

Brief Report: Posttraumatic Stress Disorder in Parents of Children With Newly Diagnosed Type 1 Diabetes

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Objective: To determine rates of posttraumatic stress disorder (PTSD) and symptoms in mothers and fathers of children with newly diagnosed type 1 diabetes.

Methods: Parents of 38 children with newly diagnosed type 1 diabetes were assessed with the Posttraumatic Diagnostic Scale 6 weeks after diagnosis.

Results: Twenty-four percent of the mothers and 22% of the fathers met full diagnostic criteria for current PTSD. In addition, 51% of the mothers and 41% of the fathers met criteria for partial or subclinical PTSD. Co-occurrence of PTSD in couples was very low. Posttraumatic stress symptomatology did not correlate with age and gender of the child, socioeconomic status, family structure, or length of hospital stay.

Conclusions: The findings support applicability of a posttraumatic stress model for investigating the psychological impact of type 1 diabetes on parents.

Key words: chronic illness; childhood illness; diabetes mellitus; posttraumatic stress disorder; parental mental health.

Since "learning that one's child has a life-threatening disease" was included as a qualifying event for posttraumatic stress disorder (PTSD) in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1994), application of a trauma model for investigating parental responses to life-threatening diseases of their children has become more prevalent (Stuber, Kazak, Meeske, & Barakat, 1998). Several studies have found elevated levels of posttraumatic stress symptoms in parents of children with chronic conditions. The epidemiological data are consistent with the trauma literature regarding re-

sponses to traumatic exposure of moderate magnitude. Groups studied to date include parents of pediatric cancer survivors (Kazak et al., 1997; Manne, Du Hamel, Gallelli, Sorgen, & Redd, 1998; Pelcovitz et al., 1996) and parents of children with severe burn injuries (Fukunishi, 1998; Rizzone, Stoddard, Murphy, & Kruger, 1994). Depending on the measures and samples used, up to 71% of parents were found to report significant levels of traumatic stress symptoms.

Several arguments support the hypothesis that posttraumatic stress may also be a viable model for studying the impact of type 1 diabetes in a child on his or her parents. First, the very onset of type 1 diabetes may be traumatizing in some cases. Some children become acutely ill and may be hospitalized in an

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intensive care unit. In these cases, parents may be confronted with the threatened death of their child. Second, in spite of improvement in treatment regimens, the condition is still associated with significant morbidity. For instance, parents have to deal with threatening medical concomitants of diabetes, such as episodes of hypoglycemia and hyperglycemia, as well as with the possibility of severe long-term medical sequelae and shortened life expectancy. Third, parents may be traumatized as a consequence of being responsible for administering a treatment that involves considerable stress. Daily injections of insulin are painful and may be experienced as a threat to the child's physical integrity. Fourth, in previous studies, parents of children with diabetes have been found to show signs of moderate to high distress in the first months after diagnosis (Chaney et al., 1997; Thernlund et al., 1996).

In summary, diagnosis of type 1 diabetes may result in a trauma with an acute phase (diagnosis, initial treatment) followed by subsequent chronic stressors (intrusive treatment, threat of hypoglycemia and hyperglycemia, threat of medical late effects). We therefore propose that diagnosis and treatment of type 1 diabetes in a child constitute traumatic events for parents and that a posttraumatic stress model should be considered to investigate the psychological impact of this chronic disease on parents.

This pilot study was designed to examine (1) rates of and co-occurrence of PTSD and PTSD symptoms in mothers and fathers of children with newly diagnosed type 1 diabetes, (2) determinants of posttraumatic stress symptoms in these mothers and fathers, and (3) differences between mothers and fathers in perceptions of life impairment due to the posttraumatic stress symptomatology.

Method

Participants

Mothers and fathers of 38 children (14 girls, 24 boys) with newly diagnosed type 1 diabetes treated in four different children's hospitals in the German-speaking part of Switzerland (cantons of Zurich, Aargau, and St. Gallen) participated in the study. Parents were recruited serially over a 18-month period and asked to participate in the study within the first 2 weeks after diagnosis if their child met all of the following criteria: (1) new diagnosis of type 1 diabetes, (2) no major systemic illness other than diabetes, (3) suffi-

cient command of the German language, and (4) no evidence of mental retardation. Parents were recruited only if their child was between 6.5 and 14 years of age at diagnosis, because the affected children took part in a separate study on psychosocial issues of diabetes. Thirty-eight (90.5%) of 42 parents whose children met the recruitment criteria agreed to participate. The main reason given by six parents for nonparticipation was that the study seemed too time consuming. Families who participated were not compensated. The mean age of the patients was 10.5 years ($SD = 2.5$). Thirty-one children (82%) lived with both biological parents. The sample was predominantly upper-middle-class (10.6% low, 76.3% middle, 13.1% upper). Thirty-one families (82%) were Swiss, and seven families (18%) had a Mediterranean country of origin (e.g., Italy, Spain, former Yugoslavia). Mean length of hospital stay at time of assessment was 14.2 days ($SD = 7.6$). Two children were initially hospitalized in a pediatric intensive care unit.

Measures

We used the Posttraumatic Diagnostic Scale (PDS; Foa, Cashman, Jaycox, & Perry, 1997). This self-report measure of posttraumatic stress disorder yields both a PTSD diagnosis according to DSM-IV criteria and a measure of PTSD symptom severity. Participants are asked to rate the presence of each of the 17 symptoms of PTSD. The scale uses a 4-point (0–3) Likert severity scale ranging from 0 = not at all, 1 = a little bit, 2 = somewhat, to 3 = very much. The questionnaire also includes nine items that assess impairment in different areas of life as a reaction to the trauma, using a yes/no format. The PDS demonstrated high internal consistency ($\alpha = .92$) and good test-retest reliability ($\kappa = .74$) in its original English version (Foa et al., 1997). Agreement between PTSD diagnoses obtained from the PDS and the Structured Clinical Interview for DSM-III-R SCID-PTSD modul was 82%. The sensitivity of the PDS was .89 and its specificity was .75. The scale is widely used for screening and assessing PTSD in clinical and research settings. This study used the German version of the PDS (Steil & Ehlers, 2000). The internal consistency of the translated scale was .91 and is thus similar to the original English scale. Concurrent validity of PDS symptom severity scores was supported by high correlations with other measures of psychopathology: Higher PDS scores were associated with greater depression on the Beck Depression Inventory (BDI) ($r = .67$), higher State and Trait anxiety on the State-Trait Anx-

Table I. DSM-IV PTSD Symptoms and Diagnosis in Mothers and Fathers as Assessed with the PDS (Foa et al., 1997)

	Mothers (<i>n</i> = 37)	Fathers (<i>n</i> = 36)	χ^2	<i>t</i>	<i>p</i>
Reexperiencing					
% that met DSM-IV criteria	89.19	91.67	0.13		.72
<i>M</i> no. of symptoms (<i>SD</i>)	2.65 (1.62)	2.56 (1.46)		0.20	.85
<i>M</i> symptom severity (<i>SD</i>)	4.74 (3.97)	4.12 (3.12)		0.49	.63
Avoidance/psychic numbing					
% that met DSM-IV criteria	24.32	22.22	0.29		.59
<i>M</i> no. of symptoms (<i>SD</i>)	1.68 (1.47)	1.50 (1.42)		0.35	.73
<i>M</i> symptom severity (<i>SD</i>)	2.81 (3.00)	2.28 (2.99)		0.58	.57
Hyperarousal					
% that met DSM-IV criteria	67.56	63.88	0.06		.81
<i>M</i> no. of symptoms (<i>SD</i>)	2.27 (1.54)	1.97 (1.30)		0.92	.37
<i>M</i> symptom severity (<i>SD</i>)	4.06 (3.36)	3.01 (2.32)		1.54	.13
All three symptom clusters					
% that met DSM-IV criteria for full PTSD	24.32	22.22	0.05		.83
% that met criteria for partial PTSD	51.35	41.67	0.69		.41
<i>M</i> PTSD total symptom severity (<i>SD</i>)	11.91 (9.15)	9.90 (7.23)		1.31	.20

xiety Inventory (STAI) ($r = .32$), and higher scores on the Symptom Checklist SCL-90-R ($r = .68$) (Steil & Ehlers, 2000). In this study, internal consistency of the PDS was .79 for fathers and .87 for mothers. Following the DSM-IV, the diagnosis of PTSD was made if participants reported at least one reexperiencing symptom, three avoidance symptoms and two arousal symptoms, and impairment in at least one life area. A symptom was rated as present if the item corresponding to the symptom was scored 1 or greater (Foa et al., 1997). Partial or subclinical PTSD was defined in a conservative, restrictive fashion: persons were required to have at least one symptom in each of the three PTSD symptom clusters (Stein, Walker, Hazen, & Forde, 1997).

Socioeconomic status (SES) was calculated by means of a 6-point score of both paternal occupation and maternal education. The lowest SES score was 2 points, the highest 12 points. Social classes were defined as follows: SES scores 2–5, low social class; SES scores 6–8, middle social class; and SES scores 9–12, upper social class.

Procedure

The study was approved by the research ethics committees of all involved hospitals. After obtaining informed written consent of the parents, questionnaires were mailed to mothers and fathers 6 weeks after diagnosis of type 1 diabetes in their child. Parents were asked to complete their questionnaires separately and not to consult each other. Thirty-seven

mothers (97.4%) and 36 fathers (94.7%) sent back their questionnaires. Demographic and medical variables were retrieved from the patient records.

Results

Presence of PTSD and PTSD Symptoms

Posttraumatic stress symptoms of the parents are listed in Table I. Twenty-four percent of the mothers ($n = 9$) and 22% of the fathers ($n = 8$) met full DSM-IV diagnostic criteria for current PTSD. In addition, 19 mothers (51.4%) and 15 fathers (41.7%) met criteria for partial or subclinical PTSD. The analysis of co-occurrence of PTSD in couples yielded an interesting result: only in two families did both parents show full PTSD at the same time. Thus, in 15 families (39% of the sample), at least one of the parents suffered from full PTSD. With regard to partial PTSD, co-occurrence in couples was slightly higher: in seven families both parents suffered from partial PTSD simultaneously. In 27 families (71% of the sample), at least one of the parents showed partial PTSD.

Because of potential dependencies between the data collected for mothers and fathers in the same family, comparison of means of symptom severity was analyzed by two-sided paired *t* tests. With regard to full and partial PTSD diagnosis (categorical variable), mothers and fathers were compared using chi-square tests. Table I shows that mothers reported a slightly higher number of symptoms and also more

severe symptoms in all symptom clusters than fathers. These differences, however, did not reach statistical significance. There were also no differences in rates of full and partial PTSD diagnosis between mothers and fathers.

Pearson product-moment correlation coefficients were computed to examine the relationship of overall PTSD symptom severity with sociodemographic and medical variables. In both mothers and fathers, PTSD symptom severity was not associated significantly with age and gender of the child, socioeconomic status, family structure (one- vs. two-parent families), and length of hospital stay. However, there was a tendency for a longer duration of hospitalization to contribute to more posttraumatic stress symptoms in fathers ($r = .34, p = .06$). The mothers and fathers of the two children initially hospitalized in a pediatric intensive care unit did not meet criteria for PTSD.

Impairment in Significant Life Areas

Chi-square analyses were used to compare the proportions of mothers and fathers that endorsed each of the nine items of the PDS assessing impairment in various life areas (DSM-IV criterion F of PTSD diagnosis). Mothers reported the greatest impact on overall level of functioning (67.6%), general satisfaction with life (59.5%), and household duties (59.5%), whereas fathers did so for leisure activities (50.0%), general satisfaction with life (47.2%), and sexuality (42.4%). In most areas mothers reported more impairments than fathers. These differences, however, were statistically significant only for overall level of functioning ($\chi^2 = 6.03, df = 1; p = .01$), household duties ($\chi^2 = 4.57, df = 1; p = .03$), friendships ($\chi^2 = 4.56, df = 1; p = .03$), and family relationships ($\chi^2 = 4.04, df = 1; p = .04$).

Discussion

This is to our knowledge the first study investigating posttraumatic stress symptomatology in mothers and fathers of children with newly diagnosed type 1 diabetes. A significant group of parents was found to meet criteria for full or partial PTSD. As co-occurrence of PTSD in couples was very low, a large proportion of families was impacted significantly. Rates of PTSD were significantly higher than those reported from large community samples (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Stein et al., 1997). Lifetime

prevalence of PTSD in young adults in Germany, a society comparable to Switzerland, was found to be 1% in males and 2.2% in females (Perkonigg, Kessler, Storz, & Wittchen, 2000). Thus, there is sufficient evidence to suggest that posttraumatic stress symptoms of parents in our sample are related to their child's illness. Notably, rates of PTSD in this study were similar to figures reported in two previous studies of mothers of pediatric cancer patients and mothers of pediatric burn survivors (Pelcovitz et al., 1996; Rizzone et al., 1994).

With regard to the etiology of PTSD, this study does not allow any definite conclusions. Two possible etiologic factors have to be considered: the shock of the diagnosis (acute stressor) and traumatic aspects of medical treatment (chronic stressors). The fact that in fathers the correlation between length of hospitalization and PTSD approached significance supports the hypothesis that treatment-related stressors may be important. However, this study was not able to identify any additional sociodemographic or medical predictors of PTSD. Possibly, subjective factors such as appraisals of the events would have been better predictors of PTSD than "objective" medical variables. In addition, pretraumatic psychopathology (such as state anxiety) in parents might also be important, but it has not been assessed within this study.

No significant differences between mothers and fathers could be found with regard to PTSD and PTSD symptom clusters. This is in line with findings by Kazak et al. (1997) in mothers and fathers of pediatric cancer survivors. However, this stands in contrast to most studies of traumatized and community population samples, which have consistently found women to have a higher risk of PTSD. One may speculate that in parents of chronically ill children, the parental role overshadows the gender effect.

Some limitations of this study may have influenced the reported PTSD rates. First, the sample was small, and no matched control group was assessed. Comparison of our PTSD rates with community samples can also be called into question, although a German study is available for comparison that should have eliminated cross-cultural bias (Perkonigg et al., 2000). Second, only one self-report measure of PTSD symptoms, the PDS, has been used. Although the reported sensitivity and specificity of the PDS are high, different rates of PTSD might have been found if structured clinical interviews had been used. Third, diagnosis of PTSD requires impairment in at least one significant life area due to the trauma reactions. Although PDS items are formulated clearly, the high

rates of impairments found in this study suggest that some of the parents may have noted impairments that are not indicative of PTSD, but rather reflect the simple reality of illness (such as hospitalization). This might have led to an overestimation of the number of parents qualifying for a diagnosis. However, the PTSD rates in this study are similar to those found in other studies of parents of children with chronic conditions (Pelcovitz et al., 1996; Rizzone et al., 1994). Thus, in spite of these limitations, we believe that there is sufficient evidence that a significant group of parents of children with newly diagnosed diabetes suffers from posttraumatic stress symptoms.

This study suggests several possible issues for future research activities. Since this is the first study investigating posttraumatic stress symptoms in parents of children with type 1 diabetes, our findings need to be replicated. The remarkably high rates of PTSD in our sample support applicability of a posttraumatic stress model for investigating the psychological impact of diabetes on parents. Longitudinal studies will have to investigate the course of posttraumatic stress reactions over time. Studies with parents of pediatric cancer survivors suggest that posttraumatic symptoms at this early stage may not be a transient phenomenon but may persist for many years (Kazak et al., 1997; Manne et al., 1998; Pelcovitz et al., 1996).

Clinical implications can be drawn from this study. Our findings confirm the need for careful evaluation of posttraumatic stress symptoms in mothers and fathers after diagnosis of type 1 diabetes in their children. PTSD may impair parental functioning. In addition, arousal symptoms are known to directly affect the use of medical services via more frequent

phone calls and office visits for reassurance (Pelcovitz et al., 1996). Early recognition of posttraumatic stress symptoms would provide opportunities for interventions that have been found to be effective in treating PTSD, thus enhancing the quality of life of families with children with newly diagnosed type 1 diabetes. Guthrie, Sargent, Speelman, and Parks (1990), for example, showed that parental relaxation training had a positive effect on the metabolic control of children with diabetes. A better understanding of the consequences of acute and chronic stress on mothers and fathers also has implications for the ill child's adjustment. The relationship between parental adjustment and the adjustment of the chronically ill child is well documented (Frank, Olmsted, & Wagner, 1991). Finally, early psychosocial interventions in symptomatic parents may have beneficial effects not only for the psychological adjustment of parents and patients but also for the short and long-term course of the illness.

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