# Online Exclusive

# Behavioral Adjustment of Children and Adolescents With Cancer: Teacher, Parent, and Self-Report

Ida M. (Ki) Moore, RN, DNS, FAAN, Julia Challinor, RN, PhD, Alice Pasvogel, RN, PhD, Katherine Matthay, MD, John Hutter, MD, and Kris Kaemingk, PhD

**Purpose/Objectives:** To describe behavioral adjustment in children and adolescents with acute lymphoblastic leukemia (ALL) and to determine whether behavioral adjustment is correlated with cognitive and academic abilities.

**Design:** Descriptive, cross-sectional design.

Setting: Two pediatric oncology treatment centers.

Sample: 47 children and adolescents who had been receiving ALL therapy for at least one year or who were off therapy for no more than three years and their parents and teachers. Wechsler Intelligence Scale for Children–Revised (WISC-R) and Wide Range Achievement Test–Revised (WRAT-R) data were available on a subset of 17 subjects.

Methods: Parent, teacher, and self-report Behavioral Assessment System for Children (BASC) ratings were used to measure behavioral adjustment. WISC-R measured cognitive abilities, and WRAT-R measured academic abilities. Demographic, family, and treatment-related data also were collected.

Main Research Variables: Behavioral adjustment and cognitive and academic abilities.

Findings: At least 20% of teacher ratings for somatization, learning problems, leadership, and study skills; parent ratings for somatization, adaptability, attention problems, withdrawal, anxiety, social skills, and depression; and self-report ratings for anxiety and attitude to school were in the at-risk range (i.e., presence of significant problems that require treatment). The majority of teacher BASC ratings were correlated significantly with WISC-R and WRAT-R scores. Self-report depression and social stress ratings were correlated significantly with some WISC-R and WRAT-R scores. Treatment-related experiences such as body image alterations and mental and emotional problems were associated with problematic behaviors, including depression, somatization, withdrawal, and social stress.

**Conclusions:** Youth with ALL are at risk for some behavioral adjustment problems, particularly anxiety, somatization, adaptability, attention, and withdrawal. Cognitive and academic abilities are associated with some dimensions of behavioral adjustment.

Implications for Nursing: Findings suggest the need for ongoing assessment of behavioral adjustment and cognitive and academic abilities of children with ALL. Behavioral interventions that target at-risk mannerisms, such as somatization, depression, anxiety, and social stress, are needed. Central nervous system treatment may contribute to behavioral adjustment problems, as well as to cognitive and academic problems. Strategies to improve academic abilities also may have a positive effect on behavioral adjustment.

# **Key Points...**

- ➤ Children and adolescents with acute lymphoblastic leukemia experience specific behavioral adjustment problems, including somatization; attention, adaptability, and learning problems; and anxiety.
- Children and adolescents who experience central nervous system treatment-related cognitive and academic problems may experience behavioral adjustment problems.
- Body image alterations during treatment may increase the risk for behavioral adjustment problems.
- Ongoing assessment of specific areas of behavioral adjustment is warranted, and interventions that target these at-risk areas are needed.

ne in every 333 children in the United States develops cancer before the age of 20, which translates into 12,400 new cases of cancer each year (Ries et al., 1999). Acute lymphoblastic leukemia (ALL), the most common pediatric tumor, comprises 2,400 of these 12,400 new

Ida M. (Ki) Moore, RN, DNS, FAAN, is a professor and a director in the Division of Nursing Practice for the College of Nursing at the University of Arizona in Phoenix; Julia Challinor, RN, PhD, is an assistant adjunct professor in the School of Nursing at the University of California, San Francisco (UCSF); Alice Pasvogel, RN, PhD, is a senior research specialist in the College of Nursing at the University of Arizona; Katherine Matthay, MD, is a professor in the School of Medicine at UCSF; John Hutter, MD, is a professor and Kris Kaemingk, PhD, is an assistant professor, both in the College of Medicine at the University of Arizona. This study was supported by the National Institutes of Health (NR02557, NR04905, and HD37816) and by the ONS Foundation and Ortho Biotech Products. Additional support was provided by the Frank A. Campini Foundation and the Bay Echo Foundation of San Francisco. (Submitted September 2002. Accepted for publication March 7, 2003.)

Digital Object Identifier: 10.1188/03.ONF.E84-E91

cancer cases. Five-year disease-free survival rates for children with cancer are 77% overall and 85% for patients with ALL (Jemal et al., 2003). Using current incidence and survival rates among children with cancer in the United States alone, approximately 400,000 human years are being saved annually; by 2010, 1 in 250 young adults will be a childhood cancer survivor (Bleyer, 1993, 1995). Aggressive therapies have led to dramatic improvements in survival, but they also have raised concerns about the impact of pediatric cancer and its treatment on quality of life and behavioral adjustment.

The primary aim of this study was to describe the behavioral adjustment of children and adolescents with ALL using teacher, parent, and self-report measures. The intent was to measure adaptive and problematic behaviors. All subjects received some type of central nervous system (CNS) treatment to decrease the risk of meningeal disease. The late effects of CNS treatment on cognitive and academic abilities have been reported since the 1980s (Kramer & Moore, 1989; Moore, Glasser, & Ablin, 1988; Moore, Kramer, & Ablin, 1986). Survivors of ALL who experience CNS late effects also may be at risk for behavioral adjustment problems. However, little is known about potential links between cognitive or academic abilities and behavioral adjustment. Therefore, a secondary aim of the study was to investigate relationships between behavioral adjustment scores and cognitive and academic abilities in a subset of subjects for whom these data were available (Moore et al., 2000).

# **Background and Literature Review**

Deficits in academic abilities following CNS treatment with whole-brain radiation have been well established (Appleton, Farrell, Zaide, & Rogers, 1990; Cousens, Ungerer, Crawford, & Stevens, 1991; Silber et al., 1992). Because of the overwhelming evidence that whole-brain radiation causes significant neurotoxicity, the majority of current CNS treatment regimens for children with ALL include intrathecal chemotherapy alone or in combination with intermediate- to high-dose systemic methotrexate. Findings suggest that chemotherapy-based CNS treatment regimens also are associated with academic problems (Armstrong, Blumberg, & Toledano, 1999; Mulhern, Armstrong, & Thompson, 1998), especially mathematics (Brown et al., 1996; Copeland, Moore, Francis, Jaffe, & Culbert, 1996; Moore et al., 2000).

Behavioral and emotional problems, including withdrawal, depression, anxiety, and attention problems, have been reported among children with ALL (Anderson, Smibert, Ekert, & Godber, 1994; Fossen, Abrahamsen, & Storm-Mathisen, 1998; Sharan, Mehta, & Chaudhry, 1999). Several studies determined that long-term survivors of childhood cancer experience a greater number of problems with social competence and more symptoms of depression compared to healthy children and siblings (Cavusoglu, 2001; Olson, Boyle, Evans, & Zug, 1993; Pendley, Dahlquist, & Dreyer, 1997; Sharan et al.).

Behavioral-rating scales and systematic observation have been used since the 1980s to assess behavioral adjustment; however, psychometric testing of instruments was limited (Shapiro & Kratochwill, 2000). More recently, comprehensive psychometric testing of instruments has been performed, and several excellent nationally standardized measures for assessing behavior in children and adolescents are available. According to Merrell (2000), "Behavior-rating scales provide summative judgments of general types of behavioral characteristics that may have occurred in a variety of settings and over a long period of time" (p. 204). Behavioral-rating scales with forms for multiple respondents allow researchers to identify problematic behavior under specific conditions. Significant behavior problems tend to be expressed consistently in different surroundings or situations and with different measurement tools (Merrell). Self-report scales complement informant behavior scales and typically measure children's and adolescents' emotional or behavioral adjustment in domains such as internalizing problems, externalizing problems, or school maladjustment (Eckert, Dunn, Codding, & Guiney, 2000).

# **Methods**

### **Design and Sample**

A descriptive, cross-sectional design was used. To be eligible to participate, patients had to be receiving ALL therapy for at least one year or be off therapy for no more than three years, report no CNS or bone marrow relapse, and be able to speak English. Children and adolescents who had not completed their first year of treatment were excluded to minimize the potential confounding effects of acute physical and emotional stress associated with a new cancer diagnosis and the consolidation phase of therapy. Individuals with CNS or bone marrow relapse were excluded because of more aggressive therapy or decreased probability for long-term survival. All eligible children and adolescents with ALL and their parents were recruited from two pediatric oncology treatment centers. The goal was to obtain a representative sample of children and adolescents with the same cancer diagnosis who had received relatively similar treatment. Institutional review committee approvals were obtained prior to subject recruitment and data collection.

### Instruments

The Behavioral Assessment System for Children (BASC) (Reynolds & Kamphaus, 1992) was used to measure behavioral adjustment. BASC is a reliable and valid measure consisting of scales that provide a comprehensive behavioral assessment of children and adolescents (see Table 1). BASC was selected because it provides an assessment of risk (internalizing problems, externalizing problems, school problems, and behavioral symptoms) as well as positive factors (adaptive skills). According to Merrell (2000), "As a thorough and comprehensive system of behavior-rating scales, the BASC is representative of the best of what is currently available" (p. 215). BASC teacher, parent, and child and adolescent self-report forms were used in this study. Content validity was established by expert judgment. Construct validity was established by determining factor structure of the scales and by correlations with other behavioral-rating scales, including the Child Behavior Checklist, Personality Inventory for Children-Revised, Conners' Parent-Rating Scales, and the Minnesota Multiphasic Personality Inventory. Reliability was established by tests of internal consistency, test-retest reliability, and interrater reliability (Reynolds & Kamphaus).

The BASC teacher- and parent-rating scales include items regarding observations of negative and positive behavioral performance. Separate forms target three age levels: preschool (4–5 years), child (6–11 years), and adolescent (12–18 years). Therefore, BASC is developmentally sensitive and

Table 1. Behavioral Assessment System for Children Composite and Scale Definitions

Scale	Definition	Score Indicating At-Risk Status <sup>a</sup>	
Adaptability	The ability to adapt readily to changes in the environment	≤ 40	
Anxiety	Feelings of nervousness, worry, and fear; the tendency to be overwhelmed by problems	≥ 60	
Attention problems	The tendency to be distracted easily and unable to concentrate more than momentarily	≥ 60	
Attitude to school	Feelings of alienation, hostility, and dissatisfaction with school	≥ 60	
Attitude to teachers	Feelings of resentment and dislike of teachers; beliefs that teachers are unfair, uncaring, or overly demanding	≥ 60	
Depression	Feelings of unhappiness, sadness, and stress that may result in an inability to carry out everyday activities or bring thoughts of suicide; belief that nothing goes right	≥ 60	
Leadership	The skills associated with accompanying academic, social, or communication goals, par- ticularly the ability to work well with others	≤ 40	
Learning problems	The presence of academic difficulties, particularly in understanding or completing school- work	≥ 60	
Self-esteem	Feelings of self-esteem, self-respect, and self-acceptance	≤ 40	
Sense of inadequacy	Perceptions of being unsuccessful in school, unable to achieve goals, and generally in- adequate	≥ 60	
Social skills	The skills necessary for interacting successfully with peers and adults in home, school, and community settings	≤ 40	
Social stress	Feelings of stress and tension in personal relationships, a feeling of being excluded from social activities	≥ 60	
Somatization	The tendency to be overly sensitive to and complain about relatively minor physical prob- lems and discomforts	≥ 60	
Study skills	The skills that are conducive to strong academic performance, including organizational skills and good study habits	≤ 40	
Withdrawal	The tendency to evade others to avoid social contact	≥ 60	

<sup>&</sup>lt;sup>a</sup> Score is more than one standard deviation, which indicates at-risk status.

has normative data for males and females in each of the three age levels. The parent and teacher forms provide composite scores for adaptive skills, externalizing problems, internalizing problems, and behavioral symptoms. The teacher form also includes a school problems composite. Composite scores are based on relevant scales. The internalizing composite is comprised of anxiety, depression, and somatization scales; the externalizing composite is comprised of aggression, hyperactivity, and conduct problems scales. The behavioral symptoms index is a measure of the overall level of problem behavior and is based on scores from the aggression, hyperactivity, anxiety, depression, attention problems, and atypicality scales. All scale, composite, and index scores are T scores with a mean of 50 and a standard deviation of 10.

The child and adolescent self-report of personality has forms at two age levels: child (8-11 years) and adolescent (12–18 years). Items elicit information regarding children's or adolescents' self-perception and emotional status. The selfreport form provides composite scores for personal adjustment, clinical maladjustment, school maladjustment, and the emotional symptoms index. Each composite is made up of relevant scales. The school maladjustment composite includes attitude to school, attitude to teachers, and sensation-seeking scales; the clinical maladjustment composite is based on anxiety, atypicality, locus of control, social stress, and somatization scales. The emotional symptoms index is comprised of scores from social stress, anxiety, interpersonal relations, selfesteem, depression, and sense of inadequacy scales. These scale, composite, and index scores are T scores with a mean of 50 and a standard deviation of 10.

Higher scale, composite, and index scores for negative behaviors (e.g., internalizing problems, externalizing problems, school problems) represent negative or undesirable characteristics; T scores greater than 60 (one or more standard deviation) are in the at-risk range. At risk is used to indicate the presence of significant problems that require treatment but may not be severe enough to warrant a formal diagnosis. A score in the at-risk range may signify potential or developing problems that require careful monitoring (Reynolds & Kamphaus, 1992). Higher scores on scales that measure personal adjustment (parent and teacher forms) or adaptive skills (child or adolescent form) represent positive or desirable characteristics. For these scales, T scores less than 40 (one or less standard deviation) are considered at risk.

Demographic (i.e., date of birth, gender, ethnicity, grade in school) and treatment-related (i.e., diagnosis, diagnosis date, CNS treatment) data were obtained for all subjects. Parents were asked whether their family had experienced residence changes, family problems, the death of a friend or family member, divorce, serious illness, or job loss during the past year because these experiences could influence behavioral adjustment. Parents were asked about treatment-related problems experienced by their child or adolescent. Treatment-related problems included mental or emotional problems during treatment, body image alterations during treatment, and energy to stay in school.

Data about general intellectual and academic abilities were available for a subset of subjects (n = 17) who also participated in a study of the cognitive and academic effects of CNS treatment for childhood ALL (Moore et al., 2000). Intellectual abilities were assessed using the **Wechsler Intelligence Scale for Children–Revised (WISC-R)** (Wechsler, 1974). Overall intellectual abilities were measured by the WISC-R Full Scale Intelligence Quotient (FSIQ). Verbal intellectual skills were measured by the WISC-R Verbal IQ (VIQ), and nonverbal or performance-based intellectual abilities were measured by the

WISC-R Performance IQ (PIQ). IQ scores have a mean of 100 and a standard deviation of 15. The **Wide Range Achievement Test–Revised (WRAT-R)** was used to assess academic achievement (Jastak & Wilkinson, 1984). Standard scores ( $\overline{X}$  = 100, SD = 15) from the reading, spelling, and arithmetic subtests were used. The number-questions subscale of the McCarthy Scales of Children's Abilities (McCarthy, 1972) was used to measure emergent math skills in children younger than the age of five at the initial (seven months after ALL diagnosis) evaluation.

### **Data Analysis**

BASC, demographic, treatment, treatment-related problems, and family data were analyzed using descriptive statistics (mean, standard deviation). Percentages were used to summarize teacher, parent, and self-report scores in the at-risk range. Pearson correlation was used to examine relationships between behavioral adjustment and intellectual and academic abilities measured 45 months after ALL diagnosis; Pearson correlation also was used to examine relationships between behavioral adjustment and family or treatment-related problems. Level of significance was set at p = 0.05.

### Results

### Sample

The final sample was comprised of 47 children with ALL. Informed consent and assent were obtained from subjects and parents; written permission to contact teachers for data collection also was obtained. The average age of subjects at the time of data collection was 9 years, 11 months (range = 5.2-16years), and the mean length of time since diagnosis was 40.4 months (SD = 21.8). The majority of children were Caucasian (60%); other ethnic groups were Hispanic (27%), Filipino (4%), African American (2%), Asian (2%), and other (5%). Fifty-six percent of the subjects were female. CNS treatment consisted of triple intrathecal chemotherapy (methotrexate, cytosine arabinoside, and hydrocortisone) (n = 31), intrathecal methotrexate (n = 15), or intrathecal chemotherapy and whole-brain radiation (n = 1). The majority of parents had completed high school, and approximately 50% of mothers and fathers had undergraduate, graduate, or postgraduate college education.

Data regarding intellectual abilities and academic achievement were obtained 7 and 45 months after ALL diagnosis on a subset of 17 children (10 females and 7 males). CNS treatment for this subset included triple intrathecal chemotherapy (n = 9) or intrathecal methotrexate (n = 8); one child received 24 Gy of whole-brain radiation in combination with intrathecal methotrexate. The mean age of this subset of participants was 10.4 years (range = 6.7–16 years), and the average length of time since diagnosis was 54.7 months (SD = 19.1). All of the fathers and 71% of mothers had graduated from high school; 64% of fathers and 50% of mothers had undergraduate, graduate, or postgraduate college education.

### **Behavioral Adjustment**

BASC teacher, parent, and child or adolescent composite and index scores are summarized (mean, standard deviation, and range) in Table 2. Scale scores in which 20% or more of T scores fell in the at-risk range (60 or more for maladaptive and 40 or less for adaptive behaviors) also are included.

Approximately 22% of children and adolescents received teacher ratings on the internalizing problems composite in the at-risk range. This finding was primarily a result of ratings on the somatization scale because 39% of children and adolescents received at-risk scores. The adaptive skills composite summarizes prosocial, organizational study, and other adaptive skills (Reynolds & Kamphaus, 1992). According to teacher ratings, approximately 18% of patients with ALL received at-risk ratings on the adaptive skills composite, particularly in the areas of leadership and study skills (21% and 24% at-risk scores, respectively). Finally, teachers rated 25% of subjects in the atrisk range for learning problems. According to Reynolds and Kamphaus, a score of 60 or higher on the learning problems scale indicates a need for careful investigation of academic skills.

According to parent ratings, 44% of their children or adolescents were at risk for internalizing problems and 29% were at risk for adaptive skills problems. Only 17% of children and adolescents received high scores on the behavioral symptoms composite, which is an indication of the overall level of problematic behavior. At least 20% of scores on 7 of the 12 parent-rating scales (somatization, adaptability, attention problems, withdrawal, anxiety, social skills, and depression) were in the at-risk range.

Fewer child and adolescent self-report scores were in the atrisk range. Approximately 16% of self-report scores for the clinical maladjustment composite, emotional symptoms index, and school maladjustment composite were 60 or greater. Only 4 (anxiety, somatization, attitude to school, and self-esteem) of the 14 self-report scales had at least 20% of scores in the at-risk range.

### **Behavioral Adjustment and Cognitive Abilities**

Mean FSIQ, PIQ, and VIQ scores obtained 7 and 45 months after ALL diagnosis were within one standard deviation of the mean (85–115) for children who received triple intrathecal chemotherapy or intrathecal methotrexate (Moore et al., 2000). FSIQ, PIQ, and VIQ scores obtained from the child who received cranial radiation were much lower and had declined dramatically from the initial evaluation completed prior to radiation treatment (126 to 71 for FSIQ, 109 to 69 for PIQ, and 114 to 77 for VIQ). Table 3 summarizes the correlations between cognitive abilities and behavioral adjustment.

FSIQ, PIQ, and VIQ scores were correlated significantly with teacher ratings on learning problems, attention problems, leadership, and study skills scales. Correlations ranged from r = -0.78 (for scales with maladaptive behaviors) to r = 0.87 (for scales with adaptive behaviors). Based on these significant correlations, the finding that the school problems composite, which reflects academic problems including problems of motivation, attention, learning, and cognition, was correlated strongly with FSIQ, PIQ, and VIQ scores was not surprising. The adaptive skills composite was correlated significantly with FSIQ and PIQ scores but not with VIQ scores (see Table 3).

Parent ratings of attention problems were significantly correlated with FSIQ, PIQ, and VIQ scores. FSIQ and PIQ scores were correlated highly with the social skills scale and the adaptive skills composite. Only the child and adolescent self-report depression and social stress scale scores were correlated strongly with FSIQ scores (r = -0.62 and -0.67, respectively) and PIQ scores (r = -0.74 and -0.87, respectively); however,

Table 2. Teacher, Parent, and Self-Report Behavioral Assessment System for Children Composite and Scale Scores

Scale	$\overline{\mathbf{X}}$	SD	Range	% at Risk
Teacher-rating scale				
Internalizing problems composite	54.00	9.96	39–79	22
Behavioral symptoms index	49.08	8.23	38–76	16
Adaptive skills composite	51.00	10.08	33–71	18
School problems composite	50.37	9.28	33–71	13
Externalizing problems composite	48.55	8.68	41-86	10
Somatization scale	58.05	15.06	42-111	39
Learning problems scale	51.45	9.65	35–68	26
Study skills scale	50.11	10.25	29-70	24
Leadership scale	49.47	9.26	34-69	21
Parent-rating scale				
Internalizing problems composite	58.69	15.46	32-97	44
Adaptive skills composite	48.11	10.65	30-72	29
Behavioral symptoms index	50.81	11.38	31–86	17
Externalizing problems composite	48.56	10.59	32–87	13
Somatization scale	62.03	16.08	37-120	49
Withdrawal scale	55.15	11.90	34-85	34
Adaptability scale	45.35	12.74	24-70	31
Attention problems scale	52.26	10.68	33-76	28
Anxiety scale	53.77	12.50	33-90	28
Social skills scale	49.84	10.63	29–71	24
Depression scale	53.41	14.28	34-100	23
Child and adolescent self-report				
Clinical maladjustment composite	48.37	11.07	34-73	17
Emotional symptoms index	48.90	8.68	36–67	17
School maladjustment composite	47.77	10.89	34-79	16
Personal adjustment composite	50.80	9.03	17–61	10
Anxiety scale	48.42	11.53	33-69	29
Somatization scale	51.92	13.22	39-82	23
Self-esteem scale	48.77	10.31	24-59	23
Attitude to school scale	49.09	10.81	36-76	22

not all correlations achieved statistical significance because of sample size limitations.

### Behavioral Adjustment and Academic Abilities

A significant decline in academic arithmetic was found from the 7- to the 45-month evaluation for children who received triple intrathecal chemotherapy ( $\overline{X}$  decline = 10 points) and for those who received intrathecal methotrexate ( $\overline{X}$  decline = 8.9 points). Mean reading and spelling scores at the 45-month evaluation were 92.3 ( $\pm$  14.2) and 93.3 ( $\pm$  18.4), respectively, in the triple intrathecal chemotherapy group and 95.5 ( $\pm$  16.7) and 94.1 ( $\pm$  12.8), respectively, in the intrathecal methotrexate group. Reading, spelling, and arithmetic scores obtained at the 45-month evaluation were much lower (55 in all areas) for the child who received intrathecal methotrexate and whole-brain radiation. Table 4 summarizes correlations between BASC scale or composite scores and WRAT-R standard scores.

WRAT-R reading, spelling, and math scores were correlated negatively with teacher ratings of learning problems and positively correlated with teacher ratings of leadership. Academic abilities (especially reading and spelling) were correlated with teacher ratings of study skills, attention problems, school problems, adaptive skills, and behavioral symptoms. In general, a trend existed for correlations between parent ratings of behavioral adjustment and academic abilities. However, the correlations did not achieve statistical significance with the exception of attention problems and reading (r = -0.59) and

spelling (r = -0.61). Importantly, negative correlations were found between academic abilities and child and adolescent self-report scores on social stress, depression, and attitude to school. However, only correlations between social stress and reading (r = -0.81) and spelling (r = -0.84) achieved statistical significance.

### Family Problems and Treatment-Related Problems

Seventeen of the 47 respondents reported experiencing no family problems during the prior year; one family did not respond to these questions. Seventeen families experienced at least one problem, including residence change, death of a family member or friend, divorce, serious illness, or job loss. Eight families experienced two of these problems, and three families reported experiencing three problems. According to parents, only two (9%) children did not have energy to stay in class. However, a greater percentage experienced physical problems (n = 14, 30%), mental or emotional problems (n = 12, 26%), and body image alterations (n = 26, 55%) during treatment. A "yes" response to mental and emotional problems during treatment was correlated significantly with BASC teacher or parent ratings of depression, learning problems, attention problems, withdrawal, leadership, and study skills (r = 0.32-0.48, p =0.05). A "yes" response to body image alterations during treatment was correlated significantly with child and adolescent self-ratings on somatization, social stress, depression, interpersonal relations, clinical maladjustment composite, and emotional symptoms index (r = 0.44 - 0.59, p = 0.01).

Table 3. Correlations Between Behavioral Assessment System for Children Scores and Wechsler Intelligence Scale for Children–Revised Intelligence Quotient

	Full Scale Intelligence Quotient		Performance Intelligence Quotient		Verbal Intelligence Quotient	
Scale	Score	p	Score	p	Score	p
Teacher report						
Learning problems scalea	-0.78	< 0.01	-0.76	< 0.01	-0.68	0.02
Attention problems scale <sup>a</sup>	-0.66	0.01	-0.68	0.01	-0.57	0.05
Leadership scale	0.87	< 0.01	0.88	< 0.01	0.74	< 0.01
Study skills scale	0.77	< 0.01	0.76	< 0.01	0.66	0.01
School problems composite <sup>a</sup>	-0.72	< 0.01	-0.73	< 0.01	-0.63	0.05
Adaptive skills composite	0.68	< 0.01	0.73	< 0.01	0.54	ns
Parent report						
Attention problems scale <sup>a</sup>	-0.79	< 0.01	-0.79	< 0.01	-0.78	0.01
Social skills scale	0.62	0.03	0.60	0.03	0.53	ns
Behavioral symptoms index <sup>a</sup>	-0.55	ns	-0.72	< 0.01	-0.39	ns
Adaptive skills composite	0.58	0.04	0.64	0.02	0.52	ns
Child and adolescent report						
Depression scale <sup>a</sup>	-0.62	0.05	-0.74	0.02	-0.42	ns
Social stress scale <sup>a</sup>	-0.67	ns	-0.87	< 0.01	-0.42	ns

a Higher composite or scale scores indicate more problems. ns—not significant

# **Discussion**

Findings from this study suggest that children and adolescents who are receiving or recently completed ALL treatment may be at risk for some behavioral adjustment problems. These children and adolescents appear to be particularly vulnerable to internalizing problems, specifically somatization, depression, anxiety, and withdrawal. Boekaerts and Roer's (1999) report of studies on stress, coping, and adjustment indicates that children with a chronic disease, including cancer, have more behavior problems compared to children without chronic disease, normative groups, and children with acute non–life-threatening illnesses. The increased behavior problems primarily are related to a higher level of in-

ternalizing problems, especially depression, somatic complaints, social withdrawal, and high anxiety. Researchers also have reported somatic complaints in long-term survivors of childhood cancer. Mulhern, Wasserman, Friedman, and Fairclough (1989) found that school problems and somatic complaints were increased fourfold relative to age-and gender-adjusted rates for peer groups in the general population. Somatic complaints could be related to other late effects of treatment and have been attributed to hypochondriacal tendencies or functional impairments (Mulhern et al., 1989). The significant correlations between body image alterations during treatment and self-report measures of behavioral adjustment found in the current study corroborate previous findings.

Table 4. Correlations Between Wide Range Achievement Test–Revised and Behavioral Assessment System for Children Scores

	Reading		Spelling		Math	
Scale	r	p	r	р	r	p
Teacher report						
Learning problems scale <sup>a</sup>	-0.91	< 0.01	-0.88	< 0.01	-0.61	0.03
Leadership scale	0.85	< 0.01	0.87	< 0.01	0.74	< 0.01
Study skills scale	0.85	< 0.01	0.83	< 0.01	0.48	ns
Attention problems scale <sup>a</sup>	-0.80	< 0.01	-0.81	< 0.01	-0.47	ns
School problems composite <sup>a</sup>	-0.86	< 0.01	-0.86	< 0.01	-0.55	ns
Adaptive skills composite	0.67	0.02	0.68	0.02	0.44	ns
Behavioral symptoms index	-0.63	0.04	-0.67	0.02	-0.34	ns
Parent report						
Attention problems scale <sup>a</sup>	-0.59	0.05	-0.61	0.01	-0.44	ns
Child and adolescent report						
Social stress scale <sup>a</sup>	-0.81	0.01	-0.84	< 0.01	-0.24	ns
Depression scale <sup>a</sup>	-0.53	ns	-0.59	ns	-0.59	ns
Attitude to school <sup>a</sup>	-0.64	ns	-0.62	ns	-0.47	ns

a Higher composite or scale scores indicate more problems. ns—not significant

In the present study, 18% of child and adolescent self-report scores were in the at-risk range for depression; high depression scores were correlated significantly with lower academic arithmetic abilities and with FSIQ and PIQ scores. Cavusoglu (2001) reported that children with cancer had significantly higher depression scores than a comparison group of healthy children and that 22% of children with cancer had scores of 19 (the cutoff point for depression) or higher on the Children's Depression Inventory. These findings underscore the need to assess for depression in cancer survivors. The current study's findings also suggest a relationship between CNS treatment-related late effects and depressive symptoms, as well as body image changes during treatment and depression.

Approximately 15% of teacher and parent behavioral symptoms index (overall level of problem behavior) ratings in the present study were in the at-risk range. This finding is in agreement with those of other researchers who reported that parents and teachers described an increased rate of clinically significant behavioral problems in children who have survived cancer. One study reported that 14% of parent ratings and 7% of teacher ratings on the Child Behavior Checklist met the criteria for poor adjustment (Newby, Brown, Pawletko, Gold, & Whitt, 2000). Butler, Rizzi, and Bandilla (1999) assessed psychological functioning in 88 children on (n = 24) or off cancer therapy (n = 64) using the Personality Inventory for Children and the Child Behavior Checklist. They found that, on average, 19% of participants were identified as having an adjustment problem on any one of the scales of the Personality Inventory for Children that measured self-control, social incompetence, internalization or somatic symptoms, and cognitive development. The most common difficulties were in the areas of cognition, somatic complaints, anxiety, and family cohesiveness. Twelve percent of the sample had adjustment difficulties according to the Child Behavior Checklist (Butler et al.). Olson et al. (1993) reported that cancer survivors who resided in a rural setting were four times more likely than their age- and gender-matched school peers to have social competence scores (parent ratings) below the normal range. In the present study, 24% of parent social skills ratings and 22% of sense of inadequacy self-ratings were in the at-risk range.

Butler et al. (1999) found that PIQ was a significant predictor of social competence, cognitive development, and withdrawal. Teacher ratings of learning problems, school problems, leadership, study skills, and attention problems also were correlated significantly with performance on a standardized measure of academic abilities (Butler et al.). The current study's findings suggest a link between intellectual abilities (that may be affected adversely by CNS treatment) and school problems, such as the ability to understand and complete schoolwork, organizational skills and study habits, the ability to concentrate, and the ability to successfully interact with peers and teachers.

Body image changes during treatment, academic abilities, and FSIQ and PIQ scores were correlated negatively with BASC self-report of social stress and depression. Eighteen percent of subjects had self-report scores in the at-risk range for depression, and 16% of self-report scores were in the atrisk range for social stress. To the researchers' knowledge, the current study is the first to examine relationships among behavioral adjustment (parent, teacher, and self-report ratings), body image alterations, and cognitive and academic abilities following CNS treatment for childhood ALL.

Previous studies of outcomes from CNS treatment for ALL have not investigated relationships between cognitive or academic abilities and specific areas of behavioral adjustment. Thus, findings from this study are preliminary and warrant replication. Future studies are needed to determine predictive relationships among these variables.

In summary, these findings suggest that, although the majority of children with cancer are not at risk for significant behavioral adjustment problems, specific areas of concern exist. Scales in which at least 25% of scores from teacher, parent, or self-ratings were at risk were somatization, adaptability, attention problems, withdrawal, anxiety, social skills, and learning problems. These areas are potential targets for behavioral and cognitive intervention strategies. Body image alterations may increase the risk for behavioral adjustment problems in children and adolescents with ALL. CNS treatment-related declines in cognitive and academic abilities were correlated with social stress and depression among cancer survivors. This is a preliminary finding on a relatively small sample, but it also underscores the need for interventions designed to improve outcomes from CNS treatment.

### Limitations

These findings were based on data collected from two pediatric oncology treatment centers. Subjects were treated according to Children's Cancer Group or Pediatric Oncology Group protocols, and treatment intensity varied across protocols. These limitations must be considered with respect to the generalizability of these findings. Oral glucocorticoids (e.g., dexamethasone, prednisone) are used routinely as part of ALL treatment. Data were not collected regarding type or dose of oral glucocorticoids; however, the researchers recognize that this also could affect behavioral adjustment and cause body image alterations. Data about intrathecal hydrocortisone was collected; the number of intrathecal hydrocortisone doses was not correlated with BASC, WISC-R, or WRAT-R variables.

### **Future Directions**

Based on an average age of 5 years at the time of cancer diagnosis and 77 years as the projected length of life, 72 years of every childhood cancer survivor's life are influenced by late effects of cancer and its treatment (Bleyer, 1993). According to Bleyer (1990), the dramatic improvement in survival from childhood cancer is worthwhile only if the quality of survival justifies the increased prolongation of life. Childhood cancer survivors have not lived long enough in adequate numbers to accurately document the overall long-term impact of late effects on quality of life. However, this population continues to increase and currently outnumbers other pediatric populations experiencing chronic conditions related to hearing, visual, or orthopedic impairments (Peckham, 1991; U.S. Department of Health and Human Services, 1997). Recognition is increasing that CNS treatment is associated with late effects that adversely impact behavioral adjustment, as well as cognitive and academic abilities. Future studies that characterize patterns of deficits and measure the efficacy of interventions designed to improve behavioral, cognitive, and academic abilities among children receiving CNS treatment for cancer are needed.

**Author Contact:** Ida M. (Ki) Moore, RN, DNS, FAAN, can be reached at kmoore@nursing.arizona.edu, with copy to editor at rose\_mary@earthlink.net.

## References

- Anderson, V., Smibert, E., Ekert, H., & Godber, T. (1994). Intellectual, educational, and behavioural sequelae after cranial irradiation and chemotherapy. Archives of Disease in Childhood, 70, 476–483.
- Appleton, R.E., Farrell, K., Zaide, J., & Rogers, P. (1990). Decline in head growth and cognitive impairment in survivors of acute lymphoblastic leukaemia. Archives of Disease in Children, 65, 530–534.
- Armstrong, F.D., Blumberg, M.J., & Toledano, S.R. (1999). Neurobehavioral issues in childhood cancer. *School Psychology Review*, 28, 194–203.
- Bleyer, W.A. (1990). The impact of childhood cancer on the United States and the world. CA: A Cancer Journal for Clinicians, 40, 355–367.
- Bleyer, W.A. (1993). What can be learned about childhood cancer from "Cancer Statistics Review 1973–1988." Cancer, 71(10 Suppl.), 3229–3236.
- Bleyer, W.A. (1995). The past and future of cancer in the young. *Pediatric Dentistry*, 17, 285–290.
- Boekaerts, M., & Roer, I. (1999). Stress, coping, and adjustment in children with a chronic disease: A review of the literature. *Disability and Rehabili*tation, 21, 311–337.
- Brown, R.T., Sawyer, M.B., Antoniou, G., Toogood, I., Rice, M., Thompson, N., et al. (1996). A 3-year follow-up of the intellectual and academic functioning of children receiving central nervous system prophylactic chemotherapy for leukemia. *Developmental and Behavioral Pediatrics*, 17, 392–398.
- Butler, R.W., Rizzi, L.P., & Bandilla, E.B. (1999). The effects of childhood cancer and its treatment on two objective measures of psychological functioning. *Children's Health Care*, 28, 311–327.
- Cavusoglu, H. (2001). Depression in children with cancer. *Journal of Pediatric Nursing*, 16, 380–385.
- Copeland, D.R., Moore, B.D., Francis, D.J., Jaffe, N., & Culbert, S.J. (1996).Neuropsychologic effects of chemotherapy on children with cancer: A longitudinal study. *Journal of Clinical Oncology*, 14, 2826–2835.
- Cousens, P., Ungerer, J.A., Crawford, J.A., & Stevens, M.M. (1991). Cognitive effects of childhood leukemia therapy: A case for four specific deficits. *Journal of Pediatric Psychology*, 16, 475–488.
- Eckert, T.L., Dunn, E.K., Codding, R.S., & Guiney, K.M. (2000). Self-report: Rating scale measures. In E.S. Shapiro & T.R. Kratochwill (Eds.), Conducting school-based assessments of child and adolescent behavior (pp. 150– 169). New York: Guilford Press.
- Fossen, A., Abrahamsen, T.G., & Storm-Mathisen, I. (1998). Psychological outcome in children treated for brain tumor. *Pediatric Hematology and Oncology*, 15, 479–488.
- Jastak, S., & Wilkinson, G. (1984). The Wide Range Achievement Test (revised ed.). Wilmington, DE: Jastak Associates.
- Jemal, A., Murray, T., Samuels, A., Ghafoor, A., Ward, E., & Thun, M. (2003). Cancer statistics, 2003. CA: A Cancer Journal for Clinicians, 51, 5–26
- Kramer, J., & Moore, I.M. (1989). The late effects of cancer therapy on the central nervous system. Seminars in Oncology Nursing, 5, 22–28.
- McCarthy, D. (1972). *McCarthy Scales of Children's Abilities*. New York: Psychological Corporation Harcourt Brace Jovanovich.
- Merrell, K.W. (2000). Informant report: Rating scale measures. In E.S. Shapiro & T.R. Kratochwill (Eds.), Conducting school-based assessments of child and adolescent behavior (pp. 203–233). New York: Guilford Press.
- Moore, I.M., Espy, K.A., Kaufmann, P., Kramer, J., Kaemingk, K., Miketova, P., et al. (2000). Cognitive consequence and central nervous system injury following treatment for childhood leukemia. Seminars in Oncology Nursing, 16, 279–290.
- Moore, I.M., Glasser, M.E., & Ablin, A.R. (1988). The late psychosocial consequences of childhood cancer. *Journal of Pediatric Nursing*, 3, 150–158.

- Moore, I.M., Kramer, J., & Ablin, A.R. (1986). Late effects of central nervous system prophylactic leukemia treatment on cognitive functioning. *Oncology Nursing Forum*, 13, 45–51.
- Mulhern, R.K., Armstrong, F.D., & Thompson, S.J. (1998). Function-specific neuropsychological assessment. *Medical and Pediatric Oncology*, 1(Suppl.), 34–40.
- Mulhern, R.K., Wasserman, A.L., Friedman, A.G., & Fairclough, D. (1989).Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, 83, 18–25.
- Newby, W.L., Brown, R.T., Pawletko, T.M., Gold, S.H., & Whitt, K. (2000). Social skills and psychological adjustment of child and adolescent cancer survivors. *Psycho-Oncology*, 9, 113–126.
- Olson, A.L., Boyle, W.E., Evans, M.W., & Zug, L.A. (1993). Overall function in rural childhood cancer survivors. *Clinical Pediatrics*, 32, 334–342.
- Peckham, V.C. (1991). Educational deficits in survivors of childhood cancer. Pediatrician, 18, 25–31.
- Pendley, J.S., Dahlquist, L.M., & Dreyer, D. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology*, 22, 29–43.
- Reynolds, C.R., & Kamphaus, R.W. (1992). Behavioral assessment system for children. Circles Pine, MN: American Guidance Service.
- Ries, L.A.G., Smith, M.A., Gurney, J.C., Linet, M., Tamra, T., Young, J.L., et al. (1999). Cancer incidence and survival among children and adolescents: United States SEER Program 1975–1995 [NIH Pub No. 99-4649]. Bethesda, MD: National Cancer Institute.
- Shapiro, E.S., & Kratochwill, T.R. (2000). Introduction: Conducting a multidimensional behavioral assessment. In E.S. Shapiro & T.R. Kratochwill (Eds.), Conducting school-based assessments of child and adolescent behavior (pp. 1–20). New York: Guilford Press.
- Sharan, P., Mehta, M., & Chaudhry, V.P. (1999). Psychiatric morbidity in children suffering from acute lymphoblastic leukemia. *Pediatric Hematol*ogy and Oncology, 16, 49–54.
- Silber, J.H., Radcliffe, J., Peckham, V., Perilongo, G., Kishnani, P., Fridman, M., et al. (1992). Whole-brain irradiation and decline in intelligence: The influence of dose and age on IQ score. *Journal of Clinical Oncology*, 10, 1390–1396.
- U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. (1997). Trends in the well-being of America's children and youth. Retrieved June 24, 2003, from http://aspe.hhs.gov/hsp/97trends/intro-web.htm
- Wechsler, D. (1974). Manual for the Wechsler Intelligence Scale for Children.

  New York: Psychological Corporation.

# For more information . . .

- Cancer Source: Follow-Up Care for Childhood Cancer Survivors
  - www.cancersourcekids.com
- ➤ Patient-Centered Guides: Childhood Cancer Survivors www.patientcenters.com/survivors
- ➤ The Children's Cause www.childrenscause.org

Links can be found using ONS Online at www.ons.org.