Childhood Leukemia Survivors and Their Return to School: A Literature Review, Case Study, and Recommendations

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Leukemias (blood cell cancers) and central nervous system tumors are the most frequently occurring types of cancer in children. Mortality rates from all childhood cancers have decreased over the past 2 decades. As a result, many childhood cancer survivors are now returning to their schools after having been successfully treated. Although most of these survivors will continue receiving ongoing medical management after cancer treatment, far fewer receive specialized educational services. The purpose of this article is to draw attention to this often-overlooked area. The authors also review the case of 1 childhood leukemia survivor as a case example, and examine the cognitive/intellectual and affective/psychosocial sequelae that resulted after routine cancer treatment. They posit that school psychologists are uniquely positioned to provide vital assessment and educational services to childhood cancer survivors, and they offer a series of recommendations for when such children present within school settings.

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INTRODUCTION

As a result of the improvement in treatment for childhood cancer, many children with cancer can be expected to survive and reenter school and social settings, either while obtaining treatment or shortly after completing treatment. Although some children return with few signs of the disease or the effects of treatment, many more experience significant or subtle deleterious effects that adversely affect their ability to function in the school or social environment (Peckham, 1991; Sexson & Maden-Swain, 1993). More than half of all children diagnosed with cancer will have leukemia or a form of brain tumor (Butler & Haser, 2006), and many of these children will be at risk for learning impairment either because of the cancer or because of its treatment (Armstrong, Blumberg, & Toledano, 1999; Butler & Haser, 2006; Gregory, Parker, & Craft, 1994; Peckham, 1989). Acute lymphoblastic leukemia (ALL) survivors in particular are known to be at risk for psychological, educational, occupational, and social problems stemming from their cancer experience and its treatment (Mannix & Boergers, 2010). It is therefore imperative that professionals in the medical and school setting work collaboratively when treating children or adolescents with cancer—especially those with ALL—to minimize such negative outcomes.

By virtue of their advanced training in child psychology, assessment, and psychometrics, school psychologists are particularly well positioned to provide vital services to survivors of childhood cancer as they reenter school. Moreover, recent literature has documented that practicing school psychologists are interested in receiving more specialized training devoted to pediatric chronic illnesses (Barraclough & Machek, 2010), and recent models have been developed to assist school psychologists in their efforts to reintegrate and assist child and adolescent cancer survivors within the school environment (Harris, 2009). In light of the emerging trend toward the optimization of school-based services for childhood cancer survivors, we offer the following literature review, case study, and best practice recommendations for school psychologists interested in expanding and refining their ability to provide such services in this area. In this article, we include information on childhood cancer survivors in general, but place special emphasis on survivors of ALL in particular—the most common form of childhood cancer.

LITERATURE REVIEW

Childhood Cancer Types

Cancer is the fourth leading cause of death in children and adolescents, after unintentional injuries, homicides, and suicide (Centers for Disease Control...
and Prevention, 2007). In children, cancer tends to cluster around 15 specific categories, each with unique features, course, and prognosis. Incidence rates for all cancers combined are highest in infants, decline until the age of 9 years and then rise again with increasing age (American Cancer Society, 2000; Keene, 1999; Ross & Davies, 2001). Incidence rates are higher for boys than for girls, and are highest in Whites and lowest in American Indians or Alaskan Natives (American Cancer Society, 2000). Central nervous system (CNS) cancers and leukemias (blood cell cancers) account for more than half of all new childhood cancer cases, with ALL accounting for approximately 75% of all pediatric leukemia cases (Butler & Haser, 2006). Because ALL is the most common form of childhood cancer affecting school-aged children, we chose it as the central focus of this article. However, much of the information presented is also particularly applicable to children affected by CNS cancers because there are significant similarities in the neurocognitive effects of medical treatment for ALL and CNS tumors (Butler & Haser, 2006).

Acute Lymphoblastic Leukemia (ALL)

ALL is a disease caused by an uncontrolled proliferation of malignant white blood cells (lymphoblasts) in the bone marrow, which leads to pathological reduction of normal blood cells and their functions and places a child at high risk for death as a result of overwhelming infection (Armstrong et al., 1999; Mulhern, 1994). Approximately 2,500 children are diagnosed with ALL each year in the United States. It is most commonly diagnosed between the age of 2 and 7 years. Children with genetic diseases such as Down syndrome, Bloom syndrome, or Fanconi anemia have a greater risk of developing leukemia than children in the general population (Keene, 1999; Linet, Ries, Smith, Tarone, & Devesa, 1999).

Mortality and Survival Rates

Childhood cancer mortality rates in the United States have declined dramatically over the past 2 decades. The overall decline in mortality for children with cancer decreased nearly 50% between 1975 and 2002 (National Cancer Institute, 2010). In addition, from 1990 to 2004, death rates declined significantly for leukemias by 3.0% per year, for brain and other nervous system neoplasms by 1.0% per year, and for all other cancers combined by 1.3% per year (Centers for Disease Control and Prevention, 2007).

The increase of incidence and dramatic decline in childhood cancer mortality in the United States represent diagnostic improvements as well as treatment-related improvements in survival (Armstrong et al., 1999; Linet et al., 1999). The overall 5-year survival rate for all childhood cancers
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combined is now 80%, with the 5-year survival rate for brain and other nervous system cancers being 71%, and leukemia being 82% (American Cancer Society, 2010). Reasons for increased survival rates include an improvement in diagnostic technology (i.e., CT scan, MRI) which results in early detection of the disease. However, the greatest effect on increased childhood cancer survival has been improved treatment such as intensive chemotherapy for leukemias (e.g., cytoxan, methotrexate, vincristine, 6-MP), which account for approximately one third of all cancers occurring before the age of 15 years (Chen et al., 1996; Kishi, Tanaka, & Ueda, 2000).

Posttreatment Leukoencephalopathy

One of the important issues for children affected with a cancer, especially leukemia, is the effects that the various cancer treatments have on the child’s current and future functioning. Specific therapy directed at the CNS is required for treating ALL with the purpose of eradicating leukemia in the brain and spine. This can take the form of irradiation or intrathecal (injected into the spinal cord) administration of chemotherapy. Although previous studies have greatly debated the long-term effects of CNS prophylactic therapy with cranial irradiation and intrathecal methotrexate on the intellectual development and academic functioning of children who have remained in continuous remission, more recent studies support the hypothesis that either treatments performed separately or in conjunction can have deleterious effects on cognitive functioning (Coniglio & Blackman, 1995; Gamis & Nesbit, 1991; Goldsby et al., 2010; Mulhern, Friedman, & Stone, 1988; Peckham, 1989).

Intrathecal administration of chemotherapy with methotrexate has been increasingly used to avoid the documented negative effects of cranial radiation treatment (Armstrong et al., 1999; Mulhern, 1994; Keene, 1999). However, recent studies also show neurotoxicity from treatment using methotrexate over the past 10 years. The development of leukoencephalopathy (cerebral subcortical calcifications) is a common form of neurotoxicity which has been linked to cognitive problems and learning disabilities (Keene, 1999). Although different theories have been forwarded to explain the underlying neurological basis of such neurocognitive dysfunction, damage to cortical and subcortical white matter has received the most attention (Askins & Moore, 2008).

Observed seizure activity during treatment for ALL is the most common reason for referral to a radiologist for neuroimaging studies during cancer treatment. The diagnosis of leukoencephalopathy is based on neuroimaging studies using CT scans and MRIs. Although previously thought to occur only in combination with irradiation treatment (Gamis & Nesbit, 1991), research now supports the notion that chemotherapy alone, through the use of intrathecal methotrexate, can produce encephalopathy (Mahoney et al., 1996). Cerebral subcortical calcifications caused by methotrexate...
leukoencephalopathy have been reported to occur in 0–51% of all cases (Lovblad et al., 1998). In addition, patients younger than 10 years of age at the time of diagnosis and treatment are more at risk for developing calcifications and epileptic seizures (Lovblad et al., 1998; Mulhern et al., 1988; Shikano, Kobayashi, & Ishikawa, 1999). Intracerebral calcifications, which occur in the basal ganglia, have the greatest correlation with neuropsychological sequelae (Gamis & Nesbit, 1991).

Other Effects of ALL and Its Treatment

Intensive treatment protocols for ALL have also been known to produce purely physical side effects, including endocrine problems, secondary cancers, and infertility (Mannix & Boergers, 2010). Factors associated with an increased risk of negative long-term effects of ALL and its treatment include younger age at diagnosis, gender and time since treatment; with earlier diagnosis and female gender being associated with poorer outcomes, and with negative effects of treatment becoming more pronounced over time (Armstrong et al., 1999; Brown et al., 1998; Holmqvist et al., 2010; Waber, Tarbell, Kahn, Gelber, & Sallan, 1992). Studies have shown that cognitive impairments are usually not immediately apparent, but materialize about 3 or more years after treatment. These cognitive problems include lower overall IQ and difficulties with verbal memory as well as recalling geometric designs (Armstrong et al., 1999; Mulhern, 1994; Waber et al., 1992). Water, Said, Cousens, and Stevens (1989) found 12-point IQ differences between 45 children with ALL who were treated with CNS prophylaxis using cranial radiation and intrathecal methotrexate and 45 siblings matched for age and gender. The study also found these children to have low attention, behavior problems, and peer problems that were hypothesized to be connected to cognitive impairments. In addition, studies have shown that children treated with intrathecal chemotherapy alone are at risk for nonverbal learning difficulties, inattentiveness, and social skills deficits that often require special education services (Armstrong et al., 1999; Waters et al., 1989).

Studies have also shown that long-term survivors of childhood cancer have a 30–40% risk of school-related problems, whereas those with ALL who are treated with cranial irradiation have 3-4 times the risk of school-related problems compared with nonirradiation children (Mulhern et al., 1988). A meta-analysis on 30 studies looking at the potential effects of cranial radiation therapy on individuals diagnosed with childhood ALL determined that this modality of treatment is associated with declines in intelligence test scores (Cousens, Waters, Said, & Stevens, 1988). Other studies have found treatment-related attention deficits in survivors of childhood ALL (Butler & Haser, 2006), with some studies showing deficits when chemotherapy was used in the absence of cranial irradiation (Buizer, de Sonneville, van den Heuvel-Eibrink, & Veerman, 2005). Reeves et al. (2007) detailed the
prevalence of slow cognitive tempo (e.g., lethargy, disorganization, attention problems) and its association with lower IQ and achievement scores among childhood ALL survivors. The neurocognitive and psychological disturbances associated with the treatment of ALL and CNS cancers has been found to be reasonably similar to those found in children who suffer from other medical conditions such as attention deficit/hyperactivity disorder or traumatic brain injury (Butler & Haser, 2006).

With regard to depression and affective sequelae in childhood cancer survivors, the literature is not entirely clear. Although some evidence indicates an increased level of affective distress in childhood cancer patients (e.g., Cavusoglu, 2001; Zebrack et al., 2002), the majority of evidence points to either equivalent or lower levels of affective distress in comparison to normative groups or healthy peers (Bragado, Hernández-Lloreda, Sánchez-Bernardos & Urbano, 2008; Canning, Canning, & Boyce 1992; Kaplan, Busner, Weinhold, & Lenon, 1987; Kersun, Rourke, Mickley, & Kazak, 2009; Phipps & Srivastava, 1997; Tebbi, Bromberg, & Mallon, 1988; Worchel et al., 1988). This literature is in sharp contrast with the meta-analytic data on depression rates in adult cancer patients (e.g., Van’t Spijker, Trijsburg & Duivenvoorden, 1997), and this phenomena is explored further in the “Case Study” section of this article.

In summary, childhood cancer survivors have been found to be at risk for multiple deficits. Those who are most at risk are individuals less than 6 to 8 years of age at the time of treatment, those treated with CNS irradiation or having had concurrent intrathecal methotrexate, and those having shown CAT scan abnormalities with CNS calcifications (Gamis & Nesbit, 1991). Recent studies have associated earlier age at diagnosis and being female as being predictive of poorer socioeconomic and academic outcomes (Holmqvist et al., 2010). Common neuropsychological and psychosocial problems found in children treated for ALL or CNS cancers may include the following: (a) intellectual decline, (b) learning disabilities, (c) decreased attention span, (d) short-term memory deficits, (e) academic achievement problems, (f) adjustment difficulties, (g) somatic complaints of undetermined etiology, (h) increased anxiety, and (i) diminished social competency (Butler & Haser, 2006; Gamis & Nesbit, 1991; Holmqvist et al., 2010; Mulhern et al., 1988; Robinson et al., 2010). In addition, although most long-term survivors of ALL remain in remission, about 5–10% will experience a CNS relapse that requires intensified treatment to the brain that may invite further neurocognitive or psychosocial complications.

Need for Specialized Services

On the basis of this literature, it seems clear that increases in childhood cancer survival rates in conjunction with our knowledge about the immediate
and long-term effects of its treatment make the need for specialized educational services great. In the past, many childhood cancer survivors have not received fully comprehensive services when they are reintroduced to school settings, or when they are concurrently receiving cancer treatment. Successful school reintegration for children diagnosed with cancer is best facilitated by a coordinated effort between and within the home, school, and hospital ecosystems; but explicit models for promoting such coordinated reintegration have been scarce (Harris, 2009). Often, school services lack the comprehensive approach to care that has been found to be so essential to the successful treatment of chronic health condition such as childhood cancer (Gregory et al., 1994; Keene, 1999; Linet et al., 1999). It is common practice for school reintegration programs to focus on getting a child with cancer mainstreamed and back into a regular educational setting. However, the desire to maintain these children at baseline levels overlooks the fact that many will have cognitive deficits when they reenter school. This can set the stage for further school-related problems due to a risk of creating a cycle of failure, frustration, depression and regression (Peckham, 1991).

Research indicates numerous immediate and long-term needs for childhood survivors of cancer. Studies have documented attendance problems and school phobia in survivors of childhood cancer, often because of a significant amount of missed school days (Williams, Ochs, Williams, & Mulhern, 1991). Treatments often change a child’s appearance, stamina, and well-being that contribute to social unease and, if not appropriately addressed, may lead to school phobia (Gregory et al., 1994). Other studies have suggested that factors contributing to the high rate of absenteeism and school phobia are related to the child’s sense of failure when he or she cannot perform at his or her expected level. A logical consequence for a child who has lost his or her abilities to perform in school includes poor self-concept, low motivation, and increases in anxiety and possibly depression (Keene, 1999; Waters et al., 1989; Williams et al., 1991).

Some childhood cancer survivors who have significant medical late effects have also been found to have poorer total self-concept, more depressive symptoms, and more external locus of control compared with those with no or with mild-to-moderate late effects (Greenberg, 1999). Studies have documented certain patterns of academic difficulties that emerge as late effects of cancer or its treatment. These include complaints about concentration or sustaining attention, basic mathematics skills, requiring inordinate amounts of review and practice before basic skills are mastered; difficulty remembering, sequencing, and following directions; difficulty organizing and learning new material; and poor performance under stress such as forgetting previously learned material (Peckham, 1991). In a recent study, the overwhelming majority of post–cancer treatment children evaluated indicated diverse and varied late effects bothersome enough to affect their participation in vigorous leisure activities, chores, and community activities (Berg, Neufeld, Harvey,
Downs, & Hayashi, 2008). Vance and Eiser (2002) reported that children with cancer tend to be more sensitive and isolated than are their peers, and Kakaki and Theleritis (2007) noted that adolescent cancer survivors may experience elevated involvement in risk-taking behaviors such as illicit drug, alcohol, and tobacco use, presumably because many may have experienced a loss of faith in their futures. Kakaki and Theleritis (2007) also noted that given the severity of these children’s medical histories, such behavioral acting out tends to be associated with amplified risk. Other research has indicated that parents of cancer survivors report more behavioral problems in general than parents of control children (Olson, Boyle, Evans, & Zug, 1993). With so many factors to consider, some studies on educational/psychological services for childhood cancer survivors have simply emphasized the importance of early intervention, and identifying those children who appear to have emotional and intellectual disabilities (Chang, 1991; Gamis & Nesbit, 1991; Peckham, 1991).

**CASE STUDY**

To demonstrate some of the considerations and factors highlighted in our literature review, select components of one particular case study are presented for illustrative purposes. Following our case study highlights, we offer general and specific best practice recommendations that school psychologists can adopt when a childhood leukemia survivor presents within his or her school setting.

The patient is a 7-year-old Caucasian female diagnosed with ALL. The patient was treated for 2 years at the pediatric oncology clinic of a large military hospital in the eastern part of the United States. Part of the treatment protocol included intrathecally administered chemotherapy (methotrexate) without intracranial radiation.

**Cognitive Sequelae**

The patient was initially referred to the child psychology clinic for a psychological evaluation because of symptoms of confusion, headaches, and automatisms (periodic behavior disturbances found in psychomotor epilepsy) occurring during chemotherapy treatment. Subsequent findings from a neuroimaging study using a CT scan and MRI indicated bilateral leukoencephalopathy, alterations in the white matter of her brain caused by calcifications (see Figures 1 and 2).

An initial baseline cognitive assessment was completed at intake, and a follow-up cognitive assessment was conducted 2 years after diagnosis to determine the extent of cognitive impairment caused by leukoencephalopathy from intrathecal methotrexate.
White areas on radiological image are significant, reflecting leukoencephalopathy with high signal throughout the semiovale bilaterally, consistent with chemotherapeutic changes.

An initial assessment using the Wechsler Preschool and Primary Scale of Intelligence-Revised revealed above-average cognitive functioning with the patient’s verbal IQ at a standard score of 99, performance IQ of 127, and full-scale IQ of 113. Subsequent testing for the 2-year follow-up after treatment revealed a significant drop (25 points) in overall cognitive functioning with a verbal IQ of 80, performance IQ of 101, and full-scale IQ of 88 (see Figure 3).

In addition, qualitative data from the patient’s mother indicated that this patient showed a slight increase in her level of distractibility, problems with organization, and a decrease in her short-term memory functioning following her cancer treatment. To be successful in school, this patient’s mother relied upon regular communication with the child’s school teacher, frequent monitoring of homework assignments, and repeated explanation and drilling of assigned material. Limited special education services and classroom accommodation were also provided to help address the cognitive deficits she acquired through cancer diagnosis and treatment.

The results from this patient’s cognitive testing are supported by the literature, indicating that either chemotherapy or radiation can produce
cognitive deficits in children. In particular, the administration of methotrexate as intrathecal chemotherapy represents a significant risk factor for cognitive impairment (Chen et al., 1996; Waber & Tarbell, 1997). Typical IQ deficits range from 5 to 20 points and have been found to persist for years after treatment, but are often not immediately present (Brown et al., 1998).

Affective/Psychosocial Sequelae

To assess for affective/psychosocial disturbance, our case study child was administered the Children’s Depression Inventory (Kovacs, 2003), and the Multidimensional Anxiety Scale for Children (March, 1997) as part of her assessment procedure at 2 years after original ALL diagnosis. Baseline data on these emotional adjustment measures were not obtained during the child’s initial pretreatment evaluation. As a result, pre/posttreatment comparisons of affective/psychosocial sequelae were not possible.

There were no significant elevations on either the Children’s Depression Inventory or Multidimensional Anxiety Scale for Children at 2 years after cancer diagnosis, indicating no clinically significant affective/psychosocial symptoms involving depression or anxiety. Although curious at face value,
The Wechsler Preschool and Primary Scale of Intelligence-Revised subtest scores at initial and follow-up assessments. The subtest plot shows intellectual decrement over approximate 2-year period after high-dose methotrexate therapy (chemotherapy) for acute lymphoblastic leukemia.

This finding is entirely consistent with the majority of the current literature indicating that pediatric cancer patients are often found to have either equivalent or less affective distress symptoms when compared with healthy peers or national normative groups (Bragado et al., 2008; Canning et al., 1992; Kaplan et al., 1987; Kersun et al., 2009; Phipps & Srivastava, 1997; Tebbi et al., 1988; Worchel et al., 1988). Although various psychological theories have been offered that attempt to explain this phenomena (e.g., see Phipps, 2007), we posit that the nature of self-report inventories in general may not be entirely sufficient to capture the affective symptomatology that may exist in some members of this population. We also speculate that alternative and more sensitive modalities of assessment may be needed.

With regard to our case study child, careful history taking and interviewing with this child’s mother revealed a number of concerns regarding emotional adjustment that were later validated through direct observation over several months of outpatient psychological treatment. Cognitive-behavioral intervention focused on personal adjustment, worry and coping/adaptation after cancer treatment for ALL. Although maternal report via clinical
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interviewing turned out to be a rich and accurate source of information regarding affective distress in the present case, this modality of assessment generally should not be exclusively relied upon because some evidence has indicated maternal reports of their children’s emotional state may be biased and may be linked to the mother’s own emotional state (Garber, Van Slyke, & Walker, 1998; Najman et al., 2001). As such, we maintain that additional, more sensitive modalities of affective/psychosocial assessment in childhood cancer survivors is needed to validly, reliably, and efficiently rule-in/rule-out emotional symptoms in this population.

BEST PRACTICE RECOMMENDATIONS FOR SCHOOL PSYCHOLOGISTS

Research indicates that many childhood cancer survivors experience consequences that result in problems with school functioning, educational development, and performance (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005; Fryer, Saylor, Finch & Smith, 1989; Wallander & Varni, 1998). However, poor neurocognitive outcome is not true for all children, and at present there is no way to reliably predict in advance which children will develop significant cognitive impairment and which will not (Askins & Moore, 2008). Although the research is mixed regarding affective/psychosocial sequelae, some evidence (including our own case study) suggests that affective symptoms should not be summarily dismissed, and that such symptoms may be a significant problem area for some childhood cancer survivors (e.g., Cavusoglu, 2001; Zebrack et al., 2002). Specific models of school reintegration and cognitive remediation for childhood cancer survivors have been developed to help these children cope with the aftereffects of cancer treatment (e.g., Butler & Copeland, 2002; Harris, 2009), and should be used to facilitate adaptation.

From our perspective, one of the most essential ingredients for any successful reintegration or remediation program is for medical practitioners and school psychologists to work collaboratively to coordinate the care of childhood cancer survivors. As noted by Wodrich (2004), children benefit when pediatric medicine and school psychology practitioners work together in a complementary fashion. Although oncologists have traditionally taken the lead in discussing neurocognitive late effects of treatment with parental caregivers, recent studies have indicated that parents also desire to have psychologists embedded within the process to help identify and remedy such deficits (Task, Green-Welch, Manley, Jelalian, & Schwartz, 2008). Studies also reveal that teachers need more information about ALL, its treatment, prognosis, and late neurocognitive effects for long-term survivors (Chang, 1991; Gamis & Nesbit, 1991; Peckham, 1991). It is important that every parent
and educator realize that learning problems are common in childhood cancer survivors and that learning problems often do not manifest themselves until years after therapy (Bradwell, 2009; Mannix & Boergers, 2010; Peckham, 1991). Studies investigating the best educational services for these children (e.g., Gamis & Nesbit, 1991; Harris, 2009; Leigh & Miles, 2002; Mulhern et al., 1988; Peckham, 1991) have recommended early identification and preventive services, with arrangements being made well in advance for school absences and eventual school reentry. Research has also shown that although survivors of leukemia and CNS tumors are significantly less likely to finish high school when compared with their siblings, such difference can be substantially diminished when special education services are provided (Mitby et al., 2003). Examples of ways to provide early identification, preventive services and special education to children with cancer, and more specifically to children with ALL, are subsequently discussed.

School Reintegration

As noted by Askins and Moore (2008), school can provide a sense of normalcy and hope during an otherwise tumultuous time, and promoting a child’s academic development during cancer treatment can engender a positive sense of self-efficacy. If a child is unable to attend school as a result of medical reasons related to cancer, eligibility for homebound instruction through his or her school district should be considered as early as possible. Eligibility for homebound instruction, as well as the manner in which it is delivered, may vary across school districts. In general, however, a physician must indicate that the child is unable to attend school for an extended period of time because of a medical condition. Homebound instruction, provided by a certified teacher, may help lessen the degree to which the child might fall behind academically. Although homebound instruction may be beneficial, it would seem that such cannot fully substitute for the myriad of experiences the child would receive by attending school. It is important to note, however, that research is lacking in this area. Nevertheless, the child should begin attending school once it is deemed appropriate for him or her to do so. To ease the reintegration process, parents and educators should meet to develop a basic plan before the child returns to the classroom. This plan should be tailored to meet the needs of the child. For example, if the child tends to be fatigued easily as a result of his or her medical issues, the reintegration plan may need to involve a shortened school day, gradually building up to a full school day. If the child is anxious about returning to school because of worries about peer and/or academic issues, the reintegration plan may require strategies to promote peer socialization (e.g., assigning a peer buddy) and/or a modified curriculum (e.g., shortened assignments). The reintegration of a student with leukoencephalopathy or other types of
brain injury to a school setting is not a one-time process, and may take several weeks (Harvey, 1995). Savage and Carter (1988) identified the following four crucial steps in the reintegration process:

1. Involvement of the school-based special education team in the hospital or rehabilitation facility.
2. Inservice training for all school-based staff who will have contact with the student.
3. Short- and long-term planning for the support services needed for the student.
4. Continued follow-up by the rehabilitation professionals.

Special Education Accommodation

In some cases, it may be appropriate for the child’s educational team (i.e., teachers, school psychologist, and parents) to consider implementing a Section 504 Accommodation Plan. Section 504 of the Rehabilitation Act of 1973 stipulates that an individual with a disability cannot be discriminated against in any setting that receives federal funds (Sattler, 2001). Under Section 504, the term disability is defined as a physical or mental impairment that “substantially limits” one or more major life activities (U.S. Department of Health and Human Services, 2006). In addition, Section 504 protects individuals with a history of a physical or mental impairment, as well as those regarded as impaired. According to the Office of Civil Rights, cancer may be considered an impairment that substantially limits a major life activity such as learning (U.S. Department of Health and Human Services, 2006). Hence, if a childhood cancer survivor requires additional services or accommodations in order to receive a free appropriate public education, his or her school district may need to implement a Section 504 Accommodation Plan. Examples of accommodations that might be appropriate to include in a Section 504 Plan are as follows: Extended work time to complete assignments, individual tutoring, peer tutoring, allowing the child to use a calculator, untimed testing or administering oral assessments, allowing the use of books on tape, using visual cues to promote memory retention, providing support in using organizational tools such as an assignment calendar, and providing an amended school day.

Upon return to the school setting, if the childhood cancer survivor demonstrates significant academic delays despite having received appropriate accommodations, parents and educators should consider referring the child for an evaluation to determine special education eligibility. Similarly, if the child demonstrate significant academic decline over time (e.g., 2–3 years), special education eligibility should be considered. Under special education law, the Individuals With Disabilities Education Act stipulates that children
with disabilities must receive a free appropriate public education through the provision of special education and related services (Sattler, 2001). Although similar to Section 504, the Act dictates that children with disabilities must have a formal, intricate individualized education plan, which documents how the school will meet the child’s needs (Sattler, 2001). For children whose educational progress is adversely affected by their medical condition, the Individuals With Disabilities Education Act category other health impairment may be appropriate. According to federal guidelines, other health impairment is defined as follows:

... limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment and that adversely affects a child’s educational performance. It may be due to a chronic or acute health problem—such as asthma, attention-deficit disorder or attention-deficit/hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, or sickle cell anemia (Sattler, 2001, p. 54).

It is important to note that the aforementioned accommodation recommendations have not been studied empirically, and their ability to meaningfully remediate cognitive/intellectual deficits in childhood cancer survivors remains untested. However, if school-based accommodation and intervention are found to be insufficient, other medical interventions may still exist. For example, with regard to pronounced attention deficits in childhood cancer survivors, Thompson et al. (2001) and Mulhern et al. (2004) have reported on the successful use of methylphenidate (Ritalin) in a group of survivors (leukemia or brain tumor) exhibiting sustained attention deficits. If required, these sorts of more intensive interventions can be explored by way of communication with the child’s attending physician (see Bradley-Klug, Sundman, Nadeau, Cunningham, & Ogg, 2010) and/or a referral back to the hospital team.

Curriculum-Based Assessment/Instructional Assessment

Many studies point to the need for regular educational testing (i.e., every 6 months to a year) to determine current cognitive functioning, and as a means of considering the developmental nature of a child’s problems (Coniglio & Blackman, 1995; Gamis & Nesbit, 1991; Mulhern et al., 1988). In school settings, however, it may not always be feasible for the school psychologist to administer full-battery, cognitive tests to students every 6 months. Therefore, we recommend that students’ academic progress be monitored regularly through the use of curriculum-based assessment and instructional assessment (Gickling & Thompson, 1985; Kovaleski, Tucker, & Duffy, 1995),
with additional cognitive assessment every 2 to 3 years. With regard to the more extensive testing every few years, Harvey (1995) and others have suggested that school psychologists take a domain-specific approach to testing children with traumatic brain injury, and we feel this recommendation is also applicable for children treated for brain and nervous system neoplasms and ALL. Although the nomenclature varies somewhat from author to author (Harvey, 1995), domain specific testing typically includes measures assessing intelligence; language, memory and concentration; sensory recognition and perception; academic achievement; behavior and personality; and affective/psychosocial functioning. In the concluding section of this article, we offer specific recommendations for the identification of instruments and assessment methods for tapping these various domains. If any of these assessment techniques reveals a consistent lack of progress or a decrement of skills, we suggest a referral back to the hospital for comprehensive neuropsychological assessment.

Affective/Psychosocial Functioning

Affective/psychosocial functioning is another important area of concern for these children. Childhood cancer survivors have been identified as being at risk for a variety of late effects, including anxiety, somatic concerns, and misperceptions about reproductive fertility. (Brown et al., 1996; Keene, 1999). However, some research has also indicated that teachers tend to rate childhood cancer patients as having fewer behavioral, emotional, and learning problems than randomly selected students without a major illness, suggesting a “halo effect” upon reentry, and a propensity for such children to “fall between the cracks” (Fryer et al., 1989, p. 565). As previously noted, the possibility of affective/psychosocial sequelae is a distinct possibility that may affect some cancer survivors and should not be overlooked. Thus, the provision of counseling services, either in individual or group format, may be needed to address emotional issues that may affect children’s educational performance.

Although the literature in this area is scarce, Karayanni and Spitzer (1984) recommended that individual school-based counseling efforts be directed mainly at the sick child on adjustment and coping issues, while group counseling interventions be aimed at helping classmates cope and deal with their emotions and feelings regarding having a classmate stricken with cancer. Benner and Marlow (1991) noted that the success of school reentry programs for children with cancer depends largely on peer acceptance. Varni, Katz, Colegrove, and Dolgin (1994) likewise found that perceived social support from an ill child’s peers is related to positive psychological adjustment more than support from either parents or teachers. Because peer support has been found to be of such great importance, specific peer
education programs have been developed to improve supportive peer interactions toward children with cancer (e.g., Benner & Marlowe, 1991; Goodell, 1984; Houlahan, 1991; Treiber, Schramm, & Mabe, 1986). However, empirical research on such programs is limited, and some evidence has indicated that these educational programs do not automatically translate into a positive attitude shift towards a peer with cancer (Treiber et al., 1986). Because the effectiveness of school-based counseling interventions and peer-based education programs remains in question, we recommend that school psychologists who embrace such programs remain vigilant for the presence of any possible iatrogenic effects that these well-intentioned yet undetermined efforts may produce.

Other adjustment concerns may also occur with childhood cancer survivors when they become aware of their loss of skills and abilities upon their return to school. An ideal learning environment should therefore include exploration of current abilities in advance of a return to school, including areas of personal awareness and competence that the child may not have had prior to their diagnosis and treatment. Such may serve as a catalyst towards building a sense of competency, self-esteem and increased motivation for school (Gamis & Nesbit, 1991; Peckham, 1991). Effective rehabilitation should also include social skills training and remedial education programs to prevent the long-term negative effects that early peer relationship problems may have on these children (Waters et al., 1989).

SPECIFIC ASSESSMENT/INTERVENTION RECOMMENDATIONS

Some helpful steps to consider when developing educational services for childhood cancer survivors, and especially survivors of ALL include the following:

- Obtain baseline cognitive/intellectual and affective/psychosocial measurement as early as possible.
- Teach basic learning skills with multimodal presentations of these subjects such as auditory, visual, and kinesthetic tasks or assignments (Gamis & Nesbit, 1991).
- Keep parents informed and use parental information as the best indicator of possible problem areas (Williams et al., 1991).
- Schedule cognitive and academic assessment every 6 and 12 months as well as regular short-interval assessments (Armstrong et al., 1999; Keene, 1999).
- Look to curriculum-based approaches to assessment and conduct content specific assessment of the child’s progress in the classroom (Armstrong et al., 1999).
• Have an awareness that a child’s areas of difficulty will emerge with time, and take a preventative approach to assessment and the provision of services. It may require 2–3 years before absolute discrepancies are noted (Brown et al., 1998).

• Include measures that assess attention and concentration, memory, visual spatial and visual motor integration abilities, processing speed, and fine motor skills.

• Re-administer tests over time for comparisons purpose, and try to select tests which make age-based normative sample comparisons possible for many years to come.

Although not yet studied empirically, classroom interventions that may be helpful include the following:

• extended work time to complete assignments
• one-to-one tutoring
• peer tutoring
• allow the child to use calculators
• untimed testing or oral assessments
• use of books on tape

Assessment methods and instruments that tap the following domains appear most relevant for school psychologists to evaluate childhood cancer/ALL survivors on:

• intelligence
• language, memory, and concentration
• sensory, recognition, and perception
• academic achievement
• behavior and personality
• affective/psychosocial

Selecting valid, reliable and age-appropriate instruments is always of paramount importance to school psychologists. However, whenever possible consideration should also be given to selecting instruments that will continue to be age-appropriate for the longest length of time in order to make subsequent re-evaluations more comparable. For example, if a child is within age limits to be tested on either the Wechsler Preschool and Primary Scale of Intelligence—Third Edition or the Wechsler Intelligence Scale for Children–Fourth Edition for cognitive assessment, the latter scale should be chosen to allow for a greater window of instrument congruence for subsequent reevaluations. *The Handbook of Psychological and Educational Assessment of Children* (2nd ed.; Reynolds & Kamphaus, 2003); *Behavioral, Social, and Emotional Assessment of Children and Adolescents* (3rd ed.;
Merrell, 2007) and Assessment of Exceptional Students (8th ed.; Taylor, 2008) are recommended as sources for identifying suitable instruments and assessment techniques for tapping the previously noted domains.

CONCLUSION

Although advances in the treatment and survival for those afflicted with childhood cancer is clearly reason to celebrate, such advances are not always free from cost. Not infrequently, cognitive, educational, and emotional sequelae remain after a child has been victorious in overcoming his or her cancer. With regard to these posttreatment effects, school psychologists are ideally positioned to monitor, assess, and intervene in important ways that can significantly contribute to the ongoing health and well-being of such children.

NOTE

1. Case information was masked and/or slightly altered to protect the identity of the case subject.

REFERENCES


