Symptoms of Posttraumatic Stress Disorder in Parents of Transplant Recipients: Incidence,Severity, and Related Factors

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ABSTRACT. Objective. To examine the incidence, severity, and factors related to posttraumatic stress disorder (PTSD) symptoms in parents of pediatric solid organ transplant recipients.

Method. A total of 170 caregivers of pediatric transplant recipients completed self-report measures of psychological functioning between 10 and 38 months after their child’s most recent transplant. Demographic data, child health variables, and ratings of medical attitudes and social functioning were also collected to help explain individual differences in psychological functioning. 

Results. Although caregivers of pediatric transplant recipients did not report elevated levels of depression or anxiety, they did report elevated levels of PTSD symptoms. Multiple regression analyses revealed that PTSD symptoms were most strongly associated with parent reports of child health, family impact of the transplant, and attitudes toward medical caregivers.

Conclusions. PTSD seems to be relatively common in parents of pediatric transplant recipients and may be largely the result of how parents perceive and interpret the transplant experience. Pediatrics 2003;111:e725-e731.

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ABBRIDEVATIONS. PTSD, posttraumatic stress disorder; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; UCLA, University of California–Los Angeles; SD, standard deviation; PDS, Posttraumatic Stress Diagnostic Scale; BDI-II, Beck Depression Inventory; STAI, State-Trait Anxiety Inventory; CHQ, Child Health Questionnaire; IFS, Impact on Family Scale; SSS, Social Support Survey.

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 cyclosporine A and tacrolimus, has dramatically improved survival rates in 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. Despite such encouraging numbers, 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. As such, with more children surviving solid organ transplantation, there has been increased attention to posttransplantation functioning, with a growing body of research examining psychosocial functioning, quality of life, and adjustment in pediatric organ transplant recipients.

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 threat that child transplant recipients frequently face and the demands of careful postoperative 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.

Descriptive reports of the impact of pediatric organ transplant on caregivers suggest that parents undergo a series of emotional stressors throughout the transplant process from the preoperative stage up to several years posttransplantation. As Gold et al11 and Meltzer and Rodrigue12 noted, 1 of the primary stressors during the preoperative phase is the wait for a suitable organ donor, with resulting apprehension, helplessness, and worry reported by parents. Furthermore, although parents are often relieved after a successful transplant surgery, they then face the uncertainty and fear of infection and/or rejection. Even when the child is finally well enough to be discharged and return home, parents must adjust to the increased responsibilities of caring for their child in the face of possible rejection without the constant medical, informational, and emotional support network of the hospital and transplant team. As Gold et al11 noted, many parents describe this phase as an “emotional roller coaster” marked by feelings of anxiety, hypervigilance, and helplessness.

In line with these qualitative reports of psychological distress experienced by parents during the process of pediatric organ transplantation, a number of empirical studies have also documented that many parents score above clinical cutoffs on self-report measures of psychological and emotional distress. For example, Tarbell and Kosmach reported that a majority of parents at both pretransplantation and 2 months posttransplantation exhibit...
ted clinically significant psychological distress on the global severity index of the Brief Symptom Inventory. Similarly, Sormanti et al found that retrospective reports from parents up to 10 years after their child’s bone marrow transplant indicated that almost 50% of parents had been significantly distressed about their mental health in connection with their child’s transplant.

A number of studies have also examined the correlates of parental distress in an effort to understand better which factors might be functionally related to parental distress. In the study by Tarbell and Kosmach, for instance, they found that family conflict, as measured by the Family Environment Scale, significantly predicted parental mental health. Sormanti et al similarly found that parental distress frequently centered on financial problems (often as a result of the costs of transplantation) and social relationship problems. The findings that parental stress is significantly related to disruptions in parents’ social functioning both within and outside the family have also been documented by several other studies and further suggest that coping resources in the form of social support and family cohesion are critical buffers for the stressors that parents face in caring for a child who has received an organ transplant.

It is particularly informative to note that parents’ family and social relationships may become particularly disrupted in the months and years after a child’s transplant. As Gold et al noted, the posttransplantation phase often entails an adjustment of family dynamics in dealing with increased caregiving responsibilities and financial burdens. It is likely, too, that extended social support networks are not as available once there is the superficial appearance of normalcy with the child returning home. Without the acute crisis of hospitalization and surgery, friends and relatives may not be as spontaneously and readily supportive to the parents. This suggests that although parents experience distress during all phases of the transplant process, the long-term postoperative adjustment may be particularly difficult. Indeed, this hypothesis is supported by research reported by Rodriguez et al that examined parents’ psychosocial functioning at 3 time periods: pretransplantation, 1 month posttransplantation, and 6 months posttransplantation. Findings indicated that overall, parenting stress tended to be higher at posttransplantation and that by 6 months, compared with 1 month posttransplantation, parents reported greater family conflict, less social support, less family integration, and less optimistic perceptions. Moreover, parents reported greater financial burdens, disrupted planning, and increased caregiver burden at both 1 and 6 months posttransplantation compared with pretransplantation.

The research to date clearly seems to indicate that parents of child transplant recipients are distressed by the transplant experience, particularly during the posttransplantation phase. Although there seems to be no particular acute traumatic event that causes such distress, it is still perhaps helpful to consider that the transplant experience as a whole, from preoperative assessment to discharge and recovery, is a traumatic event for parents. McConville et al suggested conceptualizing parental reactions to their child’s transplant operation using a stress disorder model. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) by the American Psychiatry Association lists the experiencing of a serious threat to the physical integrity of self or others and a reaction involving intense fear, helplessness, or horror among the defining features of a traumatic event for the diagnosis of PTSD or acute stress disorder. It is important to consider that although transplants usually improve or save the life of the child, they still involve the threat of death, postoperative pain, and obvious violation of physical integrity. Moreover, as research has documented, parental reactions involve high degrees of anxiety and feelings of helplessness. Although a number of studies have begun to examine the psychological distress of child transplant recipients in terms of possible PTSD symptoms, no studies have reported on possible PTSD symptoms in parents of transplant recipients.

The present study was designed to examine the hypothesis that a substantial number of parents of pediatric transplant recipients would report symptoms of PTSD during the posttransplantation phase. For understanding better the individual differences in the severity of parent reports of PTSD symptoms, several possible predisposing or related factors in parents were also examined. On the basis of previous research concerning the financial burdens and relative lack of social support that parents often face during the posttransplantation phase, it was expected that such variables would help to explain individual differences in self-reported PTSD symptoms. The results reported in this article are part of a larger, 3-year longitudinal study of psychosocial predictors of health care utilization of pediatric transplant recipients and functional outcome of their parents.

METHODS

Subject Recruitment and Procedure

The primary caregivers of all pediatric patients who had been in recovery from their initial heart, liver, or kidney transplant at University of California–Los Angeles (UCLA) for 1–3 years were eligible for inclusion in this study. The transplant recipients had to be younger than 19 years at the time of their transplant. Caregivers whose children underwent retransplant operations and those whose ongoing medical care was not at UCLA were also eligible to participate. Literacy was not a prerequisite of inclusion, as instruments could be read aloud as necessary. Parents were required to be fluent in either 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. UCLA pediatric transplant staff reviewed the potential subject list to ensure that families who were currently undergoing an acute stressor (eg, a medical crisis, 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 telephone to assess their interest in participating. The primary caregiver of the transplant recipient (mother, father, or guardian) was invited to participate. Informed consent was obtained from all participants, and assent was acquired from transplant recipients 6 years and older. All measures were completed with the help of bilingual research
assistants using an interview format of 1–2 hours’ duration conducted before or after follow-up clinic visits when possible; otherwise, subjects completed the measures via telephone.

Sample Characteristics

A total of 290 families met the aforementioned age and time since transplantation requirements. Of those, 32 children were deceased; 4 families were lost to follow-up; and 17 were ineligible because of factors such as being out of the country, absence of a primary caregiver, and severe medical or family crisis. Of the remaining 257 families, 60 parents declined and 7 parents failed to complete the interview and measures. As such, 170 parents composed the final sample for data analysis (58.6% participation rate). Nonparticipants did not differ significantly from those who participated in terms of any of the demographics that were available without informed consent: type of transplant, age and gender of the transplant recipient, and time since transplant.

Of the 170 caregivers who responded, 94.7% (n = 164) 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 white, 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; mean: 444.18 months; standard deviation [SD]: 99.42 months).

With respect to the child transplant recipients whose parents participated in the study, 18.2% (n = 31) had received at least 1 heart transplant, 14.1% (n = 22) had received at least 1 liver transplant, and 27.1% (n = 46) had received at least 1 kidney transplant. One subject had received both a liver and a kidney transplant. Although most children (85.3%; n = 145) had only ever received 1 transplant, 11.2% (n = 19) had received 2 transplants, 2.9% (n = 5) had received 3 transplants, and 1 child had received 4 transplants. The ages of child transplant recipients at the time of the most recent transplant ranged from 2 months to 228 months (19 years; mean: 85.1 months; SD: 75.7 months), and roughly half of the transplant recipients were female (47.6%; n = 81).

Procedure

Parent measures (described below) were completed in an interview format conducted between 10 months and 38 months after the initial organ transplant (mean: 18.2 months; SD: 6.8 months). A total of 64.7% (n = 110) of the parent measures were completed in English, and 35.3% (n = 60) of the measures were completed in Spanish, using translated versions of each measure (see below). Seventeen of those who completed Spanish versions indicated that they spoke English but were more comfortable completing the measures in Spanish. In-person data collection procedures were conducted with 49.4% (n = 84) of respondents, and telephone data collection procedures were conducted with 47.1% (n = 80) of respondents. The remaining 3.5% (n = 6) respondents completed measures both in-person and over the telephone.

Measures

Posttraumatic Stress Diagnostic Scale

The Posttraumatic Stress Diagnostic Scale (PDS) is a 49-item self-report scale that assesses DSM-IV symptoms of PTSD. It provides a preliminary, categorical diagnosis of PTSD as well as an overall (continuous) measurement of symptom severity. 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. Given that a significant portion of the participants primarily spoke Spanish, a Spanish version of the PDS was created by the authors of the current study with permission. The PDS was translated into Spanish by 4 psychology and medical students who were fully bilingual. After this, each new Spanish version was back-translated into English by 1 of the 3 other translators. The back-translation of the PDS was checked by 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 α = 0.89) and good concurrent validity with scores on established Spanish versions of the Beck Depression Inventory (BDI; r = 0.635, P < .001) and the State Anxiety scale (r = 0.605, 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

The BDI-II34 is a 21-item self-report scale that has been widely used in screening for depression in adults. It has high internal consistency, high content validity, and good specificity and sensitivity.26-27 A published Spanish translation of the BDI-II was used for interviews conducted in Spanish.

State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory (STAI) is a 40-item self-report scale that assesses usual (ie, trait) and current (ie, 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,29 was used for participants who were interviewed in Spanish.

Demographic Variables

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 1) respondent’s age at time of the child’s study inclusion transplant, 2) respondent’s education level, 3) patient gender, 4) patient age at time of study inclusion transplant, 5) type of insurance, and 6) acculturation. The type of insurance carried by the respondent was coded “0” for MediCal (the California version of MedicaAid) or “1” for any other type of insurance. Eighty-four (47.1%) respondents indicated that they had MediCal coverage. Acculturation was calculated using 4 items derived from the Short Acculturation Scale devised by Marín et al30 that assessed the extent to which respondents read, speak, and think in English versus Spanish.

Transplant-Related Variables

Variables reflecting characteristics of the child’s transplant were also collected as part of the Family Information Form. These included type of transplant and total number of transplants (up to and including the most recent transplant).

Child Health Questionnaire—Physical Health Factor

The Child Health Questionnaire (CHQ) Physical Health factor is a parent-report measure composed of 4 subscales that measure the parent’s perceptions of the 1) physical functioning of the child, 2) social limitations (as a result of child’s health), 3) child’s general health, and 4) bodily pain and discomfort experienced by the child. The CHQ has adequate internal consistency and discriminatory validity.31 A Spanish version developed by Landgraf et al31 was used in the present study.

Health Care Orientation Scale

The Health Care Orientation Scale is a brief, 8-item subscale of the Psychosocial Adjustment Scale: Self Report measure, which measures attitudes toward the quality of health care, expectations about illness and its treatment, and health-promoting behavior. Although originally designed to be completed by actual adult medical patients, questions were revised for the present study to reflect parents’ attitudes and expectations about their child’s health care. Cronbach’s α for this revised parent version of the Health Care Orientation Scale was 0.67, which, although somewhat low, is comparable to α between 0.47 and 0.83 on several medical populations reported by Derogatis and Derogatis.32 A Spanish version, based on the original translation by Cruz et al,32 was also adapted in reference to parents’ children. Cronbach’s α for the translated version was 0.70, somewhat higher than the 0.67 α for the English version used in this study.
Impact on Family Scale

The Impact on Family Scale (IFS)34 is a 33-item measure that assesses parents’ perceptions about the impact of a child’s illness on the family in 4 dimensions: 1) financial impact, 2) familial and social impact, 3) personal strain (eg, fatigue, day-to-day practical limitations), and 4) mastery (which measures any possible benefits of the illness, eg, bringing the family closer together). The IFS has shown good reliability34 and has been used in previous studies to evaluate the family impact of transplant surgery13 and autism.35 A Spanish version of the IFS was created by the authors of the current study, again using back-translation methods. Cronbach’s α for the Spanish version was 0.84, commensurate with that of the English version at 0.83.

Medical Outcomes Study Social Support Survey

The Study Social Support Survey (SSS)36 is a 20-item questionnaire that measures various types of social support available to an individual. Specifically, the SSS asks respondents about tangible support (in the form of practical help in case of illness), emotional support, positive interactions (eg, 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. The measure has been shown to have good internal consistency and test-retest reliability, as well as good construct validity.36 A Spanish version of the SSS was created by the authors of the current study. Cronbach’s α for the Spanish version was 0.96, commensurate with that of the English version at 0.97.

RESULTS

Parental Depressive Symptoms

Overall, parents’ scores on the BDI-II were relatively normal (mean: 10.04; SD: 9.67), suggesting that these parents did not exhibit clinical depression. Nevertheless, 27.1% of parents did exhibit at least mild depression (ie, a total score ≥14), with 49.8% of these parents scoring in the moderate to severe range.

Parental Anxiety

Given that no clinical cutoffs are available for the State Anxiety Scale of the STAI, parents’ scores on the State Anxiety Scale were compared with published State Anxiety scores reported for a control group sample of 148 parents who were recruited at hospital pediatric practices and indicated no evidence of any family member with a serious or chronic medical or psychiatric condition.37 A weighted-means analysis revealed that the 167 parents of transplant recipients in the current study with complete State Anxiety scores (mean: 34.72; SD: 11.55) did not significantly differ from the 148 parents in the healthy comparison group (mean: 35.31; SD: 12.61, t(312) = −0.04, not significant).

Parental PTSD Diagnosis and Symptom Severity

Evaluation of parents for PTSD using the PDS revealed that, although group means for overall symptom severity scores fell within the normal range (mean: 10.25; SD: 8.85), 50.6% of parents reported at least moderately severe PTSD symptoms and 44.6% of parents reported moderate to severe impairment of functioning as a result of such symptoms. Using the stricter, categorical DSM-IV diagnostic criteria, 27.1% (n = 46 of 165) 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 that between 21% and 30% of parents of childhood cancer survivors were classified as having PTSD.38 This percentage seems to be significantly higher than the 8% prevalence rates found in community-based studies.21

For the 46 subjects who met criteria for a PTSD diagnosis on the PDS, a within-subjects analysis of variance was conducted on severity scores for the 3 symptom clusters of avoidance, arousal, and reexperiencing. Results revealed a significant difference between symptom cluster severity scores (F[2,90] = 12.43; P < .001). Post hoc comparisons using the Bonferroni correction method revealed that parents who met diagnostic criteria on the PDS reported significantly more severe avoidance symptoms (mean: 8.12; SD: 3.35) than arousal symptoms (mean: 6.33; SD: 3.63; t = 3.90; P < .001) or reexperiencing symptoms (mean: 5.72; SD: 2.71; t = 4.56; P < .001). There was no significant difference between parents’ reported arousal symptom severity and reexperiencing severity symptoms (t = 1.19; P = not significant).

Predicting PTSD Symptom Severity

In an effort to understand which factors might help to explain individual differences in parent reports of PTSD symptoms as indexed by the total symptom severity score on the PDS, a 3-stage hierarchical regression analysis that examined demographic, transplant-specific, and psychosocial variables was performed. With the use of 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 data collection, 3 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: 1) child’s age at the time of transplant, 2) parent’s age at the time of transplant, 3) gender of the child, 4) acculturation, 5) respondent education, and 6) type of insurance. For determining 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: 1) type of transplant (using kidney transplants as a reference group), 2) total number of transplants (before and including the most recent transplant), and 3) 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 (ie, forced entry of demographic variables).

The third block of variables consisted of psychosocial variables: 1) health care attitude (as measured by the Psychosocial Adjustment to Illness Scale Health Care Orientation scale), 2) overall social support (as indexed by the Medical Outcomes Study Social Support Survey), and 3) 4 factors of the IFS (financial impact, familial/social impact, personal strain, and mastery). Again, stepwise procedures were used to evaluate contributions of psychosocial variables.
variables after controlling for all demographic and transplant and child health variables. For further assessing the significance of psychosocial variables as a whole, this third group of variables was subsequently entered in the model as an entire block.

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 (R²adj = 0.13; 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 (R²adj = 0.28; 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 child’s physical health, as measured by the parent’s report on the CHQ, was a uniquely significant predictor of caregiver PTSD symptom severity. Specifically, the parent’s perception of poorer general health of the child was uniquely related to more severe self-reports of PTSD symptoms in the parents.

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 IFS 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 self-reported PTSD symptom severity in parents. In addition, results showed that Health Care Orientation scores significantly predicted PTSD symptom severity; that is, parents who had more negative attitudes about their health care services and about health care in general were more likely to report more severe PTSD symptoms.

**DISCUSSION**

This study found that parents of pediatric solid-organ transplant recipients do not seem to report clinically significant levels of depression or anxiety. Although no control group was used in the present study, comparisons to published norms for the BDI and published data on a healthy control group for the STAI indicated that parents of pediatric transplant recipients do not seem to report problems with depression or anxiety any more frequently or of greater severity than would be expected in the normal population. Despite that some parents did report high levels of depression and/or anxiety, that mean scores for depression and anxiety were relatively normal suggests that depression or anxiety does not seem to be functionally related to having had a child undergo transplant surgery. This is a testimony to the resilience of parents who are faced with the life threat and repeated hospitalizations and multiple medications that are included in the pediatric transplant experience. The parents do not experience any more severe symptoms of anxiety or depression than a normal distribution of the population.

However, as has been found with parents of childhood cancer survivors, parents of pediatric solid-organ transplant recipients did report more severe symptoms of PTSD that is seen in the general population. In fact, more than half of the parents reported moderate to severe symptoms, and 27.1% reported symptoms that met the PTSD criteria for PTSD as measured by the PDS, which is similar to PTSD prevalence rates reported for parents of children with cancer. As such, unlike depression or anxiety, self-reported symptoms of PTSD do seem to be specific and relatively prevalent responses to the trauma of having a child undergo transplant surgery. The most severe symptoms reported by the 46 parents who were considered to have PTSD were those of avoidance (eg, “Feeling distant or cut off from people around you,” or, “Feeling as if your future plans or hopes will not come true”). As has been seen in other studies of PTSD, there was a

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<th>TABLE 1. Regression Model Statistics for Sets of Variables in Predicting Parental PTSD Severity Scores</th>
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<td>Variables</td>
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<tr>
<td>Time elapsed since transplant</td>
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<tr>
<td>Demographic</td>
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<td>Transplant and child health</td>
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<td>Psychosocial</td>
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* P < .001

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<th>TABLE 2. Standardized and Unstandardized Regression Weights for Significant Predictor Variables of Parental PTSD Severity Scores</th>
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<tr>
<td>Variables</td>
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<tr>
<td>CHQ Physical Health*</td>
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<tr>
<td>IFS Familial/Social Impact†</td>
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<tr>
<td>PAIS Health Orientation Scale‡</td>
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<td>IFS Mastery†</td>
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* Controlled for demographic variables.
† 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 IFS 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 self-reported PTSD symptom severity in parents. In addition, results showed that Health Care Orientation scores significantly predicted PTSD symptom severity; that is, parents who had more negative attitudes about their health care services and about health care in general were more likely to report more severe PTSD symptoms.

http://www.pediatrics.org/cgi/content/full/111/6/e725  e729
significant correlation between meeting criteria for PTSD and elevated BDI symptom severity scores ($\chi^2\ [3, N = 165] = 58.461; P = .000)$. Because depression does not seem to be increased in the transplant parents group, this suggests that depression may increase the risk of developing or maintaining symptoms of PTSD.

In an effort to understand further which other factors might be associated with PTSD symptoms, we examined 3 clusters of variables in relation to PTSD severity scores. Contrary to initial hypotheses, none of the demographic variables predicted PTSD severity scores. PTSD severity was not related to the age or gender of the child, the age or educational level of the parent, the type of insurance carried by the family, the racial or ethnic background of the parent, or the level of the parent’s 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 report of the child’s overall physical health did significantly contribute to parents’ reported levels of PTSD, with poorer health of the child related to more severe parental PTSD symptoms. Again contrary to initial hypotheses, 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 or perception of life threat might be expected to vary as a function of the number of transplants or the type of transplant. For instance, the availability of dialysis reduces the actual life threat of kidney transplantation compared with heart or liver transplantation but does not seem to diminish the parental traumatic response.

These findings underscore the importance of parents’ appraisal of events in the development of PTSD symptoms. Previous research on parents of pediatric cancer survivors has found that parents’ perceptions of life threat and intensity of treatment were significant predictors of self-reported PTSD, despite that objective measures of such treatment and life-threat variables were not significant predictors. This is consistent with the finding in the current study that parental subjective ratings of their children’s physical health were a significant predictor of parental self-reported PTSD symptom severity, whereas the type of transplant or number of transplants were not. Given that actual prognosis varies with the type of transplant operation experienced by the child and the number of previous transplants, these findings suggest that the severity of PTSD symptoms may be related more to the parent’s perception of threat than to the “objective” threat faced by the child. For instance, a parent who interprets a child’s heart transplant as a “cure” may not have posttraumatic symptoms, whereas another parent, who continues to experience helplessness and uncertainty about survival, reports PTSD.

The third set of variables examined in relation to PTSD symptom severity included 6 psychosocial variables: overall social support, 4 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 2 subscales of the IFS—perceived impact on family and social functioning and perceived benefits of the experience—and attitudes toward health care in general. Of particular interest is the finding that parents’ perceptions of how the transplant experience affected the family were related to PTSD symptoms. Specifically, parents who reported feeling that family and social functioning (eg, traveling, participating in social events, visiting with friends and relatives) was negatively affected by the transplant event also tended to have more severe self-reported PTSD symptoms. In addition, parents who reported fewer perceived benefits of the transplant in terms of family relations and cohesiveness also reported more severe PTSD symptoms. Such findings are consistent with previous research on parental reports of stressors in the posttransplantation phase and suggest that social stressors secondary to the transplant, such as disrupted planning or decreased family cohesion, may lead to maintenance of PTSD symptoms. Another possible interpretation is that these functional limitations may be a result of the avoidance symptoms of PTSD reported by the parents. This is an area for future research. It is also an area appropriate for screening for clinicians who wish to initiate interventions to reduce or prevent symptoms of PTSD and functional limitations in the families of pediatric transplant recipients.

The finding that parents’ negative attitudes toward health care services were significantly related to more severe self-reported PTSD symptoms also deserves additional examination. It may be that perceptions of health care service providers and facilities as negative and essentially hostile to the parent serve to heighten the perceived threat to the parent and child, increasing the likelihood of more severe PTSD symptoms. It is important to note, however, that the directionality of the findings for the relationship between PTSD severity and either the child health or psychosocial clusters of variables is uncertain. It may be that the findings regarding predictors of PTSD symptom severity are artifacts of a methodology that uses 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. This study also did not investigate the role of a number of potentially important psychosocial variables, such as parental conflict. Future research that uses multimethod assessment of variables such as the quality of health care service or changes in family dynamics at preoperative as well as postoperative time periods or research that manipulates 1 or more of these variables through inter-
vention or feedback to parents may help to illuminate the findings of the present study.

CONCLUSIONS

Findings from this study suggest that a relatively large subset of parents of pediatric transplant recipients report emotional and psychological distress consistent with a diagnosis of posttraumatic stress disorder, with relatively few reporting significant depression or anxiety. As such, conceptualizing pediatric transplantation as a traumatic event not only for the child but also for his or her parents seems to be a promising approach for future research and clinical work with pediatric transplant patients. Assessment of parental perceptions of helplessness and fear before and after the transplant surgery may be useful in targeting preventive interventions for parents.

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