Journal of Pediatric Psychology, 48(2), 2023, 166–175
https://doi.org/10.1093/jpepsy/jsac077
Advance Access Publication Date: 3 October 2022
Original Research Article

Emotional Well-Being of Pediatric Brain Tumor Survivors and Comparison Peers: Perspectives From Children and Their Parents

Kara L. Brown,[1] MS, Diane Fairclough,[2] DrPH, Robert B. Noll,[3] PhD, Maru Barrera,[4] PhD, Mary Jo Kupst,[5] PhD, Maria A. Gartstein,[1] PhD, Anna M. Egan,[6,7] PhD, Carolyn R. Bates,[8] PhD, Cynthia A. Gerhardt,[9,10] PhD, and Kathryn Vannatta,[9,10] PhD

[1]Department of Psychology, Washington State University, USA, [2]Department of Biostatistics and Informatics, Colorado School of Public Health, USA, [3]Department of Pediatrics, University of Pittsburgh Medical Center, USA, [4]Psychology Department, The Hospital for Sick Children, USA, [5]Department of Pediatrics, Medical College of Wisconsin, USA, [6]Division of Developmental and Behavioral Sciences, Children's Mercy Kansas City, USA, [7]University of Missouri Kansas City School of Medicine, USA, [8]Department of Pediatrics, The University of Kansas Medical Center, USA, [9]Center for Biobehavioral Health, Nationwide Children's Hospital, USA, and [10]Department of Pediatrics, The Ohio State University, USA

All correspondence concerning this article should be addressed to Kara L. Brown, MS, Department of Psychology, Washington State University, PO Box 644820, Johnson Town 233, Pullman, WA 99164-4820, USA. E-mail: kara.brown@wsu.edu

Received February 3, 2022; revisions received August 13, 2022; accepted September 18, 2022

Abstract

Objective The aim of this study was to examine the emotional well-being of pediatric brain tumor survivors (PBTS) from the perspective of children's self-reports and parents' reports relative to matched comparison peers (COMP) and their parents. It was hypothesized that PBTS would self-report more depression symptoms, loneliness, and lower self-concept than COMP. We also hypothesized that mothers and fathers of PBTS would report more internalizing symptoms and lower total competence for their children. Age and sex effects were examined in exploratory analyses. **Methods** Families of 187 PBTS and 186 COMP participated across 5 sites. Eligible children in the PBTS group were 8–15 years of age and 1–5 years post-treatment for a primary intracranial tumor without progressive disease. COMP were classmates matched for sex, race, and age. **Results** PBTS self-reported lower scholastic, athletic, and social competence, but not more depression, loneliness, or lower global self-worth than COMP. Parents of PBTS reported more internalizing symptoms and lower total competence than parents of COMP. With few exceptions, group differences did not vary as a function of child age and sex. **Conclusion** PBTS reported diminished self-concept in scholastic, athletic, and social domains, while their parents reported broader challenges with internalizing symptoms and total competence. Discrepancies between self-report and parent report require further study to inform targeted interventions for PBTS. Screening survivors for emotional challenges in follow-up clinic or in school setting may help with the allocation of psychosocial support and services for PBTS and their families.

Key words: brain tumors; oncology; pediatric; psychosocial.

Introduction

Brain tumors account for 26% of childhood cancer diagnoses, making them the second most common childhood cancer following acute lymphoblastic leukemia (American Cancer Society, 2019). With advances in treatment, three out of four children diagnosed with a malignant brain tumor (all types combined) now survive 5 or more years after their diagnosis (American Cancer Society, 2020). While mounting evidence has consistently shown that pediatric brain tumor survivors (PBTS) experience difficulties with peer relationships (Hocking et al., 2015), internalizing problems have been less consistently documented, and may reflect variations in reporting sources utilized, varying attention given to subtypes of internalizing symptoms (i.e., symptoms of depression, loneliness, and low self-concept), and reliance on comparison to instrument norms or control samples of varying quality or rigor (Fuemmeler et al., 2002). Elevated symptoms of depression relative to instrument norms have been reported for PBTS following treatment in multiple (e.g., Desjardins, Barrera, Schulte et al., 2019) but not by all studies (Radcliffe et al., 1996). Given well-documented difficulties with peers (Barrera et al., 2005; Desjardins, Barrera, Chung et al. 2019; Salley et al., 2015), it is surprising that published research has not evaluated whether PBTS self-report more loneliness. Loneliness has been studied in children with other chronic conditions (Maes et al., 2017) although not all studies find evidence of increases in these feelings (Noll et al., 1996; 2000). In typically developing children and adolescents, loneliness was associated with mental health concerns up to 9 years later, with greater duration of loneliness contributing to more adverse outcomes (Asher & Paquette, 2003; Loades et al., 2020). Further examination of loneliness in PBTS is needed to better understand the impact of documented survivor's peer difficulties in school (Barrera et al., 2005; Hocking et al., 2020; Salley et al., 2014).

Self-concept is a multi-faceted construct that includes self-judgement of competency in key domains (scholastic, social, athletic, physical, and behavioral) as well as a separate, yet coexisting, assessment of global self-worth (Harter 1985). Self-concept, along with self-esteem, have been linked with the development of internalizing and externalizing disorders (Houck et al., 2011; Jaureguizar, 2018; Sukumaran et al., 2003) in typically developing children. Problems in in areas of psychosocial adjustment noted for PBTS, particularly peer relationships and neurocognitive deficits (Schulte and Barrera, 2010; Stavinoha et al., 2018), have the potential to compromise self-concept, as well as related aspects of emotional well-being, namely internalizing symptoms and loneliness. However, research into this critical domain of psychosocial functioning in PBTS has been scarce to date, with current findings pointing to specific difficulties for PBTS in scholastic and athletic competence, compared to instrument normative data (de Ruiter et al., 2016). Given the notable importance of self-concept to psychosocial functioning and development, a better understanding of late effects for PBTS is needed. Consideration of self-concept alongside other psychosocial outcomes (e.g., internalizing symptoms, loneliness), incorporating perspectives of different informants also represent important contributions to the existing literature. Moreover, considering these late effects via a matched comparison peers (COMP) design provides a more rigorous examination of the impact of brain tumors and their treatment on well-being and psychosocial adjustment.

Parents of PBTS consistently indicated concerns with internalizing symptoms (e.g., Bonner et al., 2008; Emond et al., 2016; Radcliffe et al., 1996), but parents' perceptions of externalizing problems in this population have been mixed (see Sharkey et al., 2020 for a review). Externalizing problems have not been well-described for PBTS. Early studies (e.g., Bamford et al., 1976; Danoff et al., 1982) noted difficulties with aggression and antisocial behaviors, yet this pattern of results has not been consistently replicated (Fuemmeler et al., 2002).

Regarding both child self-reports and parent-proxy reports, the quality of normative data varies widely and often leads to comparisons with children from a different ecological niche (i.e., geographic region, and time period). Siblings differ in age and are subject to similar family/parenting influences, known to impact behavior problems and psychosocial adjustment more broadly. The present study addresses these limitations by including matched COMP, recruited from the classroom of PBTS. and matched one-to-one on sex, race, and closest date of birth. While other studies have utilized matched comparison groups based on age (e.g., Phipps et al., 2014), this work utilizes peers from the same classrooms and communities, which helps to mitigate cohort effects that can differ with external societal events. This work also addresses important gaps in research by including father's perspective and examining loneliness and self-concept in a multisite sample. Gender and age are consequential to psychosocial well-being, as related differences have been reported for a variety of psychosocial outcomes (e.g., greater peer difficulties for girls; Salley et al., 2014; greater difficulties for children diagnosed and treated at a younger age, Reimers et al., 2009).

The primary aim of this study was to compare the emotional well-being of PBTS and COMPS using parent report and child self-report to gain a more comprehensive understanding of illness and treatment related impacts across a range of outcomes, including internalizing and externalizing problems, multiple dimensions of self-concept, and loneliness. It was hypothesized that PBTS would self-report more symptoms of depression and loneliness, as well as lower self-concept across multiple domains. We also hypothesized that mothers and fathers would report more concerns about internalizing problems (i.e., depression, anxiety, social withdrawal) and lower child competence relative to COMP. Finally, group differences between PBTS and COMP as a function of child age and sex were considered, given their importance in psychological adjustment.

Methods

General Overview

This study was approved by the IRB at each of the five collaborating sites. Data collection was conducted in two phases, with each requiring a separate informed consent. Phase 1 was a classroom assessment of peer relationships (Salley et al., 2014), followed by Phase 2 which involved home visits with PBTS, COMP, and their caregivers (Ach et al., 2013).

Participants and Procedures

PBTS were identified from cancer registries and eligible for inclusion if they were between the ages of 8 and 15 years, had a history of treatment for a primary intracranial tumor, and were 1–5 years post-treatment without disease progression. PBTS were excluded if they or both of their parents were not fluent in English, had a pre-existing neurobehavioral disorder (e.g., neurofibromatosis or tuberous sclerosis), or received full-time special education. The age range of 8–15 years for selected because of theoretical, empirical, and practical considerations. First, constructs evaluated herein have been conceptualized as critical during this developmental period encompassing childhood and adolescence, with important transitions taking place, for example with respect to self-concept (Harter, 1985). Second, problems for PBTS during this period have been previously documented, identifying this as a developmental window of interest. Finally, there are a number of important practical considerations, such as these children are in school (2nd to 10th grades), making our control peer matching feasible. Importantly, at around age 8 years, children can reliably self-report mood and self-concept (e.g., Harter, 2012; Riley, 2004; Smucker et al., 1986).

Data were first collected in classrooms following permission from parents of PBTS to contact their child's school (see Salley et al, 2014 for Phase 1 details). Classmates of each PBTS were eligible to participate with written parental consent, and one was recruited for the matched COMP group based on similarity to the sex, race, and age of the PBTS. Parents of PBTS and COMP were contacted and invited to participate in a home-based assessment for Phase 2, including the data reported in this paper. If the first-choice comparison family declined, the family of the next most closely matched classmate was contacted. COMP were excluded if they had been treated by a pediatric sub-specialist in the past 6 months.

Measures

Demographic Characteristics

Caregivers reported socio-demographic characteristics of their family, including occupation and highest level of education completed. Occupations were numerically rated based on the Revised Duncan Scale scores of occupational prestige (Entwisle & Astone, 1994). Race and ethnicity were self-reported by caregivers using U.S. Census categories. Age at diagnosis and dates of treatment were extracted from the medical record.

Child Depression Inventory

The Child Depression Inventory (CDI), a 27-item scale that is a widely used self-report measure of depression (past 2 weeks) for children and adolescents, aged 7-17 years old (Kovacs, 1992). The CDI addresses cognitive, affective, and behavioral signs of depression. Each item consists of three statements varying in severity (i.e., "I feel like crying … every day, many days, once in a while") with scores of 0–2 assigned, with 2 designating the highest severity statement. Extensive data support reliability of the CDI for typically developing children ($\alpha = 0.76$–0.88) and children with chronic illness ($\alpha = 0.85$; Smucker et al., 1986; Saoji et al., 2019). Cronbach's α for the current sample was 0.84.

Self-Perception Profile for Children

The Self-Perception Profile for Children (SPPC) is a 36-item measure assessing the child's self-perception in six domains: Global self-worth, Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, and Behavioral Conduct (Harter, 1985). Each item is scored from 1 to 4, where 1 represents low self-concept and 4 represents high self-concept. Cronbach's α for the current sample ranged from 0.77 to 0.83 (mean $\alpha = 0.81$).

Loneliness and Social Dissatisfaction Questionnaire

The Loneliness and Social Dissatisfaction Questionnaire (LSDQ) is a 24-item self-report measure of a child's loneliness. Each item is rated on a 5-point Likert-like scale based on how much the statement reflects the child's experience (i.e. "Do you have friends at school?"), and these ratings are summed to produce a total score (Asher et al., 1984). Cronbach's α for the current sample was 0.88.

The Child Behavior Checklist

This widely used parent-report questionnaire addresses a range of behavior problems and competence for youth ages 6–18 years (Achenbach, 2009; Achenbach & Rescorla, 2000). The Child Behavior Checklist (CBCL) contains 113 behavior problem items, which rely on a 3-point scale (0—not true; 1—somewhat/sometimes true; 2—very/often true) producing broadband factors for internalizing, externalizing, and total problems, as well as total competence, in turn made up of subscales (Tables III and IV). Analyses were conducted with raw scores, although *T*-scores referencing gender norms are included for descriptive purposes, as recommended (Achenbach, 2009). Broad-band scores were considered "elevated" above a *T*-score of 60 (84th percentile). Reliability and validity of the CBCL has been established, with adequate criterion-related validity, inter-rater (r ranging from 0.57 to 0.88), and test–retest reliability (r = 0.80 s and 0.90 s), as well as internal consistency (α = 0.63–0.97; Achenbach & Rescorla, 2000).

Analysis Plan

Descriptive statistics (e.g., *M*, *SD*, frequencies) were conducted for demographic factors and primary variables of interest. Given that children within the same classroom were matched on age, gender, and race and likely to be of similar socioeconomic status (SES), PBTS were compared to COMP using a repeated measures mixed model (SAS Proc Mixed) with an unstructured (for parent data) covariance matrix. Even though the design implemented in this study is not longitudinal per se, a repeated measures mixed model (SAS Proc Mixed) approach with an unstructured covariance matrix is nonetheless appropriate. That is, repeated measures methods are not limited to longitudinal designs, and it can include multiple members of a family or matched pairs, and the unstructured covariance matrix was applicable, requiring fewer assumptions. Multiple comparison adjustments were made using the Holm's step-down procedure (SAS Proc MultTest) for the pre-specified primary outcomes. The CDI, LSDQ, and SPPC six subscales were considered primary child-report outcomes. Three broadband factors (internalizing, externalizing, total problems, and total competence) were designated as primary outcomes. To reduce the number of comparisons, narrowband scores on the CBCL were only interpreted when significant differences were detected on broadband factors between PBTS and COMP. Moderation of group differences in primary outcomes by child age and sex were also explored via testing the significance of differences between PBTS and COMP separately for boys and girls, as well as younger and older children based on a median split. While age could be considered a continuous variable for statistical purposes, the median split was used to keep the statistical approach similar for age and gender with respect to the exploratory analyses.

Results

Demographic Information

Of the 187 participating PBTS, average age was 11.29 years (*SD* = 2.32). Average age at brain tumor diagnosis was 7.39 years (*SD* = 3.06); average age at last treatment was 8.26 years (*SD* = 2.72); and the average time since diagnosis at recruitment was 3.78 years (*SD* = 1.97). Family demographic variables reported by caregivers were not significantly different between PBTS and COMP, except for child ethnicity (Table I).

Child-Reported Outcomes

PBTS did not self-report more depression, loneliness, or lower Global Self-Worth than COMP (Table II). Notably, 10.71% of PBTS and 6.86% of COMP self-reported scores above the clinical cutoff (>15) on the CDI. PBTS reported significantly lower scholastic competence, social acceptance, or athletic competence than COMP on the SPPC, but no significant differences for physical appearance or behavioral conduct (Table II).

Parent-Reported Outcomes (CBCL)

Internalizing Problems

Mothers and fathers reported more internalizing problems for PBTS than for COMP consistently across all subscales although for both groups averages fell below the elevated range (Tables III and IV). For internalizing problems, 26.9% of fathers and 34.4% of mothers of PBTS and 12% of fathers and 16.9% of mothers of COMP reported elevated scores (≥60).

Externalizing Problems

Externalizing problems did not differ significantly for PBTS and COMP (Tables III and IV). However, 14.3% of fathers and 20.6% of mothers of PBTS and 9% of fathers and 14.1% of mothers of COMP reported elevated scores.

Total Problems

Mothers and fathers reported significantly higher total problems for PBTS than for COMP. Analyses of subscales not incorporated in internalizing or externalizing broadband scores (thought, attention, and social problems) demonstrated significant differences between PBTS and COMP. Mothers and fathers reported more concerning thought patterns, attention difficulties, and social problems for PBTS than COMP (Tables III and IV). For total problems, 21.0% of fathers and 28.9% of mothers of PBTS reported total

Table I. *Demographic Characteristics of Pediatric Brain Tumor Survivors (PBTS), Classroom Comparison Peers (COMP), Caregivers of PBTS, and Caregivers of COMP*

Characteristic	PBTS caregivers ($N = 301$)	COMP caregivers ($N = 286$)	p-Value
Father age[a]	41.78 ± 6.36	42.84 ± 6.52	.19
Mother age	40.33 ± 6.24	41.04 ± 6.08	.30
Father education	14.29 ± 2.64	14.58 ± 2.57	.35
Mother education	14.26 ± 2.17	14.63 ± 2.23	.11
Father occupation[b]	53.58 ± 20.57	55.81 ± 20.40	.35
Mother occupation[b]	40.41 ± 22.23	43.66 ± 23.62	.17
% Married/partnered	86	89	.10
Child race			.21
% White	89	91	
% Black	4	6	
% Asian	2	2	
% other race	5	0	
Child Ethnicity			.01*
% Non-Hispanic	95	98	
% Hispanic	5	2	
Number of children living at home	2.44 ± 1.01	2.49 ± 1.04	.52
Age of target child	11.29 ± 2.32	11.26 ± 2.29	.90

Note. Plus or minus values are mean ± standard deviation.

[a] The number of fathers in the sample ($n = 101–119$) is lower than the number of mothers ($n = 182–185$) because many of the families were single parent households.

[b] Revised Duncan scores of occupational prestige. (This measure is an occupation-based measure of SES. Higher scores represent higher occupational attainment. Mean father scores were indicative of administrative support positions; mean mother scores were indicative of tradespersons.)

Table II. *Comparison of Symptoms of Depression, Loneliness, and Self-Concept for Pediatric Brain Tumor Survivors (PBTS) and Comparison Peers (COMP)*

Outcome	PBTS ($N = 187$) Estimate ± *SE*	COMP ($N = 186$) Estimate ± *SE*	Raw p	Holmes'	ES
Child Depression Inventory					
Total score	6.99 ± 0.43	6.40 ± 0.41	.30	.60	0.10
Self-perception profile					
Global self-worth	3.36 ± 0.04	3.46 ± 0.04	.05	.24	−0.18
Social acceptance	2.94 ± 0.05	3.15 ± 0.05	<.01*	.02	−0.29
Scholastic competence	2.73 ± 0.43	3.00 ± 0.05	<.01*	<.01	−0.38
Athletic competence	2.67 ± 0.06	3.02 ± 0.05	<.01*	<.01	−0.48
Physical appearance	3.08 ± 0.05	3.18 ± 0.05	.13	.39	−0.14
Behavioral conduct	3.17 ± 0.05	3.15 ± 0.05	.74	.74	0.03
Loneliness and social dissatisfaction					
Total score	30.58 ± 0.83	28.86 ± 0.67	.10	.39	0.17

Note. ES = effect size; Raw p = p-value for single test; Holmes' = adjusted p-value for multiple comparisons.

problems scores above the elevated range, while 12.0% of fathers and 15.8% of mothers of COMP reported scores above the elevated range. Again, it should be noted that averages of both groups across these broadband scores were below the elevated range cutoff.

Total Competence

Both mothers and fathers reported significantly lower levels of total competence for PBTS relative to COMP (Tables III and IV). Mothers and fathers reported significantly less involvement in Activities (i.e., sports, organizations, hobbies), lower social competence (i.e., social interaction, close friendships), and lower school competence (i.e., academic performance) for PBTS compared to COMP.

Exploratory Analyses: Age and Sex

Self-Reports

Younger, but not older, PBTS reported significantly lower scores for scholastic competence relative to COMP (age-based difference estimate = 0.25 $SE = 0.10$, $p = .02$). Female, but not male, PBTS reported lower social acceptance, relative to COMP (sex-based difference estimate = −0.29, $SE = 0.11$, $p < .01$). For athletic competence, PBTS reported

Table III. *Mother Report of Child Adjustment for Pediatric Brain Tumor Survivors (PBTS) and Comparison Peers (COMP)*

Outcome	PBTS Estimate ± *SD*	COMP Estimate ± *SD*	Raw *p*	Holmes'	ES
Total problems	53.4 ± 10.3	48.9 ± 10.5	<.01*	<.01	0.37
Internalizing problems	55.4 ± 10.6	50.2 ± 10.1	<.01*	<.01	0.45
Anxious/depressed	56.3 ± 7.6	54.3 ± 6.1	<.01*	.02	0.30
Withdrawn	57.3 ± 8.3	54.5 ± 5.7	<.01*	<.01	0.37
Somatic complaints	59.5 ± 8.7	54.9 ± 6.3	<.01*	<.01	0.57
Externalizing problems	50.3 ± 10.5	49.0 ± 10.0	0.33	0.33	0.10
Rule-breaking behavior	53.4 ± 5.3	53.5 ± 5.4	.54	1.00	−0.07
Aggressive behavior	54.4 ± 6.9	53.7 ± 6.3	.33	1.00	0.10
Other clinical scales					
Social problems	57.4 ± 8.1	54.1 ± 6.0	<.01*	<.01	0.48
Thought problems	55.9 ± 6.6	54.1 ± 5.4	.01*	.02	0.28
Attention problems	56.5 ± 7.9	54.9 ± 7.0	.02*	.02	0.24
Total competence	42.8 ± 10.7	49.8 ± 10.1	<.01*	<.01	−0.64
Activities	45.0 ± 9.6	49.4 ± 9.4	<.01*	<.01	−0.43
Social	47.0 ± 9.8	50.4 ± 9.1	<.01*	<.01	−0.25
School	41.2 ± 10.1	48.2 ± 8.1	<.01*	<.01	−0.73

Note. ES = effect size; Raw *p* = *p*-value for single test; Holmes' = adjusted *p*-value for multiple comparisons.

Table IV. *Father Report of Child Adjustment for Pediatric Brain Tumor Survivors (PBTS) and Comparison Peers (COMP)*

Outcome	PBTS Estimate ± *SD*	COMP Estimate ± *SD*	Raw *p*	Holmes'	ES
Total problems	50.7 ± 10.7	45.0 ± 10.3	<.01*	<.01	0.55
Internalizing problems	52.5 ± 10.0	46.2 ± 9.3	<.01*	<.01	0.59
Anxious/depressed	54.2 ± 5.5	52.2 ± 4.2	<.01*	<.01	0.53
Withdrawn	56.7 ± 7.1	53.0 ± 4.5	<.01*	<.01	0.55
Somatic complaints	55.8 ± 6.8	53.2 ± 5.4	<.01*	<.01	0.41
Externalizing problems	48.0 ± 9.9	44.9 ± 10.1	0.08	0.17	0.22
Rule-breaking behavior	53.0 ± 5.0	52.7 ± 4.6	.58	1.00	0.07
Aggressive behavior	53.3 ± 5.8	52.3 ± 4.4	.17	0.66	0.18
Other clinical scales					
Social problems	56.5 ± 7.0	52.2 ± 4.3	<.01*	<.01	0.75
Thought problems	54.9 ± 6.2	52.9 ± 4.1	<.01*	<.01	0.42
Attention problems	56.2 ± 7.1	53.5 ± 4.8	<.01*	<.01	0.47
Total competence	42.4 ± 11.4	51.0 ± 10.1	<.01*	<.01	−0.87
Activities	42.1 ± 10.0	48.2 ± 9.9	<.01*	<.01	−0.68
Social	47.9 ± 9.7	51.9 ± 8.9	<.01*	<.01	−0.34
School	43.6 ± 9.6	49.6 ± 7.0	<.01*	<.01	−0.85

Note. ES = effect size relative to sex-specific *SD* (standard deviation); Raw *p* = *p*-value for single test; Holmes' = adjusted *p*-value for multiple comparisons.

significantly greater difficulties than COMP overall (difference estimate = −0.33 *SE* = 0.11, $p < .01$), with a stronger effect for girls. Age and sex were not significant moderators for self-reports of depression or loneliness.

Parent Reports

Age, but not sex, differences were noted by father report, with significantly greater total problems on the CBCL for younger than for older PBTS relative to COMP (difference estimate = −8.99, *SE* = 4.15, $p = .03$). Sex, but not age, differences were noted by mother reports, with significantly greater internalizing problems for female than male PBTS relative to COMP (difference estimate = 3.63, *SE* = 1.40, $p = .01$), and a stronger effect for total competence (although this difference with COMP was significant for boys as well; difference estimate = −2.09, *SE* = 0.96, $p = .03$).

Discussion

This research examined the emotional well-being of PBTS compared to matched COMPs. PBTS did not report more symptoms of depression, loneliness, or lower global self-worth than COMPs, while indicating lower levels of scholastic, social, and athletic self-concept relative to COMP. Caregivers reported significantly more internalizing problems and lower competence for PBTS relative to COMP. The observed pattern of results indicated consistency between child self-report and caregivers' report of competence, but internalizing symptoms and loneliness findings reflect the need to improve our understanding of discrepancies between child and parent perceptions. In addition, it appears that younger and female PBTS may face some greater challenges. Child age and sex-specific findings, while exploratory and not uniform, point to potentially important moderation effects that are consistent with the existing literature (Barrera et al., 2008; Carpentieri et al., 1993; Salley et al., 2014; Winning et al., 2021).

PBTS did not self-report more symptoms of depression, loneliness, or lower global self-worth, but they did report diminished self-concept in specific competence domains, including lower social, scholastic, and athletic competence. These findings suggest that PBTS are aware of some of their challenges, supported by caregivers' reports of lower total competence on the CBCL. Notably, over 20% of fathers and over 25% of mothers of PBTS reported total problems scores above the elevated range cutoff—well above the number of fathers and mothers of COMP. Brain tumor treatment has demonstrable negative effects on athletic and scholastic performance, as well as social functioning (Ullrich & Embry, 2012). Both PBTS and their caregivers were attuned to these difficulties. Lower self-reported social competence in this study is consistent with Hardy et al.'s (2010) findings for PBTS after completion of therapy, and other previously noted social difficulties (Hocking et al., 2015). Peer perceptions of social difficulties for PBTS have been examined, with notable incongruities between PBTS self- and peer-reported peer acceptance (e.g., peer-, but not PBTS report indicated lower peer acceptance; Salley et al., 2015).

Although PBTS did not self-report more symptoms of depression, loneliness, or lower levels of global self-worth than COMPs, both mothers and fathers reported significantly more internalizing symptoms. Although average parent-report scores for internalizing symptoms in PBTS fell below the clinical cutoff, a higher proportion of parents reported elevated internalizing symptoms relative to instrument norms for PBTS than COMP. There is significant literature noting the lack of agreement between parents and children regarding child emotional difficulties (e.g., De Los Reyes & Kazdin, 2005), and this study provides another illustration of this discrepancy. However, our findings stand alone in addressing long-term adjustment of PBTS and observing greater parental concerns regarding internalizing difficulties in this context (compared to COMP). Thus, further study of survivor and parent-report discrepancies in perceptions of child emotional adjustment is needed. Illness and treatment parameters (e.g., cognitive effects of brain tumors/treatment; Stavinoha et al., 2018) could be considered as contributors to divergence between child and parent results. It would also be informative to examine factors shown to increase divergence in the developmental literature (e.g., parental depression, contributing to "over-report" of child difficulties; Gartstein et al., 2009). Parents of PBTS, deeply impacted by their child's illness, possibly over-report internalizing difficulties compared to those with no history of severe child disease (Upton et al., 2008). Alternatively, child under-reporting, possibly due to unwillingness to acknowledge some social-emotional challenges (e.g., loneliness, depression) or limited awareness could play a role.

PBTS self-report challenges for themselves in academics, social, and athletics, but do not report difficulties with loneliness, global self-worth, or depression. Simultaneously caregivers present with lingering concerns, particularly in the internalizing domain, that may speak to their continuing hypervigilance with respect to their child's wellbeing (Schmitz, 2019). It could be that PBTS do not endorse greater internalizing difficulties because of protection afforded by their developmental stage and cognitive profile. This response has been described as "hardiness", possibly limiting the adverse effects that PBTS experience (Noll & Kupst, 2007). Whereas parents' concerns do not remit when the treatment ends, children do not appear to dwell on this experience. From the standpoint of the Process Model of Coping (Lazarus & Folkman, 1984), results observed in this study suggest potential adaptive appraisal and coping by children.

In summary, PBTS self-reported diminished competence in domains known to be adversely affected by brain tumors and/or their treatment (Ullrich & Embry, 2012); they reported difficulties in social acceptance, academics, and athletic activities. Caregiver reports of lowered Total Competence for PBTS parallel PBTS' perceptions. Notably, self-reports of PBTS for depression, loneliness, and global self-worth did not suggest impairment relative to COMP, whereas caregivers reported difficulties in related areas (i.e., overall internalizing problems and their subsets). This pattern of results suggests resiliency of PBTS with respect to self-reported internalizing difficulties, despite documented impacts of the illness and treatment, and is important to recognize.

Although this study addresses important gaps in the literature, it is not without limitations. First, racial, ethnic, and cultural homogeneity, as well as the sole inclusion of English-speaking families in this study, limits the generalizability of our findings. This limitation, which is common in psychosocial oncology research, is likely a reflection of racial and ethnic disparities in healthcare, which require greater attention in their own right. In addition, this study utilized an "other" category to obtain self-reported race/ethnicity, which is not optimal, conveying minimal information (i.e., the participant did not self-identify as White, Black, or Asian), and a more extensive array of specific options should be provided in the future. It is important to note that we examined report of mothers and fathers, and conducted exploratory analyses comparing boys and girls, which reflects a binary operationalization of gender, also limiting generalizability. These definitions need to be expanded going forward to capture all individuals (e.g., same-sex parents) and to be inclusive with respect to child gender identity. The median split approach to age-related analyses warrants mention as well, given that it may limit the ability to identify moderation by reducing variance, and could be responsible for a more circumscribed set of significant age effects identified herein.

Future work would also benefit from a focus on medical treatment variables (radiation, surgery, chemotherapy; see Vannatta et al., 2007) and/or medical late effects (i.e., vision, hearing, motor, endocrine, speech, seizures; Turner et al., 2009) to further clarify possible links between diagnosis and treatments and psychosocial outcomes. It should also be noted that scoring above the 'normal' range for emotional/behavioral problems does not directly translate to a clinical diagnosis. Although there is some evidence that semi-structured interviews do not result in differential rates of DSM-based diagnoses for children with cancer and COMP (D'Souza et al., 2019), future directions for psychosocial work with PBTS could include interview-based techniques and prevention measures. Despite these limitations, this is the first study to examine several psychosocial late effects for PBTS compared to carefully matched COMP utilizing both self-report and parent report.

Clinical implications of this work highlight several domains of impaired psychosocial functioning, chief among these being social, athletic, and scholastic competence—areas of agreement between PBTS and parents. Given that PBTS and parents report social challenges, these could be the foundation for developing psychosocial interventions with attention focused on helping PBTS to fit into their social networks and develop a sense of greater competence in this domain (see Willard, 2018 for a review). A traditional approach to enhancing social competence involves instruction in social skills (Barrera et al, 2018; Schulte et al., 2014), despite little evidence of improvement in social status with peers at school. If the goal is to improve a child's social standing in the classroom, an alternative strategy might be peer-mediated training (Devine et al., 2016; Kasari et al., 2012). Interventions could also focus on remediation for scholastic and athletic difficulties, as well as setting appropriate expectations for performance in these domains.

Parents of PBTS reported elevated symptoms of depression, anxiety, social withdrawal, and somatic function compared to parents of COMP. The present findings suggest a need to monitor internalizing symptoms for PBTS (Marchak et al., 2022), potentially providing treatment and possibly intervening with parents, who clearly present with lingering concerns regarding PBTS and may benefit from their own supportive services.

Funding

American Cancer Society, Award Number: RSGPB-03-098-01-PBP; National Cancer Institute, Award Number: RO3 CA097740.

Conflicts of interest: None declared.

References

Ach, E., Gerhardt, C. A., Barrera, M., Kupst, M. J., Meyer, E. A., Patenaude, A. F., & Vannatta, K. (2013). Family factors associated with academic achievement deficits in pediatric brain tumor survivors. *Psychooncology*, *22*(8), 1731–1737. Aug

Achenbach, T. M. (2009). *The Achenbach System of Empirically Based Assessment (ASEBA): Development, findings, theory, and applications*. University of Vermont Research Center for Children, Youth, & Families.

Achenbach, T. M., & Rescorla, L. A. (2000). *Manual for the ASEBA preschool forms & profiles*. University of Vermont, Research Center for Children, Youth, & Families.

American Cancer Society. (2019, October 14). *Types of cancer that develop in children*. Cancer.org. https://www.cancer.org/cancer/cancer-in-children/types-of-childhood-cancers.html Retrieved 26 September 2020.

American Cancer Society. (2020, August 24). *Key statistics for childhood cancers*. Cancer.org. https://www.cancer.org/cancer/cancer-in-children/key-statistics.html Retrieved 26 September 2022.

Asher, S. R., Hymel, S., & Renshaw, P. D. (1984). Loneliness in children. *Child Development*, *55*(4), 1456–1464.

Asher, S. R., & Paquette, J. A. (2003). Loneliness and peer relations in childhood. *Current Directions in Psychological Science*, *12*(3), 75–78.

Bamford, F. N., Jones, P. M., Pearson, D., Ribeiro, G. G., Shalet, S. M., & Beardwell, C. G. (1976). Residual disabilities in children treated for intracranial space-occupying lesions. *Cancer*, *37*(S2), 1149–1151. https://doi.org/10.1002/1097-0142(197602)37:2+3.0.CO;2-C

Barrera, M., Atenafu, E. G., Sung, L., Bartels, U., Schulte, F., Chung, J., Cataudella, D., Hancock, K., Janzen, L., Saleh, A., Strother, D., Downie, A., Zelcer, S., Hukin, J., & McConnell, D. (2018). A randomized control intervention trial to improve social skills and quality of life in pediatric brain tumor survivors. *Psycho-oncology*, *27*(1), 91–98.

Barrera, M., Schulte, F., & Spiegler, B. (2008). Factors influencing depressive symptoms of children treated for a brain tumor. *Journal of Psychosocial Oncology*, *26*(1), 1–16.

Barrera, M., Shaw, A. K., Speechley, K. N., Maunsell, E., & Pogany, L. (2005). Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer*, *104*(8), 1751–1760. https://doi.org/10.1002/cncr.21390

Bonner, M. J., Hardy, K. K., Willard, V. W., Anthony, K. K., Hood, M., & Gururangan, S. (2008). Social functioning and facial expression recognition in survivors of pediatric brain tumors. *Journal of Pediatric Psychology*, *33*(10), 1142–1152.

Carpentieri, S. C., Mulhern, R. K., Douglas, S., Hanna, S., & Fairclough, D. L. (1993). Behavioral resiliency among children surviving brain tumors: A longitudinal study. *Journal of Clinical Child Psychology*, *22*(2), 236–246. https://doi.org/10.1207/s15374424jccp2202_10

D'Souza, A. M., Devine, K. A., Reiter-Purtill, J., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2019). Internalizing symptoms in AYA. *Psycho-oncology*, *28*(10), 2009–2016. https://doi.org/10.1002/pon.5183

Danoff, B. F., Cowchock, F. S., Marquette, C., Mulgrew, L., & Kramer, S. (1982). Assessment of the long-term effects of primary radiation. Therapy for brain tumors in children. *Cancer*, *49*(8), 1580–1586. https://doi.org/10.1002/1097-0142(19820415)49:83.0.CO;2-7

De Los Reyes, A., & Kazdin, A. E. (2005). Informant discrepancies in the assessment of childhood psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin*, *131*(4), 483–509. http://ntserver1.wsulibs.wsu.edu:2099/10.1037/0033-2909.131.4.483

de Ruiter, M. A., Schouten-van Meeteren, A., van Vuurden, D. G., Maurice-Stam, H., Gidding, C., Beek, L. R., Granzen, B., Oosterlaan, J., & Grootenhuis, M. A. (2016). Psychosocial profile of pediatric brain tumor survivors with neurocognitive complaints. *Quality of Life Research*, *25*(2), 435–446. https://doi.org/10.1007/s11136-015-1091-7

Desjardins, L., Barrera, M., Chung, J., Cataudella, D., Janzen, L., Bartels, U., Downie, A., & Fairclough, D. (2019). Are we friends? Best friend nominations in pediatric brain tumor survivors and associated factors. *Supportive Care in Cancer*, *27*(11), 4237–4244. https://doi.org/10.1007/s00520-019-04706-3

Desjardins, L., Barrera, M., Schulte, F., Chung, J., Cataudella, D., Janzen, L., Bartels, U., & Downie, A. (2019). Predicting social withdrawal, anxiety, and depression symptoms in pediatric brain tumor survivors. *Journal of Psychosocial Oncology*, *37*(1), 22–36.

Devine, K. A., Bukowski, W. M., Sahler, O. J. Z., Ohman-Strickland, P., Smith, T. H., Lown, E. A., Patenaude, A. F., Korones, D. N., & Noll, R. B. (2016). Feasibility and preliminary outcomes of a peer-mediated intervention to improve social competence of childhood brain tumor survivors. *Journal of Developmental and Behavioral Pediatrics*, *37*(6), 475–482.

Emond, A., Edwards, L., Peacock, S., Norman, C., & Evangeli, M. (2016). Social competence in children and young people treated for a brain tumour. *Supportive Care in Cancer*, *24*(11), 4587–4595.

Entwisle, D., & Astone, N. (1994). Some practical guidelines for measuring youth's race/ethnicity and socioeconomic status. *Child Development*, *65*(6), 1521–1540.

Fuemmeler, B. F., Elkin, T. D., & Mullins, L. L. (2002). Survivors of childhood brain tumors: Behavioral, emotional, and social adjustment. *Clinical Psychology Review*, *22*(4), 547–585.

Gartstein, M. A., Bridgett, D. J., Dishion, T. J., & Kaufman, N. K. (2009). Depressed mood and parental report of child behavior problems: Another look at the Depression-Distortion Hypothesis. *Journal of Applied Developmental Psychology*, *30*(2), 149–160.

Hardy, K. W., Willard, V. W., Watral, M. A., & Bonner, M. J. (2010). Perceived social competency in children with brain tumors: Comparison between children on and off therapy. *Journal of Pediatric Oncology Nursing*, *27*(3), 156–163.

Harter, S. (2012). *Self-perception profile for children: Manual and questionnaires- Revised* [Unpublished manual]. University of Denver.

Harter, S. (1985). *The self-perception profile for children* [Unpublished manual]. University of Denver.

Hocking, M. C., Parish-Morris, J., Schultz, R. T., Minturn, J. E., Brodsky, C., Shabason, E. K., & Herrington, J. D. (2020). Diminished social attention in pediatric brain tumor survivors: Using eye tracking technology during naturalistic social perception. *Neuropsychology*, *34*(3), 350–358. https://doi.org/10.1037/neu0000623

Hocking, M. C., McCurdy, M., Turner, E., Kazak, A. E., Noll, R. B., Phillips, P., & Barakat, L. P. (2015). Social competence in pediatric brain tumor survivors: Application of a model from social neuroscience and developmental psychology. *Pediatric Blood & Cancer*, *62*(3), 375–384. https://doi.org/10.1002/pbc.25300

Houck, G., Kendall, J., Miller, A., Morrell, P., & Wiebe, G. (2011). Self-concept in children and adolescents with attention deficit hyperactivity disorder. *Journal of Pediatric Nursing*, *26*(3), 239–247.

Jaureguizar, J., Garaigordobil, M., & Bernaras, E. (2018). Self-concept, social skills, and resilience as moderators of the relationship between stress and childhood depression. *School Mental Health*, *10*(4), 488–499.

Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders. *Journal of Child Psychology Psychiatry*, *53*(4), 431–439.

Kovacs, M. (1992). *Children's Depression Inventory*. MHS.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.

Loades, M. E., Chatburn, E., Higson-Sweeney, N., Reynolds, S., Shafran, R., Brigden, A., Linney, C., McManus, M. N., Borwick, C., & Crawley, E. (2020). Rapid systematic review: The impact of social isolation and loneliness on the mental health of children and adolescents in the context of COVID-19. *Journal of the American Academy of Child and Adolescent Psychiatry*, *59*(11), 1218–1239.e3.

Maes, M., Van den Noortgate, W., Fustolo-Gunnink, S. F., Rassart, J., Luyckx, K., & Goossens, L. (2017). Loneliness in children and adolescents with chronic physical conditions: A meta-analysis. *Journal of Pediatric Psychology*, *42*(6), 622–635. https://doi.org/10.1093/jpepsy/jsx046

Marchak, J. G., Christen, S., Mulder, R. L., Baust, K., Blom, J. M. C., Brinkman, T. M., Elens, I., Harju, E., Kadan-Lottick, N. S., Khor, J. W. T., Lemiere, J., Recklitis, C. J., Wakefield, C. E., Wiener, L., Constine, L. S., Hudson, M.

M., Kremer, L. C. M., Skinner, R., Vetsch, J., Lee, J. L., & Michel, G. (2022). Recommendations for the surveillance of mental health problems in childhood, adolescent, and young adult cancer survivors: A report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *The Lancet Oncology*, *23*(4), e184–e196. https://doi.org/10.1016/S1470-2045(21)00750-6

Noll, R. B., Kozlowski, K., Gerhardt, C., Vannatta, K., Taylor, J., & Passo, M. (2000). Social, emotional, and behavioral functioning of children with juvenile rheumatoid arthritis. *Arthritis and Rheumatism*, *43*(6), 1387–1396. https://doi.org/10.1002/1529-0131(200006)43:63.0.CO;2-C

Noll, R. B., & Kupst, M. J. (2007). Commentary: The psychological impact of pediatric cancer hardiness, the exception or the rule? *Journal of Pediatric Psychology*, *32*(9), 1089–1098.

Noll, R. B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W. M., & Davies, W. H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development*, *67*(2), 423–436. https://doi.org/10.2307/1131824

Phipps, S., Klosky, J. L., Long, A., Hudson, M. M., Huang, Q., Zhang, H., & Noll, R. B. (2014). Posttraumatic stress and psychological growth in children with cancer: Has the traumatic impact of cancer been overestimated? *Journal of Clinical Oncology*, *32*(7), 641–646. https://doi.org/10.1200/JCO.2013.49.8212

Radcliffe, J., Bennett, D., Kazak, A. E., Foley, B., & Phillips, P. C. (1996). Adjustment in childhood brain tumor survival: Child, mother, and teacher report. *Journal of Pediatric Psychology*, *21*(4), 529–539.

Reimers, T. S., Mortensen, E. L., Nysom, K., & Schmiegelow, K. (2009). Health-related quality of life in long-term survivors of childhood brain tumors. *Pediatric Blood & Cancer*, *53*(6), 1086–1091. https://doi.org/10.1002/pbc.22122

Riley, A. W. (2004). Evidence that school-age children can self-report on their health. *Ambulatory Pediatrics*, *4*(4 Suppl), 371–376. https://doi.org/10.1367/A03-178R.1

Salley, C. G., Gerhardt, C. A., Fairclough, D. L., Patenaude, A. F., Kupst, M. J., Barrera, M., & Vannatta, K. (2014). Social self-perception among pediatric brain tumor survivors compared with peers. *Journal of Developmental and Behavioral Pediatrics*, *35*(7), 427–434.

Salley, C. G., Hewitt, L. L., Patenaude, A. F., Vasey, M. W., Yeates, K. O., Gerhardt, C. A., & Vannatta, K. (2015). Temperament and social behavior in pediatric brain tumor survivors and comparison peers. *Journal of Pediatric Psychology*, *40*(3), 297–308.

Saoji, N., Baran, J., Gerhardt, C. A., Vannatta, K., Rotter, D., Trauth, J. M., & Noll, R. B. (2019). The psychometrics of the Children's Depression Inventory when used with children who are chronically ill and matched community comparison peers. *Journal of Psychoeducational Assessment*, *37*(5), 566–577.

Schmitz, K. (2019). Vulnerable child syndrome. *Pediatrics in Review*, *40*(6), 313–315. https://doi.org/10.1542/pir.2017-0243

Schulte, F., & Barrera, M. (2010). Social competence in childhood brain tumor survivors: a comprehensive review. *Supportive Care in Cancer : official Journal of the Multinational Association of Supportive Care in Cancer*, *18*(12), 1499–1513. https://doi.org/10.1007/s00520-010-0963-1

Schulte, F., Bartels, U., & Barrera, M. (2014). A pilot study evaluating the efficacy of a group social skills program for survivors of childhood central nervous system tumors using a comparison group and teacher reports. *Psychooncology*, *23*(5), 597–600.

Sharkey, C. M., Espeleta, H. C., Traino, K. A., Roberts, C. M., Perez, M. N., Bakula, D. M., Chaney, J. M., Alderson, R. M., & Mullins, L. L. (2020). Psychological adjustment outcomes among pediatric brain tumor survivors: A meta-analysis. *Pediatric Blood & Cancer*, *67*(10), e28644.

Smucker, M. R., Craighead, W. E., Craighead, L. W., & Green, B. J. (1986). Normative and reliability data for the Children's Depression Inventory. *Journal of Abnormal Child Psychology*, *14*(1), 25–39.

Stavinoha, P. L., Askins, M. A., Powell, S. K., Pillay Smiley, N., & Robert, R. S. (2018). Neurocognitive and psychosocial outcomes in pediatric brain tumor survivors. *Bioengineering (Basel, Switzerland)*, *5*(3), 73.

Sukumaran, S., Vickers, B., Yates, P., & Garralda, M. E. (2003). Self-esteem in child and adolescent psychiatric patients. *European Child & Adolescent Psychiatry*, *12*(4), 190–197.

Turner, C. D., Rey-Casserly, C., Liptak, C. C., & Chordas, C. (2009). Late effects of therapy for pediatric brain tumor survivors. *Journal of Child Neurology*, *24*(11), 1455–1463.

Ullrich, N. J., & Embry, L. (2012). Neurocognitive dysfunction in survivors of childhood brain tumors. *Seminars in Pediatric Neurology*, *19*(1), 35–42.

Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: A review of the literature. *Quality of Life Research*, *17*(6), 895–913.

Vannatta, K., Gerhardt, C. A., Wells, R. J., & Noll, R. B. (2007). Intensity of CNS treatment for pediatric cancer: Prediction of social outcomes in survivors. *Pediatric Blood & Cancer*, *49*(5), 716–722.

Willard, V. W. (2018). Social skills interventions for survivors of pediatric brain tumors: A review and reformulation. *Pediatric Blood & Cancer*, *65*(12), e27434. (). (), –.

Winning, A. M., Moscato, E. L., Lehmann, V., Keim, M. C., Rausch, J. R., Lipak, K. G., Himelhoch, A. C., Murphy, L. K., Prussien, K. V., Olshefski, R. S., Vannatta, K., Compas, B. E., & Gerhardt, C. A. (2021). Impact of central nervous system-directed treatment on competence and adjustment among children in early cancer survivorship. *Pediatric Blood & Cancer*, *68*(9), 1–9.