outcomes among adolescent renal transplant recipients. The association between PA and treatment non-adherence appears to support this rationale. Future studies with larger sample sizes should extend this research to explore the Self-Regulation Model in its entirety.

Another primary aim of this study was to understand which aspects of living with a transplant are perceived to be most adverse. Somewhat surprisingly, adolescents in this study did not report taking medication or painful medical procedures as the most adverse consequences associated with transplantation. Rather, not being able to engage in normative developmental activities such as sports or staying out with friends was deemed as most aversive, while feeling ill, fear, and worry about the future followed close behind. This result suggests a gap between current clinical practice, which emphasizes clinical indicators such as pain and medication adherence versus identified patient concerns, which focus on uncertainty about the future and interference with normal adolescent activities. The importance of medication adherence necessitates that it be continually assessed and emphasized, but it might be that psychosocial indicators are equally important to assess possible precursors to non-adherence and other illness outcomes (e.g., Brownbridge & Fielding, 1994; Penkower et al., 2003).

Age at most recent transplant emerged as a significant factor in association with perceived adversity, with older adolescents (i.e., 16+ years) experiencing higher levels of perceived adversity overall and in relation to medical procedures, missing school, feeling scared about what might happen, and not being able to do what others are doing. It may be that younger age at transplant results in better adjustment in adolescent transplant recipients because they have become more accustomed to the demands of living with a transplant. Also, younger age at transplant may allow time for the development of a supportive group of friends among other transplant recipients. In addition, younger transplant recipients may not feel as great a loss of independence and autonomy as an older teenager who might previously have been driving, working, and preparing for the transition to adulthood. These results suggest that those adolescents who received their transplant at an older age may be most in need of psychosocial interventions to reduce PA and promote better adjustment. (e.g., Shaw et al., 2003).

These results also suggest that the adversity that adolescents experience due to not being able to do what others are doing, talking with others about their condition, taking

medications, medical procedures, and diet and exercise restrictions may actually serve as barriers to adherence. For example, an adolescent renal transplant recipient who feels limited in his or her activities and ill-at-ease when talking with others about his or her condition may consider not taking medication as a way of de-identifying with his or her illness status. Not surprisingly, there was a trend towards significance for self-reported immunosuppressant doses late and PA for taking medication, suggesting that those who are less adherent are not just forgetting to take their medications but responding to aspects of taking medication that are seen as particularly adverse. This is consistent with Simons and Blount's (2007) research on the Adolescent Medication Barriers Scale.

These results suggest that addressing the most aversive perceived consequences of living with a renal transplant may make medication adherence and other aspects of illness management easier. Consistently utilizing a tool to identify PA of various consequences of transplantation, such as the one used in this study, may open communication between adolescents and healthcare providers regarding barriers to adherence. This is especially important given findings from this study and others (e.g., Leung et al., 1997) suggesting discrepancies between physician and adolescent perceptions of illness severity, with adolescent self-report demonstrating more significant associations with the outcomes of interest.

As with any study, there are limitations that must be mentioned. The sample size, though consistent with other studies of its kind, is small and resulted in very low power. This was due to the limited pool of renal transplant recipients available at the participating hospital. A larger number of subjects, perhaps collected through multisite investigations, would have increased the power and made it possible to detect small to medium effect size results. Another issue is that several of the scales were not previously validated or used with adolescent pediatric populations. No existing scales assessing perceived adversity of consequences of living with a specific illness could be found in the literature, necessitating the creation of the PA scales. The fact that the adolescent completed PA scale and HCP Estimation of Adversity were, for the most part, not significantly related suggests that the PA scale is indeed tapping a unique construct. Although the initial findings are interesting and internal consistency was high, further assessment of the psychometric properties of this measure are necessary and will be a future focus.

An additional issue is that interpreting the relationship between biomarkers of non-adherence and PA can be difficult. While it is not possible to determine in a cross-sectional study who differed in their length of time following surgery whether PA of these different aspects of living with ESRD somehow caused or was caused by these

high immunosuppressant levels, the results suggests that this association is worthy of further exploration. Finally, the current sample was exclusively English speaking. It will be important in future studies to include non-English speaking participants. However, the ethnicity of the participants in this investigation was roughly representative of the patients seen in the site where the investigation was conducted. In future research, greater effort should be made to include participants of diverse backgrounds and ethnicities.

As mortality rates decline and children with medical conditions are becoming adolescents and young adults with medical conditions, additional research should be conducted on understanding the developmental trajectory of perceived adversity and regimen non-adherence. While there has been increased research in recent years on illness representations as they relate to various health outcomes, the different components of illness representation remain broad and non-specific. Further assessment of these components, such as the degree of adversity of specific consequences associated with living with a particular illness, may result in a better theoretical understanding of the relationship between illness representations, coping, and outcomes. Results of this research suggest that pediatric patients who receive transplants at an older age may experience higher levels of perceived adversity than those who receive transplants when they are younger. Many adolescents struggle as they negotiate the transition from dependence to independence and from full parental responsibility for medical management to personal responsibility. Better understanding of the perceived adversity associated with different aspects of living with a chronic illness may shed some light on possible areas intervention to improve illness outcomes.

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