

Psychiatric Morbidity and Quality of Life in Children with Malignancies and Their Parents

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Abstract: Recent improvements in prognosis necessitate considering the emotional responses of children with malignant diseases and of their parents. This prospective study assessed 20 children and adolescents and their 36 parents within 2 weeks of diagnosis and after 1 and 6 months. Fifty-three percent exhibited moderate to severe posttraumatic symptoms right after diagnosis that decreased significantly after 1 month. Children with high-risk disease reported the most severe symptoms. Unexpectedly, children with low-risk disease exhibited more severe symptoms than those with moderate risk. Depressive symptoms decreased significantly during the period, but anxiety symptoms did not. Moreover, quality of life did not change. Twenty percent of parents exhibited posttraumatic symptoms on initial evaluation. Mothers' symptoms did not change, but fathers' symptoms decreased with those of their children. Several procedures and experiences were identified as causes of traumatic stress responses.

Key Words: Posttraumatic symptoms, depressive symptoms, anxiety symptoms, childhood malignancies.

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Recent advances in treating pediatric malignancies have returned a number of once-fatal conditions into life-threatening but potentially survivable conditions. Stuber (1996) noted that survivors of childhood cancer might suffer from psychological problems such as low self-esteem, depression, anxiety, poor peer relations, and low school performance, in addition to behavioral problems, persistent illness-related concerns, somatic preoccupation, and negative body image. A lifetime posttraumatic stress disorder (PTSD) prevalence of 35% (Pelcovitz et al., 1998) and a posttraumatic stress symptoms (PTSSs) prevalence of 12.5% (Stuber et al., 1996) were reported in children and adolescents with malignancies. Other studies of children with malignancies demonstrated no difference in PTSSs prevalence between these children and healthy (Barakat et al., 1997) or acute outpatient pediatric clinic (Kazak et al., 1997) controls. Their parents, however, exhibited a higher prevalence of PTSSs than comparison group parents (Barakat et al., 1997; Kazak et al., 1997). The present study aimed at prospectively assessing development

of psychiatric morbidity in children diagnosed with malignancies and in their parents, evaluating the children's quality of life, and specifying traumatic events leading to traumatic stress symptoms. We hypothesized that the prognosis of the illness would have an impact on the development of psychiatric symptoms in both the children and their parents.

METHODS

Participants

The study population consisted of children aged 7 to 18 years admitted consecutively to the Department of Pediatric Hematology/Oncology at Sheba Medical Center. The study was approved by the Institutional Review Board, the children gave their assent to participate, and their parents signed an informed consent. Children with disease diagnosed earlier than 1 week before hospitalization were excluded, as were children with a history of a major psychiatric disorder (psychosis, affective disorder), drug abuse, or mental retardation.

The children were subdivided into three subgroups by two senior pediatric hematologists (A.T., B.B.) based on clinical and laboratory characteristics (as in Pizzo and Poplack, 2002) according to severity of disease, intensity and length of treatment, and prognosis, as follows: *low-risk*, disease requiring short treatment of low intensity with a favorable prognosis (Hodgkin disease); *moderate-risk*, disease requiring treatment by a longer, more intense protocol with an intermediate prognosis (paratesticular rhabdomyosarcoma, osteosarcoma, leukemia, Burkitt lymphoma, granulosa cell tumor); *high-risk*, disease requiring treatment of a longer duration with aggressive protocols and with a guarded prognosis (high-grade glioma, desmoplastic small-round cell tumor, esthesioneuroblastoma, Ewing sarcoma, and high-risk leukemia). The department routinely provides psychosocial support to all children with cancer and their families. None of these children received psychotherapy.

Instruments

The Pediatric Oncology Quality of Life Scale (POQOLS; Drotar, 1998) is a 21-item parent-rated questionnaire of physical function and role restriction, emotional distress, and reaction to current medical treatment. The Child Post-Traumatic Stress Disorder—Reaction Index (CPTSD-RI; Pynoos et al., 1987) is a semistructured 20-item interview with the child with respect to intrusion, avoidance, and arousal symptoms, rated on a frequency scale from 0 = "none" to 4 = "most of the time." The Children's Depression Inventory (CDI; Kovacs, 1985) is a 27-item self-rated questionnaire evaluating affective, cognitive, and behavioral symptoms of depression. The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds and Richmond, 1985, 1997) is a 37-item self-report inventory evaluating apprehensive, oversensitivity/concentration, and physiological factors of anxiety. The children were also questioned about the

extent to which each of 22 characteristics of disease and treatment affected them most (*e.g.*, first meeting with the departmental physician, finding out about the cancer, nausea/vomiting, hair loss, radiation treatment, chemotherapy, and so forth). The characteristics were rated from 1 = “did not affect me at all” to 4 = “affected me immensely.” The Davidson Trauma Scale (Davidson et al., 1997) is a 17-item parent-rated instrument assessing posttraumatic symptoms in adults.

The psychiatric assessments were completed at three time points: T1, the first 2 weeks after hospitalization; T2, 1 month later; and T3, 6 months later.

Statistical Analysis

Analysis of variance with repeated measures was used to compare the symptoms of the children and their parents at the three time points, with contrasts for comparing between the time points. The children’s prognosis served as a between-subject factor. Post hoc (Tukey) was used to compare the symptoms between the various prognostic categories. Pearson correlations measured the linear association among the study variables.

RESULTS

The study group consisted of nine females and 11 males aged 7 to 17 (13.6 ± 3.6) years and 36 of their parents (20 mothers, 16 fathers). Two children were from single-parent families, and two fathers refused to participate. Seven families were unwilling to cooperate. Eight of 56 participants declined to fulfill the last evaluation. Their analyses were performed according to the intention-to-treat principle.

Table 1 summarizes the children’s psychiatric symptoms and quality of life according to disease risk at the three time points. According to analysis of variance with repeated measures, the children’s posttraumatic symptoms decreased significantly along the three time points ($F[2,16] = 8.25$; $p < .005$), with a significant decrease between T1 and T2 ($p < .05$). Severe PTSSs (score above 40) were reported by two children (10%) at T1 and T2 and by none of the children at T3. Nine children (43%) at T1, five (26%) at T2, and four

(20%) at T3 reported moderate symptoms. Both of the children with severe symptoms at T1, five children with moderate symptoms at T2, and three of the four children with moderate symptoms at T3 were in the high-risk category. Symptoms of depression decreased significantly along the three time points ($F[2,16] = 7.41$; $p < .005$). A significant decrease was found between T2 and T3. Five percent of the children suffered from significant depressive symptoms (using a cutoff score of 19) at T1, but none did so at T2 and T3. Anxiety symptoms did not change significantly along the three assessments. No significant interaction was noted between the PTSS/depressive/anxiety symptoms and the children’s level of risk. However, post hoc tests revealed that high-risk children reported significantly more symptoms than did children with moderate and low risk. The children’s quality of life did not change along the three assessments, and there was no significant interaction with risk. However, at each assessment, high-risk children showed a tendency to report a worse quality of life than children with a low or moderate risk.

The frequency of PTSSs among the mothers did not change significantly ($F[2,14] = 2.59$; $p > .05$). This was true for the severity of the mothers’ symptoms as well. There was no significant interaction with the children’s risk. The frequency of PTSSs of the fathers decreased along the time points ($F[2,12] = 3.97$; $p < .05$), but there were no significant changes in severity ($p > .05$). No significant interaction with the children’s risk was noted. The children’s symptoms were not associated with the mothers’, but were significantly correlated with the fathers’ at T2 ($r = .63$; $p < .01$) and T3 ($r = .47$; $p < .05$).

The children rated the impact of 22 disease and treatment characteristics on a 5-point scale. Four items were rated high at all three assessments: medical assessment on admission, first time the child learned he or she had cancer, nausea/vomiting, and separation from school and friends. The other items (repeated intrathecal injections, infusions/Port-a-Cath, bone marrow aspirations/biopsies, operations, hair loss, chemotherapy, irradiation, being around other sick children, difficulties in making future plans) received lower scores.

TABLE 1. Psychiatric Symptoms and Quality of Life of Children According to Risk of Disease at Three Assessment Points

Assessment scales	Risk, first assessment			Risk, second assessment			Risk, third assessment		
	Low (N = 6)	Moderate (N = 7)	High (N = 7)	Low	Moderate	High	Low	Moderate	High
CPTSD-RI	20.8 ± 11.5	17.7 ± 6.3	35.6 ± 12.5	17.3 ± 15.9	13.7 ± 8.3	26.6 ± 6.0	12.0 ± 2.5	11.3 ± 8.9	23.1 ± 15.3
CDI	10.2 ± 4.2	5.0 ± 2.2	11.7 ± 5.9	9.0 ± 4.9	6.6 ± 2.8	10.0 ± 5.3	5.8 ± 5.3	3.1 ± 4.2	6.8 ± 4.9
RCMAS	11.0 ± 1.7	8.8 ± 2.6	14.3 ± 5.1	12.8 ± 7.7	8.8 ± 2.7	16.5 ± 5.1	10.3 ± 3.9	7.6 ± 2.8	15.0 ± 6.5
POQOLS	57.8 ± 13.9	55.9 ± 26.7	83.3 ± 26.4	66.5 ± 26.5	67.6 ± 12.8	72.6 ± 23.6	58.8 ± 16.5	53.1 ± 25.1	71.0 ± 34.6

DISCUSSION

The present study monitored a cohort of children with cancer and their parents for 6 months after diagnosis. The children's PTSSs decreased significantly during the study period, with maximal decrease between the first 2 weeks of diagnosis and 1 month later. On admission, more than half the children exhibited moderate to severe PTSSs. After a month, the symptoms decreased, leaving 36% with moderate to severe symptoms.

In the present study, children with high-risk disease reported more psychiatric symptoms than those at low-risk and moderate-risk disease, and they tended to report decreased quality of life as well. This finding cannot be explained by the increased number of diagnostic or therapeutic measures taken in the high-risk group in the very early stages of the disease. Stuber et al. (2003) reported a similar finding in breast cancer survivors. In the present study, however, only the parents knew the exact prognosis and risk, making the association observed between level of risk and posttraumatic symptoms particularly interesting. Perhaps the children absorbed such information nonverbally, and the parents' unspoken feelings about their child's disease may have enhanced the psychiatric symptoms by proxy.

Unexpectedly, children with low-risk disease had more psychiatric symptoms than those with moderate-risk disease. Although the sample is too small to draw any firm conclusions, the finding might be attributed to mixed messages transmitted by treating physicians to patients and their parents, mandating different coping styles. Low-risk patients expect a curable disease and an easy and short treatment, so their first encounter with objective difficulties might intimidate and incapacitate them. Children at moderate risk are ready for a fight and may develop more realistic and adaptive coping strategies.

Symptoms of depression decreased significantly at the 6-month assessment. Published findings in this area are controversial and depend on the variability in the assessment phases. Anxiety symptoms did not change over time and were similar to levels reported in other groups of anxious children (Toren et al., 1999). The children's quality of life remained relatively constant along the assessment points but tended to be lower in children at high risk.

Our study found that approximately 20% of the parents had scores of PTSSs above the cutoff point in the first evaluation. Studies indicate that parents whose children have cancer exhibit more PTSSs than parents of healthy children (Barakat et al., 1997; Kazak et al., 1997; Pelcovitz et al., 1996). These studies were performed after treatment was completed, and the overall rates of PTSSs ranged between 7% and 30%. In the present study, PTSS scores for mothers and fathers were similar on admission, and no significant interaction was found between their symptoms and children's

risk level. Only the fathers' symptoms decreased over time, and they were positively and significantly associated with the children's symptoms at the 1-month and 6-month follow-ups. This finding may represent role or gender differences in response to trauma or a modeling effect for fathers. The dissimilar pattern of posttraumatic symptoms in children and mothers deserves attention.

Limitations

The present study is a longitudinal study of 20 children and adolescents and their 36 parents. The study group is too small to draw any firm conclusions, and its findings and trends should be further assessed with larger samples of patients using prospective multicenter controlled studies. Specific developmental issues should be addressed in assessing larger samples of various relevant age groups.

Clinical Implications

Children's posttraumatic, depressive, and anxiety symptoms were assessed longitudinally. These symptoms should be addressed, because the emotional health of a child with malignant disease is important not only in itself but also as part of the child's fighting force against cancer. For example, Shemesh et al. (2000) reported that failure to adhere to medication was significantly more common in children with PTSD. Further, information about disease severity might be nonverbally transmitted to the children. As Stuber et al. (1997) suggested, anxiety and subjective assessment of risk to life contribute to psychiatric morbidity even more than objective factors. Hence, children must be helped to deal with such nonverbal information. In addition, the relatively poor psychological resilience among children with low-risk disease should be followed up and, if replicated, addressed. Moreover, the medical staffs should be aware of the impact certain procedures and experiences have on the children as causes of traumatic stress responses. The children do not necessarily respond to the same events that the medical staff would predict.

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