HHS Public Access

Author manuscript

Pediatr Blood Cancer. Author manuscript; available in PMC 2019 October 01.

Published in final edited form as:

Pediatr Blood Cancer. 2018 October ; 65(10): e27287. doi:10.1002/pbc.27287.

Predicting Parental Distress among Children Newly Diagnosed with Craniopharyngioma

Rachel K. Peterson[1], **Jason M. Ashford**[1], **Sarah M. Scott**[1], **Fang Wang**[2], **Hui Zhang**[2], **Julie A. Bradley**[3], **Thomas E. Merchant**[4], and **Heather M. Conklin**[1]

[1]Department of Psychology, St. Jude Children's Research Hospital, Memphis, TN

[2]Biostatistics, St. Jude Children's Research Hospital, Memphis, TN

[3]University of Florida Health Proton Therapy Institute, 2015 North Jefferson Street, Jacksonville, FL 32206

[4]Department of Radiation Oncology, St. Jude Children's Research Hospital Memphis, TN

Abstract

Background—Childhood brain tumor diagnoses are stressful for families. Children diagnosed with craniopharyngioma (Cp) present with particularly challenging medical and cognitive problems due to tumor location and associated biophysiologic comorbidities. This study examined parental distress in a sample of Cp patient families treated with proton beam therapy to identify factors for targeting psychological intervention.

Procedure—Prior to (n=96) and one year after (n=73) proton therapy, parents of children diagnosed with Cp (9.81±4.42 years at baseline; 49% male) completed a self-report measure of distress, the Brief Symptom Inventory (BSI). Children completed cognitive assessment measures at baseline; medical variables were extracted from the study database.

Results—At baseline, t-tests revealed parents reported higher levels of distress than normative expectations on Anxiety, Depression, Global Severity, and Positive Symptom Distress BSI scales ($p < .05$). Linear mixed effects models revealed parent report measures of child executive dysfunction and behavioral issues were more predictive of parental distress than patients' cognitive performance or medical status ($p<.05$). Models also revealed a significant reduction only in Anxiety over time ($t = -2.19$, $p<.05$). Extensive hypothalamic involvement at baseline predicted this reduction ($p<.05$).

Conclusion—Parents are experiencing significant distress before their child begins adjuvant therapy for Cp, though parental distress appears largely unrelated to medical complications and more related to parent perceptions of child cognitive difficulties (versus child performance). Importantly, this may be explained by a negative parent reporting style among distressed parents.

*Corresponding Author: Heather M. Conklin, Department of Psychology, Mail Stop #740, St. Jude Children's Research Hospital, 262 Danny Thomas Place, Memphis, Tennessee 38105. Telephone: 901-595-3585. Fax: 901-595-4701. heather.conklin@stjude.org. Corresponding author: Heather Conklin, Ph.D., 262 Danny Thomas Place, Mail Stop 740, Memphis, TN, 38105; 901-595-3300; heather.conklin@stjude.org

CONFLICT OF INTEREST STATEMENT

No potential conflicts of interest.

Knowledge of socio-emotional functioning in parents related to patient characteristics is important for optimization of psychological intervention.

Keywords

craniopharyngioma; pediatric brain tumor; parental distress

INTRODUCTION

The diagnosis and treatment of a childhood brain tumor has a significant impact not only on the child but also his or her family. While parents generally adjust well to the pediatric cancer experience, a considerable number of parents continue to experience psychological distress, anxiety, and symptoms of post-traumatic-stress after termination of their child's cancer treatments [1–8]. Parents of these children may experience significantly worse quality of life (QoL) across the domains of physical functioning, general health, social functioning, and mental health [9–11]. Moreover, they may report feelings related to insecurity, lack of control in everyday living, greater reliance and dependence on others, chaos, and loneliness [10]. Some researchers [5, 12–15] have found that feelings of uncertainty, disease-related fear, and loneliness do not diminish overtime, and feelings of loneliness may increase over time [5].

Some predictors of parental maladjustment following a child's cancer diagnosis have been identified in the literature. For example, mothers of children with cancer report more psychological distress and perceived family conflict than their spouses [16]. In addition, while psychological distress tends to decrease over time for both parents, mothers have been found to report slightly more emotional distress than fathers up to one year post-diagnosis [17–18]. Other negative predictors of parental adjustment include low socioeconomic status (SES), recurrence of the disease in the child, limited access to social support, and worse health status of the child [6,15,19]. Though child cognitive functioning as a predictor of parental distress has not been reported in the oncology literature, having a child with greater cognitive difficulties following traumatic brain injury is associated with greater parental distress [20–22]. In contrast, for parents of children with cancer, social support, familial cohesion, and adaptability have been found to be associated with lower parental anxiety, distress and post-traumatic-stress symptoms [19, 23–26]. For example, parental adaptive style has been found to be a predictor of post-traumatic stress in guardians, as individuals that fall under the category of Low Anxiety or Repressor on the Adaptive Style Paradigm report healthier emotional functioning [27–31].

Parents of children with Craniopharyngioma (Cp) may be at particular risk of psychosocial difficulties due to the unique medical challenges of Cp. Cps are histologically benign tumors located at the base of the brain above the pituitary gland and close to critical vasculature. While the overall survival rate is high (>80%), there is a high morbidity risk secondary to tumor and treatment given tumor location [32–33]. Specifically, individuals diagnosed with Cp are at risk for headaches, nausea and/or vomiting secondary to hydrocephalus, vision changes, endocrinopathies, increased fatigue or sleepiness, and mood and/or behavior

changes. Studies report reduced health-related QoL and high levels of psychosocial morbidity [33–36].

Although Cp is a benign entity, the treatment mirrors the treatment for malignant brain tumors and routinely involves surgery and/or radiation therapy. Proton therapy, a relatively newer form of radiation therapy, has notable potential benefits over conventional radiation therapy using photons including potential sparing of greater volumes of normal brain tissue. Initial studies have shown better preservation of intellectual functioning and processing speed with proton therapy [37–38], but are limited by factors such as small sample sizes, missing data, and lack of appropriate control groups. We have previously shown that children treated for Cp show weaker cognitive performance in comparison to normative expectations prior to proton therapy, resulting from tumor effects and surgical intervention [39].

Given the active role parents play in the treatment of childhood brain tumors, better understanding of their emotional functioning can provide a fuller picture of the support needed to help families cope [65]. The present study investigated parental distress in a sample of Cp patient families to identify associated clinical and cognitive factors for targeted intervention. More specifically, parental distress was measured prior to proton beam radiation as well as one year post-treatment to identify predictors of distress at presentation and examine how parental distress may change overtime. Based on the existing literature, we hypothesized elevated parental distress at baseline that would persist a year later among some caregivers. We also hypothesized child characteristics such as increased rate of endocrinopathies or executive dysfunction, which may require greater parental management, would predict greater parental distress.

METHODS

Participants

From August 2011 to May 2016, patients diagnosed with Cp (N=110) were enrolled on a phase II trial of limited surgical intervention (resection) and proton beam radiation therapy. Participants were pediatric patients from infancy through 21 years of age diagnosed with Cp by histology, cytology, or neuroimaging. Patients with a history of treatment with fractionated radiation therapy, intracystic P-32, intracystic bleomycin, or radiosurgery, and those who were pregnant or with limited English proficiency, were excluded from enrollment. Those with premorbid neurological or neurodevelopmental conditions did not receive protocol-based cognitive evaluations. This study was approved by the Institutional Review Board, and informed consent was obtained prior to participation (RT2CR; NCT01419067).

Procedure

Some patients were selected for surgical resection based upon assessment and consultation by the neurosurgeon. Participants who received subtotal or no resection were treated with passively-scattered proton therapy. All patients included in this study sample were treated

with proton beam therapy. Total cumulative dose was 54 CGE using daily fractions of 1.8 CGE and a 5mm clinical target volume.

Demographic and clinical variables were extracted from the study database and medical charts. Extent of preoperative hypothalamic involvement (HI) was categorized as having no HI (grade 0), anterior HI (grade 1), and anterior as well as posterior HI including the mammillary bodies (grade 2) [40–41]. This categorization was based on preoperative neuroimaging after symptom onset. Extent of surgery was categorized as no surgery, placement of a catheter, or resection. Cerebrospinal fluid (CSF) diversion procedures included ventriculoperitoneal (VP) shunting and endoscopic third ventriculostomy (ETV). DI was categorized as present or not based on whether the patient was permanently placed on desmopressin prior to baseline cognitive assessment. The demographic characteristics of the sample are presented in Table 1. As indicated, Cp patients ranged in age from 0.99 to 20.15 years (M = 9.81, SD = 4.42) at baseline and were roughly balanced by gender (49% males). Parent demographic data included gender (16 males, 80 females at baseline; 15 males, 63 female at year 1) and highest level of parental education obtained (M = 14.79, SD = 2.25 at baseline; M = 14.88, SD = 2.09 at year 1), as a proxy measure of SES.

Measures

Parents completed the Brief Symptom Inventory (BSI) as a self-report measure of psychological distress within the past week. This measure has well established reliability (e.g., alpha coefficient = 0.70 – 0.88) and validity (e.g., highly correlated with the SCL-90-R subscales, with correlations from 0.88 to 0.94) and has been previously used with the oncology population [42–44]. This questionnaire assesses 9 symptom dimensions across 3 global indices [45]. For the purpose of this study, the researchers looked specifically at the Anxiety and Depression dimensions as well as Global Severity Index (GSI) and Positive Symptom Distress Index (PSDI). The GSI is a measure of overall psychological distress level; the PSDI is a measure of symptom intensity. Scores on the BSI are reported in terms of standardized T-scores, with a mean of 50 and standard deviation of 10, with higher scores indicating higher levels of distress.

Patients completed a neurocognitive assessment at baseline (pre-treatment; n=96) as well as 1 year after completion of proton therapy (n=73). An age-tailored comprehensive neuropsychological battery was administered by a trained psychological examiner. Measures selected for these analyses included measures of intellectual functioning (age-appropriate Wechsler scales [46–48]), attention (Conners' Continuous Performance Test-II [CPT-II] [49]), executive function (Wechsler Working Memory Index [WMI] [46–48], Color-Word Interference from the Delis-Kaplan Executive Function System [D-KEFS] [50], Behavior Rating Inventory of Executive Function [BRIEF] Parent Form [51]), memory (age-appropriate version of the California Verbal Learning Test [CVLT] [52–53]), adaptive function (Adaptive Behavior Assessment System, 2nd Edition [ABAS-II] Parent Form [54]), psychosocial function (Behavior Assessment System for Children, 2nd Edition [BASC-2] Parent Rating Scale [55]), and fine motor skills (Grooved Pegboard [56]).

Statistics

One sample t-tests were performed to compare mean baseline BSI scores to normative means and chi-square analysis was used to compare the proportion of clinically elevated BSI scores (t > 63) to normative expectations (10%). Linear mixed effects models were used to evaluate change over the first year as well as to identify predictors of baseline performance and change over time. Univariate predictors included patient gender, age at baseline, degree of HI, presence of DI, extent of surgical resection, presence of CSF diversion, parent gender, parental education as a proxy for SES, and all cognitive subtests listed above. Standard scores between 85 and 115, scaled scores between 7 and 13, t-scores between 40 and 50, and z-scores between −1.00 and 1.00 were considered average.

RESULTS

At baseline, t-tests indicated parents reported significantly higher levels of distress than normative means on Anxiety, Depression, GSI, and PSDI BSI scales (Table 2). Further, chi-square analyses revealed that clinical levels of anxiety and PSDI at baseline were significantly higher than expected based on population norms (Table 2).

Linear mixed effects models indicated BSI scales (Depression, Anxiety, GSI, PSDI) decreased over time; however, only the decrease in Anxiety was statistically significant (Table 3). At 1 year after completion of proton therapy, both t-tests and chi-square analyses revealed an elevation in PSDI (Table 2). Linear mixed effects models indicated parent report of child executive dysfunction (e.g., BRIEF Global Executive Composite) and behavioral issues (e.g., BASC-2 Internalizing Problems) play a more significant role in predicting parental distress at baseline ($p < .05$) than patients' cognitive performance or medical status (Table 4). However, there was evidence of isolated significant findings in the opposite direction as hypothesized (i.e., lower CPT-II Overall Index predicted higher Depression, and better D-KEFS Color Word Inhibition Switching predicted higher Anxiety). One medical variable was in the hypothesized direction (greater number of surgeries predicted higher GSI). Given this finding of potential discrepancy between parent report of cognitive skills and child performance on cognitive measures of the same construct, we created a discrepancy score for working memory (BRIEF WM scale z-score – Wechsler WMI z-score) and calculated correlations between this discrepancy score and BSI indices. These correlations revealed that a greater discrepancy (parent negative reporting style) correlated significantly with Depression, GSI and PSDI BSI indices, with a trend for correlation with the Anxiety BSI index (Table 5). Given that linear mixed effect models showed a significant reduction in Anxiety over time ($p < .05$), further analysis was conducted to explore predictors of change for this BSI scale. It was suggested that only extensive hypothalamic involvement at baseline predicted the reduction in Anxiety ($p < .05$) (Table 4).

DISCUSSION

This study demonstrated that parents of children diagnosed with Cp are experiencing distress prior to and one-year following tumor-directed treatment. More specifically, parents reported higher levels of distress than normative averages at baseline on Anxiety, Depression, Global Severity and Positive Symptom Distress BSI scales, with the rate of

clinically elevated scores significantly exceeding the normative expectation of 10% for Anxiety (19%) and Positive Symptom Distress (16%). At one year follow-up, Positive Symptom Distress remained higher than normative means with a higher than expected rate of clinical elevation (15%). The group had mean values within the average normative range suggesting some, but not all, parents were distressed. All indices of parental distress showed a decrease over time but only parent reported Anxiety reached significance. Interestingly, parental distress was largely unrelated to the child's medical status or cognitive performance on examiner-administered tasks, with the exception of isolated, perhaps spurious, variables. However, parent perceptions of child cognitive difficulties (versus child performance) was predictive of their distress (e.g., BRIEF Global Executive Composite, BASC-2 Internalizing Problems Index). Of particular note, the more discrepant parent report of child cognitive performance was from their child's actual cognitive performance (negative reporting style), the more distressed the parent reported being on the BSI.

Compared to the existing literature, the current findings add mixed support. Consistent with the greater literature base, parental distress persists over time for some parents. That is, while many parents are coping well, particularly a year after treatment initiation, there is a subset that continues to be distressed and may profit from early intervention. As previously discussed, a significant number of parents of pediatric cancer patients experience psychological distress, anxiety, and symptoms of post-traumatic-stress even after termination of their child's cancer treatments, with some parents experiencing psychological symptoms up to 5 years post-treatment [1–15]. Inconsistent with the literature, our findings suggest that parent gender is not predictive of parental distress. For example, some research has found maternal caregivers to report more psychological distress and perceived family conflict than their spouses [16]. This may best be explained by differences in specific measures used across studies or a small percentage of male caregivers in the current study. In addition, parental education as a measure of SES was not predictive of parental distress as has been previously shown in the literature. This may suggest that parental education is not the best proxy measure of SES.

A number of meaningful conclusions with clinical implications can be drawn from this study. First, the findings may suggest children having greater cognitive and behavioral issues in the real-world setting have parents that are most distressed. Alternatively, and perhaps more importantly, these findings may best be explained by a negative parent reporting style; whereby, the most distressed parents overly report negative child characteristics. This is similar to the findings in the adult breast cancer literature whereby women who are more depressed report greater cognitive problems, irrespective of their actual cognitive performance [57].

Research has shown problem-solving skills training can be used to address a wide range of emotional problems including depression and anxiety arising from chronic conditions such as cancer [58–62]. Problem-solving skills training was developed to target parental distress (not psychopathology), and could be adapted to specifically address illness related stressors. For example, Sahler et al., found caregivers of children recently diagnosed with cancer are distressed regardless of specific oncological diagnosis and the Bright IDEAS Problem Solving Skills Training is an acceptable intervention that helped to alleviate this distress

[60–61]. Problem-solving intervention focuses on developing constructive problem-solving attitudes and skills with the aims of enhancing psychological and behavioral functioning [62]. Within the context of chronic illness, individuals learn new skills and strategies, thereby improving one's quality of life. This technique may be most appropriate to parents of children with certain medical conditions. For example, given that a higher number of surgeries predicted increased GSI, it may be beneficial to teach coping skills to these parents to specifically get through surgeries with the least distress. Further, increased HI at baseline predicted a decrease in anxiety overtime. Teaching coping strategies to parents for caring for a child with multiple endocrinopathies and their complicated medical management may be beneficial.

Second, monitoring and intervening with parents appears warranted. This includes immediate and ongoing screeners and support for families during diagnosis and treatment of Cp, with attention to parents who report significantly more distress or negativity as treatment continues. While some distress may resolve without intervention, early intervention could expedite the natural adjustment process and/or provide future protection (e.g., in the case of relapse). Furthermore, social support, familial cohesion, and adaptability have all been found to be associated with lower parental anxiety, distress and symptoms consistent with post-traumatic-stress symptoms [17, 19–25]. Therefore, access to social support via support groups, as well as cognitive behavioral individual and family therapy for parents may prove promising. Future research could compare problem-solving training for caregivers to support groups, cognitive behavioral therapy, and/or family therapy.

This study assessed parental distress within a large group of patients with Cp receiving proton beam radiation therapy, which has not previously occurred in the literature. Ultimately, this allows for better understanding of parental socio-emotional functioning as their children undergo modern medical intervention. In addition, better understanding of parental distress within this population can inform psychological intervention. However, there are limitations associated with this study. First, we do not have information on psychological interventions provided to parents; while we anticipate the rate of parental intervention was low based on patterns of service provision at this site, this may have impacted levels of distress over time. Second, lack of knowledge regarding caregiver premorbid psychiatric history and/or temperament limits our understanding of the causal or correlational relationship with long-term psychosocial functioning as some research has found a positive relationship between parent self-efficacy, adaptive style, and short-and long-term psychosocial functioning, regardless of treatment outcomes [26–30, 63]. Future studies may consider and control for premorbid parental conditions as well as investigate changes in parental distress across time and determine when socio-emotional functioning returns to normative baseline rates, with or without intervention. Finally, given prior findings of increased distress associated with parenting in general, parents of healthy children, matched on socioeconomic factors, could be included as a control group in future work [64].

Acknowledgments

The authors thank the patients and their families who volunteered their time to participate in this study. We would also like to thank Sean Phipps, Ph.D. for his editorial input. This work was supported, in part, by the National Cancer Institute (St. Jude Cancer Center Support [CORE] Grant [P30-CA21765]) and the American Lebanese

Syrian Associated Charities (ALSAC). Portions of this paper were presented at the annual meeting of the International Neuropsychological Society in Boston, MA, 2016.

LIST OF ABBREVIATIONS

ABAS-II	Adaptive Behavior Assessment System – Second Edition
BASC-2	Behavior Assessment System for Children – Second Edition
BRIEF	Behavior Rating Inventory of Executive Function
BSI	Brief Symptom Inventory
CGE	Cobalt Gray Equivalent
Cp	Craniopharyngioma
CPT-II	Continuous Performance Test – Second Edition
CSF	Cerebrospinal Fluid
CVLT	California Verbal Learning Test
DI	Diabetes Insipidus
DKEFS	Delis-Kaplan Executive Function System
ETV	Endoscopic Third Ventriculostomy
GHQ-30	General Health Questionnaire - 30
GSI	Global Severity Index
HI	Hypothalamic Involvement
M	Mean
mm	millimeters
PSDI	Positive Symptom Distress Index
QoL	Quality of Life
SD	Standard Deviation
SES	Socioeconomic Status
SSERQ	Situation-Specific Emotional Reaction Questionnaire
VP	Venriculoperitoneal
WMI	Working Memory Index

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TABLE 1

Demographic and clinical characteristics

Variable	n	Percentage
Patient Gender		
Male	47	49.0
Female	49	51.0
Parent/Respondent Gender		
Male	16	16.7
Female	80	83.3
Hypothalamic Involvement[a]		
Grade 0	17	17.7
Grade 1	26	27.1
Grade 2	53	55.2
Diabetes Insipidus[b]		
Yes	52	54.2
No	44	45.8
Surgical Category[c]		
Resection	70	72.9
Catheter	16	16.7
No Surgery	10	10.4
CSF Diversion[d]		
Yes	33	34.4
No	63	65.6
Growth Hormone Peak Value[e]		
Normal	15	19.2
Deficient	56	71.8
Severe	7	9.0

	Mean ± SD	Range
Age at Baseline Assessment	9.81 ± 4.42	0.99 – 20.15
Number of Surgeries	1.58 ± 1.23	0.00 – 8.00
Growth Hormone Peak Value[e]	2.42 ± 4.49	0.10 – 29.20

[a] Grade 0 - No hypothalamic involvement; Grade 1 - Anterior hypothalamic involvement; Grade 2 - Anterior and posterior hypothalamic involvement including mammillary bodies and area behind mammillary bodies [40–41]

[b] Status before proton beam radiation therapy

[c] Patients with multiple surgeries classified based on most extensive/invasive procedure

[d] Includes patients who received either CSF shunt or endoscopic third ventriculostomy

[e] Growth Hormone Peak Value categorized as Normal (>3), Deficient (>0.1 but <3.0), or Severe (<0.1)

TABLE 2

Baseline and year 1 parental distress (BSI indices) and comparison with normative expectations

BSI Measure	Mean ± SD	p-value[a]	% Elevated	p-value[b]
Baseline Depression	52.38 ± 8.90	0.0104*	12	0.414
Baseline Anxiety	52.66 ± 10.75	0.0174*	19	0.001*
Baseline Global Severity Index	53.05 ± 9.88	0.0032*	13	0.247
Baseline Positive Symptom Distress Index	54.54 ± 8.21	<.0001*	16	0.021*
Year 1 Depression	50.93 ± 8.67	0.3617	9	0.480
Year 1 Anxiety	50.05 ± 10.21	0.9635	7	0.937
Year 1 Global Severity Index	51.16 ± 10.66	0.3539	9	0.480
Year 1 Positive Symptom Distress Index	53.23 ± 9.80	0.0079*	15	0.001*

[a] *p*-values obtained using t-tests comparing sample means with a normative mean of 50 and SD of 10

[b] *p*-values obtained using chi-square tests, where, in a normative population, 10% would be expected to be “elevated”, defined as having a t score >63

* p< .05

TABLE 3

Change in parental distress (BSI indices) in first year of treatment

Baseline				Rate of change per year		
Outcome	**Estimate**	**Standard Error**	**p-value[a]**	**Estimate**	**Standard Error**	**p-value[b]**
Depression	52.41	0.90	<.0001*	−1.40	1.13	0.2203
Anxiety	52.73	1.07	<.0001*	−2.48	1.13	0.0318*
Global Severity Index	53.06	1.04	<.0001*	−1.78	1.12	0.1179
Positive Symptom Distress Index	54.43	0.93	<.0001*	−1.44	1.05	0.1774

Linear mixed effects modeling for change in BSI from baseline to one year post (random intercept only)

[a] p-value obtained by comparing model estimate at baseline to normative mean of 50

[b] p-value obtained by comparing model rate of change per year to 0

* p< .05

TABLE 4

Predictors of BSI Anxiety at baseline and change over time among caregivers

Predictor	Subgroup	Baseline				Rate of Change			
		Estimate	SE	P_1	P_2	Estimate	SE	P_1	P_2
Caregiver Gender	Male	54.21	2.51	0.0974	.5117	−2.01	2.82	.4790	.8488
	Female	52.42	1.16	0.0414*		−2.61	1.26	.4790	
Caregiver Education		44.07	7.06	0.4023		1.70	7.90	.8308	
Patient Age at Baseline		51.89	2.61	0.4716		−1.88	2.87	.5135	
Number of Surgeries		51.08	1.74	0.5369		−3.15	2.13	.1437	
GH Peak Value		53.36	1.33	0.0138*		−3.43	1.36	.0142	
Surgery Group	Catheter	55.48	2.61	0.0401*	.1705[f]	−3.67	2.65	.1709	.7596[a]
	Resection	52.54	1.25	0.0465*	.4128[g]	−2.28	1.34	.0943	.9907[b]
	No	49.60	3.34	0.9050		−2.23	3.84	.5630	
	Surgery								
CSF diversion	No	52.97	1.32	0.0278*	.7570	−2.47	1.40	.0813	.9878
	Yes	52.27	1.83	0.2204		−2.51	1.96	.2053	
Diabetes Insipidus	No	52.27	1.58	0.1558	.7050	−3.96	1.70	.0233	.2592
	Yes	53.08	1.44	0.0363*		−1.37	1.51	.3674	
HI	Grade 0	52.06	2.58	0.4283		2.25	2.73	.4138	
	Grade 1	51.45	2.07	0.4871	.8547[h]	−1.76	2.04	.3919	.2444[c]
	Grade 2	53.63	1.44	0.0144*	.5972[i]	−4.19	1.48	.0061	.0422[d]

Pediatr Blood Cancer. Author manuscript; available in PMC 2019 October 01.

Predictor	Subgroup	Baseline				Rate of Change			
		Estimate	SE	P_1	P_2	Estimate	SE	P_1	P_2
Wechsler[a]									
Verbal Comprehension		43.45	7.17	0.3635		−9.26	8.36	.2885	
Perceptual Reasoning		45.08	6.70	0.4646		−5.40	7.86	.4949	
Working Memory		46.40	6.99	0.6082		−5.62	7.67	.4676	
Processing Speed		46.53	6.08	0.5699		−.69	7.30	.9246	
CPT-II[b]									
Omissions		51.52	4.52	0.7383		.89	6.74	.8952	
Commissions		54.17	5.53	0.4540		−10.58	6.61	.1174	
Hit RT		55.17	5.67	0.3646		−1.97	7.86	.8037	
Overall Index		53.10	1.40	0.0303*		−3.21	1.74	.0722	
Grooved[c] Pegboard									
Dominant Hand		51.88	1.23	0.1298		−2.72	1.33	.0469	
Nondominant Hand		52.08	1.26	0.1027		−2.81	1.42	.0541	
D-KEFS[d]									
Inhibition Completion Time		50.66	4.53	0.8854		−5.39	6.00	.3765	
Inhibition Switching Completion Time		43.20	4.15	0.1074		1.91	5.44	.7284	
CVLT-C[e]									
Total		47.83	3.68	0.5578					
Short Delay-Free Recall *z*-score		52.25	1.32	0.0928					

Predictor	Subgroup	Baseline				Rate of Change			
		Estimate	SE	P_1	P_2	Estimate	SE	P_1	P_2
Long Delay-Free Recall z-score		52.36	1.34	0.0826					
BRIEF[j]									
Behavioral Regulation Index (BRI)		40.28	4.86	0.0488*		−5.06	6.24	.4211	
Working Memory		44.87	4.49	0.2556		−6.22	5.94	.2990	
Metacognition Index (MI)		43.44	4.93	0.1871		−8.13	6.21	.1961	
Global Executive Composite (GEC)		39.75	4.28	0.0186*		−6.56	5.50	.2375	
BASC-2[k]									
Externalizing Problems		34.72	4.79	0.0019*		−2.02	5.58	.7191	
Internalizing Problems		38.63	4.06	0.0061*		−4.86	5.20	.3538	
Attention Problems		46.22	4.41	0.3935		−3.27	5.74	.5712	
ABAS-II[l]									
General Adaptive Composite (GAC)		61.91	6.28	0.0608		.70	7.42	.9255	

Univariate linear mixed effects modeling for predictors of change;

*p< .05

Baseline P_1 is for the difference between the group or subgroup mean and the normative mean

Baseline P_2 is for the difference between subgroup means, when applicable

Rate of Change P_1 is for investigating whether the rate of change for the corresponding group or subgroup is 0

Rate of Change P_2 is for the difference of the rates of change between subgroups, when applicable

[a]To assess intelligence, children were assessed with an age appropriate Wechsler scale (i.e., WPPSI-III for children 3 to 5, WISCIV for children 6–16, and WAIS IV for children >=17).

[b]Children under 6 were not administered the CPT-II.

[c] Children under 5 were not administered the Grooved Pegboard.

[d] Children under 8 were not administered the DKEFS.

[e] Children under 6 were not administered the CVLT-C.

[f] Difference in Anxiety scores between patients who received catheters versus and no surgery

[g] Difference in Anxiety scores between patients who received resection versus no surgery

[h] Difference in Anxiety scores between HI grade 0 and HI grade 1

[i] Difference in Anxiety scores between HI grade 0 and HI grade 2

[j] Behavior Rating Inventory of Executive Function (BRIEF) Parent Form

[k] Behavior Assessment System for Children, 2nd Edition (BASC-2)

[l] Adaptive Behavior Assessment System, 2nd Edition (ABAS-II)

TABLE 5

Parent reporting style and parental distress

	Negative Reporting Style[a]	*p*[b]
Depression	−0.293	0.011 *
Anxiety	−0.228	0.050 †
Global Severity Index	−0.381	0.001 *
Positive Symptom Distress Index	−0.272	0.022 *

[a] Calculated from difference in performance measure of working memory (WISC-IV WMI) and parental report of working memory (BRIEF WM), with larger negative scores indicating a parent reporting higher problems than reflected in performance scores

[b] *p*-values from Pearson correlations

* $p<.05$;

† $p<.10$