Brief Report: The Risk of Posttraumatic Stress Disorder in Mothers of Children Diagnosed with Pediatric Cancer and Type I Diabetes

Laura Stoppelbein, PhD and **Leilani Greening, PhD**
Department of Psychiatry and Human Behavior, The University of Mississippi Medical Center

Abstract

Objective—To evaluate the risk of and predictors of enduring and late-onset posttraumatic stress disorder (PTSD) among mothers of children diagnosed with type I diabetes and cancer.

Method—Mothers ($N = 99$) of children diagnosed with cancer or diabetes for at least 12 months completed a structured clinical interview for PTSD and self-report measures of PTSD, depression, anxiety, and stressful life events.

Results—There was no significant difference in the rate of PTSD between the two groups. Overall, fewer mothers (7%) met criteria for PTSD on the structured clinical interview than those on a self-report measure of PTSD (17%). Mothers who reported more depressive symptoms, anxiety, and stressful life events tended to report significantly more PTSD symptoms.

Conclusions—The findings extend prior research regarding the prevalence rate and predictors of PTSD and PTSD symptoms in pediatric populations. It is recommended that clinicians exercise caution when interpreting prevalence rates for PTSD that are derived from self-report measures.

Keywords

cancer; chronic illness; diabetes; PTSD; PTSD checklist

Recent research (Landolt et al., 2002; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003) has revealed that up to 25% of mothers of children diagnosed with type I diabetes meet criteria for posttraumatic stress disorder (PTSD), and an additional 50% may be experiencing subclinical symptoms. Given that a diagnosis of a life-threatening illness qualifies as a potential cause of PTSD, type I diabetes could be a precipitant of PTSD for patients and their family members (American Psychiatric Association, 2000). Landolt et al. reported prevalence rates for mothers of children with diabetes that are higher than those for the general population (1–10%; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995), but similar to rates for mothers of children with cancer (10–54%; Kazak et al., 1997; Pelcovitz et al., 1996). However, it is important to note that Landolt et al.'s rates are based on the samples of children who were diagnosed with diabetes 5–6 weeks before testing. The relatively recent diagnosis suggests that the mothers could have been experiencing residual symptoms of acute stress and may not necessarily reflect their risk for more enduring or late-onset PTSD. Hence, the purpose of the present study was to examine the risk of enduring or late-onset PTSD in mothers of children who were diagnosed with type I diabetes for at least

All correspondence concerning this article should be addressed to Laura Stoppelbein, Department of Psychiatry, and Human Behavior, The University of Mississippi Medical Center, 2500 North State Street, Jackson, Mississippi, 39216-4505. lstoppelbein@psychiatry.umsmed.edu.

1 year. Families usually adjust to living with diabetes within a year (Northam, Anderson, Adler, Werther, & Warne, 1996); hence, 12 months was deemed a sufficient length of time for any acute stress reactions to have subsided.

Other family members also can be at risk of PTSD (Landolt et al., 2002, 2003); however, we focused on mothers because women are twice as likely as men to develop PTSD (Kessler et al., 1995). In addition to assessing the rate for enduring or late-onset symptoms, we compared the mothers' risk of PTSD to the risk of mothers of children diagnosed with cancer. Although both diabetes and cancer are life-threatening illnesses, Landolt et al. (2003) found mothers of children diagnosed with cancer to be twice as likely as mothers of children with diabetes to meet criteria for PTSD 5–6 weeks after their children were diagnosed. Many of the children with cancer were likely still in the early phases of painful treatments, possibly making the threat of death appear more salient to the mothers. We hypothesized that the mothers' risk of PTSD would not be as high after this initial phase. More specifically, we did not expect a significant difference between mothers of children with cancer and those of children with diabetes on their risk of PTSD at least 1 year after their children had been diagnosed. We also examined how much variance the various risk factors commonly linked to PTSD including depressive symptoms, anxiety, and previous stressful life events (Landolt et al., 2003) might explain in the mothers' report of symptomatology.

Other than Landolt et al.'s (2002, 2003) studies of *newly* diagnosed pediatric patients and their families, this is the first study known that evaluated the risk of PTSD in mothers of children diagnosed with type I diabetes. This study is different from previous studies because the risks for more enduring or late-onset symptoms rather than the risks of acute symptoms were assessed among mothers of children with diabetes. In addition, we used both a structured clinical interview and a self-report measure of PTSD because Landolt et al. (2002) noted that their prevalence rates could have been inflated by using a self-report measure. This study offers potentially important implications for triage for a psychiatric disorder known to be associated with an increased risk for poor health and higher health care use (Kimerling, Clum, & Wolfe, 2000). Theorists also might find the results useful for advancing research on the application of the posttraumatic stress model to pediatric populations.

Method

Participants

Mothers ($N = 110$) were recruited from pediatric oncology and endocrinology clinics while they accompanied their child for their medical appointment. Criteria for exclusion included (a) a history of a psychiatric diagnosis for the mother, (b) child diagnosed with cancer or diabetes <12 months, (c) child diagnosed with a recurrence of cancer, and (d) other immediate family members diagnosed with a chronic illness. Given that the goal of the study was to examine PTSD precipitated by the diagnosis of cancer or diabetes, the first criterion was included so that we could control for prominent risk factors such as previous diagnoses of PTSD and other psychiatric disorders (Breslau, 2001). Only one mother was excluded because of a previous psychiatric diagnosis; none had been diagnosed with PTSD. Mothers who had other family members diagnosed with a chronic illness were excluded because previous experience with a disease could desensitize or sensitize mothers to the risks of the disease depending on the nature of their prior experience with a life-threatening illness. Two mothers were excluded because they had other family members diagnosed with diabetes. Eleven women declined to participate citing the lack of time as the reason. Of the 99 participants, 53% had a child diagnosed with cancer and 47% had a child diagnosed with type I diabetes mellitus. Most of the children with cancer were diagnosed with acute

lymphoblastic leukemia (37%), followed by brain tumor (23%), neuroblastoma (14%), lymphoma (12%), sarcomas (10%), and acute myelogenous leukemia (4%). Nearly one third (27%) of the children with cancer were receiving treatment. Most of the children diagnosed with diabetes (80%) were receiving daily insulin injections; the remaining 20% were on an insulin pump.

Descriptive statistics for each illness group and the sample are summarized in Table I. The mothers were on average 38 years old and were from semi-skilled working-class households. Unequal n analyses of variance revealed significant differences between the two illness groups for the child's age and gender. Post hoc Scheffe tests revealed that the children with diabetes were older and chi-square tests revealed that significantly fewer boys were in the diabetes group. There were no significant group differences on the other variables in Table I including the percentage of mothers meeting criteria for PTSD.

Measures

Demographic Questionnaire—Participants completed a brief questionnaire that included questions about disease-related and demographic information. Demographic data were used to compute a Hollingshead index (Hollingshead, 1975) as a measure of the participants' socioeconomic status (SES).

Structured Clinical Interview for DSM-IV-PTSD Module—The Structured Clinical Interview for DSM-IV-PTSD (SCID-PTSD) module is a structured clinical interview designed to assess for PTSD using DSM-IV criteria (First, Gibbon, Spitzer, & Williams, 2002). A dichotomous score indicating whether the interviewee currently meets or does not meet the criteria for PTSD is derived from responses. Administration time was approximately 10 min.

Posttraumatic Stress Disorder Checklist-Civilian Version—The Posttraumatic Stress Disorder Checklist-Civilian Version (PCL-C) is a 17-item self-report measure of PTSD symptoms for adults as based on DSM-IV criteria (American Psychiatric Association, 2000; Weathers, Litz, Herman, Huska, & Keane, 1993). Respondents indicate on a 5-point Likert scale ranging from 1 (*not at all*) to 5 (*extremely*) the applicability of statements for the past month. A sum score of 50 or more merits a PTSD diagnosis (Weathers et al., 1993). Internal consistency was high, Cronbach $a = .94$, and was equally high in the present study, $a = .94$. Construct validity is also supported by high correlations ($rs > .75$) with other validated measures of PTSD (Ruggiero, Del Ben, Scotti, & Rabalais, 2003).

State-Trait Anxiety Inventory—The State-Trait Anxiety Inventory (STAI) is a self-report measure of situational (STAI-S) and trait anxiety (STAI-T; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Each scale consists of 20 items asking respondents to rate on a 4-point scale how much they agree with the statements. Internal consistency was high (as = .90 and .93 for STAI-T and STAI-S, respectively) and was high in the present study, as = .92 and .94, respectively. Test-retest reliability is acceptable for the STAI-T, with a median coefficient of .76.

Beck Depression Inventory-II—The Beck Depression Inventory-II (BDI-II) is a 21-item self-report measure of depressive symptoms. Respondents rate along a 4-point scale ranging from 0 to 3 the severity of symptoms for the past 2 weeks. Cutoff scores for clinically significant symptoms are <14 (minimal), 14–19 (mild), 20–28 (moderate), and >28 (severe). The scale has high internal consistency, moderate concurrent validity, and discriminates between depressive and anxiety symptoms (Beck, Steer, & Brown, 1996). Internal consistency was also high for the present sample (Cronbach $a = .92$).

Life Events Checklist—A checklist similar to a measure used by Breslau (2001) was developed to assess for previous trauma exposure. Sixteen events commonly linked to PTSD (Breslau, 2001; Ruggiero et al., 2003) and that include the events defined as qualifying events for a PTSD diagnosis in the DSM-IV (American Psychiatric Association, 2000) were listed. Respondents indicated whether they experienced or witnessed someone experience the event and how long ago the event occurred. Events endorsed were summed for a total score.

Procedure

After obtaining IRB approval, mothers were invited to participate in the study while they waited for their child's medical appointment. The mothers were informed that the goal of the study was to learn about the impact of living with a chronic illness and that their participation was voluntary. After giving written consent, the mothers completed self-report measures in a private room and were interviewed by a psychologist trained in administering the SCID. The child was supervised by a child life study volunteer while the mother participated. All forms were coded with a random number to ensure the confidentiality of responses. On the completion of participation, the mothers were thanked and paid $30.00 for their time.

Results

Statistical analyses for predicting PTSD were performed for the two illness groups combined because there was no group difference for the mothers' risk (Table I). Approximately 7% of the mothers met criteria for PTSD on the SCID, whereas a higher percentage (17%) met criteria using the PCL-C PTSD diagnosis. The rate for subclinical PTSD, as measured by the SCID, was 25% (diabetes = 25%; cancer = 27%). Subclinical PTSD is defined as meeting two of the three diagnostic symptom clusters specified in the DSM-IV for PTSD (American Psychiatric Association, 2000). Bivariate correlations for the SCID-PTSD diagnosis, mother's age, race/ethnicity, SES, child's age, child's gender, length of time since the child's diagnosis, BDI-II score, STAI-T and STAI-S scores, and total stressful life events score were only significant for the SCID-PTSD diagnosis and four variables—race/ethnicity, BDI-II score, and STAI-T and STAI-S scores, $r = .23–.33$, $p < .05$. A logistic regression analysis with these four variables as predictors of the SCID-PTSD diagnosis was statistically significant, $\chi^2(4) = 10.40$, $p = .03$; however, none of the variables emerged as statistically significant predictors at the .05 probability level. Similar analyses with the PCL-C PTSD diagnosis revealed that the BDI-II score, STAI-T and STAI-S, and stressful life events were significant correlates of diagnostic status, $r = .29–.61$, $p < .005$. A logistic regression analysis with these variables predicting the PCL-C PTSD diagnosis was also found to be statistically significant, $\chi^2(4) = 17.78$, $p = .004$. However, only the BDI-II score was marginally significant, $\chi^2(1) = 3.10$, $p = .07$. Mothers reporting more depressive symptoms were more likely to meet diagnostic criteria for PTSD.

Correlational analyses with mother's age, race/ethnicity, SES, child's age, child's gender, length of time since the child's diagnosis, BDI-II score, STAI-T and STAI-S scores, total stressful life events score, and the *continuous* sum PCL-C score revealed that SES, the BDI-II, STAI-T and STAI-S scores, and stressful life events were significant correlates of the PCL-C score, $r = .25–.77$, $p < .05$. A simultaneous regression analysis with these variables as predictors of the sum PCL-C score was statistically significant, $F(5, 93) = 40.98$, $p < .0001$, $r^2 = .68$. Four variables emerged as significant correlates including the BDI-II score ($\beta = .29$, $p = .04$), STAI-T ($\beta = .29$, $p = .004$), STAI-S ($\beta = .24$, $p = .04$), and stressful life events ($\beta = .16$, $p = .009$). Mothers scoring higher on these variables tended to report more PTSD symptoms.

Supplementary analyses were conducted to evaluate the PCL-C's diagnostic utility. Using the SCID-PTSD diagnosis as the criterion, we correctly classified 5 mothers with PTSD, incorrectly classified 2 as not diagnosed, incorrectly classified 12 as diagnosed, and correctly classified 80 as not diagnosed. The PCL-C yielded a sensitivity of .71, a specificity of .87, a positive predictive power of .29, a negative predictive power of .98, and an overall diagnostic efficiency of .86.

Discussion

Less than 10% of mothers of children diagnosed with type I diabetes or cancer were found to meet criteria for PTSD, using a structured clinical interview more than 1 year after their children were diagnosed. Mothers from each illness group were equally vulnerable, suggesting that there were no illness-specific differences for enduring or late-onset PTSD. The disfiguring and aversive treatments and uncontrollable aspects of cancer might lead some people to assume that mothers of cancer survivors would be at a greater risk of PTSD. However, this does not necessarily seem to be the case. Perhaps the children's survival contributed to the mothers' relatively low risk (Greening & Dollinger, 1992).

The 7% prevalence rate for PTSD is lower than the published rates for the parents of children with cancer or who were recently diagnosed with diabetes (Kazak et al., 1997; Landolt et al., 2002, 2003; Pelcovitz et al., 1996). Landolt et al.'s (2002, 2003) higher rate for mothers of children with diabetes, however, may actually reflect the rate for acute stress symptoms because the mothers were assessed about a month after their children were diagnosed. Interestingly, we observed a rate that is more comparable to previously reported rates using a self-report measure (17%), suggesting that methodological issues might influence epidemiological rates for PTSD. Our different rates using the SCID and PCL-C and our evaluation of the PCL-C's diagnostic utility are consistent with a similar study conducted by Manne, Du Hamel, Gallelli, Sorgen, and Redd (1998). Based on their and our findings, the PCL-C appears to be a useful screening tool that should be followed up with further testing when a person scores in the clinical range. The disadvantage of using the PCL-C with mothers of pediatric populations, however, appears to be the risk of diagnosing PTSD when an individual does not have the disorder, causing unnecessary and costly follow-up assessments and services. Clinicians might find the risk of missing cases more unacceptable than the cost of being overinclusive at the initial screening or vice versa. Researchers, on the contrary, might find the risk of over-diagnosing a threat to the validity and generalizability of their findings.

A more optimal cutoff score for diagnosis might improve the PCL-C's diagnostic utility. However, selecting a cutoff score hinges on the consequences of a positive or negative result, as increasing a measure's sensitivity occurs at the expense of its specificity. Another variable to consider is the criterion standard used to diagnosis PTSD. Although the SCID-PTSD module has been used as a gold standard for diagnosing PTSD (Blanchard, Jones-Alexander, Buckley, & Forneris, 1996), another measure such as the clinician-administered PTSD scale (CAPS; Blake et al., 1995) might yield different results.

We likely obtained a more conservative rate for PTSD with the SCID because the structured interview format fostered more opportunities to clarify any misinterpretations of the test items. In addition, unlike the PCL-C, the SCID included psychosocial impairment as a necessary criterion for PTSD, which further restricted the number of diagnoses. Others have raised concerns regarding the PCL-C's discriminative validity (Widows, Jacobsen, & Fields, 2000) and suggest that further psychometric investigations are warranted. Manne et al. (1998), however, found the PCL-C to be acceptable but recommended using the symptom

cluster method with pediatric populations instead of a cutoff score because they found this method to be more sensitive (1.0) and specific (.92).

The relatively low rate of PTSD observed in the present study underscores how well parents tend to cope over the long term with their child being diagnosed with a life-threatening illness. The 7% prevalence rate is slightly lower than Breslau's (2001) base rate for survivors of traumatic events (9.2%) but is nearly half the risk estimated for survivors of high-impact events (e.g., assault; Breslau, 2001). The low base rate, however, does not negate the possibility that parents might still experience subclinical levels of PTSD. Up to 25% of the mothers in the present study met criteria for subclinical PTSD. However, most of these mothers met the minimum one reexperiencing symptom, which was usually being reminded of the illness, and two hyperarousal symptoms, which included being hypervigilant about their child's health; few met the minimum three avoidance symptoms, suggesting a generally low level of pathology. Kazak et al., (2006) offer a similar conclusion in their recent presentation of a model for conceptualizing parents' reactions to medical conditions.

Methodological Limitations

The sample's low SES status may have biased the results because of the possible risk for secondary adversities and, therefore, precludes generalizations to other SES groups. Nevertheless, the observed rate of PTSD was still relatively low despite the sample's low SES, thereby challenging this variable as a methodological shortcoming. A second limitation of the study is the restricted focus on cancer and diabetes. Unique features of these diseases and treatments may preclude generalizing the findings to other illnesses. Along the same lines, comparison of the results to mothers of children without chronic illnesses is limited by our failure to include a control group. Further research is recommended in which the mothers' risk of PTSD is compared to that of a control group. Finally, although we included covariates commonly linked to PTSD, data on other factors including social support were not collected and limit conclusions about other possible correlates that merit consideration.

Conclusion

Mothers of children diagnosed with cancer or diabetes seem to be at a relatively low risk of experiencing enduring or late-onset PTSD. Although most parents tend to adjust well after an initial adjustment phase, some mothers might still continue to experience stress reactions. Many of these mothers continue to nurture their children, but the stress of the illness and aspects of the treatment might interfere with their personal and interpersonal adjustment. Hence, health professionals might screen the parents of children with chronic illnesses to ascertain whether they could benefit from stress management. Mothers who score high on a measure of anxiety and or who have a history of stressful life events may be particularly vulnerable. By the same token, clinicians should recognize that most parents tend to cope well and to make attempts to reinforce their adaptive coping skills.

Acknowledgments

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Table I

Descriptive Statistics

Variable	Diabetes ($n = 46$)	Cancer ($n = 53$)	Total ($N = 99$)	F/χ^2 test	p
Age in years, mean (*SD*)	38.87 (7.39)	36.87 (8.89)	37.80 (8.24)	1.46	.23
Ethnicity/race (%)					
African American/Caucasian	60 (40)	51 (49)	55 (45)	0.79	.38
Marital status (%)					
Unmarried	15	9	12	9.41	.15
Married	48	70	60		
Divorced	22	8	15		
Separated	9	5	7		
Living with partner	2	4	2		
Widowed	4	4	4		
SES, mean (*SD*)	27.15 (5.40)	27.43 (4.99)	27.30 (5.16)	0.07	.79
Hollingshead classes I & II (%)	0	0	0	0.07	.97
Hollingshead class III (%)	35	37	37		
Hollingshead class IV (%)	51	50	51		
Hollingshead class V (%)	11	13	12		
Child's age, mean (*SD*)	12.09 (3.11)	9.98 (5.90)	10.96 (4.90)		
Child's gender (%)					
Female (male)	65 (35)	45 (55)	55 (45)	3.95	.05
Time since diagnosis, mean (*SD*)	3.67 (2.30)	3.79 (2.82)	3.74 (2.69)	0.03	.85
SCID-PTSD diagnosis (%)	6.5	7.5	7	0.04	.84
PCL-C PTSD diagnosis (%)	17	17	17		
PCL score, mean (*SD*)	34.98 (15.04)	32.19 (15.07)	33.48 (15.04)	0.85	.36
BDI-II score, mean (*SD*)	13.51 (11.52)	12.19 (8.70)	12.80 (10.06)	0.42	.52
Trait anxiety T score, mean (*SD*)	56.62 (14.29)	56.53 (11.80)	56.57 (12.93)	0.00	.97
State anxiety T score, mean (*SD*)	55.69 (14.84)	57.06 (12.10)	56.43 (13.38)	0.25	.62
Stressful life events, mean (*SD*)	4.20 (2.47)	3.83 (2.72)	4.00 (2.60)	0.48	.48

BDI, Beck depression inventory; PCL-C, posttraumatic stress disorder checklist-civilian version; SCID-PTSD, structured clinical interview for DSM-IV posttraumatic stress disorder; SES, socioeconomic status.