Published in final edited form as:
J Dev Behav Pediatr. 2010 ; 31(9): 713–719. doi:10.1097/DBP.0b013e3181f17c52.

A pilot study comparing traumatic stress symptoms by child and parent report across pediatric chronic illness groups

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Abstract

Objective—Researchers have recently used a framework of traumatic stress to describe the psychological functioning of children experiencing a chronic illness and their families; however, few studies are available directly comparing symptoms across disease groups. The current study compared traumatic stress symptoms of youth being considered for solid organ and bone marrow transplantation, youth diagnosed with Human Immunodeficiency Virus (HIV), youth diagnosed with sickle cell disease (SCD) and their parents. Correlates of traumatic stress across these populations were also examined.

Method—Participants included 64 youth and caregiver dyads with previously scheduled appointments at one of three specialty clinics. Parents completed measures of family demographics, traumatic stress symptoms, and child functional status. Youth (n=45) and parents each completed self-report and parent-proxy measures of youth traumatic stress symptoms.

Results—10% of youth by self-report, 18% of youth by parent-proxy report, and 13% of caregivers described symptoms suggestive of PTSD. Parents of pediatric transplant self-reported greater symptoms than caregivers of youth with HIV and SCD ($p<.05$). While child functional impairment did not predict child symptoms, a trend was found where parents experiencing more traumatic stress symptoms themselves reported their children experienced greater symptoms by parent-proxy report ($p=.07$).

Conclusion—Findings suggest that while most children and parents across disease groups report sub-clinical levels of traumatic stress symptoms, traumatic stress symptoms may be especially salient for families of pediatric transplant candidates. While interventions are currently available to treat PTSD symptoms, they will likely need to be individualized to meet the needs of specific disease groups.

Keywords

PTSD; children; parents; chronic illness

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INTRODUCTION

Although prevalence rates vary, there is little disagreement that chronic illness affects a significant number of children and adolescents in the United States. Data suggest up to 19.3 percent of children have special health care needs in the United States [1]; however, these numbers only allude to the significant burden families of chronically ill youth often face. In addition to practical concerns, such as financial difficulties and increased health care usage [2], reviews suggest that youth and their parents experience significant psychosocial symptoms while they cope with a particular pediatric disease. While the majority of researchers note that youth and parents do not experience clinically significant symptomatology (i.e., symptoms severe enough to meet diagnostic criteria for a specific mental health diagnosis), researchers frequently document symptoms of distress and/or impairment [3]. Such symptoms are important given their frequently documented relationship to treatment adherence. Rates of nonadherence, generally estimated at 50 percent [4], often increase when psychosocial difficulties are also present (e.g., [5]), and may result in poor disease outcomes.

While psychosocial difficulties may adversely affect treatment adherence, research examining psychosocial functioning in pediatric populations continues to lack a cohesive framework to thoroughly explain youth and family functioning. The use of a comprehensive model to explain the psychosocial functioning of youth and their families may be especially important in helping clinicians develop appropriate interventions applicable to a variety of pediatric conditions. To this end, the current study used a model of traumatic stress to describe the psychosocial functioning of youth and parents across pediatric populations. Originating in the Posttraumatic Stress Disorder (PTSD) literature, traumatic stress symptoms refer to the emotional and/or cognitive symptoms related to re-experiencing a traumatic event, avoidance of stimuli associated with the event, and persistent arousal symptoms [6]. However, in contrast to the dichotomy inherent in an actual diagnosis of PTSD, the traumatic stress model allows individuals to fall across a continuum where individuals can exhibit few or many symptoms [7–8]. Although only a minority of youth and parents meet the criteria for a diagnosis of PTSD, evidence suggests that up to 80 percent of children and families experiencing illness or injury experience some traumatic stress symptoms [9].

A number of studies now suggest that a diagnosis of a medical illness is a traumatic event that may lead to PTSD (e.g., [10]). In fact, researchers across pediatric cancer (e.g., [11]), acute injury [12], transplantation [13–16], human immunodeficiency virus (HIV) [17] and sickle cell disease (SCD) [18] have documented that youth and/or parents report traumatic stress symptoms related to the youth's diagnosis. It may be that the child's medical regimen, procedures, related complications, and/or possible decreased life-expectancy serve to threaten the youth's "physical integrity" [6] and lead to the experience of PTSD symptoms. For example, in a review of the adult PTSD literature, authors describe HIV as a "clearly life threatening" disease which may produce PTSD symptoms [19]. Moreover, 93% of a sample adolescents and young adults described receiving their HIV diagnosis as traumatic [17]. Unfortunately, few studies directly compare symptoms between disease groups and differences in methodology and conceptualization between individual studies make comparisons between disease groups difficult. Thus, how symptoms vary across groups remains uncertain. Given that a model of prevention and intervention for traumatic stress has been previously tested in pediatric medical settings [20], understanding possible differences in symptoms may have important clinical implications, especially for healthcare facilities treating youth with a wide range of presenting diagnoses. In one of the few studies available, researchers found that youth receiving liver transplants reported greater traumatic stress symptoms than children undergoing routine surgery or youth with other chronic illnesses [13]. This pilot study will further add to this literature and determine if differences in symptoms exist between other disease groups. If differences are found, it may be that traumatic stress interventions are more salient or effective

for particular disease groups (e.g., those groups demonstrating greater symptoms). For example, compared to pediatric HIV and SCD, where life expectancy has been greatly extended by improved treatment regimens (e.g., [21]), children and families entering the pre-transplantation process are facing more acute life threat [22] that may result in a greater number of traumatic stress symptoms.

While various factors may help explain possible differences in traumatic stress symptoms between disease groups, there are only a few studies examining possible correlates of symptoms within a particular population. For example, Schreier and colleagues [12] and Shemesh and colleagues [23] found that youth's traumatic stress symptoms were significantly related to parents' own experience of traumatic stress. Other researchers have described that youth functional status was significantly related to traumatic stress symptoms by both youth self-report and parent proxy-report of youth symptoms [24]. Although these are only two possible correlates of youth's traumatic stress symptoms, research in this area remains limited. If a model of traumatic stress is able to adequately describe the psychological functioning of children and families, then determining possible correlates of these symptoms has important implications for later intervention.

The current pilot study examined parent and child traumatic stress symptoms by (1) comparing rates of traumatic stress symptoms across three populations with previously documented traumatic stress symptoms: transplant candidates, youth diagnosed with HIV, and youth diagnosed with SCD and (2) examining possible correlates of traumatic stress symptoms across these three populations. It was expected that transplant candidates and their parents would describe greater traumatic stress symptoms and that parental traumatic stress and child functional status would be related to child traumatic stress across disease groups.

METHOD

Participants and Procedures

The current study included 23 solid organ (heart, lung, heart/lung, liver, and kidney) and stem cell transplant candidates, 28 youth diagnosed with sickle cell disease, 13 youth diagnosed as HIV positive, and their caregivers. Youth ranged in age from 2 to 17 years old (11.2 ± 4.8). Youth were distributed across gender (45% female) and diagnosed with their current medical condition up to 17.9 years prior to their date of participation in the current study (7.5 ± 5.6 years). Caregivers ranged in age from 20 to 70 years old (40.2 ± 11.7 years), were primarily mothers (70.7%), married (44.1%) and reported a median family income of 20,000–29,999 dollars per year. Demographic characteristics of participants across disease group are further summarized in Table 1. Inclusion criteria required that youth were aged 2–18 years, had a previously scheduled outpatient appointment in an outpatient clinic, and that a parent or other legal guardian accompanied youth to their scheduled appointment. Additional inclusion criteria for youth with HIV included knowledge of current HIV diagnosis. Exclusion criteria included the presence of a psychiatric or neurocognitive disorder that would inhibit their ability to participate or the inability to read or understand English.

Pediatric transplant candidates were recruited from youth referred for a routine, outpatient, pre-transplant psychological evaluation. Families were approached for participation prior to this scheduled appointment. Consent and/or assent were obtained to use measures completed as part of their routine evaluation (recruitment rate = 93% of families approached). Three transplant candidates did not complete measures and were subsequently excluded from analyses (final n = 23). Youth diagnosed with SCD (recruitment rate = 97%) and HIV (recruitment rate = 81%) and their caregivers were approached during previously scheduled outpatient appointments in separate pediatric specialty medical clinics. Reasons for refusal included lack of time and lack of interest in research. Consent and/or assent (assent for youth

aged 8 to 17 years, consent for youth aged 18 years) were obtained and measures completed prior to leaving the clinic. The local Institutional Review Board approved all procedures.

Measures

Demographic questionnaire—Caregivers completed a questionnaire created for the current study requesting general family demographic information and information regarding the youth's medical history.

Impact of Events Scale–Revised (IES-R)—Caregivers completed a 22-item, self-report measure of current life distress. Individuals rated how distressing items were over the previous seven days on a five-point likert scale from 0 (not at all distressing) to 4 (extremely distressing). Items are summed to calculate a general composite total score where higher score indicate greater distress. A total score of 30 or more is recommended as suggestive of a PTSD diagnosis. The measure has demonstrated good reliability and validity in adult populations [23,25]. Reliability for the total score in the current sample was good ($\alpha = .96$).

Functional Disability Inventory (FDI)—Caregivers completed a 15-item measure of children's general physical functioning. Caregivers rated their child on various physical activities over the past two weeks on a four-point likert scale from 0 (no trouble) to 3 (impossible). Items are summed to calculate a total score where higher scores indicate greater functional disability. The measure has been reliability used across various pediatric populations [26–27]. Reliability for the total score in the current sample was good ($\alpha = .95$).

UCLA Posttraumatic Stress Disorder Reaction Index (PTSRI)—Youth (aged 8 years and above) and caregivers completed age-appropriate, self-report or parent-proxy versions of the PTSRI, a measure of youth posttraumatic stress symptoms [28]. Therefore, only 45 youth, a subset of the total sample, completed the self-report PTSRI measure (see Table 2). The measure includes a 17-item likert scale corresponding to DSM-IV-TR symptom criteria for PTSD. The measure's authors recommend a total score 38 or higher as suggestive of PTSD. The measure has been reliably used to measure traumatic stress symptoms across a number of pediatric populations [14,23,29–30]. Reliability for both child self-report ($\alpha = .92$) and parent-proxy report ($\alpha = .94$) total scores in the current sample was good.

Statistical Analyses

Descriptive analyses (e.g., mean, standard deviation) were conducted across variables of interest and demographic variables. Z-tests were completed to compare the percentage of youth and parents reporting symptoms suggestive of a PTSD diagnosis with national normative data. To assess differences in traumatic stress symptoms across groups, separate analysis of covariance (ANCOVA) equations compared traumatic stress symptoms by youth self-report, parent-proxy report, and caregiver self-report of symptoms. Univariate ANCOVA models, rather than MANCOVA models, were used due to differences in sample size by reporter. Only demographic variables differing significantly between groups in preliminary analyses were entered as covariates into the models. Planned contrasts (transplant = reference group) were conducted to further examine significant main effects by group. Hierarchical regression analysis determined possible correlates of youth traumatic stress symptoms. Related demographic variables were included in the first block of each regression equation and child physical status (FDI total score) and caregiver self-reported traumatic stress symptoms (IES-R total score) were entered into the second block of the equation. Dependent variables included youth self-reported traumatic stress symptoms (Child PTSRI total score) or parent-proxy-reported traumatic stress (Caregiver PTSRI total score). SPSS 15.0 for Windows (2007) was used for all analyses.

RESULTS

Preliminary Analyses

Preliminary ANOVA analyses revealed significant differences between disease groups across child minority status ($p < .01$), child's longest hospitalization in days ($p < .01$), and parent age ($p < .01$). These variables were included in subsequent ANCOVA and regression analyses. Descriptive statistics across variables of interest by disease group are shown in Table 2. Of note, parent-proxy PTSRI scores were significantly correlated with child PTSRI scores ($r = .48$, $p < .01$), parent self-reported IES scores ($r = .27$, $p < .05$), and child age ($r = .27$, $p < .05$).

Ten percent of youth reported rates of traumatic stress symptoms suggestive of a diagnosis of PTSD by self-report (15.4% of transplant candidates, 8.3% of children diagnosed with HIV, 6.7% of children diagnosed with SCD). In contrast, 18% of caregivers reported their children demonstrated symptoms suggestive of a diagnosis of PTSD (18.8% transplantation, 15.4% HIV, 19.0% SCD) and 12.9% of caregivers self-reported rates of symptoms suggestive of a PTSD diagnosis (14.3% transplantation, 7.7% HIV, 14.3% SCD).

Compared to previously published data in an adolescent community sample (PTSD prevalence = 3.5%)[31], a greater number of transplant candidates ($z = 2.44$, $p < .05$) and children diagnosed with SCD ($z = 2.96$, $p < .01$) reported symptoms suggestive of a PTSD diagnosis by parent-proxy report. Compared to previously published data in an adult community sample (PTSD lifetime prevalence = 1.3%)[32], a greater number of parents of transplant candidates ($z = 4.12$, $p < .01$) and children diagnosed with SCD ($z = 4.97$, $p < .01$) reported symptoms suggestive of a PTSD diagnosis on the IES-R.

Differences in Traumatic Stress Symptoms across Groups

The ANCOVA model examining differences in caregiver self-reported traumatic stress symptoms (n = 62) indicated a significant main effect for group (F [2,37] = 3.69, $p < .05$, $\eta^2 = .17$). Post-hoc analyses revealed that caregivers of pediatric transplant candidates reported they experienced greater traumatic stress symptoms than caregivers of children diagnosed with HIV ($p < .05$, $d = .41$) and SCD ($p < .05$, $d = .18$). The ANCOVA model examining differences in child self-reported symptoms (n = 45) indicated the main effect for group approached significance (F [2,22] = 2.72, $p = .09$, $\eta^2 = .20$). No significant main effect of group was found for parent-proxy-reported symptoms (n = 57, F [2,31] = .71, $p = 0.5$, $\eta^2 = 0.04$).

Correlates of Traumatic Stress Symptoms

The overall hierarchical regression model predicting child self-reported traumatic stress was not significant (F [5,25] = .93, $p = .48$, $R^2 = .19$) and did not reveal significant main effects for either child physical functioning or caregiver self-reported traumatic stress symptoms. The overall model predicting parent-proxy reported traumatic stress symptoms was also not significant (F [5,34] = 2.00, $p = .11$, $R^2 = .26$); however, analyses revealed that the effect of caregiver self-reported traumatic stress symptoms approached significance when entered into the model ($\beta = .35$, $p = .07$). Caregivers reporting greater traumatic stress symptoms for themselves also reported their children experienced greater symptoms by proxy-report.

DISCUSSION

Taken together, results from the current pilot study support two primary conclusions. First, results demonstrating differences in traumatic stress symptoms between disease groups (statistically significant for parent self-report, approaching significance for child self-report) suggest that a traumatic stress model may be more salient for specific populations. Second, parents are not necessarily impartial judges of their children's functioning; their own

experience of traumatic stress may influence how they view their children's overall adjustment. Of note, findings provide important preliminary evidence that parents of pediatric transplant candidates may experience greater traumatic stress symptoms than do parents of other chronic illness groups. Interestingly, rates of traumatic stress symptoms reported by transplant candidates were similar to those previously reported in the pediatric oncology literature using identical measures [33]. It may be that the transplant process is perceived as more traumatic for families of pediatric transplant candidates who haven't had as long to adjust to their current diagnosis and who may face a more uncertain treatment course and outcome [22]. Of note, while not statistically significant, families of transplant candidates reported a shorter time since diagnosis compared to children diagnosed with HIV and SCD. In addition, pediatric pre-transplant candidates experienced significantly longer hospitalizations on average. These differences may help explain our study's findings.

Furthermore, differences were found despite the low overall rates of symptoms reported. Across groups, most individuals reported sub-clinical levels of stress and only a minority of participants reported symptoms suggestive of a diagnosis of PTSD. However, compared to national data [31–32], rates of symptoms suggestive of a diagnosis were higher than rates of PTSD reported in the general community and indicate a number of children and parents are having difficulty coping with the child's diagnosis. Additional studies examining traumatic stress symptoms in youth with and without (i.e., healthy) chronic illnesses will further clarify the relative contribution of a chronic illness and/or other traumatic event (e.g., injury, parental illness) to the experience of traumatic stress symptoms. Such information will be especially valuable for pediatric primary care providers, who are likely to see youth with a wide range of presenting problems.

Interestingly, the overall regression models predicting child-self reported and parent-proxy-reported traumatic stress symptoms were not statistically significant. Parent self-reported traumatic stress symptoms did trend toward significance (p=.07) when entered into the model predicting parent-proxy report of symptoms, suggesting that parents' own difficulties adjusting to their children's disease may influence how they interpret their children's functioning. Perhaps low overall rates of parent traumatic stress and child functional impairment made it more difficult to find a significant relationship. Other diseases-specific or psychosocial variables (e.g., previous or comorbid psychological difficulties) not included in this study may also be accounting for the differences in traumatic stress observed in the current study. Future research should continue to explore other possible predictors of traumatic stress symptoms in pediatric transplant, HIV, and SCD populations.

Despite these findings, it is important to recognize certain limitations. First, this pilot study's small sample size limited the number of variables tested and only a subset of the youth sample were able to complete the self-reported PTSRI measure. This may have limited our ability to find statistically significant differences between groups. Given the low overall incidence of the diseases studied, multi-site studies and collaboration across institutions is integral to examining these groups in greater depth. However, current data detected small to medium effect sizes and provides important areas of consideration in relation to traumatic stress. Second, there was significant variability between participants in our study. While significant differences in demographic variables were controlled for in subsequent analyses, differences between participants may have made it more difficult to perceive differences in the variables of interest. For example, future longitudinal studies may find that youth with previously diagnosed mental health disorders may be at increased risk of developing traumatic stress symptoms. Third, the generalizability of our study's findings should be considered carefully. Of note, both the small samples recruited and limited assessment batteries limit the conclusions that can be drawn regarding the functioning of pediatric populations in other areas or the functioning of children and families over time. Fourth, transplant candidates may have tried

to portray themselves in a more favorable light (i.e., minimize current symptoms) while completing questionnaires as measures were administered as part of their pre-transplant psychological evaluation. Given that transplant candidate families reported greater symptoms than other groups, the actual magnitude of these differences may be larger than was demonstrated by the current data.

Despite these limitations, the current study included several unique elements that have not previously been included in the traumatic stress literature. First, our study assessed traumatic stress symptoms of children by both youth self-report and parent-proxy-report and the traumatic stress symptoms of parents themselves. Such measurement provides a more comprehensive examination of the psychosocial functioning of families as a whole. Given previous literature in pediatric cancer suggesting that at least one member of a family experiences some traumatic stress symptoms during the course of a child's illness [33], measurement of both child and parent symptoms is necessary to understand a family's overall psychological functioning. Second, our study attempted to determine possible predictors of traumatic stress in the pediatric population. While some researchers have begun to examine possible factors related to traumatic stress in pediatric populations, the majority of existing research is descriptive in nature and includes few other variables of interest. Third, our study included three separate pediatric chronic illness populations: pre-transplantation, HIV, and SCD. While several researchers have recognized the promise of a model of traumatic stress in understanding pediatric chronic illness, few researchers have directly compared traumatic stress symptoms across separate disease groups. Given the wide range of measurement tools available to describe traumatic stress symptoms, making comparisons across different studies is difficult. This pilot study affords important preliminary evidence across separate disease groups that parents and children, regardless of disease, experience some traumatic stress symptoms. Such data provide additional support for the applicability of and need for further examination of traumatic stress in pediatric populations.

That most participants, regardless of their condition, reported at least some traumatic stress symptoms suggests that a model of intervention similar to that of Kazak and colleagues [7] may be appropriate. Clinicians working with youth from any of the three populations included here may consider applying a model of traumatic stress to understanding the functioning of the youth they treat. Assessing the functioning of both youth and their families provides primary care providers an opportunity to identify youth and families at-risk for later difficulties, match the intensity of services to individual family needs, and allocate psychosocial resources appropriately. For example, early and continued screening of traumatic stress symptoms at regularly scheduled clinic visits can identify those families reporting few symptoms and where brief anticipatory guidance regarding medical treatment and family adjustment may be useful. Likewise, screening can help clinicians plan appropriate interventions for those families reporting greater symptoms. Current data is not only meant to substantiate the need for additional research in the area of traumatic stress, but also to encourage clinicians to consider models of intervention from other disease groups that may useful in their own practice. Of note, the Surviving Cancer Competently Intervention Program (SCCIP), a brief family-based intervention, successfully reduces traumatic stress symptoms in cancer survivors and can likely be applied to other populations [20]. Finally, in other families, where a family member may report symptoms suggestive of a PTSD diagnosis, a psychological referral may be needed to provide more intensive treatment (e.g., cognitive behavioral therapy [34]) and individualized support.

Acknowledgments

SOURCES OF SUPPORT: Funding received by the National Institutes of Health (T32 HD007524-04) and the Center for Pediatric Psychology and Family Studies (Department of Clinical and Health Psychology, University of Florida) to LI.

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Table 1

Demographic characteristics of participants by disease group

	Pre-Transplant	HIV	SCD
Child age (years)	11.3 ± 4.6	13.2 ± 2.4	10.1 ± 5.5
Female child gender	40%	54.5%	58.3%
Child race			
Caucasian	47.6%	15.4%	-
African American	38.1%	46.2%	100%
Other	14.3 %	38.5%	-
Longest hospitalization (days)	45.6 ± 53.9	13.14 ± 21.08	9.0 ± 12.6
Time since diagnosis (months)	56.2 ± 68.3	125.3 ± 59.0	97.6 ± 61.1
Parent relationship to child			
Mother	87.0%	30.7%	78.3%
Father	8.7%	23.1%	4.3%
Grandparent	-	23.1%	8.7%
Other	4.3%	23.1%	8.7%
Parent marital status			
Married	63.2%	38.4%	33.3%
Single	21.1%	15.4%	40.7%
Divorced	15.8%	23.1%	18.5%
Other	-	23.1%	7.5%
Family income			
≤ $9,999	11.8%	23.1%	27.2%
$10,000 – $19,999	23.5%	7.7%	22.7%
$20,000 – $39,999	29.4%	31.0%	36.3%
≥ $40,000	35.3%	38.2	9.1%

Table 2

Descriptive statistics among variables of interest by disease group

	Pre-Transplant	HIV	SCD	Total
Parent PTSRI total [a]	10.9 ± 9.6	13.5 ± 11.7	10.2 ± 10.8	11.2 ± 10.6
n	18	13	26	57
Child PTSRI total [b]	18.8 ± 13.6	18.1 ± 15.2	15.5 ± 12.9	17.2 ± 13.5
n	14	12	19	45
IES-R total [c]	17.6 ± 17.1	11.4 ± 12.7	14.5 ± 18.3	14.9 ± 16.8
n	21	13	28	62
FDI total	9.2 ± 12.9	2.2 ± 2.7	6.6 ± 10.6	6.4 ± 10.4
n	17	13	28	51

[a] Parent proxy-report of child traumatic stress symptoms.

[b] Child self-reported traumatic stress symptoms.

[c] Parent self-reported traumatic stress symptoms.

Note: PTSRI: UCLA Posttraumatic Stress Disorder Reaction Index; IES-R: Impact of Events Scale – Revised; FDI: Functional Disability Inventory, HIV: Human Immunodeficiency Virus; SCD: Sickle Cell Disease.