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Parental stress predicts functional outcome in pediatric cancer survivors

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Abstract

***Background*: Childhood cancer survivors are at risk for long-term neurocognitive and psychosocial morbidities. Research has seldom examined the relationship between these morbidities; thus, little empirical evidence exists concerning overall salience and how morbidities converge to impair day-to-day functioning. An increased understanding of functional impairment resulting from the pediatric cancer experience can inform early risk identification as well as sources for intervention. The purpose of this study was to characterize the frequency/severity of functional impairment and identify significant neurocognitive and psychosocial determinants of functional impairment.**

***Methods*: Fifty child–parent dyads were enrolled. Children were aged 7–19 years who were at least 2 years postdiagnosis with leukemia/lymphoma and were recruited through a pediatric oncology late effects clinic. Parents completed questionnaires, rating their own adjustment to their child's illness as well as their child's level of functional impairment, while a brief neuropsychological exam was administered to children.**

***Results*: Twenty-six percent of the sample evidenced clinically significant functional impairment. Regression analyses indicated that neurocognitive deficits did not predict functional impairment, whereas parental stress was a significant predictor.**

***Conclusions*: Although children demonstrated both neurocognitive deficits and functional impairments, results favor psychosocial factors, such as parental stress, as a predictor of overall functional impairment. The implications of this study suggest that late effects aggregate to impact day-to-day functioning in pediatric cancer survivor populations and parental stress may serve as a marker for heightened risk. The results suggest that broader functional domains, especially school and self-care domains, should be evaluated and considered when identifying potential targets for psychosocial interventions.**

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Over the past two decades, survival rates for children diagnosed with cancer have increased significantly. Leukemia and lymphoma, the most prevalent forms of childhood cancer, demonstrate a remarkable advancement in 5-year survival (80–85%) [1]. Unfortunately, survivors are at risk for long-term morbidity resulting from the disease and treatments [2,3]. Adverse late effects include treatment-related physical effects, neurocognitive deficits [4], and psychosocial problems [3].

Although research has provided information regarding specific types of late effects experienced by survivors, little is known regarding how late effects converge and disrupt children's day-to-day functioning. Functional impairment (FI) represents an emerging construct within pediatric health, defined as the extent to which children are unable to perform daily activities such as physical, social, and personal activities [5]. Conceptually, FI is ensconced within the framework posed by the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps, which links pediatric disease states to disease consequences [6]. This framework emphasizes the impact of the disease on day-to-day functioning.

Inherent within this framework is a distinction between symptoms and their consequences [7]. This distinction is supported by existing literature, as previous research has indicated that although a relationship exists between isolated psychological symptoms and broad FI, the relationship is not perfect [7]. Although there is a relationship between symptoms and impairment, FI represents an independent construct and can be measured in addition to specific psychological symptoms. Research suggests that FI outcomes emerge at different stages after pediatric traumatic brain injury [8] and attention deficits [9].

Functional impairment is the impact of a disease or disorder that limits a child's functioning in family, school, or community activities. FI is referenced to population normative data and is distinct from adaptive functioning. Adaptive functioning solely measures a child's role performance across a variety of domains, whereas FI specifically assesses the level of impairment across salient daily activities related to academic/work functioning, interpersonal functioning, and self-care. Adaptive functioning represents clusters of behavior that can lead to FI. Moreover, FI represents a related but distinct construct from

quality of life (QOL). QOL can be conceptualized as the subjective impact of a disease state upon a child's life. QOL assesses an individual's perceptions of life satisfaction within the context of personal goals and standards [10]. In contrast, FI offers a normative assessment of disease impact by assessing concrete behavioral anchors, which include performance on specific activities [7].

Much of the research surrounding pediatric cancer late effects has emphasized psychological symptoms, such as psychosocial adaptation, and neurocognitive deficits. This approach overlooks the impact of the disease on day-to-day functioning. Research emphasizing QOL allows for an understanding of disease impact; however, it falls short given its method of subjective assessment and lack of specific and observable behavioral anchors. FI helps address these shortcomings by attempting to map all of these variables (e.g., neurocognitive deficits, psychosocial adaptation, and QOL) onto observable behaviors by assessing activities that are particularly salient to the child's life. Three major FI domains in which day-to-day functioning may be disrupted have been identified: interpersonal relations, school/work functioning, and self-care/self-fulfillment [5]. Identifying the degree to which pediatric cancer survivors experience FI serves to determine the focus for psychosocial interventions. Figure 1 provides a conceptual model of FI within the context of pediatric cancer.

Determinants of FI in cancer survivors may include both child neurocognitive functioning and parental adaptation. Neurocognitive functioning is a common late effect [4]. Research indicates that the cognitive impairments are heterogeneous, as survivors exhibit deficits in the domains of attention, executive functioning, memory, information processing speed, and visual–spatial skills [11]. Neuroimaging studies have revealed structural abnormalities such as leukoencephalopathy, intracerebral calcifications, and white matter alterations that are related to neurocognitive deficits [2,12]. There is limited empirical work exploring the link between neurocognitive deficits and FI in pediatric cancer survivors. Another source of influence for child FI is parental adaptation, as parents have been shown to demonstrate high levels of stress, distress, overprotection, and uncertainty and to perceive their child as vulnerable [13]. Parental adaptation plays an influential role in children's psychological adjustment, and parental maladjustment can lead to problematic outcomes [14,15]. Because FI is a relatively novel construct, no empirical work has determined a link between parental adaptation difficulties and children's functional capacity.

The current study builds upon the extant research on neurocognitive deficits that have been reported in survivors [4] and the body of research that has pointed to parental adaptation problems as a contributor to outcomes [16]. The current study sought to assess the frequency of FI in pediatric leukemia/lymphoma survivors and determine the relative contribution of neurocognitive function and parental adaptation upon child FI. We hypothesized that FI could be predicted primarily by neurocognitive deficits in the survivors and, to a lesser extent, parental adjustment.

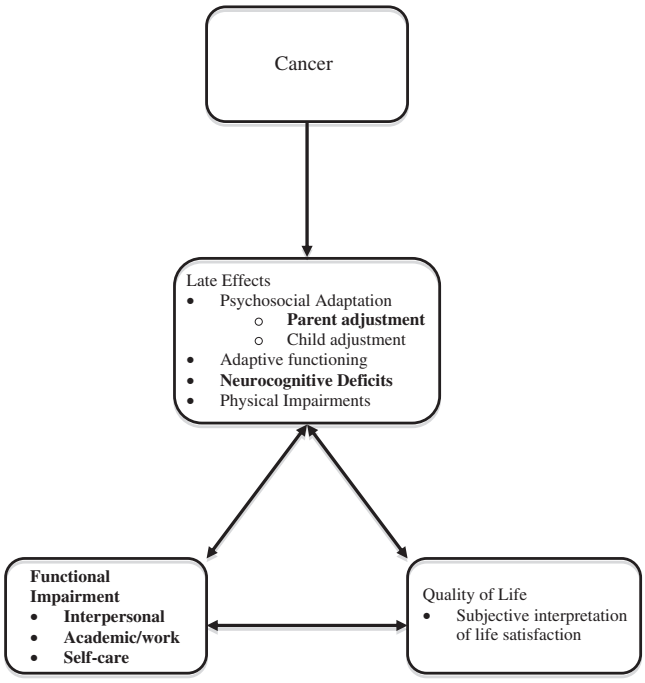

Figure 1. Conceptual model of functional impairment within the context of pediatric cancer

Method

Participants

Participants included 50 English-speaking pediatric leukemia/lymphoma survivors and their parents. Eligible children were aged 7–19 years, previously treated for leukemia or lymphoma, at least 2 years posttreatment. Individuals excluded from the study were children who did not have the ability to successfully complete neurocognitive testing (e.g., IQ < 70) and parents who were unable to complete questionnaires in English. Seventy-six percent of study-eligible survivors agreed to participate. Qualitative observations revealed that participants were more likely to decline participation when they were approached at the end of the clinic day.

Procedure

The study was reviewed and approved by the Human Research Review Committee. Parents of potential participants were recruited and enrolled by a trained research assistant during the pediatric oncology survivor's clinic visit. Prior to their clinic visit, candidate participants were screened by clinic staff to determine eligibility and introduced to the study via mail prior to the clinic visit. The

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mail contained information regarding the study, as well as consent/assent materials for review.

Consent/assent was obtained at the clinic visit, and children subsequently completed a 20- to 30-min neurobehavioral exam. Parent psychosocial measures and the parent report of child FI were separately completed.

Measures

Child neurobehavioral measures

All children completed a brief neurobehavioral exam, administered by a psychometrist. Test selection was based upon research that included measures with known test–retest reliability and accuracy in predicting global intellect, reading skills, and mathematics skills [4]. The neurobehavioral exam included the following measures (in order of administration): (1) Developmental Test of Visual-motor Integration [17], a measure of visual-motor integration abilities; (2) Digit Span (ages 6–17 years: Wechsler Intelligence Scales for Children, fourth edition [18]; ages 18–19 years: Wechsler Adult Intelligence Scales, fourth edition [19]), a measure of auditory attention and working memory; (3) Trail Making Tests [20], brief visual attention/scanning and switching; (4) Purdue Pegboard Test [21], a measure of fine motor control; and (5) Controlled Oral Word Association Test [22], a measure of rapid word production/expressive language abilities.

Parental adaptation

Parent Protection Scale [23]: This is a 25-item self-report measure assessing protective parenting behaviors. Respondents rate each statement on a 4-point scale ranging from 0 ('never') to 3 ('always'), which indicates the degree to which the statement is descriptive of their child's behavior. Higher scores represent greater levels of parental protective behaviors. A clinically significant overprotective behavior is represented by a score of 39 or greater (+1 standard deviation (SD)) [23,24], indicating that 25% of the reference group meets the criterion [25]. Criterion validity, using criterion-referenced clinical history as the basis for comparison, has been demonstrated [26]. High internal reliability ($\alpha = 0.73$) and high test–retest reliability ($r = 0.86$, $p = 0.001$) have been reported [25]. The Cronbach alpha for the current pediatric leukemia sample was 0.61.

Child Vulnerability Scale [26]: Parental perceptions of child vulnerability were assessed with this eight-item scale using Likert responses from 0 ('definitely false') to 3 ('definitely true'), where higher scores reflect greater perceived child vulnerability. Validation studies indicate that a cutoff total score of 10 reflects significant perceived vulnerability [27,23], with 24% of the reference group meeting this criterion. Adequate internal reliability has been demonstrated (Cronbach alpha = 0.74) [26] and test–retest reliability established ($r = 0.84$) [25]. The Cronbach alpha for the current pediatric leukemia sample was 0.72.

Parenting Stress Index/Short Form [28]: This is a 36-item norm-referenced parent report that produces a score on three subscales including parental distress, parent–child dysfunctional interactions, and difficult child, as well as an overall summary score. A clinical cutoff score of 90 is recommended for the Parenting Stress Index/Short Form (PSI/SF) [28], with 10% of the reference group meeting this criterion. Validity for the short form is similar to that for the full-length PSI and has been established with populations including parents of children with asthma and diabetes [29,30]. Two-week test–retest reliability of the full-length PSI with the PSI/SF is 0.95 [28]. The Cronbach alpha for the current pediatric leukemia sample was 0.90.

Care of My Child with Cancer Scale [31]: This assessed the time and difficulty associated with providing care for a child diagnosed with cancer with 34 items. Care of My Child with Cancer Scale (CMCCS) was used to assess the demands of illness-related caregiving and caregiver burden. Item responses are structured on a 5-point Likert scale for both time (ranging from >5 h/week to none) and effort (ranging from 'a great deal' to 'none'). Parents are instructed to indicate both the amount of time and the amount of effort per week required to complete such caregiving tasks. Higher scores are indicative of less care. Construct validity, internal consistency (Cronbach alpha = 0.93), and test–retest reliability ($r = 0.90$) have been established [31]. The Cronbach alpha for the current pediatric leukemia sample was 0.96.

Uncertainty Management and Coping Skills Scale for Parents [32–34]: This scale is a 25-item measure assessing parent's acquisition of uncertainty management skills. The scale was adapted from the Self-control Scale [33], Mishel's scales for adult cancer [32], and the Multidimensional Scale of Perceived Social Support [34]. Content of the Self-control Scale assesses parent utilization of cognitive reframing and problem-solving strategies. Higher scores indicated better coping. The Multidimensional Scale of Perceived Social Support assesses communication with medical staff and perception of support systems. Higher scores indicate more communication with health professionals. Mishel and colleagues [32] have reported internal consistency for the cognitive reframing, problem-solving, and communication dimensions. The Cronbach alpha for the current sample was 0.77.

Functional impairment

Child FI was assessed with the Brief Impairment Scale (BIS) [5], a 23-item measure that provides parent

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perceptions of child impairment along three domains: interpersonal relations, school/work functioning, and self-care/self-fulfillment. The BIS is intended to assess the degree to which children (ages 4–17 years) struggle in a range of activities. Responses are on a 4-point Likert scale ranging from 0 ('no problem') to 3 ('serious problem'). Convergent validity has been demonstrated by significant correlations ($r = -0.53$, 0.52, and -0.52; $p < 0.001$) between the BIS and the Children's Global Assessment Scale [5]. Concurrent validity was assessed by comparing mean scores in a group of mental health service users versus those in nonusers. Results indicated that service users demonstrated higher mean scores than nonusers. Additionally, the BIS has internal consistency (Cronbach alpha range 0.81–0.88) and demonstrated test–retest reliability. The Cronbach alpha for the current pediatric leukemia sample was 0.89.

Statistical approach

Descriptive statistics were calculated for demographic variables, parental adjustment variables, neurocognitive data, and BIS scores. Descriptive statistics were calculated using the transformed *Z*-scores for all neurocognitive data. A one-sample *t*-test was used to compare the results of neurocognitive testing with a normative population. An omnibus repeated-measures multivariate analysis of variance was employed to assess differences in impairment across the three domains of functioning (e.g., work/school, interpersonal, and self-care/self-fulfillment), and paired-sample *t*-tests were conducted as a follow-up.

Principal component analysis (PCA) with varimax rotation was employed as a data reduction technique, in order to consolidate both parental adjustment and neurocognitive measures and isolate independent constructs. Multiple regression was selected as the procedure to explore the variables of interest and their relationship to FI. Stepwise regression was selected as the analytic technique given the exploratory nature of the study and recognizing the limitation that this technique capitalizes upon chance relationships.

Results

Child and parent demographic characteristics

Participant sociodemographic characteristics are presented in Table 1. Child survivors' mean length of time since treatment termination was 5.6 years ($SD = 2.4$; range 2–10 years). Child survivors' ($n = 50$) mean age was 12 years ($SD = 2.6$; range 7–18 years). Cancer diagnoses included acute lymphoblastic leukemia ($n = 33$; 82.5% of participants), acute myelogenous leukemia ($n = 3$; 7.5% of participants), Hodgkin's lymphoma ($n = 2$; 5% of participants), and non-Hodgkin's lymphoma ($n = 2$; 5% of participants). Children receiving cranial radiation treatment comprised 8% ($n = 4$) of the sample. Ten participants were missing data on diagnosis-related and treatment-related variables (e.g., diagnosis, treatment, and time since diagnosis), as their medical records were not available for review.

Table 1. Child leukemia/lymphoma survivor demographic characteristics ($N = 50$)

Characteristic	*n*	%[a]
Child age		
Mean years of age (standard deviation)	12 (2.6)	
Range (years)	7–18	
Child sex		
Female	22	44
Child ethnicity		
Non-Hispanic, White	16	32
Hispanic	27	54
Asian	3	6
American Indian/Alaska native	3	6
Other	1	2
Child education		
Receiving special education services	8	16
No special education services	42	84
Parental marital status		
Married	27	56
Not married, living with significant other	7	14
Single	9	18
Divorced	5	10
Highest parental educational level		
High school diploma or less	16	33
At least 1 year of college	7	14
Associate degree	4	8
Bachelor's degree	11	22
Postgraduate	7	14
Professional/vocational training	3	6
Yearly household income		
<$30,000	16	32
$30,001–50,000	7	14
$50,001–70,000	9	18
>$70,000	16	32

[a]No demographic data for two participants.

Child neurocognitive deficits in survivors of leukemia/lymphoma

The comparison of survivors' neurobehavioral performance with normative reference data is summarized in Table 2. Deficits ranged from 0.5 to 1 SD below the mean. These findings are consistent with research indicating that pediatric cancer survivors demonstrate deficits across domains of neurocognitive functioning [11,35,36].

Parental adaptation

Results of parental adaptation findings are presented in Table 3. Parents of leukemia/lymphoma survivors were much more likely to experience clinically elevated overprotective behaviors but were less likely to report parental stress or perceive their child as vulnerable. Parents experiencing clinically elevated adaptation difficulties were derived from clinical cutoffs identified within the Parent Protection Scale [23],

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Table 2. Child leukemia/lymphoma survivor neurocognitive performance compared with normative group

Test	Survivor, *M* (*SD*)	*t*	Clinically elevated scores (%) in sample[a]
VMI[b]	89.50 (16.50)	−4.49**	40
Digit Span[c]	8.54 (3.20)	−3.18**	46
Trails A[d]	−0.29 (1.17)	−1.75	20
Trails B[d]	−0.96 (2.49)	−2.73**	38
Purdue Pegboard[d]			40
Right hand[d]	−0.70 (0.79)	−6.20**	
Left hand[d]	−0.92 (1.11)	−5.88**	40
Both hands[d]	−0.95 (1.10)	−6.10**	48
Verbal fluency[d]	−1.11 (1.68)	−4.65**	56

SD, standard deviation.
[a]< 1 standard deviation.
[b]Developmental Test of Visual-motor Integration, standard score (*M* = 100, *SD* = 15).
[c]Wechsler Intelligence Scales for Children, fourth edition, or Wechsler Adult Intelligence Scales, fourth edition, scaled score (*M* = 10, *SD* = 3).
[d]Z-score (*M* = 0, *SD* = 1).
[e]Controlled Oral Word Association Test raw score.
**$p < 0.01$.

Child Vulnerability Scale [26], and PSI/SF [28]. Clinical cutoff scores were not derived for other parental adjustment measures that were lacking normative data (i.e., CMCCS and Uncertainty Management and Coping Skills Scale for Parents).

Functional impairment in survivors of leukemia/lymphoma

Analysis of FI began with an examination of total raw scores for the BIS (range: 0–33; $M = 9.6$, $SD = 7.6$). Bird and colleagues [5] suggest that a cutoff score greater than or equal to 14 should be used to determine the proportion of children considered impaired and in need of services. On the basis of this cutoff, 26% of the sample demonstrated clinically significant total FI scores. An omnibus repeated-measures multivariate analysis of variance was used to examine differences across the three BIS domain raw scores (e.g., work/school, interpersonal, and self-care/self-fulfillment), with results indicating significant differences across the domains ($F(2, 48) = 3.847$, $p < 0.05$). *Post hoc* analyses revealed less impairment reported in the interpersonal domain ($M = 2.5$, $SD = 2.6$) than in the school/work domain ($M = 3.8$, $SD = 4.4$), $t(49) = -2.297$, $p = 0.026$, and the self-care/self-fulfillment domain ($M = 3.2$, $SD = 2.2$), $t(49) = -2.117$, $p = 0.039$. These results suggest that pediatric cancer survivors are rated by their parents as demonstrating the greatest levels of impairment in the school and self-care/self-fulfillment domains and less impairment in interpersonal functioning.

Factor analysis

Transformed *Z*-scores for neurocognitive measures were entered into the PCA. Parental adjustment summary scores from the Parent Protection Scale, Child Vulnerability Scale, and CMCCS were entered into a separate PCA. Coping and communication index scores from the Uncertainty Management and Coping Skills Scale for Parents and three index scores from the PSI were included in the PCA. An eigenvalue greater than 1 was used as the criterion for factor inclusion. For the neurocognitive data, results indicated a two-factor solution that accounted for 60% of total variance (factor loadings range: 0.49–0.86). A general cognitive ability factor was composed of verbal fluency skills, processing speed, working memory, and executive functioning skills. A motor control factor included tasks measuring child fine motor control and visual-motor integration skills.

For the parental adaptation data, results indicated a three-factor solution, which accounted for 69% of the variance (factor loadings range: 0.6–0.9). The parental stress factor included all subscales from the PSI/SF. Parental attitudes and perceptions surrounding their child's illness comprised a second factor (coping styles and perceptions of child vulnerability). Parental involvement/care (overprotective behaviors, communication with health providers, and the effort and time involved in child care) was the final factor. See Table 4 for factor loadings, eigenvalues, and accounted variance.

Regression analysis

The main hypothesis for this study predicted that child neurocognitive deficits would be predictive of FIs. A secondary hypothesis predicted that poor parental adjustment would contribute to FI. Four separate regression analyses were run in which the outcome variable of interest included the BIS total score as well as the three separate domain scores

Table 3. Pediatric leukemia/lymphoma survivor parental psychosocial adjustment

Parental adjustment measure	*M* (*SD*)	Range	Clinically elevated scores (%) in sample
Parent Protection Scale	33.0 (5.9)	19–48	30
Child Vulnerability Scale	4.0 (3.0)	0–13	6
Parenting Stress Index/Short Form	64.5 (17.3)	39–112	8
Care of My Child with Cancer	63.3 (12.6)	22–75	NA
Uncertainty Management and Coping Skills Scale for Parents, coping subscale	151.1 (34.4)	31–200	NA
Uncertainty Management and Coping Skills Scale for Parents, communication subscale	17.5 (3.0)	4–20	NA

NA, not applicable (i.e., no reference group criterion); SD, standard deviation.

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Table 4. Factor analysis results

	Neurocognitive testing	
	Factor 1: general cognitive	Factor 2: motor
Beery Visual-motor Integration	0.439	0.490
Digit Span	0.763	0.010
Trails A	0.466	0.401
Trails B	0.716	0.321
Purdue, right	−0.219	0.803
Purdue, left	0.212	0.773
Purdue, both	0.343	0.782
Verbal fluency	0.860	0.032
Eigenvalue	3.327	1.48
% variance	30.653	29.457
Total variance		60.11

	Parental adaptation		
	Factor 1: parental stress	Factor 2: parental attitudes/perceptions	Factor 3: care/involvement
Care of My Child with Cancer	−0.330	0.324	−0.682
Coping	0.123	0.770	0.202
Communication	−0.073	0.292	0.606
Parent Protection Scale	−0.121	0.310	0.776
Child vulnerability	0.132	0.790	0.086
Parental stress, dysfunctional interactions	0.766	0.133	0.008
Parental stress, parental distress	0.877	−0.025	0.090
Parent stress, difficult child	0.877	−0.25	0.090
Parental stress, total summary	0.877	−0.025	0.090
Eigenvalue	3.279	1.855	1.107
% variance	35.527	17.163	16.651
Total variance			69.341

(e.g., interpersonal, school/work, and self-care/self-fulfillment). Demographic information and neurocognitive and parental adjustment summary scores that emerged from the factor analysis were entered stepwise, in three different blocks, with demographic variables including child age, sex, ethnicity, and household income entered as the first block. Results indicated that household income accounted for approximately 12% of the variance in BIS scores ($R^2 = 0.116$, $F(1, 45) = 5.877$, $p = 0.019$, $B = -0.713$, $p = 0.019$). This relationship was in the expected direction and suggested that lower household income was associated with higher FI. Parental stress accounted for a significant amount of variance in total BIS scores not already accounted for by household income (R^2 change = 0.134, $F(1, 44) = 7.840$, $p = 0.008$). This complete model, which included household income and parental stress as predictors, was significant and accounted for 25% of the total variance in FI ($R^2 = 0.249$, $F(2, 44) = 7.305$, $p = 0.002$). Subsequent regression analysis sought to determine whether this relationship would occur for child BIS domain scores. Child and parental stress predicted a significant amount of the variance in child school/work impairment ($R^2 = 0.258$, $F(1, 44) = 7.522$, $p = 0.009$, $B = 0.361$, $p = 0.013$). Parental stress predicted child interpersonal impairment ($R^2 = 0.102$, $F(1, 45) = 5.123$, $p = 0.028$, $B = 0.864$, $p = 0.028$). Child age predicted self-care impairment ($R^2 = 0.222$, $F(1, 45) = 12.82$, $p = 0.001$, $B = 0.406$). These findings indicate different sources of contribution to child-reported BIS domain scores.

Discussion

Previous research has revealed that pediatric cancer survivors are at risk for a variety of late effects following diagnosis and treatment, including physical malfunctions, chronic health conditions, neurocognitive deficits, and psychosocial problems [2–4]. Late effects have been studied in isolation, and the extent to which these converge and impact children's day-to-day living has been unknown. The current study introduced a novel approach to the study of pediatric cancer late effects by measuring impairments across functional domains and by incorporating both neurocognitive deficits and parental stress as potential explanatory mechanisms of FI.

On the basis of the distribution of scores on the BIS, the results indicate that survivors demonstrate a range of functional deficits in school/work, interpersonal relations, and self-care/self-fulfillment. The observed proportion of FI was substantial, as 26% demonstrated clinically elevated scores. Although the BIS is a recent outcome measure, the observed proportion in this pediatric sample is sizeable and

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suggests that the risk of FI is elevated for survivors of pediatric leukemia/lymphoma. Moreover, we observed that the proportion of impairment in self-care/self-fulfillment and school/work domains evidenced greater impairment relative to social interpersonal functioning. Although we observed an increased risk for FI, findings indicated that parental adaptation, rather than neurocognitive deficits, was associated with child FI. Thus, our initial hypothesis that neurocognitive deficits predict FI was not supported by the data.

Observations of neurocognitive deficits in this study were, however, consistent with previous research. Childhood survivors demonstrated significant neurocognitive deficits, as evidenced by their below normative levels of performance. Contrary to expectations, however, there was no relationship between these distinct neurocognitive deficits and overall FI. This finding can be understood upon closer examination of neurocognitive performances. Although results indicated that survivors demonstrated below normative levels of neurocognitive functioning, performances still remained within the average range. Given this, neurocognitive deficits may not have been so severe as to impact day-to-day functioning. In contrast, high levels of parental stress were predictive of higher levels of FI. This finding is consistent with previous research that has established a relationship between poor parental adaptation and other child psychosocial outcomes in pediatric cancer [37–39]. Although results suggest a significant relationship between parental stress and FI, results indicate that parents of childhood cancer survivors demonstrate adequate psychosocial adjustment. It may be that parents who have children who are more functionally impaired consequently demonstrate higher levels of stress. Findings further suggest a significant relationship between socioeconomic status, as measured through household income, and FI. This is consistent with previous research that has identified socioeconomic status as a risk factor for poor outcomes in pediatric cancer survivors [40].

These findings address the impact of late effects on day-to-day functioning in a large number of survivors. As such, the routine assessment of FI is warranted in pediatric cancer survivors. Whereas family stress associated with a child's cancer diagnosis has been frequently reported [41], increased parental stress *after* treatment may be a marker to identify children at heightened risk for FI. In addition to routine evaluation, the results suggest that broader functional domains, especially school and self-care domains, should be considered when identifying potential targets for psychosocial interventions.

This study represents a novel approach to the study of late effects, although there are several limitations. Although this sample of pediatric leukemia/lymphoma survivors demonstrated substantial rates of FI, no control group was employed, making the determination of whether the rates of FI in this population are significantly different from those in other pediatric illnesses impossible. Moreover, common method variance may account for the observed correspondence between parental stress and child FI, as parents were reporting on their own stress as well as their perceptions regarding their child's impairment. Parental stress could have had an undue impact upon perceptions of child FI. Moreover, it may be necessary to assess FI from several sources (e.g., teachers) to accurately gauge the impact for cancer survivors, much like what is carried out in the workup for attention disorders. Given these limitations, the current findings should be interpreted with caution. Subsequent research should include additional markers of FI including others' observations of the child. Future research should include healthy controls in order to capture the complex manner in which FI affects survivors. Finally, the study was limited by a small sample size.

The current study represents a first step in understanding how late effects aggregate to create functional deficits. Future research needs to provide details on the nature and severity of FI, which could be accomplished by broadening the inclusion criteria to a range of pediatric cancer diagnoses. Over 75% of the variance in FI remained unaccounted for, indicating the need for future research to identify other salient factors associated with FI. On the basis of these findings, additional parental factors that might predict child FI include direct measures of parental depression, anxiety, and posttraumatic stress symptoms [39,42–44].

Conclusion

Research regarding functional outcomes of pediatric cancer survivors has been rather limited, as neurocognitive and parental adaptation late effects have not been examined in relation to children's possible FI. This study addressed children's FI and found that, according to parent reports, survivors experience impairment in school/work, interpersonal relations, and self-care/self-fulfillment. Neurocognitive deficits and parental adaptation did not significantly predict FI; however, a general measure of parental stress was associated with children's functional outcomes. This study offers preliminary evidence suggesting that research exploring characteristics of FI and risk factors among all pediatric cancer survivors is warranted.

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Conflict of interest

The authors have declared that there is no conflict of interest.

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