

## Adjustment in Childhood Brain Tumor Survival: Child, Mother, and Teacher Report<sup>1</sup>

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*Examined the adjustment of 6- to 18-year-old children and adolescents (n= 38) 2 to 5 years postdiagnosis of brain tumor with respect to standardized measures of anxiety and depression; self-perceptions; and adaptive living skills. Child, mother, and teacher report data were used. Maternal adjustment (anxiety and depression, parenting stress) was also assessed. Children and adolescents surviving brain tumors reported themselves to be generally within the normal range. However, maternal ratings of social problems were higher than normative scores and significantly lower than norms on social problems, scholastic competence, and communication skills. Teacher ratings on the Teacher Rating Form were all within normal limits. Maternal adjustment measures were within the normal range, although the Parent-Child Dysfunctional Interaction subscale of the Parenting Stress Index was elevated. No differences in scores were found between children in regular and special education, or between children who had received radiation and those who did not. This sample of survivors of pediatric brain tumors and their mothers had relatively mild problems in adjustment, supporting a competency-based view of the adaptation of pediatric patients and their families.*

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Survival is a welcome outcome of treatment for increasing numbers of children with cancer and their families, including patients who have brain tumors. Most

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psychological research on childhood cancer survival is based on former leukemics. The generalizability of these data is not established, particularly for brain tumors. Indeed, patients with brain tumors are often explicitly excluded from studies of psychological adjustment because their disease and treatment are seen as different from, and more damaging than, other cancers. Pediatric patients who survive brain tumors cope with the direct physiological insult caused by the tumor itself, the treatments (neurosurgery, chemotherapy, and/or high dose central nervous system irradiation) and treatment related sequelae (e.g., impaired health, extensive school absence, familial stress).

As survival rates for children with brain tumors increase, from about 8% to 50–60% over the past two decades (Duffner & Cohen, 1992), the psychosocial implications of survival warrant further empirical investigation. Earlier reports supported the general association of central nervous system involvement (including brain tumors) with poor psychological adjustment, increased psychopathology, difficulties in school achievement, lower rates of marriage than siblings, increased health problems, and functional impairment (Breslau, 1985; Kelaghan et al., 1988; LeBaron, Zeltzer, Zeltzer, Scott, & Marlin, 1988).

The risk for increased cognitive impairment is very high (Mulhern, Ochs, & Kun, 1991; Silber et al., 1992). The greatest risk, in terms of loss of IQ points, appears to be for children diagnosed before age 7 (Radcliffe et al., 1992). Older children, however, have deficits in memory, sequential processing, fine-motor coordination, and physical stamina, and receive special education and/or tutorial services at rates above expectation for their IQ level (Radcliffe et al., 1992). With regard to psychological adjustment, Mulhern, Carpentieri, Shema, Stone, and Fairclough (1993) reported comparable scores on the Child Behavior Checklist (CBCL) in patients with brain tumors and other cancers. Their data provide support for increased internalizing difficulties, including somatic complaints, and lower scores on activities and social competence.

There is insufficient research addressing family adjustment to a child's surviving a brain tumor. In general, once treatment is completed, parents express relief, but also anxieties about long-term sequelae (Kupst & Schulman, 1988). Although there is no evidence for serious psychopathology in parents of patients who have completed treatment, some interesting findings have emerged. Parental distress has been shown to be higher in survivors who require ongoing special education services (Kazak & Meadows, 1989). In addition, parents of leukemia survivors reported significant amounts of posttraumatic stress symptoms, highlighting the potential long-term impact of childhood cancer (Kazak et al., *in press*). The applicability of these findings for survivors of brain tumors has not been established.

The present study assessed psychological adjustment of children and adolescents 2 to 5 years after diagnosis of a brain tumor, and their mothers. It is the first, to our knowledge, to evaluate child and maternal adjustment among brain tumor survivors at this follow-up interval and to evaluate child and maternal

adjustment incorporating child, parent, and teacher report data. There are three general aims and hypotheses:

Aim I. To identify the psychosocial status of children and adolescents who are 2 to 5 years postdiagnosis of a brain tumor. *Hypothesis 1:* Children and adolescents who have been successfully treated for brain tumors will show poorer levels of psychological adjustment relative to well-normed instruments. Using child, parent, and teacher report, brain tumor survivors will have more internalizing symptoms (e.g., anxiety, depression), poorer self-perceptions, and lower levels of adaptive living skills.

Aim II. To identify the psychosocial impact of having a child with a brain tumor on mothers of former patients. *Hypothesis 2:* Mothers of children successfully treated for a brain tumor will have higher levels of distress than normative scores, including higher levels of parenting stress, anxiety, and depression.

Aim III. To identify factors associated with relatively good adjustment among a sample of children surviving brain tumors. *Hypothesis 3:* Radiation treatment and need for current educational support services will be associated with poorer child adjustment.

## METHOD

### Participants

Participants were 38 children (25 male, 13 female), ages 6 to 18 ( $M = 11.4$  years,  $SD = 3.5$ ), 2 to 5 years postdiagnosis of a brain tumor at a regional neuro-oncology program, and their mothers ( $n = 38$ ) and teachers ( $n = 33$ ). Participants had the following tumor types: primitive neuroectodermal tumor (PNET), posterior fossa ( $n = 10$ ), ganglioma ( $n = 5$ ), astrocytoma not otherwise specified ( $n = 4$ ), pilocytic astrocytoma ( $n = 4$ ), craniopharyngioma ( $n = 4$ ), mixed glioma ( $n = 3$ ), ependymoma ( $n = 3$ ), chiasmatic glioma ( $n = 3$ ), meningioma ( $n = 1$ ), and anaplastic astrocytoma ( $n = 1$ ). The location of the tumors were both cortical ( $n = 20$ ) and noncortical ( $n = 18$ ).

Ethnicity was Caucasian ( $n = 36$ ) and biracial ( $n = 2$ ). Current family status was obtained through medical chart review: two-parent families ( $n = 30$ ); single parent ( $n = 3$ ); unknown ( $n = 5$ ). Mean socioeconomic status (SES) based on occupation codes from Hollingshead (1975) was 5.94 ( $SD = 1.89$ ), characteristic of semiprofessionals (e.g., technicians, owners of small businesses, clerical and sales workers). Median SES was 6.00.

### Procedure

Tumor registry data indicated 112 eligible patients, meeting inclusion criteria for age, date of diagnosis, and tumor type. Of these, 42 (38%) could not be located (letters were returned and phone numbers were not listed), leaving a potential  $n$  of

70. Of these, the parents of 14 (20%) refused, providing reasons such as lack of time and not wanting to think about their child's illness and treatment experience. The parents of the remaining 80% ( $n = 56$ ) agreed by phone to participate in the study and were sent questionnaire packets. Forty-two families, or 60% of the eligible participants ( $42/70$ ) returned completed packets. Three of these were completed by fathers and one by another relative; these are not reported in this paper which utilizes only mother data. When a completed questionnaire was returned, the Vineland Adaptive Behavior Scale was administered by phone by trained examiners ( $n = 30$ ). The Teacher Report Form was sent to families and forwarded to the child's teacher who returned the form directly to us ( $n = 33$ ).

The following data were extracted from clinic records: degree of tumor removal; use of a shunt; extent of radiation therapy and chemotherapy. Most (60%) of the sample received total surgical resections of their tumors; 29% had partial resections; 2% had biopsy only; and 9% had no surgery. Of the total sample, 13 patients (31%) had ventriculoparietal shunts. The majority had radiation therapy; 28% had craniospinal radiation with additional radiation to the local tumor area; 36% had local radiation only; and 36% had no radiation therapy. Thirty-six percent received chemotherapy. Forty-one percent of participants were in special education placements. Participants and nonparticipants did not differ significantly by gender [ $\chi^2(1,70) = 1.41, p > .05$ ], age [ $t(68) = 1.62, p > .05$ ], or tumor type [ $\chi^2(13,70) = 9.12, p > .05$ ].

## Measures

### *Child Self-Report*

*The Children's Depression Inventory* (CDI; Kovacs & Beck 1977) is a 27-item self-report scale. Statements represent severity levels of depressive symptoms and are assigned a numerical value of 0, 1, or 2. The CDI has adequate internal consistency and test-retest reliability, and convergent validity (Finch, Saylor, & Edwards, 1985). Total score is a measure of depression.

*The Children's Manifest Anxiety Scale-Revised* (CMAS-R; Reynolds & Richmond, 1978) is a 37-item self-report inventory of anxiety in children and has satisfactory internal consistency and test-retest reliability. The CMAS-R has been found to distinguish children with anxiety disorders from those without a psychiatric diagnosis (Perrin & Last, 1992). Total CMAS-R anxiety score is used for all children in the study.

*The Self-Perception Profile for Children* (SPP; Harter, 1985) is a 36-item self-report scale for children 8 to 12 years which evaluates global self-worth and five additional subscales: Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, and Behavioral Conduct. The 45-item Self-Perception Profile for Adolescents (Harter, 1988) has parallel subscales and was used for participants over age 12.

### *Parent and Teacher Report on Child*

*The Child Behavior Checklist* (CBCL) and *Teacher Report Form* (TRF; Achenbach, 1991) were completed by parents and teachers. Each is a list of 112 problem behaviors that the informant rates for the child: 0 = (*not true*); 1 (*somewhat or sometimes true*); 2 (*very often or often true*). The CBCL and TRF generate broad-band scores for Externalizing, Internalizing, and Social Competence scales (social, scholastic, involvement in activities).

### *Mother Report on Child*

*The Vineland Adaptive Behavior Scale* (VABS; Sparrow, Balla, & Cicchetti, 1984) assesses the adaptive functioning of individuals from birth to age 19 by parental report. The scales include three domains for our age group, each with strong split-half reliabilities: Communication ( $r = .89$ ); Daily Living Skills ( $r = .90$ ); and Socialization ( $r = .86$ ) (Sparrow et al., 1984). Test-retest reliabilities are also strong ( $r > .80$ , for 2–4 week intervals).

### *Mother Self-Report*

*The Beck Depression Inventory* (BDI; Beck, 1967) is a 21-item self-report inventory of depressive symptoms in adults. The BDI assesses motivational, cognitive, affective, and behavioral components of depression, has excellent split-half reliability, and correlates with other validated measures of depressive symptoms.

*The State-Trait Anxiety Inventory* (STAI; Spielberger, Gorsuch, & Lushene, 1973) is a 40-item self-report measure assessing state (i.e., how an individual feels at the moment) and trait anxiety (i.e., how an individual usually feels). It has predictive validity across diverse samples and correlates highly with other anxiety measures. The Trait scale was used in the present study.

### *Mother Report on Child and Parent–Child Interaction*

*The Parenting Stress Index-Short Form* (PSI-SF; Abidin, 1990) is a 36-item questionnaire completed by parents. The PSI-SF has three scales (Parental Distress; Parent–Child Dysfunctional Interaction; and Difficult Child). It has satisfactory internal consistency, test-retest reliability, and concurrent validity with the full length PSI (Abidin, 1990).

### **Statistical Analysis**

To test Hypotheses 1 and 2,  $t$  tests were performed comparing sample scores with norms. Hypothesis 3 was tested with two series of  $t$  tests, comparing mean

scores on the dependent variables by educational placement and radiation treatment. To correct for multiple comparisons, Bonferroni corrections were applied, with a  $p$  level of .01 accepted as statistically significant.

## RESULTS

### *Hypothesis 1: Patient Outcome*

**Child Report.** Contrary to Hypothesis 1, children and adolescents reported themselves to be within normal limits (Table I). Survivors rated themselves as significantly less anxious and depressed than their normative counterparts, CDI,  $t(37) = 3.83, p < .001$ ; CMAS-R  $t(37) = 5.33, p < .001$ . The survivors of brain tumors also reported themselves to be less athletically competent than normative values on the Harter Scales,  $t(32) = 3.86, p < .01$ .

**Mother Report.** Mothers rated their children as significantly lower in overall social competence, CBCL Social Competence,  $t(37) = 3.70, p < .001$ , and scholastic competence, CBCL Scholastic Competence,  $t(37) = 4.51, p < .001$ , compared with normative peers. They also perceived their children as having a significantly higher degree of social problems compared to norms, CBCL Social Problems Subscale,  $t(37) = 3.59, p < .001$ . Mothers rated their children as having significantly greater difficulties in communication skills on the VABS,  $t(29) = 2.78, p < .01$ . In addition, mothers rated interactions with their children as significantly more problematic than the normative sample, PSI Parent–Child Interaction,  $t(37) = 3.83, p < .001$ .

**Teacher Report.** Contrary to hypothesis, teachers did not report significant differences between study participants and normative peers on the Teacher Report Form.

### *Hypothesis 2: Maternal Outcome*

Contrary to hypothesis, mothers did not rate themselves as significantly different from norms with regard to depression,  $t(37) = 1.51, ns$  ( $M_{\text{sample}} = 5.6, SD = 5.8; M_{\text{norms}} = 7.3, SD = 6.9$ ), trait anxiety,  $t(37) = 1.46, ns$  ( $M_{\text{sample}} = 37.7, SD = 11.1; M_{\text{norms}} = 34.8, SD = 9.2$ ), and parental distress on the PSI-S,  $t(35) = .23, ns$  ( $M_{\text{sample}} = 26.1, SD = 7.5; M_{\text{norms}} = 26.4, SD = 7.2$ ).

### *Hypothesis 3: Factors Associated with Adjustment*

Contrary to hypothesis, there were no significant differences on the  $t$  tests in the dependent measures for special education placement, nor for radiation treatment.

Table 1. Means and Standard Deviations: Child Outcome<sup>a</sup>

Measure	<i>n</i>	Sample		Test norms		<i>p</i>
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Child report						
CDI	38	6.34	5.0	9.65	7.3	<.001
CMAS-R	38	9.05	5.0	13.8	5.8	<.001
SPP-Self Worth	32	3.09	0.83	3.02	0.67	
SPP-Athletic	32	2.44	0.88	3.02	0.73	<.01
SPP-Conduct	32	3.14	0.76	2.80	0.55	
SPP-Appearance	32	2.75	0.85	2.79	0.71	
SPP-Scholastic	32	2.74	0.70	2.85	0.67	
SPP-Social	32	2.79	0.75	2.94	0.65	
Mother report						
CBCL: Externalizing	35	48.7	10.5	50.1	9.8	
CBCL: Internalizing	35	54.8	11.0	50.1	9.8	
CBCL: Social Prob.	35	60.9	11.5	53.9	5.9	
CBCL: Activities	34	44.3	10.0	48.1	7.1	
CBCL: Scholastic	32	40.5	9.9	48.4	7.0	<.001
CBCL: Social Comp.	35	41.8	10.2	48.2	7.2	<.001
PSI: Interaction	35	23.6	7.5	18.7	4.8	<.001
PSI: Difficult child	35	30.6	10.6	26.0	6.7	
VABS: Com	30	91.0	17.2	100.0	14.8	<.01
VABS: Skills	30	95.4	18.6	100.5	14.7	
VABS: Social	30	93.4	14.8	100.2	14.5	
Teacher report						
CBCL: Externalizing	33	48.61	8.1	50.6	9.2	
CBCL: Internalizing	33	51.42	10.3	50.3	9.5	
CBCL: Social prob.	33	55.88	8.8	54.1	6.1	

<sup>a</sup>BDI = Beck Depression Inventory; CBCL = Child Behavior Checklist; CDI = Children's Depression Inventory; CMAS-R = Children's Manifest Anxiety Scale, Revised; SPP = Social Perception Profile; PSI = Parenting Stress Index; VABS = Vineland Adaptive Behavior Scale. Sources for test norms: BDI (Lightfoot & Oliver, 1985); CBCL & TRF (Achenbach, 1991); CDI (Finch et al., 1985); CMAS-R (Reynolds & Richmond, 1978); PSI (Abidin, 1990); SPP (Harter, 1985, 1988); STAI (Spielberger et al., 1973); Vineland (Sparrow et al., 1984). Test norms for the SPP were computed by summing the norms from Harter (1985, 1988), using the norms with the largest sample for each gender and grade level for each subject, and dividing by the number of subjects. For *t* tests, the median sample size of the various standardization samples reported by Harter (1985, 1988) used to compute means and standard deviations for the present study were used in the *t* test formula.

## DISCUSSION

The prevailing view that children who survive brain tumors have poorer psychosocial outcomes than children within the general population is challenged by these findings based on self, mother, and teacher report, 2 to 5 years after treatment. Our study is the first to examine this population using the recommended multiple-respondent, multiple-instrument methodology for quality of life (Mulhern et al., 1989). The data are consistent with studies of behavioral

adjustment and family outcome among other groups of chronically ill children, which generally find modest differences between chronically ill and normal children (e.g., Lavigne & Faier-Routman, 1992). Mothers of survivors of childhood brain tumors also rated themselves in a manner consistent with the instrument norms for anxiety and depression. These findings speak to the resilience and competence of brain tumor survivors and their families. There are, however, several facets of the data that warrant further consideration.

The child report data provide evidence that these children see themselves much like other children. They described themselves as significantly *less* anxious and depressed than normative peers. This has been a consistent finding in the pediatric cancer literature (Canning, Canning, & Boyce, 1992; Greenberg, Kazak, & Meadows, 1989). It remains unclear whether these findings are due to actually experiencing fewer depressive symptoms, denial of symptoms, or are otherwise related to the experience of survival. Global measures may not tap psychological phenomenon specific to cancer survival. It is therefore important to investigate more specific sequelae of cancer and its treatment (e.g., memories of treatment, beliefs about illness) to understand the ways that survivors think about their experiences and function in their daily lives.

Similar to the survivors themselves, the teacher report data indicate overall similarity to other students. Indeed, it is mothers who reported the most discrepant data in this study. Mothers perceived that their children had significantly more social and communication difficulties than normative peers and indicated that they were relatively difficult children to parent. Mothers typically have an in-depth and experienced perspective on these children. Their perceptions must certainly be taken very seriously. Data from other family members (e.g., fathers, siblings, grandparents) would be helpful to establish the extent to which these perceptions are consistent across the family system. Family members knew the child prior to their illness and therefore may consider different information from teachers, or the children themselves, when responding to questionnaires.

There may be sampling biases that could affect the data. Although the respondents and nonrespondents did not differ in terms of age, gender, and tumor type, there could be other factors influencing the responses of this sample. For example, families of those children more severely affected may not have chosen to participate because of the burden already experienced of caring for a child with disabilities. These families might also wish to avoid confronting the degree of difficulties experienced by themselves and their child. Conversely, the respondents might be those with the more difficult problems, choosing to use the study as an opportunity to make their difficulties known to the study personnel. Although this study found relatively few differences between this group of pediatric brain tumor survivors and normative groups, the differences that did emerge are consistent with general views held by clinicians: The children are less athletically competent, receive special education in larger



numbers, are more difficult to parent, and are viewed by parents as having social problems. Replication with larger samples is important to fully understand the implications of the data.

Although radiation therapy has been associated very closely with cognitive difficulties, it was not associated with poorer child or maternal adjustment. Nor was special education placement. The high percentage of students receiving special education services (41%) in our study is comparable to previous studies of children with brain tumors (Kun et al., 1983; LeBaron et al., 1988; Radcliffe et al., 1992). It is possible that these children received educational assessments and appropriate educational placements and that they are in fact in suitable educational settings that foster well-being, for child and family alike. Unlike earlier cohorts of childhood cancer survivors, potential learning difficulties are now better understood.

Although research on adjustment to childhood brain tumor survival is at a very early stage of development, future steps can be outlined. First, although we present data from 2 to 5 years after diagnosis as indicative of "survival," this period represents an early stage of survival. It will be informative to follow these cohorts of brain tumor survivors longer in order to determine the long-term psychological outcome, for them and their families. Second, prospective studies tracking children and families from diagnosis through treatment will be informative in terms of understanding the interactive impact of disease, treatment, individual, and family variables over time. In the present study, for example, children and mothers could have had greater adjustment problems during the first year postdiagnosis. Third, multiple respondents provide a richness of perspectives which can help shape future research in this field. That is, while discrepancies among child, parent, and teacher-report are not unusual and can certainly be complex, they are enlightening. Our data suggest, for example, that future investigation of criteria used by teachers and parents may help clarify why the teachers rated the children as better adjusted than did their mothers.

More broadly, the individual and familial coping mechanisms that allow many children to develop fairly normally following having a brain tumor are not well defined. The study of child and family responses to brain tumor remains important to continue, both to better understand successful adaptation as well as to determine areas that warrant intervention.

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