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## Cognitive, Adaptive, and Psychosocial Functioning of Infants and Toddlers Treated for Cancer

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COGNITIVE, ADAPTIVE, AND PSYCHOSOCIAL FUNCTIONING OF INFANTS  
AND TODDLERS TREATED FOR CANCER

by

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A Thesis

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## Abstract

Background: Many children with cancer are diagnosed during infancy and toddlerhood (<3 years of age), potentially resulting in disrupted and/or missed developmental opportunities. Diagnoses that affect the central nervous system are among the most common and are associated with an increased risk of neurocognitive problems. Unfortunately, there is a paucity of research regarding the functioning of very young children treated for cancer. The objective of this study was to describe the cognitive, adaptive, and psychosocial functioning of infants and toddlers with cancer evaluated at a hospital-based psychology clinic. Method: Data from 32 infants and toddlers with cancer and/or immunological disorders ( $M_{\text{age}} = 24.6 \pm 6.6$  months; 56.3% male) who completed clinically-referred assessments in a hospital psychology clinic from 2010-2015 were abstracted. Indicators of cognitive, adaptive, and psychosocial functioning were collapsed across measures prior to analyses. Results: Infants and toddlers were 13.32 months post-diagnosis ( $SD = 9.12$ , range 0 - 34.44 months) with a majority off-therapy at the time of assessment (59.4%). The majority of patients had brain (28.1%) or solid tumors (46.9%). Mean early cognitive scores were significantly below expectations,  $t(24) = -9.02$ ,  $p < .001$ . Adaptive functioning,  $t(27) = -7.03$ ,  $p < .001$  and some indices of psychosocial functioning were also significantly below expectations. Differences in early cognitive functioning were present based on diagnostic category but not treatment status. Conclusion: Infants and toddlers with cancer appear to be at significant risk for weaknesses in cognitive, adaptive, and psychosocial functioning, though some domains within psychosocial functioning are preserved. The surprising severity of deficits warrant the need for further investigation and consideration of this population to ensure optimal functional development.

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## Cognitive, Adaptive, and Psychosocial Functioning of Infants and Toddlers Treated for Cancer

Infancy and toddlerhood mark the largest developmental changes during the human lifespan, concurrent with a time of significant brain development (Casey, Giedd, & Thomas, 2000; Jernigan, Baaré, Stiles, & Madsen, 2011; Stiles, 2008). Specifically, very young children rapidly acquire skills across cognitive, adaptive and psychosocial domains. To achieve optimal development, infants and toddlers require predictability, consistency, reciprocal interactions, warmth, perceived security, and opportunities to explore and experiment within their environment (National Research Council and Institute of Medicine, 2000). Recent advances in neuroscience have increased understanding of the pivotal role of early social interactions in brain development (Meltzoff & Kuhl, 2016). Interruption and insult during this critical period, such as a cancer diagnosis and required treatments, have the potential to result in significant and long-lasting effects (Anderson & Kunin-Batson, 2009; Olsson, Perrin, Lundgren, Hjorth, & Johanson, 2014).

Many children with cancer are diagnosed and treated during infancy and toddlerhood (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). As such, the ongoing development of these very young children may be disrupted due to a number of factors, including isolation related to treatment, prolonged stays in the hospital, medical procedures, and removal from typical routines. This disruption may have the consequence of diminishing those essential needs for social interaction, exploration, and predictability which may impact later development (see Harman, Wise, & Willard, 2017 for a review). Fortunately, advances in treatment have dramatically increased the survival rates of children with cancer over the past few decades (Abdullah, Qaddoumi, & Bouffet, 2008). Subsequently, there has been an increased awareness of

the need to understand the impact of treatment and diagnosis on the social, emotional, behavioral, and overall developmental functioning of children with cancer.

Very young age at diagnosis is typically considered a significant risk factor for development of later adverse problems (Mulhern et al., 2001). This is particularly true for neurocognitive late effects in children with diseases and treatment that affect the central nervous system (CNS; e.g., brain tumors, acute leukemias) (Moleski, 2000; Mulhern, Merchant, Gajjar, Reddick, & Kun, 2004). Despite these risks, there is a paucity of literature on the cognitive and psychosocial functioning of infants and toddlers treated for cancer. Existing research has focused mainly on the potential for preserving neurocognitive functioning of young children under the age of three through the avoidance of cranial radiation therapy (Dhall et al., 2008; Lafay-Cousin et al., 2009). Limited work has also focused on the functional outcome of young children treated for brain tumors. Specifically, Stargatt and colleagues (2006) investigated the cognitive and adaptive development of children diagnosed with brain tumors during infancy and found delays in multiple domains of adaptive function at diagnosis along with cognitive deficits during follow-up at age 5 and 6. Similarly, Bornstein and colleagues (2012) prospectively studied the neurodevelopment of very young children with non-CNS affecting cancers (i.e., retinoblastoma, neuroblastoma, acute leukemia) and found deficits within motor, mental, and language skills compared to healthy controls. Several recent papers (Fay-McClymont et al., 2017; Willard, Leung, Huang, Zhang, & Phipps, 2014; Willard et al., 2014) have also highlighted the potential vulnerabilities of this age range for deficits or declines in cognitive and adaptive functioning. Specifically, Willard and colleagues (2014) longitudinally studied infants and toddlers with retinoblastoma through their first 5 years of life and observed significant declines over time in developmental and adaptive functioning (e.g., socialization, communication, and motor skills).

Similarly, in a prospective longitudinal study, patients treated with total body irradiation demonstrated declines in cognitive functioning (e.g., IQ) 1, 3, and 5 years following stem-cell transplant (Willard, Leung, et al., 2014). Moreover, a retrospective study of young patients with medulloblastoma treated with chemotherapy and irradiation sparing approach demonstrated deficits across domains in a quarter of the sample regardless of prevention efforts via treatment strategy (Fay-McClymont et al., 2017). Despite the salient findings of these few studies providing evidence that very young children are at risk, there is still very limited research regarding the cognitive and psychosocial functioning of this population. Subsequently, there is a critical need for a more explicit focus across domains. Specifically, cognitive, communication, adaptive behavior, social, emotional/behavioral, and motor skills are all areas of functioning that could be affected by the developmental disruption of cancer treatment and thus lead to delays or deficits.

Given the critical nature of infancy and toddlerhood on later development and the limited cancer-specific research on this age range, the objective of this paper was to characterize the cognitive, adaptive, and psychosocial functioning of very young children (under the age of three years) treated for cancer. Using a clinical sample of children evaluated within a hospital-based psychology clinic, we hypothesized that those patients with CNS-affecting diagnoses (e.g., brain tumors) would demonstrate greater deficits in functioning across domains, though we also expected that most children assessed would demonstrate emerging weaknesses in at least some domains of functioning.

Spelled out: Consistent with previous albeit limited studies examining the cognitive and adaptive outcomes of very young children treated for CNS-affecting cancers (Fay-McClymont et al., 2017; Stargatt et al., 2006), it is hypothesized that patients with CNS-affecting diagnoses

(e.g., brain tumors) will demonstrate greater deficits in functioning across cognitive, adaptive, and psychosocial domains. Moreover, consistent with the few studies that have investigated very young children with non-CNS affecting cancers (e.g., solid tumors) (Bornstein et al., 2012; Willard et al., 2014), it is hypothesized that most patients assessed will demonstrate emerging weaknesses in at least some domains of functioning.

Research Question: Given the critical nature of infancy and toddlerhood on later development and the very limited cancer-related research on this specific age range; what are the characteristics of the cognitive, adaptive, and psychosocial functioning of very young children (<3 year of age) treated for cancer?

Hypotheses: Patients with diagnoses that affect the central nervous system (e.g., brain tumors) will demonstrate greater deficits in functioning across cognitive, adaptive, and psychosocial domains, relative to patients with other types of cancer.

Most patients assessed will demonstrate emerging weaknesses in at least some domains of functioning regardless of diagnostic category (brain tumor versus solid tumor).

## **Method**

### **Participants**

The sample for this study included 32 very young children under the age of 36 months ( $M = 24.6 \pm 6.6$  months). The majority of patients were male ( $n = 18, 56.3\%$ ) and Caucasian ( $n = 22, 68.8\%$ ). All primary diagnostic categories were represented, including solid tumors ( $n = 15, 46.9\%$ ), brain tumors ( $n = 9, 28.1\%$ ), leukemias ( $n = 4, 12.5\%$ ), and non-malignancies treated with bone marrow transplant ( $n = 4, 12.5\%$ ). The most common diagnosis was retinoblastoma ( $n = 10, 31.3\%$ ). The majority of patients were off-therapy at the time of assessment ( $n = 19, 59.4\%$ ) with an average of  $10.78 \pm 7.75$  months off therapy, and a mean of 13.32 months since

diagnosis (median = 11.4, *SD* = 9.12, 0 - 34.44 months). Treatment plans varied with a majority of patients receiving chemotherapy ( $n = 23$ , 71.9%). Notable was one patient with a premorbid diagnosis of Down syndrome and another with 13q deletion syndrome, both associated with developmental and learning difficulties (Baud et al., 1999; Grieco, Pulsifer, Seligsohn, Skotko, & Schwartz, 2015). Less than a third of patients ( $n = 9$ , 28.1%) received a psychological diagnosis of cognitive disorder not otherwise specified, unspecified delay in development, or mixed development disorder following their assessment. See Table 1 for more detailed demographic and treatment information.

## **Measures**

**Cognitive functioning.** Two measures were utilized by clinicians to assess early cognitive functioning with 29 (90.6%) patients administered such a measure during their evaluation. Most patients were administered the Mullen Scales of Early Learning ( $n = 18$ ; Mullen, 1995) with the remaining administered the Bayley Scales of Infant and Toddler Development, Second Edition ( $n = 11$ ; Bayley, 1993). For analytical purposes, the primary indices of interest that were collapsed across measures included Cognitive Composite, Gross Motor, Fine Motor, Expressive Language, and Receptive Language. The Cognitive Composite for both measures is presented as a Standard Score ( $M = 100$ ,  $SD = 15$ ). Scores for the other subscales – initially presented as T-scores or scaled scores – were converted to standardized z-scores using the standard normative mean for comparison purposes. The Mullen demonstrates satisfactory internal consistency with a high median value of .91 for cognitive composite (early learning) and other domains median values ranging from .75 - .83, as well as good construct validity (Mullen, 1995). The Bayley correlates with other cognitive instruments and is sensitive to performance differences in normative samples and samples at risk for delays with good to

excellent internal consistency reliability coefficients ranging from .86 (fine motor skills) to .91 (cognitive composite and gross motor skills) (Bayley, 1993).

**Adaptive functioning.** Adaptive functioning was assessed via the parent-report versions of the Vineland Adaptive Behavior Scales, Second Edition (VABS-2; Sparrow, Cicchetti, & Balla, 2005) and the Adaptive Behavior Assessment System, Second Edition (ABAS-2; Harrison & Oakland, 2003). Most patients ( $n = 29$ : 48.3% ABAS-2) completed an adaptive measure as part of their battery. Similar scores across these two measures included an overall Adaptive Functioning Composite as well as indicators of Socialization, Communication, Daily Living, and Motor Skills. Given differences in standardized scores available for these two measures, the scaled scores for Communication and Motor Skills in the ABAS-2 were converted to standard scores in order to compare across measures. Internal consistency reliability coefficients range from .81 (motor skills – scale) to .97 (adaptive composite) for the ABAS-2 and is equally reliable for assessing individuals with different clinical diagnoses (Harrison & Oakland, 2003). The VABS-2 demonstrates good to excellent reliabilities ranging from .89 (daily living composite) to .97 (adaptive composite) with supported evidence of construct validity and correlates with the ABAS-2 (Sparrow, Cicchetti, & Balla, 2005). See Table 2 for a more detailed list of internal consistency reliabilities measured by coefficient alpha for parent-report measures.

**Psychosocial functioning.** Psychosocial functioning was assessed for nearly half of the patients ( $n = 14$ ) via two parent-report measures. Most parents (85.7%) completed the Child Behavior Checklist (CBCL; Achenbach, 1991) and the remainder completed the Behavior Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004). Domains consistent across these measures included indicators of Internalizing Behavior, Externalizing Behavior, Aggression, Anxiety, Withdrawal, Somatization, Attention Problems,

and Pervasive Developmental Problems. All scores are presented as age-standardized T-scores ( $M = 50$ ,  $SD = 10$ ). The CBCL consistently demonstrates good construct validity and internal consistency coefficients are high for internalizing and externalizing (.90 and .94, respectively) as well as between good and excellent for most of the subscales ( $\alpha = .75 - .94$ ) (Achenbach, 1991). Internal consistency reliabilities measured by coefficient alpha for the BASC-2 range from .77 (anxiety – scale) to .87 (externalizing behavior – composite). Further, the BASC-2 correlates with other scales that reflect current behavioral dimensions (Reynolds & Kamphaus, 2004). See Table 2 for a more detailed list of measure reliabilities.

### **Procedure**

Cognitive and psychosocial assessment data of infants and toddlers with cancer were retrospectively abstracted from the medical records of a pediatric-focused cancer institution. All participants completed a clinically-referred assessment in a hospital-based psychology clinic between 2010 and 2015. Participants were eligible for this study if they were under the age of three years at the time of assessment and diagnosed with a malignancy and/or a non-malignancy treated with bone marrow transplant. Institutional Review Board approval was obtained prior to data abstraction. Overall, 32 infants and toddlers met inclusion criteria for this study.

Data abstracted from the medical charts included demographic (e.g., age, race, gender) and medical (e.g., diagnosis, treatment) information. The psychological assessment data included measures of early developmental, adaptive, and psychosocial functioning. As all data were clinically collected, the present study was limited to the measures chosen by individual clinicians, rather than a standard battery. Assessment data were collapsed and combined across similar measures and domains when possible.

## **Analytical Plan**

Descriptive statistics were used to characterize the sample for each domain including mean, standard deviation, and percentage in the at-risk or clinically significant range, which are operationalized as one and two standard deviations above or below the normative mean – depending on the measure. The mean scores for participant functioning in each domain were compared to the published normative mean for each measure using one-sample t-tests. Independent samples were used to examine differences in functioning based on clinically-relevant risk factors: diagnostic category (brain tumor versus solid tumor) and treatment status (on-therapy versus off-therapy) and when sample size in a group was less than 9, we elected to use non-parametric statistics – in this case the Mann-Whitney U test. Finally, differences among group means for the early cognitive composite and overall adaptive composite were examined by gender as well as whether a psychological diagnosis was assigned, deferred, or not given using analysis of variance (ANOVA).

## **Results**

### **Descriptive Analyses**

One-sample t-tests and mean scores for all domains are available in Table 3 (cognitive functioning) and Table 4 (parent-reported adaptive and psychosocial functioning). All cognitive domains were significantly below the normative mean. For the cognitive composite, a majority of patients achieved scores that fell one or two standard deviations below the mean (44% and 20%, respectively) with average scores significantly below normative expectations [ $M = 78.12$ ,  $SD = 12.13$ ,  $t(24) = -9.02$ ,  $p < .001$ ]. A majority of patients (80%) achieved scores in the extremely low to low average range with no patients in the high average to superior ranges. For all domains of cognitive functioning, significantly more patients than would be expected fell one

and/or two standard deviations below the normative mean (27.0 - 44.0% and 19.2 - 40.0%, respectively).

Overall, parent-reported adaptive functioning scores were also lower than would be expected (Table 4). For all domains of adaptive functioning, significantly more patients than would be expected fell one and/or two standard deviations below the normative mean (21.5 - 39.1% and 17.2 - 32.1%, respectively). The average overall adaptive functioning composite score was significantly below normative expectations [ $M = 78.89$ ,  $SD = 15.88$ ,  $t(27) = -7.03$ ,  $p < .001$ ] with patients averaging in the delayed (i.e., low) range. Scores were also significantly below normative expectations for the social, daily living, communication, and motor skills composites (Table 4).

In contrast, parent-reported psychosocial functioning was generally within normal limits, with a majority of mean scores falling within the average range (Table 4). However, mean scores for aggression [ $M = 55.07$ ,  $SD = 6.12$ ,  $t(13) = 3.10$ ,  $p = .008$ ], somatization [ $M = 55.00$ ,  $SD = 8.71$ ,  $t(13) = 2.15$ ,  $p = .05$ ], attention problems [ $M = 57.57$ ,  $SD = 8.91$ ,  $t(13) = 3.18$ ,  $p = .007$ ], and pervasive developmental problems [ $M = 60.77$ ,  $SD = 11.51$ ,  $t(12) = 3.38$ ,  $p = .006$ ] were significantly above the normative mean, indicating more problems than would be expected. Further, all domains within psychosocial functioning had at least one patient fall within the at-risk and/or clinically significant elevation range (7.1 - 35.7% and 7.1 - 23.1%, respectively).

### **Predictors of Functioning**

Non-parametric analyses using the Mann-Whitney test were completed to compare patients based on diagnostic category and treatment status on the cognitive and adaptive composites. Results revealed a statistically significant difference in the cognitive composite based on diagnostic category [ $U(19) = 23.5$ ,  $p = .02$ ] with patients with solid tumors

demonstrating significantly greater cognitive scores (Mdn = 84) than those with brain tumors (Mdn = 75). In contrast, results indicated that there was not a significant difference in parent-reported adaptive functioning based on diagnostic category between patients with brain tumors (Mdn = 68) and solid tumors (Mdn = 87), [ $U(20) = 38.5, p = .14$ ]. Further, there were no significant differences for cognitive [on: Mdn = 82; off: Mdn = 76,  $U(24) = 62, p = .29$ ] or adaptive functioning [on: Mdn = 85.5; off: Mdn = 74.5,  $U(27) = 90, p = .39$ ] based on treatment status (on versus off) at the time of assessment.

Results revealed no differences in functioning based on gender [Cognitive:  $F(1, 23) = 1.67, p = .21$ ; Adaptive:  $F(1, 26) = 0.81, p = .38$ ]. In contrast, there was a significant difference between groups based on if a diagnosis was assigned, deferred, or not given following the evaluation for overall adaptive functioning [ $F(2, 25) = 5.54, p = .01$ ]. Specifically, those patients who received a psychological diagnosis post-assessment had the lowest adaptive outcomes. In contrast, there was not a significant difference between groups based on psychological diagnosis for early cognitive functioning [ $F(2, 22) = 1.22, p = .32$ ].

## **Discussion**

The objective of the current study was to characterize the cognitive, adaptive, and psychosocial functioning of clinically-referred infants and toddlers diagnosed with cancer. A vast majority of our sample demonstrated clinically significant impairments in cognitive functioning. Indeed, almost all patients in our sample exhibited below average cognitive functioning, with none exceeding the average range. Consistent with this finding, a majority of our sample demonstrated significant impairments in adaptive functioning. In contrast, psychosocial functioning was broadly within normal limits, though several subscales – aggression, somatization, attention, and pervasive developmental problems – were significantly greater than

normative means. Functioning within overall cognitive and adaptive domains exhibited little variance irrespective of diagnostic category, treatment status or gender, though patients with brain tumors demonstrated significantly lower cognitive functioning as compared to patients with solid tumors. While our sample was potentially biased by clinical referral, ultimately, results suggest that infants and toddlers treated for cancer – irrespective of known risk factors – potentially represent a population that may be predisposed to cognitive and psychological delays.

In contrast with expectations based on extant literature (Mulhern & Butler, 2004; Stargatt et al., 2006), infants and toddlers with brain tumors did not consistently demonstrate more adaptive difficulties than infants and toddlers with non-CNS diagnoses (i.e., solid tumor). However, these findings are in keeping with more recent research that has demonstrated cognitive and adaptive deficits in young children and toddlers treated for non-CNS diagnoses (Bornstein et al., 2012; Willard, Leung et al., 2014; Willard, Qaddoumi et al., 2014). In combination, these findings further assert the need for additional systematic longitudinal assessment of functioning of young children with cancer, regardless of diagnosis. Certainly these findings are in contrast with studies of older children, and suggest that very young children with cancer may need to be viewed differently than older children. Indeed, given the potential influence of insecure attachment, diminished predictability, and missed developmental opportunities for infants and toddlers who spend their early years undergoing treatment, an increased recognition and focus on infants and toddlers with cancer is critical.

Congruent with a need for further study is a need for early detection of deficits, which is critical for early intervention and prevention efforts. Given the malleability of early development, infants and toddlers may benefit from remediation or prevention of deficit through increased referrals to early intervention services (Guarlnick, 2011; Harman, Wise, & Willard,

2017; Hebbeler et al., 2007). Harman and colleagues (2017) recently highlighted the existing evidence concerning the various developmental risk factors for children with cancer under three years of age and the associated long-term sequelae. Given the provided evidence and as experts in their respective fields, it is their recommendation that all infants and toddlers with cancer be systematically referred for Early Intervention services as soon as possible after initial diagnosis. Fortunately, state funding is provided for Early Intervention services for infants and toddlers with developmental delays or those at risk for delays through Part C of the Individuals with Disabilities Education Act (Individuals with Disabilities Education Act, 2004). These services – which often includes rehabilitation services as well as psychological therapies for the child and family – can be implemented within the hospital, community center, or home, depending on the child and family’s need. Further, these early intervention services do not focus solely on the infant/toddler, but rather engage in an efficacious family-centered approach to ensure optimal developmental outcomes (Harman et al., 2017; Hebbeler et al., 2007).

This study has a number of limitations that should be noted. The biggest limitation is the small sample size. Given the methodology of a retrospective chart review, we were constrained by the sample that was assessed during our timeframe. Thus, analyses may be interpreted as pilot data and had a larger sample size been available, the effects may have been more pronounced. Further, our sample was clinically-referred. As such, there may be potential bias in regards to the severity of the findings. Referrals to our psychology clinic are frequently made for routine surveillance given the cognitive and adaptive risks for these patients (Bornstein et al., 2012; Fouladi et al., 2005; Stargatt et al., 2006), though a portion of our sample was likely referred due to clinician concern for developmental delays. Regardless, the significance of deficits within our sample – most notably within cognitive functioning – was concerning and warranted report

irrespective of this potential bias. Moreover, our findings are generally consistent with other studies of infants and toddlers with brain tumors and retinoblastoma that were prospectively followed (Fay-McClymont et al., 2017; Fouladi et al., 2005; Sands et al., 2010; Willard, Qaddoumi, et al., 2014). Additionally, as all data were clinically-collected, the present study was limited to those measures that were utilized which required collapsing and combining of scores across measures, thus limiting sample size in some domains. This was particularly true for measures of psychosocial functioning, which were infrequently administered. Given our findings, and in keeping with recent practice standards (Kazak et al., 2015), we would recommend that clinicians start systematically assessing psychosocial functioning in concert with cognitive and adaptive functioning as early as possible. Finally, it is well known that socioeconomic status, environment, and parent factors influence cognitive functioning and developmental outcomes in young children (Kingston, McDonald, Austin, & Tough, 2015; Nagayoshi et al., 2017; Caspi et al., 2016). However, this information was not accessible for our sample as it is not systematically collected during clinical assessments at our institution. Prospective studies should ensure collection of this information to determine if these factors play a moderating role in the cognitive and psychosocial functioning of infants and toddlers treated for cancer.

Results of this study highlight the potential vulnerability of infants and toddlers' cognitive, adaptive, and psychosocial development when treated for cancer. Functional weaknesses appear to be present irrespective of the traditional risk factors of diagnosis and treatment status. Consequently, there is a strong need to better understand the developmental trajectory of infants and toddlers treated for cancer – especially those with non-CNS affecting diagnoses. Future research must prospectively assess these young patients and also seek to

intervene in order to promote the best possible developmental outcomes. As such, future studies must have an increased focus on adapting and applying intervention and prevention efforts.

Ultimately, further investigation of infants and toddlers treated for cancer is truly critical in order to identify and address these core deficits as early as possible, thereby promoting normalized and positive developmental trajectories of this population.

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## Appendix A: Tables

**Table 1.** Demographic and treatment information ( $N = 32$ )

	<i>N (%)</i>
<i>Demographic Information</i>	
Gender	
Male	18 (56.3)
Female	14 (43.8)
Race	
White	22 (68.8)
Black	7 (21.9)
Other	3 (9.4)
Age at Assessment (months)	
Mean	24.6
Standard Deviation	6.6
Range	8.04 – 35.52
<i>Diagnostic and Treatment Information</i>	
Diagnostic Category	
Solid Tumor	15 (46.9)
Brain Tumor	9 (28.1)
Leukemia	4 (12.5)
Non-malignancy	4 (12.5)
Age at Diagnosis (months)	
Mean	11.16
Median	11.88
Standard Deviation	7.92
Range	0 – 25.56
Treatment	
Surgery	15 (46.9)
Chemotherapy	23 (71.9)
Radiation Therapy	3 (9.4)
Transplant	6 (18.8)
Time Since Diagnosis (months)	
Mean	13.32
Median	11.4
Standard Deviation	9.12
Range	0 – 34.44
Treatment Status	
On Therapy	13 (40.6)
Off Therapy	19 (59.4)
Months Off Therapy	10.78 ± 7.75 (0 - 24.84)
Psychological Diagnosis	
Assigned	9 (28.1)
Deferred	12 (37.5)
Not Given	11 (34.4)

**Table 2.** Internal consistency: Coefficient alpha reliabilities of parent-report measures

<i>Adaptive Functioning</i>	<i>Vineland-II</i>	<i>ABAS-II</i>
Adaptive Composite	.97	.97
Social Composite	.93	.91
Communication Composite <sup>a</sup>	.92	.87
Daily Living Composite	.89	.93
Motor Skills Composite <sup>a</sup>	.90	.81
<i>Psychosocial Functioning</i>	<i>CBCL</i>	<i>BASC-II</i>
Internalizing Behavior	.90	.85
Externalizing Behavior	.94	.87
Aggression	.94	.78
Anxiety	.84	.77
Withdrawal	.80	.82
Somatization	.75	.79
Attention Problems	.86	.86
Pervasive Developmental Problems	*	*

<sup>a</sup> Domain in Vineland-II, Scale in ABAS-II

\* Not provided in CBCL or BASC-II manuals

**Table 3.** Cognitive functioning

<i>Cognitive Functioning</i>	<i>N</i>	<i>Mean ± SD</i>	<i>Range</i>	<i>t</i> <sup>†</sup>	<i>p</i>	<i>N (%) 1 SD</i>	<i>N (%) 2 SD</i>
Cognitive Composite <sup>a</sup>	25	78.12 ± 12.13	55 – 100	-9.02	<.001	11 (44.0)	5 (20.0)
Gross Motor Skills <sup>b</sup>	20	-1.69 ± .96	-3.00 – 0	-7.86	<.001	6 (30.0)	8 (40.0)
Fine Motor Skills <sup>b</sup>	26	-1.45 ± 1.14	-3.00 – .40	-6.48	<.001	8 (30.7)	8 (30.8)
Expressive Language <sup>b</sup>	26	-1.14 ± .86	-3.10 – 0	-6.73	<.001	7 (27.0)	5 (19.2)
Receptive Language <sup>b</sup>	26	-1.11 ± 1.14	-3.00 – .67	-4.95	<.001	11 (42.3)	5 (19.2)

<sup>a</sup> Standard score: normative mean = 100, *SD* = 15; 1 *SD* < 85, 2 *SD* < 70

<sup>b</sup> Standardized z-score: normative mean = 0, *SD* = 1; 1 *SD* < -1, 2 *SD* < -2

<sup>†</sup> One-sample t-test against the normative mean

**Table 4.** Parent-reported adaptive and psychosocial functioning

<i>Adaptive Functioning</i> <sup>a</sup>	<i>N</i>	<i>Mean ± SD</i>	<i>Range</i>	<i>t</i> <sup>†</sup>	<i>p</i>	<i>N (%) 1 SD</i>	<i>N (%) 2 SD</i>
Adaptive Composite	28	78.89 ± 15.88	51 – 118	-7.03	<.001	6 (21.5)	9 (32.1)
Social Composite	29	87.97 ± 16.06	59 – 124	-4.04	<.001	8 (27.6)	5 (17.2)
Communication Composite	23	87.13 ± 17.83	55 – 115	-3.46	.002	6 (26.1)	4 (17.4)
Daily Living Composite	23	83.48 ± 15.13	58 – 118	-5.24	<.001	9 (39.1)	4 (17.4)
Motor Skills Composite	20	83.70 ± 15.57	60 – 115	-4.68	<.001	6 (30.0)	4 (20.0)
<i>Psychosocial Functioning</i> <sup>b</sup>						<i>N (%) ≥ 60</i>	<i>N (%) ≥ 70</i>
Internalizing Behavior	14	53.50 ± 11.48	37 – 73	1.14	.28	3 (21.4)	1 (7.1)
Externalizing Behavior	14	55.00 ± 10.21	35 – 73	1.83	.09	5 (35.7)	1 (7.1)
Aggression	14	55.07 ± 6.12	41 – 65	3.10	.008	4 (28.6)	0 (0)
Anxiety	14	51.79 ± 7.06	43 – 73	0.95	.36	0 (0)	1 (7.1)
Withdrawal	14	56.79 ± 14.27	40 – 91	1.78	.10	2 (14.3)	2 (14.3)
Somatization	14	55.00 ± 8.71	43 – 80	2.15	.05	1 (7.1)	1 (7.1)
Attention Problems	14	57.57 ± 8.91	50 – 73	3.18	.007	1 (7.1)	3 (21.4)
Pervasive Developmental Problems	13	60.77 ± 11.51	48 – 82	3.38	.006	2 (15.4)	3 (23.1)

<sup>a</sup> Standard score: normative mean = 100, *SD* = 15; 1 *SD* < 85, 2 *SD* < 70

<sup>b</sup> T-score: normative mean = 50, *SD* = 10

<sup>†</sup> One-sample t-test against the normative mean