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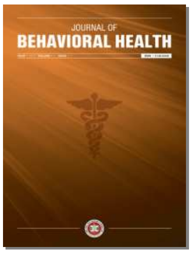

Original Research

Parent Involvement and Neurocognitive Functioning in Childhood Cancer Survivors.

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Abstract

Background: Despite speculation that environmental factors, such as family factors, may influence functional outcomes in children who have received neurotoxic treatments for cancer, there has been minimal research in this area. The importance of parental behaviors in support of their child's learning and cognitive performance has been well-established across a wide range of populations and ages. To date, no study has investigated these parental behaviors in reference to outcomes in children at risk for cancer-related neurocognitive dysfunction. We hypothesized that parental "pro-learning" behaviors would be positively associated with cognitive outcomes in children diagnosed with cancers involving the Central Nervous system (CNS) or who have had intensive CNS therapy.
Methods: Relationships between parental behaviors and their child's cognitive performance (IQ) were evaluated using a revised version of an assessment tool developed to identify the presence and frequency of parenting behaviors that promote learning. A sample of 56 parents of childhood cancer survivors ages 6 through 18 and their children were evaluated. Associations between various clinical and parental factors were examined.
Results: ANCOVA results showed significant differences in IQ performance based on level of parent involvement for children older than age 3 years at cancer diagnosis. IQ scores for children with higher levels of parent pro-learning behaviors were approximately 12 points higher compared to lower levels. Child's age at diagnosis, cranial radiation, and parents' pro-learning behaviors at home were significant predictors of child FSIQ in a multivariate regression model. Parent socioeconomic status was significantly associated with parents' belief in their ability to help their child with learning and school success.
Conclusions: The present findings provide preliminary support for the hypotheses that environmental factors, such as parent involvement, may be associated with functional outcomes in children at risk for cancer-related neurocognitive dysfunction, and highlight the need for more research in this area.

INTRODUCTION

While the incidence of childhood cancer is low compared to adult cases, advances in medical treatment have led to dramatically improved survival rates such that the number of survivors is now substantial and increasing[1]. With increased survival rates, quality of life and functional outcomes are important considerations, especially because the children are at significant risk for long-term side effects, including cognitive impairments, secondary to disease and treatment-related factors [2]. Cancers or treatment for cancer that involve the Central Nervous System (CNS) are associated with recognized risks of neurocognitive deficits, and cranial radiation therapy is associated with the most deleterious cognitive effects [3-4]. Child's age at diagnosis and treatment has been established as an important clinical factor, with younger age predicting more adverse cognitive late effects [5-6]. While specific underlying neurocognitive functions (e.g. attention skills) are impacted, the daily manifestations of these typically are in intellectual and academic performances, particularly within the educational settings. Such impairments are of concern as they can have far-reaching consequences on educational, occupational, and functional attainments into adulthood [7-8].

Clinical trials to evaluate the effectiveness of varied intervention approaches to treat the neurocognitive and behavioral late effects, including cognitive remediation and pharmacological management, have been initiated [9-10]. While these approaches are encouraging, there are limitations ranging from medication side effects associated with pharmacotherapeutic intervention to the considerable personnel and financial requirements associated with clinic-based, therapist-delivered cognitive remediation programs [11]. Furthermore, benefits have been mostly modest thus far for the subgroups of responders [9-10]. The need for alternative or complementary approaches, particularly those that are preventive in nature, is apparent to those immersed in the field.

Understanding the environmental factors that may mitigate adverse impacts of neuro-toxic treatments on cognitive and functional outcomes is a helpful initial step in designing and evaluating prevention trials with a behavioral component. Unfortunately, there is a dearth of research regarding such influences in the childhood cancer population. Support for this approach, however, is evident in recent studies from the neuropsychological and brain injury literature that suggest environmental factors, such as family influences, are significant predictors of children's cognitive outcomes after acquired traumatic brain injury (TBI)[12-16]. Recovery in math skills was enhanced in children with severe TBI who were from less stressed families relative to no change in children from families with high stress. Additional research has found that socioeconomic disadvantage was associated with more behavioral sequelae in children with TBI. Statistically significant and clinically meaningful differences in academic and behavioral performance were demonstrated in a study of the moderating impact of family environment in children with traumatic brain injury[12]. Given that post-injury progress in children with TBI is influenced by family factors, we considered the possibility of a similar association in the trajectory for children treated with neuro-toxic treatments for cancer.

A possible mechanism underlying the more positive outcomes in TBI children from less stressed families pertains to parent support. Specifically, parents who are experiencing high stress or are from disadvantaged circumstances may have limited resources to invest in efforts to enhance the child's recovery, or they may be burdened by other stressors that distract them from remedial efforts [12]. Enriched environments may also provide more opportunities to enhance behavioral adjustment and learn compensatory skills. Specifically, in the educational literature it is known that when parents constructively interact with their children's learning behaviors and support the home learning environment, children achieve better academic outcomes. Parents' helping or specific "pro-learning" behaviors at home often make the difference between children who do poorly in school and those who do well [17-18]. These behaviors include direct monitoring of, instruction and assistance with, and verbal encouragement of academic progress and homework; parent communication with teachers about their child's learning; seeking out opportunities to promote child's cognitive development; and providing stimulating activities at home [19-25].

Based on these findings from the educational literature, which demonstrate the importance of parental behaviors and involvement in their child's education for cognitive and academic achievement across a wide range of populations and ages, we hypothesized that parental behaviors would be associated with cognitive outcomes in survivors of childhood cancer. We conducted an exploratory study to examine associations between parent involvement and cognitive outcomes in pediatric survivors of CNS-involved cancer and/or treatments (e.g. Leukemia, brain tumor, etc). Specifically, we hypothesized that children with parents who engaged in higher levels of "pro-learning" behaviors would have better cognitive performance than children with similar medical histories but lower levels of parental involvement. We also explored associations between clinical and demographic factors and selected parenting behaviors and beliefs.

METHODS

Participants

The sample was recruited at Children's Hospital Los Angeles over a pre-determined 6 month period for this IRB approved study. Families were eligible if their child was between the ages of 6 and 18 with CNS-involved cancer or treatment, in remission or with stable disease, and enrolled in school. Diagnoses included brain tumors (*n* = 29; 51.7%), leukemia (*n* = 21; 37.5%), and non-Hodgkin's lymphoma (*n* = 6; 10.7%). About two-thirds of the children (*n* = 38;

67%) received chemotherapy without cranial radiation; 18 (32%) received cranial radiation (mean total dose = 4841cGy; *SD* = 1400).

A total of 56 parents (47 mothers and 9 fathers of 21 girls and 35 boys) participated, with the following ethnic distribution: 64% Latino, 23% Caucasian, 1% African-American, 1% Asian, and 8% Multi-racial. All parents had some English fluency; however, twenty-seven parents (48.2%) spoke mostly Spanish at home while 29 (51.8%) spoke mostly English at home. These two language groups did not differ significantly in child clinical and demographic factors such as mean age at testing, age at diagnosis, diagnosis type, and dose of radiation. The mean child age at testing for the total sample was 11.19 years (*SD* =2.85); average age at diagnosis was 4.52 years (*SD* = 3.19). The majority of children were from families with married parents (75%). In terms of education, 70% of the parents had a high school education or less, while 30% were college educated.

Procedure

Invitation letters were mailed to eligible parents, followed by phone or in person contact to recruit and coordinate for the study. Study assessments were coordinated around the children's scheduled medical appointments at the hospital to increase convenience. Each parent participant completed the self-report parent measure, while their child was administered the Wechsler Abbreviated Scale of Intelligence,[29] a nationally standardized instrument that yields a Full Scale IQ (FSIQ), Verbal Scale IQ (VSIQ), and Performance Scale IQ (PSIQ). The IQ score was deemed to be an appropriate estimate of general cognitive functioning as it is highly correlated with educational achievement and has featured prominently in school planning for children with a wide variety of developmental disabilities and learning problems[30]. Parents received $25.00 and children received $10.00 for their participation.

Parent Measure

Parent Belief and Behaviors Questionnaire (PBQ) plus the three additional subscales, Parent Cancer Perception, Parent Self-Efficacy, and Future Expectations/Beliefs is an 84-item, likert-scale, parent-report measure developed by the first three authors to measure parents' participation in "pro-learning" behaviors that are conceptually and empirically associated with cognitive and academic promotion for children.

The PBQ included items adapted from checklists assessing parent involvement in intellectual and cultural activities developed by Grolnick and Slowiaczek[21] and parenting variables used in research studies by the National Center for Education Statistics[33]. The items assessed the level of parental engagement in specific pro-learning behaviors, such as helping with homework, building their child's cognitive skills, having contact with their child's school, and utilizing community resources in an effort to promote their child's cognitive and academic development. In addition, this questionnaire assessed parent expectancies regarding their child's future capacities and achievements, as well as parent perceptions of their child's current cognitive and school functioning.

The original PBQ consisted of 6 theoretically derived scales: Parents' Pro-learning Behaviors at *Home,* Parents' Pro-learning Behaviors regarding *School,* Parents' *Help-Seeking* Behaviors to promote child learning*,* Parents' perception of child's *Current Functional Status,* and Parents' *Expected Occupation of* child's educational attainment [31]. The internal reliability coefficients for the majority of these subscales in a community sample of 121 parents of typical/healthy children between the ages of 6 and 18 years old ranged from reasonably good (α = .71) to very good (α = .90) [31]. (**Table 1).**

For the current study, additional items were added to the PBQ to assess parent beliefs about cancer and its effects on learning and cognitive skills, (labeled the Parent "*Cancer* Perception" scale), and parent's belief in their ability to help their child with learning and school success (labeled the "Parent Self- *Efficacy*" scale), and future expectations (label the *Future Expectations/Beliefs* about their child's ability to live and thrive independently. Sample items are presented in **Table 2**.

This modified version of the PBQ is referred to as PBQ-revised (PBQ-R). Reliability analyses were conducted using the current sample for the six original subscales, plus the two additional subscales, Parent *Cancer* Perception and Parent Self-*Efficacy*. Results were found to be generally similar to the community sample, with most subscales having good reliability, with the exception of Parent *Help-Seeking* Behaviors, which demonstrated poor reliability (α = .36) (**Table 1**). Total scale reliability was good for both the community (α = .83) and the clinical sample (α = .88)[31-32].

The dimensionality of the conceptually-derived scales was also evaluated for the current clinical sample using a principal components factor analysis with Varimax (orthogonal rotation). An examination of the Kaiser-Meyer Olkin measure of sampling adequacy indicated the sample was factorable (KMO=0.58). The rotated solution yielded three components with eigen values >1.0 that accounted for 67.43 percent of the total variance. Three scales of parental pro-learning behaviors, *Home, School*, and *Help-Seeking,* loaded on the same factor, and were broadly labeled the "Parental Involvement" scales. Three other scales measuring parent perceptions of the child and beliefs about the future, *Functional Status*, *Expectation Occupation*, and *Cancer*, all loaded on a separate factor, and were broadly labeled the "Parental Perception" scales. A third factor included the parent self- *Efficacy* and *Future Expectations/Beliefs* scale. See Table 2

Table 1. Scale Reliabilities for the Parent Belief and Behaviors-Revised Questionnaire (PBQ-R)

		Cronbachs's Alpha		
Scale Name	**Number of Items**	**Community Sample N=121**	**Cancer Sample N=56**	**Description**
Parent Involvement Scales				
Parents' pro-learning behaviors at Home	12	.83	.85	Parents' pro-learning behaviors at home to promote learning and school success in their child, e.g., checking homework.
Parent's pro-learning at School	19	.90	.77	Parents' behaviors at the child's school, e.g. talk to teacher about child's academic progress.
Parents help-Seeking Behaviors	5	.71	.36	Parents' behaviors to seek out information and resources to facilitate child's learning and development, e.g., seeking a tutor to help the child, parenting books, etc.
Parent Perception Scales				
Child's current functional Status	3	.61	.57	Parent's perceptions of the child's current cognitive and functional skills.
Expected Occupation	20	.75	.84	Parent's expectations about the child's future educational attainment.
Cancer Perceptions	11	n/a	.87	Parents perception about cancer related issues.
Parental Self-Efficacy	12	n/a	.64	Parent belief in ability to help their child with learning and school issues.
Future Expectations/Beliefs	9	.71	.86	Parent's beliefs about the child's ability to live independently and thrive as an adult.
Other	10	.63	.70	Additional parent behaviors not included in Home, School, or Help-Seeking, e.g., cooking with the child or using the computer with the child.

Table 2. *Sample Items from the PBQ-R Scales*

Parent Involvement Scales
Pro-learning Behaviors at Home Scale Sample Items: *How often do you...* Check to make sure your child's homework is complete. Discuss your child's school progress with your child. Practice cognitive or academic concepts with your child, such as multiplication tables or vocabulary building words.
Pro-learning Behaviors at School Scale Sample Items: *How often do you...* Talk with your child's teacher about his/her school progress. Attend open house or other events at your child's school. Volunteer to help out in your child's classroom.
Parent Help-Seeking Behaviors Scale Sample Items: *How often do you...* Ask teachers or school staff about things you can do to support what is learned at school. Seek out reading materials to guide you in your parenting skills. Ask your child's doctor or other health care professional how to improve your child's thinking, memory, or attention.
Parent Perception Scales
Current Functional Status Scale Sample Items: *Please rate your child's ability to...* Your child's ability to make friends and socialize at age level. Your child's ability to do the schoolwork that is expected at his/her grade level. Your child's ability to get along with his/her brothers, sisters, and family members.
Expected Occupation Scale Sample Items: *Please rate your educational hopes and goals for your child....* Graduate from high school. Graduate from college. Complete trade school.
Cancer Scale Sample Items: *Please rate the following...* How much do you currently know about the school and learning needs of children diagnosed with cancer? How much do you know about your own child's school and learning needs since becoming ill? How much have your child's school and learning skills changed since his/her cancer diagnosis?
Efficacy Scale Sample Items: *Please rate the following...* I can do things to help my child's school and learning problems. I am able to talk with my child's teacher about my child's needs and problem areas. I feel that I am good at finding resources within the community to help my child (i.e., community centers, tutoring, etc.).
Future Expectations/Beliefs Scale Sample Items: *Please rate your beliefs about the following...* In the future, my child will be able to live independently on his/her own and become a self-sufficient adult. Your child's ability to get married and has his/her own family. Your child's ability to help the family by doing chores and helping around the house.
"Other" Scale Sample Items: *How often do you...* Cook with your child. Talk to your child about current events. Play board games with your child, such as Memory or Monopoly.

RESULTS

Children's IQ Scores

Children of the predominantly English-Speaking and predominantly Spanish-Speaking parents were compared on their mean IQ scores using two sample t-tests. There was no significant difference between the two groups on Full Scale IQ, Verbal IQ, or Performance IQ. The mean IQ scores for the total sample placed within the lower range of the average range (FSIQ = 92.37 91, *SD* = 16.71; VSIQ = 92.73, *SD* = 18.80; PSIQ = 92.98, *SD* = 15.00).

Parent Involvement and Child's Cognitive Functioning (IQ)

Analyses of Covariance:

Descriptive examination of the parent involvement scales showed a skewed distribution, even after various transformations of the data, as the parents tended to rate themselves highly on parental involvement. A median split was used to divide the *Home* scale (12 items) into "low" and "high" involvement groups. The same was done for the other two parent involvement scales of "*School*" and "*Help-Seeking*". A series of one-way ANCOVAs were then performed to assess the hypothesized relationships between parent pro-learning behaviors on behalf of their child and the child's cognitive outcomes. Each parent involvement scale ("*Home*", "*School*", and "*Help-Seeking*") was used as the independent variable with child IQ as the dependent variable. Prior to running these analyses, the distribution of children whose treatment had included cranial radiation was examined in both groups for all three scales and found not to be statistically different. In consideration of the existing literature regarding the influence of the child's age at cancer diagnosis and treatment on long-term neurocognitive outcomes, the analyses were run using child's age at diagnosis as a covariate. The ANCOVA results showed trends for differences in the child's IQ performance based on "high" versus "low" parent involvement on the *Home* scale for FSIQ and PSIQ, but not for VSIQ. See **Table 3**. Similar effects were not found for the other two parent involvement scales.

In consideration of the existing research which shows that very young children who undergo CNS-directed treatments (chemotherapy, radiation, etc) experience more severe brain injury, we reasoned that environmental resources would minimally mitigate IQ outcomes in such a subgroup, and therefore repeated the ANCOVA restricting the sample to only children who were older than age 3yrs at initial diagnosis (*n* = 34). Results demonstrated significant differences in IQ scores between "high" and "low" pro-learning behaviors on the *Home* scale (See **Table 4**). IQ scores for children whose parents had high pro-learning levels were consistently in the average range, while IQ scores for children with low parent pro-learning levels were approximately 12 points lower and placed in the low average range relative to the normal reference group. Level of parent behaviors on the *School* and *Help-Seeking* scales did not show similar effects on the child's IQ scores.

Table 3. Differences in Child IQ Scores based on High and Low Parent Involvement at Home Controlling for Age at Diagnosis.

	Standard Scores			ANCOVA		
	n	*M*	*SD*	*F*	*p*	η^2
FSIQ						
High Parent Involvement	28	95.93	17.43	3.49	.067	.062
Low Parent Involvement	28	88.82	15.46			
VSIQ						
High Parent Involvement	28	96.07	19.23	2.45	.12	.044
Low Parent Involvement	28	89.32	18.00			
PSIQ						
High Parent Involvement	28	95.96	16.69	3.03	.086	.055
Low Parent Involvement	28	90.00	12.77			

$^*p < .05$. $^{**}p < .01$.

Table 4. Differences in Child IQ Scores based on High and Low Parent Involvement at Home Controlling for Age at Diagnosis for Children ≥ 3 years at Diagnosis.

	Standard Scores			ANCOVA		
	n	*M*	*SD*	*F*	*p*	η^2
FSIQ						
High Parent Involvement	14	100.78	12.67	9.29	.005**	.23
Low Parent Involvement	20	87.15	15.07			
VSIQ						
High Parent Involvement	14	100.29	12.98	6.18	.018*	.17
Low Parent Involvement	20	87.35	19.33			
PSIQ						
High Parent Involvement	14	100.79	14.90	7.66	.009**	.20
Low Parent Involvement	20	88.75	11.90			

$*p < .05$. $**p < .01$.

Regression Analyses

Multiple regression analyses were then conducted to assess the relationship between cognitive outcome, using FSIQ as the criterion, and various potential predictors. Specifically, the child's age at diagnosis, radiation (yes (n = 12) vs. no (n = 21)), and the parent involvement *Home* scale, were entered as predictors. The regression model with this combination of three predictors was significant, adjusted $R^2 = .31$, $F(3, 29) = 5.81$, $p = .003$, explaining 31% of the variance in child FSIQ. Cranial radiation ($\beta = -.40$, $p = .029$, age at diagnosis ($\beta = .45$, $p = .010$) and the *Home* scale ($\beta = .32$. $p = .053$) were all significant predictors of child FSIQ.

Correlation Analyses

Pearson's correlations evaluated the associations between clinical and demographic factors and scores on the parenting scales for the entire sample (See **Table 5**). There was a significant negative correlation between child's current age and parent's engagement in pro-learning behaviors at home and at school, suggesting that parents are more actively engaged in such activities for younger aged children. Similar negative correlations were observed between the parent behavior scales and child age at diagnosis, where parents of children diagnosed at a younger age reported higher frequency of pro-learning behaviors at home and school on behalf of their child. There was a significant correlation between mother's socioeconomic status and parenting efficacy, suggesting that parents from higher SES backgrounds reported greater sense of self-efficacy in their ability to help their child with learning and school activities. Radiation was negatively correlated with parent's perception of child's current behavioral functioning and with their future expectations of the child. This is consistent with what is known about the adverse effects of cranial radiation on developmental abilities, where children who received radiation are at higher risk for developmental disruption compared to those who did not receive it.

Table 5. Correlations Between Clinical and Demographic Factors and Parent Scales

	Current Age	Age at Diagnosis	Cranial Radiation	Diagnosis	Maternal SES
Parent Pro-Learning Behaviors at *Home*	-.517**	-.355*	-.149	-.050	.055
Parent Pro-Learning Behaviors at *School*	-.306*	-.274*	-.136	-.211	-.709
Parent *Help Seeking* Behavior	-.218	.005	.013	.030	-.012
Parent Self-*Efficacy*	-.003	-.105	.077	.022	.271*
Parent *Future Expectations* of Child	-.239	.035	-.462**	.195	-.239
Parent Perception of Child's *Current Functioning*	.001	.166	-.311*	.108	.001

$* p < .05$, $** p < .001$

DISCUSSION

The present findings provide preliminary support for our hypotheses that parent behaviors and perceptions are associated with cognitive functioning in children with CNS-involved cancer and/or treatment. The findings of significant differences between high versus low levels of parent involvement (i.e., the "Pro-learning behaviors at *Home*" scale) and cognitive performance (i.e. IQ score) suggest the potential for environmental factors to influence neurocognitive or functional outcomes. This potential to positively influence the child's functional outcomes despite possible CNS injury is consistent with findings from the learning disability and traumatic brain injury literature, but appears to be the first such report in a sample of childhood cancer survivors. The specifics of this potential require further investigation, ranging from the need to identify the critical elements necessary for a positive impact to understanding the subgroups for whom this potential is feasible. In our study, we observed significant differences in IQ scores based on level of parent involvement only when the sample was restricted to children who were older than age 3 yrs at diagnosis. This suggests that environmental factors such as parent involvement may be an influential factor only if the brain injury is to a relatively less severe degree. Our data on the associations between child age and parent involvement factors also hint at a possible reciprocal influence such that child factors (e.g. age), may influence parents' behaviors.

Limitations of the study include the possibility of reporting bias as the parent measure was self-reported rather than observed. Also, while the predictive validity of our parent questionnaire has been supported by data from a separate sample of childhood cancer survivors which found that higher levels of "pro-learning behaviors" were significantly associated with lower adaptive problems as measured by the Behavior Assessment System for Children (BASC)[33-35], we acknowledge that the construct validity is not yet extensively documented. Of note, the self-report of pro-learning behaviors at home scale was found to be a sensitive measure in a recently completed pilot intervention trial which aimed to increase pro-learning parenting behaviors using educational training provided to parents of children with cancer-related cognitive dysfunction [36-37]. Also, the findings of a relationship between IQ performance and selected parenting factors in this study tend to further support the validity of the measure.

The families in this study chose to participate as it was convenient to do so because they were scheduled to be at the hospital for their child's medical appointment, and so it is possible that the sample may not represent the full spectrum of families with childhood cancer survivors. Further, the present study relied upon standardized intelligence testing; future investigations should incorporate classroom performance or daily living adaptive measures, which may more closely represent "functional" outcomes. At the same time, it will also be useful to examine neurocognitive outcomes with more specific tools than the abbreviated IQ measure employed in this study.

Along with small sample size, another limitation of this study is that it is cross-sectional and assesses these relationships after the time period in which long term neurocognitive side effects typically emerge. A prospective, longitudinal assessment of how environmental factors, including specific pro-learning parent behaviors, influence the development and trajectory of cognitive late effects in a sufficiently powered sample is warranted. Despite the limitations, the study provides data that has not previously been reported in this patient group, and the results could serve as a preliminary step toward hypothesis-driven research to further examine the potential role of environmental factors, such as parenting practices, to optimize functional outcomes in survivors of childhood cancer.

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