LEARNING PROFILES OF SURVIVORS OF PEDIATRIC BRAIN TUMORS

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ABSTRACT

By 2010 it is predicted that one in 900 adults will be survivors of some form of pediatric cancer. The numbers are somewhat lower for survivors of brain tumors, though their numbers are increasing. Schools mistakenly believe that these children easily fit pre-existing categories of disability. Though these students share some of the characteristics of other types of disabilities, they present a unique constellation of challenges that require flexibility and adjustment on the part of schools and teachers. Survivors demonstrate a constellation of late effects which may change and increase in intensity over time; they are not static. The changes appear to be greater than those delineated for students with learning disabilities, in that they appear to be more than a response to new environmental expectations.

Most of these children were not identified as eligible for special education prior to their diagnosis with brain tumors. For many survivors, following the acute phase of illness and a period of home instruction, the expectation of the educational environment is that the student will be able to perform in the same way that that student did before diagnosis. In actuality the diagnosis and treatment of brain tumors in children typically result in a significant number of new challenges for the child. Sometimes these changes do not occur immediately and there may be a disconnection between the time that the student receives treatment and the time that the problems are noted.

This article provides information about the range of late effects evidenced by survivors. It describes a retrospective study of evaluation data from the Survivor Education and Reintegration Support Program at Carlow University. The program is designed to support schools, families and survivors as they adjust to the issues of survivorship. Information gathered on late effects and some suggestions for how schools may successfully address the myriad needs of survivors will be provided.

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Many survivors of pediatric brain tumors will live well into adulthood (Meadows, 2006). Teachers and schools will be expected to provide high quality educational experiences for an ever-increasing number of these individuals. Almost all children treated for brain tumors, even those only treated with surgery who may show no immediate signs of difficulty, have a significant risk for learning problems in the years after treatment (Armstrong, 2003). The mechanisms that underlie the learning difficulties are not fully understood. A brain tumor is a mass of unnecessary cells growing in the brain (American Brain Tumor Association, 2007). It can arise in any part of the brain, but there are common brain tumors that occur in children (e.g., medullablastoma). Injuries from a tumor, complications of surgery, exposure to radiation therapy of the brain, and some kinds of chemotherapy that affect brain development have all been linked to learning problem in survivors (Children's Brain Tumor Foundation, 2007; Eiser, 1998; Facts about Pediatric Brain Tumors, 2007; Phillips, 2006). Damage to a specific structure of the brain (e.g., surgery or tumor) or damage to small blood vessels (calcification) or to junior cells that affect growth and development after treatment is believed to be the main cause of learning late effects. Problems associated with brain development after treatments are often not recognized until the child reaches the age at which other children demonstrate that ability, while survivors may not (Nathan et al., 2007). Problems associated with damaged structures themselves are seen almost immediately. Pre-existing learning disabilities, lack of opportunity to learn because of prolonged hospitalization, genetic factors that increase or decrease the effects of treatment, and other factors such as poverty, malnutrition or accidents unrelated to cancer may be influence whether a survivor experiences learning late effects (Armstrong, 2003).

Because the attention of schools has focused of late on addressing the requirements of NCLB and IDEA and because of professional focus on issues such as inclusion, the field of special education has moved away from its historically exquisite sensitivity to exploring the specific needs of "new" populations of children with disabilities (Barkon, 2002, 2006). Exploration of these issues is beyond the scope of this article, but suffice it to say that teachers' knowledge and skills regarding the learning needs of this group have not kept pace with the growing number of survivors. Very little attention in the special education literature has been devoted to understanding the common learning profiles of survivors. Those that do usually focus on the more numerous group of survivors—children who have survived Acute Lymphocitic Leukemia (ALL). Most of the literature focused on survivorship issues has come from the medical literature and the most common recommendation regarding school issues has been to ask the schools to develop 504 Plans or Individual Education Plans (Monaco & Smith, 2003; Nathan et al., 2007). This recommendation presupposes that school professionals understand the educational needs of these students. This confidence may be misplaced.

The knowledge-base of those charged with developing special educational services for survivors is sorely lacking. There are no courses devoted to this topic and in crowded introductory and methods of instruction in special education courses, little to no time is spent on this group. Some introductory texts in special education now include a discussion of survivors, usually in a chapter devoted to other health impairments (e.g. Smith, 2004, which mentions luekemia explicitly and encourages teachers to address physical fatigue in ways similar to other students with chronic and fragile medical conditions[p. 328]). In the 2010 edition of the Smith and Tyler text, discussion of cancer survivors is limited to a table listing types of health conditions and describing cancer under the category of chronic illness in which the child "may be too ill to profit from classroom instruction when undergoing treatment" (p. 307). No mention is made of late effects that may impact classroom performance. Other texts do not mention issues of cancer or survivors at all (e.g. Friend, 2008; Heward, 2009; Taylor, Smiley, & Richards, 2009; Turnbull, Turnbull, & Wehmeyer, 2010). Texts that address the range of disabilities that teachers may encounter in classrooms vary as well in their presentation of issues faced by survivors of cancer from not at all (e.g. Batshaw, Pellegrino, & Roizen, 2007) to providing somewhat more information on survivors (e.g. Brumback, Mathews, & Shenoy, 2001, 2 pages).

As a result, when faced with the task of designing education for survivors, schools and teachers return to the familiar and retrofit teaching techniques for survivors usually from one of two existing categories of special education: learning disabilities and/or traumatic brain injury. This article familiarizes the reader with the specific learning profile of survivors of pediatric brain tumors and offers teaching strategies that may prove useful with this group. However, before approaching this task, it will provide some background and context.

BACKGROUND AND STATISTICS

Survivors of pediatric brain tumors represent the second largest group of cancer survivors among children and adolescents. Each year more than 3,400 children and adolescents are diagnosed with brain tumors with an average of 9 students diagnosed each day of the year. Five-year survival rates, though lower generally than other forms of childhood cancers, have been slowly increasing over the last few decades and currently stand at between 54 and 60 percent (Facts about Pediatric Brain Tumors, 2007). There are approximately

10,000 adult survivors of all childhood cancer and this number is increasing by 500 each year.

The sites of brain tumors in children differ significantly from tumors in adults. Whereas 90% of adult tumors arise in the cerebral hemispheres, 40% of pediatric brain tumors originate in the cerebellum, brain stem or fourth ventricle. Tumors arising in these areas (and the resultant treatments) often produce a predictable pattern of deficits, which in turn produce predictable patterns of academic difficulties. Childhood brain tumors usually arise in the brain as the primary site of disease, unlike the situation in adults, in whom brain metastasis from tumors outside the central nervous system is more common (Packer & Pollack, 2001).

The deficits produced by the tumor will depend on the location and the rate of growth. For instance a benign, slow growing tumor near the optic nerve will affect vision. Recent discoveries identifying a role for the cerebellum in language processing help to explain the unexpected association of even low grade cerebellar tumors that are completely removed surgically with cognitive problems in surviving children (Barkon, 2002).

Childhood survivors of medullablastoma illustrate the complex interplay between tumor location, biology, treatment and neurocognitive dysfunction. Medullablastoma is a malignant tumor, which usually arises in the cerebellar hemispheres, adjacent to the fourth ventricle. Accounting for approximately 20% of pediatric brain tumors in most series, approximately 50-60% of children with medullablastoma can be cured with currently available combinations of craniospinal external beam radiation treatment and chemotherapy. Because medullablastomas have a tendency to spread throughout the nervous system, radiation treatment typically targets the entire brain and spinal cord. Although continuous refinements of the combination treatment regimens have attempted to decrease the injury to normal growing brain caused by radiation, survivors of treatment for medullablastoma frequently have neurocognitive deficits (Barkon, 2002; Barkon & Karas, 2007).

The most widely used classification systems for brain tumors divide tumors arising in the brain tissue itself into malignant or high grade, and benign or low grade, based on the biological behavior of the tumors. A malignant brain tumor is usually rapidly growing, invasive and demonstrates the propensity to spread to distant sites in the brain and spinal cord by way of the cerebrospinal fluid (American Brain Tumor Association, 2007). A brain tumor is considered low grade or benign when it is slow growing and rarely spreads to other distant parts of the brain (American Brain Tumor Association, 2007). Roughly one-fourth of the brain tumors diagnosed in children are characterized as low grade or benign (Ris et al., 2008). Survival numbers track the occurrence of malignant tumors, while numbers of children who are living with benign tumors and their treatment effects are usually not included. Even a low grade tumor can be life-threatening, particularly if it is located where it compresses structures that control vital life functions such as breathing or blood circulation (Children's Brain Tumor Foundation, 2007).

Survivors of low-grade tumors have been found to have lower than expected measured IQs, as well as compromised adaptive behaviors, which impact the degree of success in using cognitive skills in a functional, goal-directed manner (Ris et al., 2008). Benign tumors can be very destructive, particularly among young children in whom the brain is still rapidly developing. Intracranial tumors may invade and displace critical areas of the brain related to function (Gurney, Wall, Jukich, & Davis, 1999). Inclusion of benign tumors increase the Central Nervous System (CNS) tumor incidence rate by 28% from 29.4 to 37.6 per million person-years. Increases were 17% for children aged 0-4 years, 17% for children aged 5-9, 31% for children aged 10-14 years, and 51% for adolescents aged 15-19 years (Gurney, Wall, Jukich, & Davis, 1999). When survivors with benign brain tumors are included, incidence and prevalence figures increase significantly. Whether a tumor is benign or malignant, it has the potential to take-over "real-estate" in the brain of the developing child and may crowd out brain tissue that would otherwise be devoted to normal brain functions. Both types of tumors have the potential to impact the learning profiles of survivors.

SURVIVORSHIP

More than twenty years ago, the National Coalition for Cancer Survivorship advocated for a change in the definition of survivorship that recognized the increasing effectiveness of treatment and the empowerment of survivors (Rowland, Hewitt, & Ganz, 2006). Anyone who is living with cancer, from the moment of diagnosis and through the balance of life, should be considered a survivor. Surviving cancer entails a "continual or ongoing process, a holistic experience of living with, through, or beyond cancer." (Rowland et al., 2006). The change in terminology was designed to foster a change in the nature of communication and understanding of quality of life in the context of cancer. The change has not yet been fully recognized in the context of schools, one of the most important normalizing elements in the lives of child survivors and their families (Children's Brain Tumor Foundation, 2007).

Families and students struggle with a "new normal" that is life after diagnosis and treatment. At the same time they want a return to life as it was. Schools receive back a student who is often changed in a way that is at first difficult to recognize, but who is not the same as before this life-changing event and no one knows quite what needs to be done. Often initially the student is welcomed back to the same place occupied before diagnosis and sometimes for a while that is good enough. A recent prospective study that followed 67 survivors over a period of 10 years found that as early as three years after diagnosis and treatment, sixty percent of survivors had experienced difficulty with academic achievement, with 21 percent of these students receiving education in self-contained classrooms and an additional 38 percent in included classrooms while receiving additional support in resource settings (Aarsen, et al., 2009). It is important for schools and teachers to understand the learning profiles and educational needs of these students.

STAGES IN SURVIVORSHIP

Researchers have identified three relatively distinct stages or phases in the disease and treatment process: an *acute* stage, from diagnosis through the first year of treatment; a *follow-up* stage during which early effects of the tumor and its treatment are evident; the third stage is the *late effects* stage and may occur two to five years after treatment is completed (Bloom, 2002). Mullan (1985) refers to these phases as "seasons of survival" because each has its own character, focus and set of challenges. In the acute survival phase treatment may include surgical resection, which results in a hospital stay and recovery process that is of varying length depending on the type of surgery and the immediate effects. There may be a period of rehabilitation required as a result of the surgery and/or the location of the tumor. The goal is to support the child and family through the very difficult treatment process, on the assumption that a relatively normal life is possible following successful treatment (Eiser, 1998).

During the *follow-up* phase early effects of the treatment include emotional stress and distress, energy reduction and fatigue, physical weakness and symptoms such as nausea or vomiting in response to therapies. Obviously, at this time the child may be absent from school often and unavailable for learning whatever is happening in the classroom at that time. Most schools deal relatively effectively with this phase and often provide hospital or home instruction when the child is well enough to participate (Barkon, 2002). This stage has its own specific dangers and challenges. One educationally related challenge is the selection of appropriate home instructors (Barkon, 2002). The instructor should be a person who has an expectation of survival for the child. The child will return to school and, therefore, must be kept up to date with the curriculum so that return to the classroom may happen at or near a level that would be expected without the occurrence of the tumor and its treatment.

The teacher should be familiar with the student if possible and with the expectations of the classroom at the very least. The most effective teacher is often the child's general education classroom teacher, if that choice is available.

The third stage of survivorship occurs after the early effects have been noted, addressed and may no longer be obvious. The *late efffects* stage may continue for the remainder of the life of the survivor. There are ongoing health effects, psycho-social effects and cognitive and learning effects. Because these late effects often become evident long after the diagnosis and treatment of the tumor, schools may not view them as manifestations of cancer effects and may attribute them to other causes.

UNDERSTANDING SURVIVORSHIP

Survivors experience problems and issues that may persist throughout lifetime (Goldman, 2008; Ris & Beebe, 2008). The effects of tumors and their treatment on school performance and learning may be profound and will likely change as the length of time of survival increases.

Students who are survivors are recognized under the Individuals with Disabilities Education Act (IDEA '04) as being eligible for special education under the category of *other health impaired*, though the only type of cancer that is specifically listed is leukemia. Often families, students, and schools are reluctant to classify a survivor as a person with a disability when the student first returns to school following diagnosis and treatment. The student must demonstrate both a recognized disability as well as the necessity for special education due to that disability in order to continue to make progress in school to be considered eligible for special education services (IDEA, 20 USC 1401 §(3)(A)(i) and (ii)). Survivors may not meet both criteria until significantly after the diagnosis and treatment have occurred.

With the number of survivors of pediatric brain tumors continuing to increase, most special educators, at some point in their teaching careers, will be responsible for designing and implementing the educational experience of a survivor. Unlike the population of students with learning disabilities, traumatic brain injuries and attentional deficits, probably no single teacher or school will be expected to develop effective interventions for groups of survivors, but given the challenges that a survivor has already faced, it is important that schools and teacher develop strategies that maximize the potential success of individual survivors. To do that teachers and schools need to develop an understanding of the unique learning profiles of these students. The remainder of this article will familiarize the reader with the common characteristics and school experience of survivors of brain tumors and will provide some guidance in effectively addressing those characteristics and needs.

WHO ARE THE SURVIVORS?

Survivors have a unique constellation of characteristics. Survivors are both similar to and different from other categories of children with disabilities. The groups with which they are most likely to be conflated are students with learning disabilities and students with traumatic brain injuries. There is definitely overlap with both groups in terms of cognitive characteristics and attentional weaknesses.

Learning Disabilities

Students with learning disabilities are those who have "a disorder in one or more basic psychological processes involved in the understanding or using of language, spoken or written, that may manifest in an imperfect ability to listen, think, speak, read write or spell, or to mathematical calculations . . ." (IDEA, 20 USC 1401 §602 (30)(A)) This definition is sufficiently broad to encompass a number of learning problems demonstrated by survivors. However, the evolving literature on learning disabilities has identified a number of core characteristics that are commonly shared, including phonological awareness difficulties, difficulties decoding written words and concomitant problems that often flow from these core deficits (Berninger, 2008; Fletcher, Lyon, Fuchs, & Barnes, 2007). Survivors of brain tumors may share some of these characteristics especially in the areas of strategy development and deployment (Meltzer, 1993). They may experience learning problems in the same academic areas. However, the specific patterns of deficits are quite different and unique to survivors. The types of interventions most likely to be effective with survivors are liable to have overlaps as well as differences.

Traumatic Brain Injury (TBI)

IDEA defines TBI as:

> "an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psycho-social behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma." [34 Code of Federal Regulations §300.7(c)(12)]

The injury can cause changes in how a person learns and acts in school. Sometimes children with TBI are thought to have a learning disability, emotional disturbance, or mental retardation. (Office of Special Education Programs of the U.S. Department of Education, 2008).

There are logical reasons for using either LD or TBI to analogize the learning profiles and needs of survivors. Survivors often have difficulty learning in school and they most certainly have had an insult to the brain, though it is not an injury as described in the definition of TBI. If one uses the tools and understandings of learning that are generated by LD and TBI that is to the good. The danger comes when one uses the existing categories to obscure the specific pattern of needs of survivors.

SURVIVORS' LEARNING CHALLENGES

Survivors of brain tumors often experience a range of academic difficulty (Aarsen, et al., 2009; Barkon, 2002; Barkon & Karas, 2007; Spinelli, 2003; Sullivan, Fulmer & Zigmond, 2000). Children most significantly impacted are those who received cranial radiation (Aarsen et al., 2009). Problems noted by researchers have included processing difficulties, physical difficulties, executive functioning difficulties and social difficulties (Nathan et al., 2007). Aarsen et al. (2009) identified processing speed and attentional weaknesses among all suvivors in their study. Depending on the location of the tumor, they identified deficits in language, visual-spatial memory, and executive functioning, as well.

The medical community refers to these difficulties as cognitive "late effects" because though they are treatment related, they often occur some time after treatment has been completed (Carey, Barakat, Foley, Gyato, & Phillips, 2001; Eiser, 1998; Mulhern & Palmer, 2003a; Mulhern & Palmer, 2003b; Mulhern, Reddick, Palmer, Glass, Elkin, Kun, Taylor, Langston & Gajjar, 1999). Late effects are relatively common and may be quite debilitating. According to Armstrong (2003), Nathan et al. (2007) and Aarsen et al. (2009) what one sees as a late effect is really damage to an area of the brain that had not yet been called into action at the time of diagnosis and treatment. Schatz, Kramer, Ablin, and Matthay (2000) suggest that the deficit is due to damage to a basic cognitive function such as processing speed and/or working memory that is required for a higher cognitive skill such as fluid reasoning. It is not a "new" effect but rather the result of an insult that resulted either from the tumor or during treatment, and when that area of the brain is called upon, it does not function in the expected manner (Armstrong, 2003). Though there is no uniform neuropsychological profile of a pediatric brain tumor survivor, deficits are frequently noted in specific areas. Some of those areas include: intellectual ability, as noted above, memory, concentration and attention, visual-perceptual ability and language. Slower processing speed may result in a cascade of difficulties that impact academic performance. The most obvious is that children respond more slowly to questions and ongoing events in the classroom, as well as outside the classroom setting. They take longer to digest information and respond appropriately. Slow processing speed has the potential to affect learning and the ability to make good judgments. Sometimes the child's affect may change, not only as a result of the experiences, but also as a direct result of the disease and its treatment (Wolfe-Christensen, Mullins, Scott, & McNall-Knapp, 2007; Wong, Hardy, Willard, Bonner, & Gururangan, 2007). Survivors of pediatric brain tumors may forget things. They may have difficulty remembering what they have read. They may have trouble keeping up with schoolwork and have trouble with writing assignments, especially papers and reports. They may also have difficulty with mathematics, especially tasks involving automatic use of math facts. These learning profiles are complicated by the child's profiles prior to diagnosis, which may or may not have been known. Many of the effects noted are fluctuating; profiles continue to change for years after successful treatment. Further complicating the picture is the fact that many of these neurocognitive late effects occur significantly after treatment and the impact of these late effects increases over time from a treatment (Spinelli, 2003; 2004).

Areas which seem to be unaffected by cancer treatment include the ability to

- learn and remember information that is heard
- understand the application of math concepts
- use spoken language to communicate understanding of concepts and new material
- recall information accurately if given enough time; to be creative (National Children's Cancer Society, 2008).

RETROSPECTIVE CLINICAL STUDY

The Survivor Education and Reintegration Support Program (SERS) has been in existence since 2003 at Carlow University. It was initially envisioned as a multi-disciplinary support program for survivors, their families and schools. It has undergone several iterations since that time in response to funding. It has always had an evaluation component in addition to its function as an advice and advocacy resource for survivors and parents. The retrospective study reported here is based on evaluation data from 7 of 12 survivors followed by the SERS program. Where available, information from all twelve subjects is provided. The distinction between data for 7 based on evaluation and information from all 12 will be noted in the results section.

Table 1.

Survivor Education and Reintegration Support Program by Tumor and Treatment.

Type of Tumor	# of students	% of students
Medullablastoma	8	67
Oligodentroglioma	1	.08
Hypothalmic GPA	1	.08
Ewing's Sarcoma	1	.08
Germ Cell Tumor	1	.08
Type of Treatment		
Surgical Resection	9	75
Radiation and/or Gamma Knife	9	75
Chemotherapy	11	92

N = 12

SUBJECTS

Formal psychoeducational evaluations were conducted with 7 of the twelve survivors served; they ranged in age from 7 through 21, grades in school ranged from 2nd grade through sophomore in college. Survivors were three months to two years post-treatment. Only one of these 7 had been identified as having a disability prior to the diagnosis of a brain tumor. Two survivors, including the one with a learning disability, were identified as gifted. Eight of the 12 subjects were survivors of medullablastoma. Of the remaining subjects each had a different type of pediatric brain tumor: oligodentroglioma, hypothalamic GPA, Ewing's sarcoma of the skull and a germ cell tumor. Five of the 7 students who underwent formal psycho-educational evaluation were diagnosed with medullablastoma; one had Ewing's sarcoma of the skull and one had an oligodentroglioma. All but one of the 7 had surgery, radiation and chemotherapy. The remaining subject had only surgery. Table 1 provides demographic of tumors and types of treatment of all 12 survivors.

METHOD

The 7 survivors who are the focus of this study were evaluated by the author, who is an educational diagnostician with more than 25 years of experience, has a doctoral degree in the field of learning disabilities, holds a National Certification for Educational Diagnosticians (NCED) and currently serves on the NCED Board of Directors. The formal diagnostic tool used was the *Woodcock-Johnson III (WJIII) Tests of Cognitive Ability* and *Tests of Academic Achievement.* The set of subtests used was individualized to address the specific difficulties presented by survivors, but a set of core subtests was administered to each student.

Data on fatigue and support for executive functioning processes and attentional weaknesses were gathered from the *School Experience Questionnaire* which was completed by parents at the time survivors were evaluated. The *School Experience Questionnaire* was developed from the medical literature that delineated the known learning characteristics of survivors and the learning characteristics of students with learning disabilities. It is used for parents to provide background information about survivors that may not be revealed through formal testing. It is also used in structuring discussion with parents and schools whether or not a formal evaluation is conducted. Though evidence from these interactions is anecdotal in nature, it too supports the findings reported below.

Results of evaluations were culled for shared areas of weakness. Weakness was defined as a score in or below the low average range (standard scores of 89 or below) on the *WJIII.* These scores were then gathered to create a learning profile for survivors and are reported in the aggregate.

RESULTS

Results of the evaluations demonstrate a consistent pattern of weaknesses in areas of cognitive ability assessed on the *Woodcock Johnson III,* physical and executive functioning weaknesses, and academic problems that relate to difficulties of processing speed and executive functioning. Weaknesses in cognitive efficiency, cognitive fluency, retrieval fluency and processing speed and executive processes were found in a number of survivors. Tasks on which only one survivor demonstrated difficulty were not included in the constellation of challenges for survivors unless that difficulty was a component of a larger cluster, like cognitive efficiency or processing speed. The decision to do this was based on the understanding that survivor learning profiles included strengths and weaknesses that are particular to that individual in addition to those that are shared with other survivors. These areas include broad cognitive abilities of cognitive efficiency, such as visual matching, decision speed, numbers reversed and memory for words. Weaknesses were identified in cognitive fluency including retrieval fluency, decision speed, and rapid picture naming. Executive processes were also an area of weakness. Tasks contributing to executive processes are numbers reversed, auditory working memory, concept formation, and planning and pair cancellation. Table 2 shows the number of

Table 2.

Evaluation Data from Woodcock Johnson III- Test of Cognitive Ability
N= 7

COGNITIVE AREA	# of survivors exhibiting problems in this area	% of survivors exhibiting problems in this area
BROAD COGNITIVE ABILITY		
Cognitive Efficiency (incorporates visual matching, decision speed, numbers reversed, memory for words)	5	72
Thinking Ability (incorporates visual-auditory learning, retrieval fluency, spatial relations, picture recognition, sound blending, auditory attention, concept formation, and analysis and synthesis)	2	29
Cognitive Fluency (incorporates retrieval fluency, decision speed, rapid picture naming)	3	43
Processing Speed (incorporates visual matching and decision speed)	3	43
Short-term Memory (incorporates numbers reversed and memory for words)	1	14
Executive Processes (incorporates numbers reversed, auditory working memory, concept formation, planning, pair cancellation)	3	43
NARROW COGNITIVE ABILITY		
Decision Speed	3	43
Long Term Retrieval	2	29
Concept Formation	2	29
Delayed Recall	3	43
Visual Auditory Learning	3	43

Table 3.

Academic "Late Effects" of Survivors of Pediatric Brain Tumors.

ACADEMIC AREA	# of survivors exhibiting problems in this area (N = 7)	% of survivors exhibiting problems in this area (N = 7)
Academic Fluency, including retrieval fluency (and/or fluency weakness in at least one of the following academic areas: reading, math, writing)	7	100
Story Recall	3	43
Understanding Directions	3	43
Math Calculations	3	43
Passage Comprehension	1	14

survivors with difficulties in particular areas measured by the *WJIII Tests of Cognitive Ability.*

The areas of common academic fluency weakness include all areas of reading, writing and mathematics, story recall, understanding directions and math calculations. Table 3 records the academic areas that are impacted in survivors as measured on the *WJIII Tests of Academic Achievement.*

Physical Difficulties, Executive Functioning and Fatigue

Data on physical difficulties and executive functioning were gathered through the *School Experience Questionnaire* (Barkon, 2001). The questionnaire was completed by the parents of the 7 survivors with whom a formal psychoeducational evaluation was conducted. Physical difficulties were noted in 2 survivors of medullablastomas. Fatigue was described by 100% of the parents. All of the parents reported that their children take longer than other students in their grades to complete assignments both at school and at home. Organizational difficulties were noted in 5 survivors. Attention weaknesses were also noted in all 7 of the survivors. Table 4 describes these findings.

Table 4.

Physical Problems and Related Executive Function Difficulties,
School Experience Questionnaire
N = 7

Problem Area	Number of Students with this difficulty	Percentage of Students with this difficulty
Fatigue	7	100
Motor and Balance	2	29
Completing homework in a "timely" fashion	7	100
Organizational Problems	5	71
Attentional Problems	5	71

DISCUSSION

The incidence of pediatric brain tumors is small compared to other cancers and diseases that may result in the need for specialized education. Numbers are low at any one center that treats survivors. As a result, most studies that seek to describe survivor profiles have relied on data from small groups. This impacts the statistics available for exploring survivor characteristics and many centers combine data to increase the validity of findings. The study reported herein is on 7 of the 12 survivors served by the SERS program, but is representative of the numbers seen by many centers. Few centers that treat children with brain tumors have formal programs that support survivors who return to school. Most rely on schools to know how to address emerging educational needs.

Major areas of weakness among survivors are cognitive and academic fluency, processing speed, cognitive and academic efficiency, executive function difficulties and fatigue. Each of these areas incorporates and affects a number of component skills and abilities that are important for learning. Each has the potential to profoundly impact school performance for survivors. Each of the component abilities must work competently and proficiently, individually and in concert, across many domains to support the ability of survivors to learn new information and skills effectively. Figure 1 is a graphic representation of the overlapping relationship between 1) processing speed, cognitive and academic fluencies and efficiencies, 2) weaknesses in executive function and skills and 3) cancer-related fatigue that are the hallmarks of late effects in survivors of pediatric brain tumors. Each is described in a detailed section below.

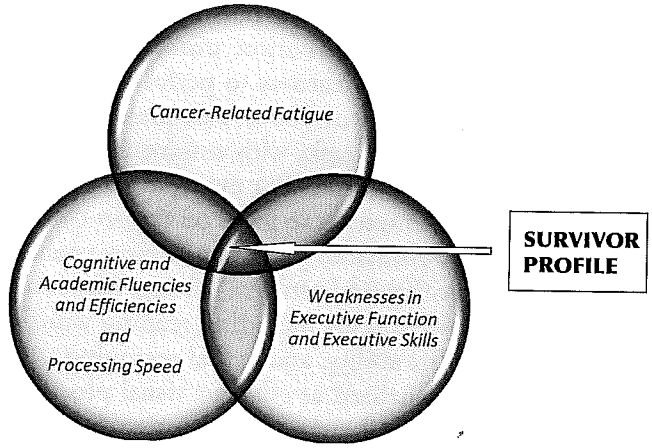

Figure 1

Learning Profile of Survivors: Venn Diagram

PROCESSING SPEED

Processing speed is the pace at which one is able to perform basic cognitive abilities (Mather & Jaffe, 2002; Wodrich & Schmitt, 2006). The influence of processing speed on cognitive and academic functioning is particularly pervasive because such activity is hierarchical—higher cognitive activities arise from the coordinated activities of more basic cognitive operations. Reasoning ability, for example, is dependent on the simultaneous availability and manipulation of several sources of information (knowledge, emotions, goals, problem-solving strategies, among others). When processing speed is slowed all aspects of cognitive functioning become less efficient and each cognitive activity is time-consuming and cumbersome. Palmer, Goloubeva, Reddick, and Glass (2001) and Palmer, Reddick, and Gajjar, (2007) indicate that slower processing speed serves to flatten the learning curve of survivors and that it is this rather than an outright lose of intellectual functioning that causes the apparent loss of intellectual ability. The earlier understanding of the impact of tumor and treatment on IQ was that brain tumors and their treatment can result in as much as a 2-point per year drop in IQ points over a 5-year post-treatment period (Cohen, Lacey, & Duffner, 1994; Mulhern, Reddick, Palmer, Glass, Elkin, & Kun, 1999). Speed of processing is identified as among the first deficits to emerge following radiation therapy to treat tumors in the posterior fossa of the brain (Mabbott, Penkman, Witol, Strother, & Bouffett, 2008).

Processing speed is operationalized in multiple ways in fields such as cognitive psychology, language development, reading disabilities, and genetics.

In fact, there are many related terms (e.g. naming speed, rapid naming, lexical retrieval, temporal processing, information processing, response time). Adequate processing speed enables learners to perform basic tasks without conscious effort (Wodrich & Schmitt, 2006). Adequate speed of processing supports the performance of simple tasks with automaticity so that attention can be focused on more complex tasks. For example, in reading decoding, fluid word recognition enables students to focus on deeper comprehension of tasks. In math, facility and automaticity with basic facts enable students to focus on more complex algorithm and problem solving. Moreover, processing speed underlies many cognitive skills including reading word recognition, reading comprehension, verbal ability, and verbal reasoning. Academic processing speed may be operationalized as efficient visual processing, working memory, long-term memory and supports executive functioning that is required to produce correct responses to rudimentary reading, mathematical, and written language tasks. (Berninger & Richards, 2002; Brenner & Mooney, 2008; Mather & Jaffe, 2002).

COGNITIVE AND ACADEMIC FLUENCIES AND EFFICIENCIES

Slowing of processing speed affects the efficiency and fluency with which survivors accomplish cognitive and academic tasks. Each of these represents interrelated abilities. Cognitive efficiency is defined as the capacity of the cognitive system to process information with ease and precision (Schrank & Flanagan, 2003; Schrank, Flannagan, Woodcock, & Mascolo, 2002;). It incorporates short-term and working memory and the speed with which academic decisions are made.

Cognitive fluency is the ease and speed by which simple cognitive tasks are performed, while academic fluency refers to automaticity of and facility with basic skills that support or inhibit performance in school related tasks or reading, writing and math as a group or individually (Mather & Jaffe, 2002). For the purposes of this paper, the weaknesses in various fluencies and efficiencies are incorporated in the discussion of processing speed.

FATIGUE

Fatigue is the feeling of being physically, mentally and emotionally tired. Cancer-related fatigue is defined as "a persistent and subjective sense" of exhaustion that often occurs with cancer and its treatment (American Cancer Society, 2005). Cancer-related fatigue is characterized by diminished energy and functional deficiency, which may be acute, episodic, or chronic and is correlated with health status, emotion, pain, cognitive functioning and role functioning (Lai, Kupst, Suzanne, Kelly, Bode, & Goldman, 2007).

The nature of this fatigue is different from common tiredness. Cancer-related fatigue can persist over time and may interfere with usual activities. It can be severe in nature and often causes distress in those experiencing it. Rest does not always relieve cancer-related fatigue (American Cancer Society, 2005). Cancer-related fatigue can vary in its unpleasantness, severity and the time it is present; be overwhelming and compromise one's sense of well-being; make spending time in social situations challenging; and decrease one's ability to continue normal activities, such as attending school and completing assignments. Individuals suffering cancer-related fatigue describe it as feeling weak, tired, exhausted, weary, worn-out or slow; having no energy; being unable to concentrate. They may describe a feeling of heaviness in limbs, not having the energy to complete everyday tasks and having feelings of sadness, irritability or frustration. Ninety percent of those in active treatment for cancer report experiencing fatigue and 30-75% report symptoms of fatigue continuing for months to years following the completion of treatment (American Cancer Society, 2005). It lasts for a longer period of time in the post treatment period than is generally acknowledged. Younger survivors (age <12) conceptualize fatigue in physical terms. Older survivors (ages 13-18) describe the essential characteristics of fatigue as physical or mental/emotional exhaustion or a combination (Lai et al., 2007).

WEAKNESSES IN EXECUTIVE FUNCTION AND EXECUTIVE SKILLS

Executive control may be considered unitary in the sense that it is in charge of both external action and internal planning for action. The cognitive processes that enable individuals to engage in goal-directed or problem-solving behavior; metacognitive knowledge about tasks, and the flexible use of learning strategies plus explicit and implicit learning are all part of this critical capacity. Executive function works to integrate such factors as time, novelty, complexity, and possibly ambiguity. It plays a central role in goal setting or identifying a problem, developing a plan, executing the plan, flexibility, attention and memory systems to guide the individual in carrying out the plan (*e.g.*, working memory), and evaluation or self-monitoring (Dawson & Guare, 2009; Meltzer, 2007). Without efficient executive processing, an individual may demonstrate difficulty selecting the cognitive skills needed to effectively and efficiently design a plan of action, coordinating the skills necessary to implement the plan, applying those skills in a correct order and/or evaluating actions as successes or failures relative to intentions. Survivors evidence difficulties in all of the areas of executive functioning, particularly as they reach the teenage years (Armstrong, 2003).

DESIGNING SCHOOL EXPERIENCES FOR SURVIVORS

Most survivors will continue to be educated in inclusive general education settings. Whether they are formally identified as eligible for special education services or not, they will likely require specialized instruction designed to meet their new learning profiles. Many of the learning problems faced by survivors exist at the intersection of fatigue, processing speed and executive functioning, rather than in a particular or isolated academic area. As a result, many areas of academic functioning may be affected and the impact may be experienced differently on any given day, resulting in fluctuating difficulties. This moving target may resist direct remediation, but there are many ways that schools and teachers can support students' learning and progress in school.

UNIVERSAL DESIGN FOR LEARNING

One of the most powerful models for supporting the school success of survivors is Universal Design for Learning (UDL). Universal Design for Learning

> "refers to a process by which a curriculum (i.e., goals, methods, materials, and assessments) is intentionally and systematically designed from the beginning to address individual differences. With curricula that are universally designed, much of the difficulties of subsequent "retrofitting" and adaptation can be reduced or eliminated–and a better learning environment for all students can be implemented" (Rose & Wesson, 2008).

As a process, UDL is sufficiently flexible to address many of the diverse needs found in classrooms, including those of survivors. UDL is a seemingly straightforward way to address the individualized learning needs of individuals with a range of disabilities, drawing on and extending effective teaching practices that customize instruction for individual learners (Coyne, Ganley, Hall, Meo, Murray, & David, 2006). Its implementation requires understanding and interweaving ideas and strategies that have been available in education and psychology for some time, e.g., multiple intelligences (Gardner, 1983, 1999), research on learning styles and preferences (Dunn & Dunn, 1987; Kolb, 1984), learning as process (Graves, Cooke, & LaBerge, 1983), reciprocal teaching (Palinscar & Brown, 1986), differentiated instruction (Tomlinson, 1999), teaching as coaching (O'Donnell, 1998), and cooperative learning (Johnson & Johnson, 1986; Wood, Algozzine & Avett, 1993) in novel ways. To the extent that UDL draws upon and extends teaching approaches that may be familiar to teachers, it is all the more easily incorporated into curriculum, classroom and lesson design (Meo, 2008). In these approaches teachers support learning rather than transmit knowledge. UDL requires an additional shift in how learning differences are viewed. In a UDL classroom, it is the curriculum itself that is seen as flexibly adapting to the challenges posed by student difference, rather than the student who must adapt in order to learn from an inflexible curriculum.

Three key principles that define UDL are providing learners with multiple means of representation, multiple means of expression and multiple means of engagement. Multiple means of representation refers to providing many ways for students to obtain the information deemed important to learn. Information may be presented traditionally through textbooks, on screen with screen-readers, through books on tape or in any other mode that meets the needs of survivors. Representation options include those that customize the display of information (e.g. size of text or text that uses color for cues and emphasis); options that provide alternatives for auditory information (e.g. text-to speech options, and visual analogs for prosody, such as emoticons); options that provide alternatives for visual information (e.g. graphics, physical objects and spatial models to convey perspective or interaction) (Rose & Wesson, 2008). Many suggestions for incorporating UDL into classrooms require the availability and use of technology; other suggestions relate to the design of curriculum, lesson plans and classroom set-up. Many more suggestions for means of representation may be found in the growing literature on the implementation of UDL (Rose & Meyer, 2006; Rose, Meyer, & Hitchcock, 2005; Rose & Wesson, 2008).

Multiple means of expression permits students many different ways to demonstrate that they have learned what has been taught to them. In a UDL classroom there will be options for expressive skills and fluency, in the media used for communication of learning, in the tools used for composition and problem solving, in the scaffolds provided for practice and performance, in the options that guide effective goal-setting, planning and strategy development, and that facilitate managing information and resources. Options are also part of providing multiple means of engagement. These options are designed to increase engagement and interest in learning by offering individuals choice and autonomy in making decisions, to increase self-regulation of learning and to help sustain effort and persistence despite experiencing academic difficulties. Many more examples of the means to implement these core UDL principles may be found in Rose and Wesson (2008).

Schools that use UDL principles in classroom and lesson design, understand the learning profiles, and anticipate the learning needs of survivors in that design will likely address a number of the challenges presented by survivors present in those rooms. Principles of UDL may be implemented in the full range of settings in which survivors are educated.

In addition to classroom and lesson design that support their learning, it is important for survivors to develop clear, in-depth understanding of their own individual learning styles and needs and to develop skills for self-advocacy so that they can get what they need from teachers and school. These adaptive behaviors require a certain level of maturity and are not usually available to younger survivors. However, it is important to begin developing these proficiencies as early as possible in a student's school career. When UDL is utilized in classrooms and schools, students are encouraged to explore and understand their own learning styles and preferences.

ADDRESSING PROBLEMS OF FATIGUE, PROCESSING SPEED AND EXECUTIVE FUNCTIONING

There are accommodations that teachers and schools can employ even in the absence of comprehensive integrated UDL environments. Academic accommodations are "practices and procedures in the areas of presentation, response, setting, and timing/scheduling that provide equitable access during instruction and assessments for students with disabilities" (Thompson, Morse, Sharpe, & Hall, 2005, p. 14). An accommodation is also a "change to suit a new purpose" (Danforth & Gabel, 2006). Accommodations are not meant to reduce the learning expectations for students (Thompson, Morse, Sharpe, & Hall, 2005), rather they should be designed to provide the support necessary for the student to succeed in mastering the content and skills that make up the curriculum. Acommodations are not interchangable; teachers must understand the purpose served by an accommodation in order for it to be employed profitably.

Learning strategies are alternately "processes that are consciously devised to achieve particular academic goals" (Meltzer, 1993, p. 95); or an individual's approach to a task that includes how a person thinks and acts when planning, executing and evaulating performance on a task and its outcomes (Lenz, Clark, Deshler, & Schumaker, 1988). Teaching strategies are teacher behaviors that support learning and the development of learning strategies on the part of students. Table 5 presents a number of teaching strategies and accommodations that can be deployed to support the learning challenges posed by survivors. The table is organized by the principles of UDL (means of representation, expression and engage) and by the common challenge characteristics (fatigue, processing speed and executive functioning difficulties) that survivors display. Some are strategies that teachers may use with students identified with other learning differences as well. The suggestions are drawn from a number of sources and many are not exclusive to survivor needs (Armstrong, 2003; Keene, 2003; Leigh, 2003; Mather & Jaffe, 2002; Mather, Wendling, & Woodcock, 2001; Meltzer, 2007; Schrank & Flanagan, 2003; Schrank,

Table 5.

Teaching Strategies and Accommodations and for Survivors Grouped by UDL Principles and Options.

UDL Principles and Options	Characteristic		
Multiple Means of REPRESENTATION:	Fatigue	Processing Speed	Executive Function
Options For Perception	• Simplify directions • Provide written directions that can be accessed by the student when needed	• Use color and font (and other text markers) to emphasize important ideas	• Write key points on the board • Use visual aids
Options For Language And Symbols	• Allow students to tape record lessons • Provide classroom aides and/or notetakers • Allow calculator use after mastery has been demonstrated	• Provide written outline of material *(fatigue)* • Use multi-sensory methods of instruction *(engagement)*	• Teach students to identify keywords in text and operational signs in math • Use graphic organizers to scaffold learning
Options For Comprehension	• Provide copy of peer or teacher notes to increase listening in class and reduce writing	• Use graphic organizers to identify the big ideas and important details *(executive function)* • Provide opportunities to repeat and relearn material that might have been missed due to slow processing and/or fatigue	• Ask students to repeat/discuss plans before beginning tasks • Allow students to observe task first • Structure information and tasks so that the most critical are able to be clearly identifiable

Table 5.

(Continued)

UDL Principles and Options	Characteristic		
Multiple Means of ACTION AND EXPRESSION	Fatigue	Processing Speed	Executive Function
Options For Physical Action	• Modify assignments, e.g. do every third problem • Give extra time to complete assignments • Provide an extra set of books at home • Provide untimed testing • Schedule academic subjects at times when student is least likely to be fatigued	• Provide structure to tasks to minimize physical effort. • Monitor time spent on homework and be flexible in adjusting academic requirements if processing speed negatively impacts sufficient rest time and productive effort	• Break assignments into short clearly identified, sequential steps
Options For Expressive Skills And Fluency	• Allow student to submit work by computer rather than through handwriting • Use a speech-to-text program • Reduce written requirements	• Provide additional time for student to think through his response to any question or task. • Do not assume that because processing speed is slowed, the student is unable to accomplish the task.	• Allow student to complete assignments using graphic organizers that provide structure to responses in a format that minimizes physical effort.

UDL Principles and Options	Characteristic		
Multiple Means of ACTION AND EXPRESSION	Fatigue	Processing Speed	Executive Function
Options For Executive Functions	• Give student options to demonstrate learning through a range of methods. This may vary based on the level of fatigue. • Accept student's demonstration of knowledge based on his level of energy on a given day. • Teach student to identify the early signs of fatigue and to grant breaks to recover.	• Modify long-term assignments and give extended time for those assignments to be completed. • Identify the steps involved and monitor the student's success and completion of each step rather than waiting for the entire assignment to be completed.	• Provide afternoon check-out to organize homework • Provide a clear, predictable schedule • Provide an individual daily assignment sheet • Assist students in creating a color-coded organizational system • Create a homework task and parent communication system that supports ability to check status and location of assigments

Table 5.

(Continued)

UDL Principles and Options	Characteristic		
Multiple Means of ENGAGEMENT	Fatigue	Processing Speed	Executive Function
Options For Recruiting Interest	• Allow student choices that will not comprise information/skills learned, but will maximize engagement and efficiency of learning. • Assess small increments of knowledge at a time. (Due to the ongoing effect of fatigue that interferes with the student's ability to rely predictably on her energy level to sustain the stamina required for studying large amounts of information at a time.)	• Provide study guides and other cues about upcoming evaluations that help may help student to use her study time effectively. This will help her focus her learning time more efficiently and may allow her to work to learn when fatigue has abated.	• Provide small group instruction • Pair students to check work • Provide volunteer homework buddy

UDL Principles and Options	Characteristic		
Multiple Means of ENGAGEMENT	Fatigue	Processing Speed	Executive Function
Options For Sustaining Effort And Persistence	• Provide daily one-to-one tutoring • Schedule classes in close physical proximity to each other • Give breaks at short and regular intervals based on students ability to sustain effort.	• Allow student to demonstrate learning of the content of courses through means other than testing that requires memorization and immediate manipulation of learned materials as sometimes the student will be unable to access information learned in such situations.	• Explicitly teach learning strategies in ways that are able to be implemented • Provide study skills training and study skills class
Provide Options For Self-Regulation	• Give advance notice of assignments so that the student can use energy reserve effectively. When the student feels sufficient energy to accomplish the assignment, rather than on a time-scheduled determined by school and teacher.	• Give student the opportunity to use all of the various strategies he has developed and to demonstrate them to teacher(s)	• Teaching specific memory strategies and how to recognize which strategy may be most useful in a variety of situations, such as taking notes versus remembering factual information for a test. Examples: verbal rehearsal, chunking, making ridiculous visual images composed of items that one has to remember and creating first-letter mnemonic strategies

Flannagan, Woodcock, & Mascolo, 2002). Some strategies are based on the author's experience in interacting with survivors, families and schools that serve survivors. Several address more than one characteristic or difficulty simultaneously. The suggestions may be implemented in whatever setting the survivor is being educated, whether in an inclusive classroom, a learning support room or a special class for students with disabilities.

RECOMMENDATIONS FOR CLASSROOMS WITH SURVIVORS

The conceptual framework for UDL may seem overwhelming at the outset. However, there are still interventions based on UDL concepts that can be implemented to support survivors without a full commitment to the incorporation of UDL for the entire classroom. The following list contains recommendations to address specific challenges presented by survivors of pediatric brain tumors. The recommendations are phrased as teacher strategies and teacher behaviors that support survivors' classroom success and may be incorporated into 504 plans and/or Individual Education Plans. Recommendations are explicitly connected to the learning challenges presented by survivors so that the teacher can understand the rationale for its implementation (Byrnes, 2008).

- The student is given regular breaks in the academic day at intervals to be determined, but may be as often as every 20 minutes so that the individual has time to "regroup" before fatigue hits. The student should be taught to identify the early signs of fatigue. Frequent breaks allow the student opportunities to recover.
- Testing is done in small chunks, such as a chapter at a time; ideally only one at a time, but no more than two at a time. Such testing will not penalize the student for the ongoing effects of treatment and will still provide an opportunity to demonstrate that the student has learned the required material. Due to the ongoing effect of fatigue that interferes with the student's ability to rely predictably on an adequate energy level to sustain the stamina required for studying large amounts of information at a time, testing large amounts of material may actually penalize the student for being a cancer survivor, rather than supporting educational success.
- The student is provided study guides and other cues about upcoming evaluations that may help the student to use study time effectively. This will help focus learning time more efficiently and may allow the student to learn when the fatigue has abated. (also addresses processing speed)

- Whenever possible the student is allowed to demonstrate that the content of courses has been learned through means other than testing, which requires memorization and immediate manipulation of learned materials. Sometimes the ability to access information learned may be limited in such situations.
- The student is given the opportunity to use all of the various learning strategies that have been developed and to demonstrate them to the teacher(s). This supports the student's learning how to learn and to function independently, given the new, post-treatment learning profile.
- The student is taught to expand the strategy repertoire and should be permitted to use the strategies in any learning situation for which those strategies are effective.
- Because it takes the student longer to complete work due to processing speed and fatigue, assignments are strategically designed to maximize energy and cognitive resources, so that the individual is doing what absolutely must be done to demonstrate mastery of the material or concept. Modify the amount of homework required without changing the purpose of the homework (e.g. completing only odd-numbered problems on a math page).
- Give advance notice of and directions for assignments so that the student can use the energy reserve effectively. In this way, the student may complete the assignment when there is sufficient energy, rather than on a time schedule determined by school and teacher.
- Because organization facilitates memory and long-term retrieval, teach the student to use strategies for organizing all types of information and tasks, including the content of reading material, school-related material and notes, information for a test, and tasks that need to be accomplished.
- Incorporate structured, systematic strategy instruction designed to enhance student motivation and effort. Strategies should be explicitly taught and directly linked to the curriculum in order to enhance the student's performance in school. (Meltzer, 2007)
- Encourage student to use external memory devices to increase memory efficiency, such as writing things down in notebooks or appointment books, placing things that need to be remembered in places they will be seen and using physical prompts.
- Enhance meaningfulness of information to be remembered by explicitly connecting information to be remembered with information already meaningful and in long term memory and by using concrete examples, pictures and/or imagery in the learning process.

CONCLUSION

Survivors of pediatric brain tumors demonstrate a unique constellation of difficulties that form a new type of challenge to them, their families and their schools. As the number of survivors continues to climb, it is increasingly likely that many schools and teachers will be expected to provide high quality education to these students. The familiarity of most teachers with the specific needs of these students is sorely lacking. This article is meant to address this gap in knowledge.

Common learning profiles of survivors include weaknesses in processing speed, and executive functioning which combine in a synergistic manner with fatigue which continues well beyond the time of active treatment of the disease. This synergy creates a changing educational landscape for survivors that teachers can either ameliorate or exacerbate depending on their understanding and flexible response to characteristics. Though the study reported here is based on a relatively small number of survivors, the findings support the developing literature. The intervention suggestions are provided to assist teachers and schools in supporting the school success of survivors.

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PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

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