

## Health Care Utilization: Pediatric Organ Transplantation

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## Introduction

The study “ Health Care Utilization: Pediatric Organ Transplantation” was designed to investigate the relationship between psychosocial factors and health care utilization for pediatric solid organ transplant recipients, as an initial step towards developing interventions which might improve outcome and be cost-efficient. Variables considered included

- The prevalence and severity of symptoms of Posttraumatic Stress Disorder (PTSD), depression, and anxiety in parents of pediatric kidney, heart, and liver transplant recipients
- Access of the family to concrete resources such as telephone or transportation, social support, socioeconomic status, acculturation, and type of medial insurance
- Parental report of child health, impact of the illness on the family, and perceived attitudes of the medical team
- Health utilization costs for the transplant recipient (with focus on inpatient stays and intensive care unit days for infection and rejection)

One-hundred seventy caretakers of pediatric transplant recipients completed self-report measures at approximately one year post transplant, and annually for the following two years (three time points). Health care utilization was evaluated using medical statistics from the hospital. Transplant pediatrician or clinical nurse specialists provided ratings of perceived adherence to medications, clinic visits, and overall instructions.

The present report does not cover all of the data collected in the study. At the time of this writing, Time Three data collection is not quite complete. We anticipate completing data collection in March 2003. We will then be able to do our final data analysis and preparations of papers on the full set of findings.

In the meantime, however, we have found the first two years of data to yield a number of interesting results. We have submitted and are revising for publication in Pediatrics a paper based on the Time One data. We found that although caretakers of pediatric transplant recipients did not report significant levels of depression or anxiety compared to published norms, they did report elevated levels of PTSD symptoms. Multiple regression analyses revealed PTSD symptomatology was most strongly associated with parent reports of child health, familial impact of the transplant, and medical attitudes. PTSD appears to be relatively common in parents of pediatric transplant recipients and may be the result of how parents perceive and interpret the transplant event.

The primary study also led to an offshoot that became a doctoral dissertation, and is now being prepared for publication. This sub-study of 100 adolescent transplant recipients found that over 20% of the recipients reported symptoms consistent with a diagnosis of PTSD. Data from both studies have been presented at Children’s Hospital of Boston,

Mount Sinai in New York, and Memorial Sloan Kettering Hospital in New York. The line of research has led to collaboration with other transplant centers on traumatic response to pediatric transplantation and the relationship of PTSD to non-adherence. We are currently in the process of preparing a collaborative paper based on an invited presentation we gave this fall discussing the “worst moments”, memories which serve as traumatic reminders of the transplant experience.

Over the next year, we will complete analyses on Time Three data, and complete our evaluation of the relationship between psychosocial predictors, health care utilization, and functional outcome variables. We are already developing an expansion of this line of investigation through our involvement with the National Child Traumatic Stress Network, funded by Substance Abuse and Mental Health Services Administration. We will work with other clinical researchers in Boston, New York, Seattle, and Philadelphia to develop interventions for parents and their children dealing with life threatening medical illnesses.

### **Review of Literature**

Solid organ transplantation, formerly a last option for terminally ill children, has now become the treatment of choice for a number of serious medical conditions. The advent of safer and more effective immunosuppressive medications, such as Cyclosporin A in 1983 and, more recently, Tacrolimus, has dramatically improved survival rates over the past 15 years. In 2000, the 3-year survival rate ranged from 94% to 97% for pediatric kidney recipients, 74% to 84% for liver transplant recipients, and 70% to 79% for heart transplant recipients (United Network for Organ Sharing, 2001). Despite such encouraging numbers, it is important to note that organ transplantation is not so much a “cure” for a particular end-stage disease as it is a transition from an often chronic and life-threatening disease to a second chronic condition – living with and caring for a transplanted organ (LiBiondo-Wood, Bernier-Henn, & Williams, 1992). As such, with more children surviving solid organ transplantation, there has been increased attention to post-transplant functioning as evidenced by the growing body of research examining psychosocial functioning, quality of life, and adjustment in pediatric organ transplant recipients (e.g., Almond et al., 1991; DeBolt, Stewart, Kennard, Petrik, & Andrews, 1995; Fukunishi & Kudo, 1995; House, Dubovsky, & Penn, 1983; Uzark et al., 1992; Windsorova, Stewart, Lovitt, Waller, & Andrews, 1991; Wray, Radley-Smith, & Yacoub, 1992; Zamberlan, 1992).

An important part of the assessment of the psychosocial impact of organ transplant surgery on children is a consideration of how organ transplant surgery affects the psychosocial functioning of the parents of transplant recipients. Given the life-threatening condition child transplant recipients are frequently in, and the demands of careful post-operative care, it is understandable that parents of such children might experience tremendous emotional stress which, in turn, might compromise their own emotional health and ability to provide needed care for their children. Very little research has been conducted on the direct psychological manifestations of such increased stress in parents of child transplant recipients. One of the few studies that have directly examined parents’ psychological distress found that 51% of parents of liver/intestine transplant recipients reported experiencing clinically significant symptoms on the Global Index of Distress of the Brief Symptom Inventory (Tarbell &

Kosmach, 1998). Unfortunately, such findings did not allow for a detailed examination of specific disorders or symptoms that may have contributed to such clinically significant elevations.

Research with parents of pediatric cancer patients provides a reasonably good parallel for understanding what emotional and psychological difficulties parents of transplant recipients might be experiencing. Several studies have indicated that parents may react to a child's cancer with significant levels of depression (e.g., Manne, Miller, Meyers, Wollner, Steinherz, & Redd, 1996; Van Dongen-Melman, Pruyn, De Groot, Koot, Hahlen, & Verhulst, 1995) and anxiety (e.g., Dahlquist, Czyzewski, Copeland, Jones, Taub, & Vaughn, 1993). It may seem intuitively obvious that parents of childhood cancer patients are vulnerable to depression and anxiety given the life-threatening nature of cancer. Of particular interest, however, is that a number of recent studies have shown that between 21% and 30% of parents of childhood cancer patients report at least moderate levels of posttraumatic stress disorder (PTSD, e.g., Kazak, et al., 1998; Pelcovitz et al., 1996). Moreover, these levels of PTSD symptomatology were significantly more severe and more frequent when compared with parents of healthy children, suggesting that PTSD is functionally related to the experience of dealing with the stress of a child with cancer.

In the past, transplant centers recognized the challenges of dealing with a chronically ill child through additional support provided by a combination of social workers, nurse coordinators or case managers (Becker, Drachman and Kirscht, 1972). However, concern about costs in the highly competitive health care market has eroded the availability of many concrete supportive services. Unfortunately, reduction in psychosocial support services may lead to increases in more costly medical service utilization. For example, researchers have demonstrated that use of a case manager on a kidney transplant service can result in cost savings, due to decreased medical utilization, such as shortened length of hospital stay (Hauser, 1995). Given the parents central role in ongoing medical adherence, the impact of this illness on parent functioning is a critical variable to be studied.

### **Study Design and Methods**

The primary caretakers of all pediatric heart, liver, or kidney transplant recipients who had received their initial transplant at UCLA 1 to 2 years before entry into the study were eligible for inclusion in this study. The transplant recipients had to be less than 19 years of age at the time of their transplant. Recipients were not excluded if they underwent re-transplant operations, or did not receive their ongoing medical care at UCLA. Literacy was not a pre-requisite of inclusion, as instruments could be read aloud as necessary. Caregivers participating were required to be fluent in spoken English or Spanish and currently living in the United States.

A list of all recent pediatric transplant recipients was obtained from the UCLA hospital database, and the UCLA pediatric transplant staff reviewed the potential subject list to ensure that families who were currently undergoing an acute stressor (e.g., a medical crisis or death) were not contacted. Informational letters describing the study and self-addressed, stamped return postcards were sent to all eligible families in accordance with Institutional

Review Board requirements. Those who indicated their refusal via postcard were not contacted again. All others were contacted by phone to assess their interest in participating. The research team continued to call the families for six months after the one year anniversary date. If they did not express an interest to participate by the sixth month they were classified as “lost to follow up”, unless they verbally declined. The primary caregiver of the transplant recipients (mother, father, or guardian) was asked to participate. Informed consent was obtained from all participants and assent acquired from transplant recipients 6 years and older. Interviews of one to two hours’ duration were conducted before or after follow-up clinic visits when possible; otherwise, subjects participated via phone. In the event that a family began an interview and did not complete the measures, they were scheduled for a follow-up interview to complete the assessment. Families were contacted once a week for up to six months. If the interview was not completed within six months they were classified as “incomplete”.

## **Measures**

Posttraumatic Stress Diagnostic Scale (PDS). The PDS (Foa, 1995) is a 49 item self-report scale which assesses DSM-IV symptoms of Posttraumatic Stress Disorder (PTSD). It provides a preliminary diagnosis of PTSD as well as an overall measurement of symptom severity. The instrument is nationally recognized and is widely published. The PDS has been shown to have good internal consistency and test-retest reliability, as well as satisfactory convergent and concurrent validity as assessed by clinical diagnoses of PTSD (using a standardized diagnostic interview) and self-report measures of depression and anxiety (Foa, Cashman, Jaycox, & Perry, 1997).

Given that a significant portion of the participants in the current study primarily spoke Spanish (i.e., 35.3%), a Spanish version of the PDS was created for the current study with permission from Dr. Foa. The PDS was translated into Spanish by four psychology and medical students who were fully bilingual. Following this, each new Spanish version was back-translated into English by one of the three other translators. The back-translated versions of the PDS were then compared to the original and assessed for accuracy. The Spanish translations that best matched the original English items were then compiled into a complete Spanish version of the PDS. Analyses of participants’ responses on the new Spanish version of the PDS revealed acceptable internal consistency (Chronbach’s alpha = .89) and good concurrent validity with scores on established Spanish versions of the Beck Depression Inventory ( $r = .635, p < .001$ ), and the State Anxiety scale ( $r = .603, p < .001$ ). As such, the psychometric properties of the Spanish version of the PDS designed for use in the current study were thought to justify analyses of the PDS on the sample as a whole.

Beck Depression Inventory (BDI-II). The BDI-II (Beck, Steer, & Brown, 1996) is a 21 item self-report scale, which has been widely used in screening for depression in adults. It has high internal consistency, high content validity, and good specificity and sensitivity (Dozois, Dobson, & Ahnberg, 1998; Richter, Werner, Heerlein, & Kraus, 1998). A published Spanish translation of the BDI-II (Beck, et al., 1996) was used for interviews conducted in Spanish.

State Trait Anxiety Inventory (STAI). The STAI (Spielberger, 1983) is a 40 item self-report scale that assesses usual (i.e., trait) and current (i.e., state) levels of physical and cognitive manifestations of anxiety. The STAI has the benefit of being a widely used measure of anxiety and has demonstrated good reliability and validity. A Spanish version of the STAI, translated by Salman (1998), was used for those participants interviewed in Spanish.

Demographic Variables. The demographic form was developed for the present study and included acculturation. Demographic variables were collected during the parent interview using a brief “Family Information Form” developed as part of this study. The demographic variables included in the analyses were: a) respondent’s age at time of child’s most recent transplant, b) respondent’s education level, c) patient gender, d) patient age at time of most recent transplant, e) type of insurance, and f) acculturation. The type of insurance carried by the respondent was coded “0” for MediCal (the California version of Medicaid), or “1” for any other type of insurance. Variables reflecting characteristics of the child’s transplant were also collected as part of the “Family Information Form.” These included: a) type of transplant, and b) total number of transplants (up to and including the most recent transplant). Acculturation was calculated using 4 items derived from the Short Acculturation Scale devised by Marin, Sabogal, Marin, Otero-Sabogal, & Perez-Stable (1987) that assessed the extent to which respondents read, speak, and think in English versus Spanish.

Child Health Questionnaire – Physical Health Factor. The measure is a comprehensive quality of life measure that includes physical, psychosocial well-being and functioning. This measure has been widely validated and has been translated for use in 10 countries. The CHQ Physical Health factor (Landgraf, Abetz, & Ware, 1996) is a parent report measure comprised of 4 subscales that measure a) physical functioning of the child, b) social limitations (due to child’s health), c) the child’s general health, and d) bodily pain and discomfort experienced by the child. The CHQ has adequate internal consistency and discriminatory validity (Landgraf et al., 1996). A Spanish version developed by Landgraf et al. (1996) was used in the present study.

Health Care Orientation Scale. A widely used self-report measure was used to assess parental functional outcome. The *Psychosocial Adjustment to Illness Scale (PAIS)* (Derogatis and Derogatis, 1990) is a 46 item self-report instrument, initially designed to assess the adaptation of adult patients to major, usually chronic, medical conditions. It has also been used to measure the psychosocial adaptation of non-ill family members. Scoring yields subscale scores on 7 primary domains of adjustment: 1) Health Care Orientation, 2) Vocational Environment, 3) Domestic Environment, 4) Sexual Relationships, 5) Extended Family Relationships, 6) Social Environment and 7) Psychological Distress. For the present study the Health Care Orientation scale was used to assess parental attitudes toward the quality of health care, expectancies about illness and its treatment, and health promoting behavior. Although originally designed to be completed by adult medical patients, questions were revised for the present study to reflect parents’ attitudes and expectancies about their child’s health care. A Spanish version, based on the original

translation by Cruz, Cruz, & Rios, (1991), was also adapted in reference to parents' children.

Impact on Family Scale (IFS). The IFS (Stein & Riessman, 1985) is a 33-item measure which assesses parents' perceptions about the impact of a child's illness on the family in four dimensions: a) financial impact, b) familial and social impact, c) personal strain (such as fatigue and day-to-day practical limitations), and d) mastery (which measures any possible benefits of the illness, such as bringing the family closer together). The IFS has shown good reliability (Stein & Riessman, 1985) and has been used in previous studies to evaluate the family impact of transplant surgery (Rodrigue, MacNaughton, Hoffmann, Graham-Pole, Andres, Novak, & Fennell, 1997) and autism (Rodrigue, Morgan, & Geffken, 1992). A Spanish version of the IFS was created by the authors of the current study, using back-translation methods.

Medical Outcomes Study Social Support Survey (SSS). This 20 item self-report measure assesses emotional/informational, tangible, affectionate and positive social interaction for adults (Sherbourne & Stewart, 1991). Specifically, the SSS asks respondents about tangible support (in the form of practical help in case of illness), emotional support, positive interactions (such as having someone to "have a good time with"), and affection. For purposes of the current study, an overall support index score was calculated to reflect the combination of each type of social support. This instrument has been tested with 2987 patients dealing with chronic medical conditions. The measure has been shown to have good internal consistency and test-retest reliability, as well as good construct validity (Sherbourne & Stewart, 1991). A Spanish version of the SSS was created by the authors of the current study, using back-translation methods.

### **Statistical Techniques**

To determine the degree of psychological disturbance experienced by parents of transplant recipients, scores on psychological outcome variables were compared with published data using the same measures on the BDI and STAI. A series of univariate and multivariate methods were used to analyze the variables. A three-stage hierarchical regression analysis was then performed to determine which demographic, transplant specific, and psychosocial variables might help to explain the severity of PTSD symptoms in parents as indexed by the total symptom severity score on the PDS. Specifically, using the total symptom severity score on the PDS as the dependent variable, and after controlling for the time elapsed between the transplant date and the date of the parent interview, three separate blocks of variables were analyzed using stepwise procedures. The first block of variables consisted of demographic variables, assumed to be relatively independent of the transplant: a) child's age at the time of transplant, b) parent's age at the time of transplant, c) gender of the child, d) acculturation, e) respondent education, and f) type of insurance (private versus MediCal). To determine whether any of these demographic variables uniquely and significantly predicted PTSD symptom severity scores, stepwise procedures were used with the criterion of  $p < .05$  for entry and  $p > .10$  for removal.

The second block of variables consisted of transplant and child health variables: a) type of transplant (using kidney transplants as a reference group), b) total number of transplants (prior to and including the most recent transplant), and c) the child’s physical health (as indexed by the CHQ Physical Health factor). Stepwise procedures were again used on this second group of variables after controlling for all demographic variables (i.e., forced entry of demographic variables).

The third block of variables consisted of psychosocial variables: a) health care attitude (as measured by the PAIS Health Care Orientation scale), b) overall social support (as indexed by the MOS Social Support Survey), and c) four factors of the Impact on the Family Scale (financial impact, familial/social impact, personal strain, and mastery). Again, stepwise procedures were employed to evaluate contributions of psychosocial variables after controlling for all demographic and transplant and child health variables. In order to further assess the significance of psychosocial variables as a whole, this third group of variables was subsequently entered in the model as an entire block.

## Results

Two hundred ninety families met the aforementioned age and time since transplant requirements. Of those, 32 children were deceased, 4 families were lost to follow up, and 17 were ineligible due to factors such as being out of the country, absence of a primary care taker, and severe medical or family crisis. Of the remaining 237 families, 60 parents refused and 7 parents failed to complete the interview and measures. As such, 170 parents comprised the final sample for data analysis (58.6% participation rate).

Of the 170 caretakers who responded, 84.7% (n = 144) were mothers of the transplant recipient, 10% (n = 17) were fathers, and 5.3% (n = 9) were legal guardians. Consistent with the demographics of the overall population of pediatric transplant recipients at UCLA, 52.4% (n = 89) identified themselves as “Latino,” 34.1% (n = 58) identified themselves as “Caucasian,” and 7.1% (n = 12) identified themselves as “African American.” The remaining 6.5% (n = 11) identified themselves as “Asian” (n = 6), “Middle Eastern” (n = 3), and “Mixed” (n = 2). The age of respondents ranged from 216 months (18 years) to 739 months (61.6 years; M = 444.18 months, SD = 99.42 months).

	American Indian or Alaskan Native	Asian or Pacific Islander	Black, not of Hispanic Origin	Hispanic	White, not of Hispanic Origin	Other or Unknown	TOTAL
Female	0	6	11	80	53	2	152
Male	0	3	1	9	5	0	18
Unknown	0	0	0	0	0	0	0
TOTAL	0	9	12	89	58	2	170

With respect to the child transplant recipients whose parents participated in the study, 18.2% (n = 31) had received at least one heart transplant, 54.1% (n = 92) had received at least one liver transplant, and 27.1% (n = 46) had received at least one kidney transplant. One subject had received both a liver and kidney transplant. Although most children

(85.3%, n = 145) had only ever received one transplant, 11.2% (n = 19) had received two transplants, 2.9% (n = 5) had received three transplants, and one child had received four transplants. The ages of child transplant recipients at the time of the most recent transplant ranged from 2 months to 228 months (19 years,  $M = 85.1$  months,  $SD = 75.7$  months), and roughly half of the transplant recipients were female (47.6%, n = 81).

Parent interviews were conducted between 9 months and 38 months following the first organ transplant ( $M = 18.2$  months,  $SD = 6.8$  months). A total of 64.7% (n = 110) of the interviews were conducted in English, and 35.3% (n = 60) of the interviews were conducted in Spanish, using translated versions of each measure. Seventeen of those interviewed in Spanish indicated they spoke English, but were more comfortable being interviewed in Spanish. In-person interviews were conducted with 49.4% (n = 84) of respondents and phone interviews were conducted with 47.1% (n = 80) of respondents. The remaining 3.5% (n = 6) respondents were interviewed both in-person and over the phone.

### Parental Depressive Symptomatology

A comparison group for BDI scores was obtained from data published on a study of 55 parents of children diagnosed with cancer (Manne, Miller, Meyers, Wollner, Steinherz, & Redd, 1996). Given that the BDI-IA (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) was used in that study, the BDI-II scores obtained from parents of transplant recipients in the current study were calibrated to the BDI-IA scale using the equipercentile equating method reported in Beck, Steer, & Brown (1996). A weighted-means analysis revealed that BDI scores for the 170 parents of pediatric organ transplant recipients ( $M = 8.41$ ,  $SD = 8.7$ ) were significantly lower than BDI scores reported for 55 parents of children who had recently been diagnosed with cancer ( $M = 11.8$ ,  $SD = 7.3$ ,  $t(222) = -2.85$ ,  $p < .05$ ).

A second comparison was made using data for 120 normal undergraduate students published in the BDI-II manual (Beck et al., 1996). Interestingly, results revealed that the 170 parents of transplant recipients had significantly lower BDI-II scores ( $M = 10.04$ ,  $SD = 9.67$ ) than the sample of 120 college students ( $M = 12.56$ ,  $SD = 9.93$ ,  $t(287) = -2.15$ ,  $p < .05$ ). There were no significant differences between year one and year two BDI scores.

	Time 1	Time 2
BDI Mean scores	10.04	9.13

\*\* Year three data is currently being collected.

### Parental Anxiety

Scores on the State Anxiety Scale of the STAI were compared to State Anxiety scores reported for a sample of 148 parents recruited at hospital pediatric practices who reported no evidence of any family member with a serious or chronic medical or psychiatric condition (Kazak, Barakat, Meeske, Christakis, Meadows, Casey, Pentai, & Stuber, 1997). A weighted-means analysis revealed that the 167 parents of transplant recipients in the current study with complete State Anxiety scores ( $M = 34.72$ ,  $SD = 11.55$ ) did not

significantly differ from the 148 parents in the healthy comparison group ( $M = 35.31$ ,  $SD = 12.61$ ,  $t(312) = -0.04$ , n.s.).

A second analysis was conducted on State Anxiety scores for a comparison group of 451 working adult females published by Spielberger (1983). Results also showed no significant differences between the parents of transplant recipients and working adult females ( $M = 35.20$ ,  $SD = 10.61$ ,  $t(618) = -0.47$ , n.s.).

There were no significant differences between year one and year two State Anxiety scores.

	Time 1	Time 2
State Anxiety Mean Scores	34.72	33.49

\*\* Year three data is currently being collected.

### Parental PTSD Diagnosis and Symptom Severity

Evaluation of parents for PTSD using the PDS revealed that 25.4% (n=43/169) of the parents were classified as meeting criteria for PTSD. Although statistical comparisons to other populations are not possible, this percentage is commensurate with data showing between 21% and 30% of parents of child cancer survivors were classified as having PTSD (e.g., Barakat, Kazak, Meadows, Casey, Meeske, & Stuber, 1997). Moreover, this percentage appears to be significantly higher than the 8% prevalence rates found in community-based studies (APA, 2000). Time 2 parents showed a similar prevalence pattern with 24% (n=32/131) meeting criteria for PTSD.

There was a significant correlation between parents who were positive for PTSD and elevated Beck Symptom Severity Scores ( $\chi^2(3, N = 165) = 58.461$ ,  $p = .000$ ). The lowest percentages of depressive symptoms were in the minimal category 13.3% (n=16/120) followed by the mild category 45% (n=10/22). Interestingly, all of the parents in the moderate depressive range were positive for PTSD (n=13/13), while in severe range the rate dropped to 70% (n=7/10).

Total symptom severity scores for those parents who met diagnostic criteria and for those who did not were compared, respectively, to published norms for individuals diagnosed with PTSD using the SCID and an at-risk population who were not diagnosed with PTSD using the SCID (Foa, et al., 1997). For the 43 parents who were classified as having PTSD on the PDS, the mean symptom severity score was 20.21 ( $SD = 7.63$ ). A weighted-means analysis revealed that these parents reported significantly less symptom severity than 128 individuals diagnosed with PTSD using the SCID ( $M = 33.59$ ,  $SD = 9.96$ ,  $t(168) = -9.17$ ,  $p < .001$ ). Interestingly, for 106 parents who were not classified as having PTSD on the PDS, the mean symptom severity score ( $M = 6.63$ ,  $SD = 6.12$ ) was similarly significantly lower than an at-risk population who did not meet criteria for PTSD using the SCID ( $M = 12.54$ ,  $SD = 10.54$ ,  $t(223) = -5.23$ ,  $p < .001$ ).

### Predicting PTSD Symptom Severity

The finding that least 25.4% of parents in this study appear to meet diagnostic criteria for PTSD suggests that PTSD symptoms are a significant issue for a subset of parents of

transplant recipients, and should be considered as a target for intervention. As such, a three-stage hierarchical regression analysis was performed to determine which demographic, transplant specific, and psychosocial variables might help account for severity of PTSD symptoms in parents as indexed by the total symptom severity score on the PDS.

Results of the hierarchical regression analysis with respect to each group of variables, controlling for earlier groups of variables, are presented in Table 1. As can be seen, although the demographic variables did not account for individual differences in PTSD symptom severity scores, transplant and child health variables did significantly predict PTSD symptom severity scores after controlling for demographics ( $R^2_{adj.} = .13, p < .001$ ). Similarly, after controlling for both demographics and transplant and child health variables, the set of psychosocial variables also significantly predicted PTSD symptom severity scores ( $R^2_{adj.} = .28, p < .001$ ).

**Regression Model Statistics for Sets of Variables in Predicting Parental PTSD**

**Severity Scores**

Variables	R <sup>2</sup>	R <sup>2</sup> <sub>adj.</sub>	F Change
Time elapsed since transplant	.02	.01	2.68
Demographic	.06	.01	1.01
Transplant and Child Health	.19	.13	5.72**
Psychosocial	.36	.28	5.77**

\*\*\* $p < .001$

Results of the stepwise analyses conducted on each set of variables as outlined above are presented in Table 2. These analyses revealed that after controlling for demographics, the parent perception of child’s physical health, as measured by the CHQ, was a uniquely significant predictor of caregiver PTSD symptom severity. Specifically, parental report of poorer general health of the child was uniquely related to more severe PTSD symptomatology in parents.

Table 2

**Standardized and Unstandardized Regression Weights for Significant Predictor**

**Variables of Parental PTSD Severity Scores**

Variables	<u>B</u>	<u>SE B</u>	$\beta$
CHQ Physical Health <sup>a</sup>	-.147	.036	-.322***
IFS Familial/Social Impact <sup>b</sup>	.608	.160	.315***
PAIS Health Orientation Scale <sup>b</sup>	.707	.264	.223**
IFS Mastery <sup>b</sup>	.590	.276	.159*

<sup>a</sup> Controlled for demographic variables

<sup>b</sup> Controlled for demographic and transplant/child health variables

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

With respect to the psychosocial variables, results revealed that after controlling for both demographics and transplant/child health variables, the Familial/Social Impact factor score and the Mastery factor score from the Impact on the Family Scale both significantly predicted PTSD symptom severity. Specifically, greater perceived impact of the transplant on family and social functioning, and less perceived familial benefits of the transplant were significantly and uniquely related to greater PTSD symptom severity in parents. In addition, results also showed that Health Care Orientation scores significantly predicted PTSD symptom severity, such that those parents who had more negative attitudes about health care services and health care in general were more likely to report greater PTSD symptom severity.

**Worst Moments as Self Reported by Transplant Recipients**

To get a sense of the transplant experience from the perspective of the recipient, we asked 104 adolescent pediatric transplant *recipients* to describe the worst moments they experienced during their transplant experience. Their responses were assigned to categories consistent with the “A” criteria from the DSM-IV.

<b>Intrusion on Physical Integrity</b>	<b>46</b>
<b>Helplessness</b>	<b>27</b>
<b>Extreme Fear</b>	<b>23</b>
<b>No worst moment</b>	<b>7</b>
<b>Uncodeable</b>	<b>1</b>

## N 104

Intrusion on Physical Integrity (n=46) included any statements that involved scars, cosmetic issues, and an inability to perform physically. For example, “The hardest/worst moment in regards to receiving my most recent kidney was when I was put on the different steroids and my looks changed and I felt extremely ugly and looked absolutely horrible”. An example of Helplessness (n=27) is, “When they (the doctors) told me I needed a new heart, I wanted to die because I was already in the hospital for 2 months and I just wanted to leave hospitals”. An example of an Extreme Fear (n= 23) statement is, “My worst moment was when I knew I was going to die any day, at any hour at the hospital”. The Uncodeable statement was too general to be assigned to any one category: “The three days after”. Many in the “No Worst Moment” category were too young at the time of the transplant experience to recall a specific worst moment. However, two of these responses were truly reporting no worst moments.

“There was nothing hard about it” (male, current age 19.8 years, kidney transplant recipient at age 15.5)

“Nothing” (female, current age, 17.5 years, kidney transplant recipient at age 13.6 years)

There were three responses that specifically mentioned the issue of taking medications, or interest due to the problem with adolescents taking medications:

“Taking the nasty medicine” (male, current age 13 years, transplant age 1.7 years)

“My parents and I would argue about taking my medication or I would sometimes be lectured if I forgot about them” (female, current age 13 years, transplant at age 1.8 years)

“Taking medicine every morning and every night” (male, current age 14 years, transplant at age 2.1 years)

## Discussion

Parents of pediatric solid organ transplant recipients do not report clinically significant levels of symptoms of depression or anxiety. Comparisons to published data using the same measures with normative samples indicated that parents of pediatric transplant recipients do not appear to report symptoms of depression or anxiety any more frequently or of greater severity than would be expected in the normal population. Despite the fact that some parents did report high levels of depression and/or anxiety, comparisons to other samples did not reveal significant differences, suggesting that depression or anxiety is not functionally related to having had a child undergo transplant surgery.

Although reassuring, these findings are emotionally counter-intuitive, given the stressors parents face in the course of medical life-threat to a child. It may be that symptoms of depression and anxiety are more prevalent in parents earlier in the transplant process, during the uncertainty and stress of waiting for a suitable organ donor and the stormy period often experienced in the first year after the transplant. Indeed, it may be that once a child has successfully stabilized after receiving a solid organ transplant, as the children in

this study had, parents feel a certain sense of relief and renewed hope. The decrease in hopelessness and helplessness may then mitigate any prior anxiety or depression.

Examination of parents' reports of PTSD symptoms revealed that a substantial proportion of parents did meet diagnostic criteria for PTSD, as measured by the PDS. Moreover, the percentage of parents who have PTSD (25.4%) is similar to prevalence rates reported for parents of children with cancer and substantially larger than what would be expected in normal populations (APA, 2000). As such, unlike depression or anxiety, self-reported symptoms of PTSD does seem to be a specific and relatively prevalent reaction to the trauma of having a child undergo transplant surgery. However, in the realm of traumatic events, this experience would appear to be one of moderate severity. The severity of symptoms reported by parents in this study was significantly less than a comparison sample of individuals diagnosed as having PTSD using the SCID. Depression appears to contribute to the risk of sustained PTSD symptoms. Parents with moderate and severe Beck Symptom severity scores were more likely to meet diagnostic criteria for PTSD.

In an effort to further understand what factors might be associated with PTSD symptomatology, three clusters of variables were examined in relation to PTSD severity scores. The first block of variables consisted of demographic variables, the second of transplant and child health variables and the third of psychosocial variables. Interestingly, none of the demographic variables predicted PTSD severity scores. Specifically, PTSD severity was not related to the age or gender of the child, the age or education level of the parent, the type of insurance carried by parents, or the level of parents' acculturation.

A second cluster of predictors – transplant specific and child health variables – did significantly predict individual differences in parents' reported PTSD symptom severity. When considering the unique contributions of each of the specific predictors, it was found that the parental reports of their child's overall physical health did significantly contribute to parents' reported levels of PTSD such that the poorer health of the child was related to more severe parental PTSD symptoms. Interestingly, neither the type of transplant nor the total number of transplants experienced by the child was related to parents' PTSD severity. These findings are surprising given that the severity of trauma might be expected to vary as a function of these factors which are related to increased morbidity and mortality. For instance, the availability of dialysis would be expected to reduce the actual life threat of kidney transplantation compared to heart or liver transplantation. Such findings may underscore the importance of considering how parents' *appraisal* of events relates to the development of PTSD symptoms. The severity of PTSD symptoms appears to be more related to the parents' impression of threat than the "objective" threat as perceived by the medical team. One parent may interpret a child's heart transplant as a "cure" for a life-threatening condition, while another parent may respond to a child's heart transplant with helplessness and uncertainty about survival. This is supported by the relationship between parental ratings of children's physical health and parental self-reports of severity of PTSD symptoms. This hypothesis consistent with findings from research on parents of pediatric cancer survivors (Kazak et al., 1998) which found that parents' perceptions of life-threat and intensity of treatment were significant predictors of self-reported PTSD. Physicians'

ratings of “objective” measures of treatment and life-threat intensity were not significant predictors of parental PTSD symptoms. This suggests an area for intervention research.

The third set of variables examined in relation to PTSD symptom severity included six psychosocial variables: overall social support, four subscales of the IFS (financial impact, personal strain, familial/social impact, and mastery), and the parents’ attitude toward health care services. Although the entire cluster of psychosocial variables was significant in predicting PTSD severity, examination of unique contributions of each predictor variable revealed that the strongest predictors of PTSD symptom severity were two subscales of the IFS -- perceived impact on familial and social functioning and perceived benefits of the experience -- and attitudes toward health care in general. Of particular interest is the finding that parental perceptions of how the transplant experience impacted the family was related to severity of PTSD symptoms. Specifically, parents who reported feeling that family and social functioning (e.g., traveling, participating in social events, visiting with friends and relatives) was negatively impacted by the transplant event also tended to have more severe self-reported PTSD symptoms. Additionally, parents who reported fewer perceived benefits of the transplant in terms of family relations and cohesiveness also reported more severe PTSD symptoms. It also appears that parents who were able to “reframe” the transplant as having had positive consequences for the family were less likely to report sustained PTSD symptoms. Although this study was not designed to examine such an interpretation conclusively, these findings do suggest this interpretation as a possible direction for future intervention research .

The finding that parents’ negative attitudes toward health care services were significantly related to more severe self-reported PTSD symptoms is also interesting. It may be that perceptions of health care service providers and facilities as negative and essentially hostile serves to heighten the perceived threat to the parent and child. As a consequence of such heightened perceived threat, it is likely that the transplant experience would be interpreted as more traumatic than it otherwise might be, resulting in more severe PTSD symptoms.

It is important to note, however, that the directionality of the findings for the relationship between PTSD severity and child health or psychosocial variables is uncertain. It may be that the findings regarding predictors of PTSD symptom severity are artifacts of a methodology utilizing only self-report measures. Likewise, it may be that parents who experience PTSD symptoms have a tendency to perceive things such as their experience with health care providers as more negative. In other words, it is possible that PTSD symptoms serve to bias parents’ perceptions in other areas as more negative. Future research that utilizes multi-method assessment of variables such as the quality of health care service or changes in family dynamics at pre-operative as well as post-operative time periods, or research that manipulates one or more of these variables through intervention or feedback to parents may help to illuminate the findings of the present study.

In conclusion, findings from this study suggest that a relatively large subset of parents of pediatric transplant recipients report some emotional and psychological distress. The nature of such distress, however, appears to be more consistent with a diagnosis of PTSD rather than depression or anxiety. Possible factors that may relate to individual differences

in PTSD symptom severity include negative attitudes toward health care and the perception that the transplant had a negative impact on family functioning. The majority of parents did not report clinically significant psychological distress. Parents' reports of depression and anxiety symptoms did not differ from those of healthy adults. Such results may best be seen as a testament to the resiliency of parents dealing with tremendously challenging medical events.

The collection and analysis of the Time Three data and the Health Care Utilization data are still ongoing. We expect to submit a report on these findings in the spring of 2003.

## **List of Products**

### **Peer-reviewed articles**

Young, GS, Mintzer, LL, Seacord, D, et al. 2002. "Posttraumatic Stress Disorder in Parents of Transplant Recipients." *Pediatrics*, *In press*.

Mintzer, L.L., Stuber, M.L., Seacord, D.L., Castaneda, M., Mesrkhani, V. (2002) "Traumatic Stress Symptoms in Adolescent Organ Transplant Recipients." In preparation.

Glover, D., Shemesh, E., Seacord, D., Stuber M.L. (2002). "Worst Moments: Exploration of what is Traumatic about life threatening Pediatric Illnesses." In preparation.

Mintzer, L.L., 2001 "Posttraumatic Stress Disorder in Adolescent Solid Organ Transplant Recipients." Unpublished doctoral dissertation, Northwestern University, Evanston, IL.

### **Presentations**

Seacord, D, Mintzer, L.L, Young, GS, Stuber, M.L. "Worst Moments: Adolescents' Descriptions of Traumatic Medical Events." Presented before the International Society for Traumatic Stress Studies, Baltimore, MD, November 2002.

Stuber, M.L. "PTSD in Pediatric patients." Presented before Grand Rounds at University of Rochester School of Medicine, Rochester, N.Y., June 2002.

Stuber, M.L. "PTSD in Pediatric Organ Transplant recipients." Presented before Grand Rounds at Children's Hospital of Boston, Boston, MA., June 2002.

Mesrkhani, V.H., Seacord, D., , Mintzer, L.L., Castañeda, M., Stuber, M.L. "The Effects of Parental Depression and Perceived Social Support on Medical Adherence among Pediatric Heart, Kidney and Liver Recipients." Presented before the Alliant International University, May 2002.

Stuber, M.L. "PTSD in Parents of Pediatric Organ Transplant Recipients." Presented before the International Society of Traumatic Stress Studies, Annual meeting, New Orleans, LA., November, 2001.

Mintzer, L.L., Seacord, D., Mesrkhani, V.H., Castañeda, M., Stuber, M.L. "PTSD in Parents of Pediatric Organ Transplant Recipients: Second-year Results of a 3-year Longitudinal Study." Presented before the International Society for Traumatic Stress Studies, Annual meeting, New Orleans, LA., November, 2001.

Stuber, M.L. "Traumatic response to childhood illness." Presented before Grand Rounds at Oliveview Medical Center, Los Angeles, CA., August, 2001.

Lau, A., Mintzer, L.L., Seacord, D., Stuber, M.L. "Assessing Health Beliefs in Adolescent Transplant Recipients." Poster presentation presented before the Pediatric Academic Societies Annual Meeting, Baltimore, MD, April 2001.

Mintzer, L.L., Mesrkhani, V.H., Seacord D., Stuber, M.L. "Issues in Treatment: Efficacy, Adverse Events and Adherence." Paper presentation, presented before the American Academy of Psychosomatic Medicine Annual Meeting, Palm Springs, CA., November 2000.

Mintzer, L.L., Seacord, D., Mesrkhani, V.H., Castañeda, M., Stuber, M.L. "PTSD in Parents of Pediatric Organ Transplant Recipients: Preliminary Results of a Three-year Longitudinal Study." Poster presentation, presented before the Academy of Psychosomatic Medicine Annual Meeting, Palm Springs, CA, November 2000.

Mintzer, L.L., Seacord, D., Mesrkhani, V.H., "PTSD and Medical Adherence in Pediatric Organ Transplant Recipients and their Parents." Symposium presentation, presented before the International Society for Traumatic Stress Studies Annual Meeting, San Antonio, Texas., November, 2000.

Osborne, W., Mintzer, L.L., Seacord, D., Mesrkhani, V.H., Stuber, M.L. "Parental Depression and Medical Adherence in Pediatric Organ Transplant Recipients." Poster presentation, presented before the American Academy of Child and Adolescent Psychiatry, New York, N.Y., October, 2000.

Stuber, M.L., Seacord, D., Mintzer L.L., Mesrkhani, V., "PTSD in Parents of Pediatric Organ Transplant Recipients." Presented before the American Academy of Child and Adolescent Psychiatry., New York, N.Y., October, 2000.

Reddy, R., Stuber, M.L., Seacord, D. Sue, L. "Enhancement of Compliance and Pediatric Transplantation Outcomes: The Development of a Pathway for the Transition from Dialysis to Renal Transplantation." Poster presentation, presented before the American Academy of Child and Adolescent Psychiatry. October, 1999.



## References

- Almond, P. S., Morell, P., Matas, A. J., Gillingham, K. J., Chau, K. S., Brown, A., Kashtan, C. E., Mauer, S. M., Chavers, B., & Nevins, T. E. 1991. Transplanted children with long-term graft function have an excellent quality of life. Transplantation Proceedings. 23: 1380-1381.
- American Psychiatric Association. 2000. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, DC: American Psychiatric Association.
- Barakat, L. P., Kazak, A. E., Meadows, A. T., Casey, R., Meeske, K., & Stuber, M. L. 1997. Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. Journal of Pediatric Psychology. 22: 843-859.
- Beck, A. T., Steer, R. A., & Brown, G. K. 1996. Beck Depression Inventory-Second Edition: Manual. San Antonio, TX: The Psychological Corporation.
- Beck, A. T., Ward, C., Mendelson, N., Mock, J., & Erbaugh, J. 1961. An inventory for measuring depression. Archives of General Psychiatry. 4: 53-63.
- Becker, M.H., Drachman, R.H. & Kirscht, J.P. 1972. Predicting mothers compliance with pediatric medical regimens. Medical Care. 81(4): 843-854.
- Cruz, D., Cruz, V. J., & Rios, V. 1991. PAIS-SR: Spanish Translation. Towson, MD: Clinical Psychometric Research, Inc.
- Dahlquist, L., Czyzewski, D., Copeland, K., Jones, C., Taub, C., & Vaughan, J. 1993. Parents of children newly diagnosed with cancer: Anxiety, coping and marital distress. Journal of Pediatric Psychology. 18: 365-376.
- DeBolt, A. J., Stewart, S. M., Kennard, B. D., Petrik, K., & Andrews, W. S. 1995. A survey of psychosocial adaptation in long-term survivors of pediatric liver transplants. Childrens Health Care. 24: 79-96.
- Derogatis, L. R., & Derogatis, M. F. 1990. The Psychosocial Adjustment to Illness Scale (PAIS & PAIS-SR): Administration, Scoring & Procedures Manual-II. Towson, MD: Clinical Psychometric Research, Inc.
- Dozois, D. J. A., Dobson, K. S., & Ahnberg, J. L. 1998. A psychometric evaluation of the Beck Depression Inventory-II. Psychological Assessment. 10: 83-89.
- Foa, E. B. (1995). Posttraumatic Stress Diagnostic Scale: Manual. Minneapolis, MN: National Computer Systems.
- Foa, E. B., Cashman, L., Jaycox, L., & Perry, K. 1997. The validation of a self-report measure of posttraumatic stress disorder: The posttraumatic diagnostic scale. Psychological Assessment. 9: 445-451.
- Fukunishi, I., & Kudo, H. 1995. Psychiatric problems of pediatric end-stage renal failure. General Hospital Psychiatry. 17: 32-36.
- Hauser, S.P. 1995. Case management of kidney transplant recipients. ANNA Journal. 22 (4): 369-374.
- House, R., Dubovsky, S. L., & Penn, I. 1983. Psychiatric aspects of hepatic transplantation. Transplantation. 36: 146-150.
- Kazak AE, Barakat LP, Meeske K, et al. 1997. Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. Journal of Consulting Clinical Psychology. 65 (1): 120-129

Kazak, A. E., Stuber, M. L., Barakat, L. P., Meeske, K., Guthrie, D., & Meadows, A. T. 1998. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. Journal of the American Academy of Child and Adolescent Psychiatry. 37: 823-831.

Kazak, A.E., Barakat, L.P., Meeske, K., Christakis, D., Meadows, A.T., Casey, R., Penati, B., & Stuber, M.L. 1997. Posttraumatic stress symptoms, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. Journal of Clinical and Consulting Psychology. 65 (1): 120-129.

Landgraf, J. M., Abetz, L., & Ware, J. E. 1996. Child Health Questionnaire (CHQ): A user's manual. Boston, MA: The Health Institute, New England Medical Center.

LiBiondo-Wood, G., Bernier-Henn, M., & Williams, L. 1992. Impact of the child's liver transplant on the family: Maternal perspective. Pediatric Nursing. 18: 461-466.

Manne, S. Miller, D., Meyers, P. Wollner, N., Steinherz, P., & Redd, W. H. 1996. Depressive symptoms among parents of newly diagnosed children with cancer: A 6-month follow-up study. Children's Health Care. 25: 191-209.

Marin, G., Sabogal, F., Marin, B., Otero-Sabogal, R., & Perez-Stable. 1987. Development of a short acculturation scale for Hispanics. Hispanic Journal of Behavioral Sciences. 9:183-205.

Mazariegos, G.V., Reyes J. 1999. What's new in pediatric organ transplantation. Pediatrics in Review. 120 (11): 363-75.

Montenegro L.M., Ward A., McGowan F.X., et al. (1998). New directions in perioperative management for pediatric solid organ transplantation. Journal of Cardiothoracic Vascular Anesthesia. 12 (4): 457-472.

Pelcovitz, D., Goldenberg, B., Kaplan, S., Weinblatt, M., Mandel, F., Meyers, B., & Vinciguerra, V. 1996. Post-traumatic stress disorder in mothers of pediatric cancer survivors. Psychosomatics. 37: 116-126.

Reyes, J., Mazariegos, G.V. 1979. Pediatric transplantation. Surgical Clinics Of North America. 1: 163-89.

Richter, P., Werner, J., Heerlein, A., Kraus, A., & Heinrich, S. 1998. On the validity of the Beck Depression Inventory: A review. Psychopathology. 31: 160-168.

Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. 1992. Families of autistic children: Psychological functioning of mothers. Journal of Clinical and Child Psychology. 19: 371-379.

Rodrigue, J. R., MacNaughton, K., Hoffmann, R. G., Graham-Pole, J., Andres, J. M., Novak, D. A., & Fennell, R. S. 1997. Transplantation in children: A longitudinal assessment of mothers' stress, coping, and perceptions of family functioning. Psychosomatics. 38: 478-486.

Salman, E. 1998. Research Edition Spanish Translation: State-Trait Anxiety Inventory (Form Y). Redwood City, CA: Mind Garden, Inc.

Sherbourne, C. D., & Stewart, A. L. 1991. The MOS Social Support Survey. Social Science in Medicine. 32: 705-714.

Spielberger, C. 1983. Manual for the State-Trait Anxiety Inventory (Form Y). Palo Alto, CA: Consulting Psychologists Press.

Stein, R. E. K., & Riessman, C. K. 1980. The development of an Impact-on-Family Scale: Preliminary findings. Medical Care. 18: 465-472.

Tarbell, S. E., & Kosmach, B. 1998. Parental psychosocial outcomes in pediatric liver and/or intestinal transplantation: Pretransplantation and the early postoperative period. Liver Transplantation and Surgery. 4: 378-387.

United Network for Organ Sharing (n.d.). Retrieved November 19, 2001 from <http://www.unos.org>.

Uzark K.C., Sauer S.N., Lawrence K.S., Miller J., Addonizio L., Crowley D.C. 1992. The psychosocial impact of pediatric heart transplantation. Journal Heart Lung Transplant. 11 (6): 1160-7.

Uzark, K. C., Sauer, S. N., Lawrence, K. S., Miller, J., Addonizio, L., & Crowley, D. C. 1994. The psychosocial impact of pediatric heart transplantation. Journal of Heart and Lung Transplantation. 11: 1160-1167.

Van Dongen-Melman, J. E. W. M., Pruyn, J. F. A., De Groot, A., Koot, H. M., Hahlen, K., & Verhulst, F. C. 1995. Late psychosocial consequences for parents of children who survived cancer. Journal of Pediatric Psychology. 20: 567-586.

Windsorova, D., Stewart, S. M., Lovitt, R., Waller, D. A., & Andrews, W. S. 1991. Emotional adaptation in children after liver transplantation. Journal of Pediatrics. 119: 880-887.

Wray, J., Radley-Smith, R., & Yacoub, M. 1992. Effect of cardiac or heart-lung transplantation on the quality of life of the pediatric patient. Quality of Life Research. 1: 41-46.

Zamberlan, K. 1992. Quality of life in school-age children following liver transplantation. Maternal Child Nursing Journal. 20: 167-229.