CHILDREN WITH CANCER: SCHOOL RELATED ISSUES

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ABSTRACT

School gives purpose to a student's life. Today, students with cancer and cancer survivors are encouraged to continue their educational experiences to maintain a sense of normalcy. This manuscript discusses the research findings on medical, physical, and cognitive issues that students with cancer and cancer survivors may encounter in their search for normalcy within school. It also presents a discussion of the implications of these findings for educators and provides possible actions to discover and meet the needs of these students.

Cancer can be defined as "a large variety of diseases in which the cells have a unique capacity for unregulated, excessive growth and have the ability to invade local, or sometimes distant, tissues and organs in the body" (Heller, Alberto, Forney, & Schwartzman, 1996, p. 314). According to Link (1990), "cancer is not a single disease but a large and heterogeneous group of diseases which share certain biological and pathological features" (p. 43). Different types of cancer are more common at different ages and each type has a different prognosis

for long-term survival. The number of children who are surviving cancer has increased in the past several decades such that "childhood cancer has evolved from an inevitably fatal illness to a life-threatening chronic disease" (Bessell, 2001, p. 345). As the survival rate improves, more children return to school during their treatment and/or after treatment has finished and remission has begun (Bafile, 2000). Educators have the primary responsibility for providing these children with a successful education experience, but generally they have not received the training nor emotional preparation for dealing with the issues that accompany the diagnosis and subsequent treatment of a child with cancer (Bessell, 2001). Thus, there is a need for educators to become knowledgeable about types of childhood cancer, the types of treatments and their side effects, the late effects of treatment, and the impact all of these things may have on the child's success in the educational environment (Heller et al., 2009).

TYPES OF CHILDHOOD CANCER

There are eight different types of cancer that are seen most often in children. The frequency of occurrence, the age of onset and the treatment options differ for each (see Table 1). The most common type of childhood cancer is leukemia, that is, cancer of the bone marrow. It accounts for approximately one-third of all childhood cancers (27%) (The Leukemia & Lymphoma Society, 2008). Tumors of the Central Nervous System are another common type of childhood cancer and include tumors of the brain tissue and tumors of the spinal cord. Brain tumors are the second most common (21%) type of childhood cancer after leukemia (Kline, Silver, & Russell, 2001). These two groups account for more than 50% of all childhood cancers.

Other forms of childhood cancer are not as prevalent. Lymphoma is a cancer of the lymph nodes and can be of two types, Hodgkin's disease or Non-Hodgkin's disease. These two cancers each account for 4% of childhood cancers (American Cancer Society, 2006). Neuroblastoma, a tumor of the adrenal glands, chest and abdomen, is the most common non-leukemic cancer of childhood accounting for approximately 7% of childhood cancers (American Society of Clinical Oncology, 2008). Nephroblastoma, also known as Wilms Tumor, is a cancer of the kidney and the next most common childhood cancer accounting for approximately 5% of the identified cancers (American Society of Clinical Oncology, 2007). Nephroblastoma is often genetic in nature and is aligned with certain genetic syndromes such as Beckwith-Wiedemann syndrome, Costello syndrome, and syndromes resulting from altered, damaged or missing genes such as Trisomy 18 (American Society of Clinical Oncology, 2007).

There are three types of cancer that are rare, that is, with each accounting for less than 5% of all childhood cancer. The most common of these is bone cancer, a type of cancer that arises in the structure of the bone instead of in the bone marrow as in leukemia. Bone cancers account for approximately 4% of all childhood cancer (American Cancer Society, 2008). Rhabdomyosarcoma, a cancer of the skeletal muscle, is a highly malignant tumor that accounts for 3% of childhood cancers and Retinoblastoma is a cancer that arises in the tissues of the retina in the eye. It has the most infrequent occurrence of less than 3% of all childhood cancers (American Cancer Society, 2008).

Table 1

Survey Results for Special and Regular Educators (n=160)

	Q1	Q2	Q3	Q4	Q5	Q6	Q7A	Q7B	Q7C
Special Education	Yes-22% No-78%	Yes-13% No-19% Don't Know-68%	Yes-4% No-96%	Classroom-8% Restroom-11% Nurse's Office-77% Teacher's Lounge-4%	Yes-17% No-83%	Yes-23% No-77%	Yes-49% No-51%	Yes-43% No-57%	Yes-28% No-72%
Regular Education	Yes-0% No-100%	Yes-10% No-16% Don't Know-74%	Yes-5% No-95%	Classroom-8% Restroom-7% Nurse's Office-85% Teacher's Lounge-0%	Yes-14% No-86%	Yes-13% No-87%	Yes-47% No-53%	Yes-36% No-64%	Yes-32% No-68%

Lymphoma Hodgkin's Non-Hodgkin's	A group of cancers that originate in the lymphatic system	Lymph nodes	8%	10 to 20 years
Neuroblastoma	A tumor that develops from neural tissue	Adrenal glands, chest, & abdomen	7%	Babies & very young children
Nephroblastoma (Wilm's Tumor)	A malignant growth on or in the kidneys	Kidneys	5%	6 months. to 10 years

*Data compiled from information provided on the following websites: American Cancer Society, American Society of Clinical Oncology, Kids Cancer Care, and The Leukemia-Lymphoma Society.

TREATMENT OPTIONS

In the treatment of all cancers, the goal of the various treatment choices and regimens is to cure whenever possible. Cure is defined as "a complete and indefinite remission—the disappearance of all clinical evidence of the disease" (Heller, Alberto, Forney, & Schwartzman, 1996, p. 318). When considering the time frame of a cure, cancer is considered a cure if no cancer is present after 5 years of treatment (Falvo, 1999).

According to Link (1990), the selection of treatment or intervention for childhood cancer is a complex decision with the treatment chosen dependent on the type and stage of the cancer. Treatment is typically initiated as soon as possible after diagnosis. The treatment choices to be discussed are surgery, systemic chemotherapy, radiation, and maintenance chemotherapy (see Table 2 for a list of childhood cancers and their most common treatments).

SURGERY

For cancerous tumors, surgery was, and continues to be, one of the major choices for initial treatment (Kids Cancer Care, 2007). Surgery involves the removal of the tumor only, simple surgery, or removal of the entire organ and/or surrounding tissues, known as radical surgery. Surgery may be preceded or followed by other medical treatments such as radiation therapy or chemotherapy especially when the cancer has spread within the child's body (Heller, Alberto, Forney, & Schwartzman, 1996). For some types of cancer, such as Rhabdomyosarcoma, the use of surgery is not warranted as chemotherapy and radiation therapy provide appropriate treatment alone.

CHEMOTHERAPY

Chemotherapy is the introduction of anticancer medications into the bloodstream or cerebrospinal fluid in order to distribute materials toxic to cancer to all parts of the body (KidsHealth, 2007). The effect of these drugs is to prevent the cancerous cells from continuing to over-proliferate (Best, Heller, & Bigge, 2005; Falvo, 1999). This type of treatment is most useful with the leukemias and with cancer that has spread widely to other organs.

RADIATION

Radiation therapy consists of the use of high-energy emissions to damage the structure of the cancerous cells and thus prevent the cells from growing and reproducing while attempting to not damage the normal tissue nearby (National Cancer Institute, 2003). In some instances, internal radiation, known as brachytherapy, is used. This type of radiation therapy consists of inserting small amounts of radioactive material into the body or the tumor itself. Radiation therapy may be used alone or in conjunction with surgery or chemotherapy.

SIDE EFFECTS OF TREATMENTS

All treatments for cancer have accompanying side-effects whose appearance depends on the type of treatment, the dosage, the age, and the gender of the child (Brink, 2008). Parents and physicians must make a difficult decision of how to balance the type and level of treatment to ensure a cure while ensuring that the child's future quality of life is not negatively impacted.

Table 2

Childhood cancers and their most common treatment options

Types of Cancer	Most Common Treatment Options		
	Surgery (both simple and radical)	Chemotherapy (both systemic and maintenance)	Radiation Therapy
Leukemia		X	X
Brain Tumor	X	X	X
Lymphoma		X	X
Neuroblastoma	X	X	X
Nephroblastoma	X	X	X
Bone Cancer	X	X	X
Rhabdomyosarcoma		X	X
Retinoblastoma	X	X	X

The American Cancer Society (2006a) states:

> Just as the treatment of childhood cancer requires a very specialized approach, so does aftercare and monitoring for late effects. Careful follow-up after cancer treatment allows for early recognition of and attention to the after-effects of treatment. (p. 1)

NEUROLOGIC SYNDROME

The majority of children who receive chemotherapy or radiation therapy experience a variety of side-effects, known as neurotoxic reactions (Boman, 2007; Brink, 2008; Kids Cancer Care, 2007; McDougal, 1997; National Cancer Institute, 2003). These neurotoxic reactions, known as neurologic syndrome, may occur within hours to days of the treatment (acute reactions), or days to weeks later (subacute reactions) (Karraker, 2005). Acute reactions usually include nausea and vomiting while subacute reactions may include motor dysfunctions, seizures, and cognitive issues. In most instances these reactions

are reversible once treatment has ended (see Table 3 for a list of most common neurotoxic reactions according to treatment).

NEUROCOGNITIVE LATE EFFECTS

Delayed reactions, known as late effects or neurocognitive late effects, may also appear months to years later (American Cancer Society, 2006b; Brink, 2008; Carmichael, 2008; DeAngelis, 2003; Karraker, 2005; Lavach & Hart, 2008). Late effect reactions are serious and often irreversible. These include cognitive, or neuropsychological, deficits such as a decline in intellectual ability, decline or delay in academic achievements, and an increase in issues related to memory functioning, both short and long-term (Ariffin, 2002; Spiegler, Bouffet, Greenberg, Rutka, & Mabbott, 2004). In addition, language skills, fine motor skills, visual and spatial skills, and attention/distractibility may be impacted (Armstrong, 2001). [For more discussion of the late effects of cancer treatment, see the American Cancer Society website.]

RETURN TO SCHOOL

As previously mentioned, there has been a significant increase in the survival rate of children treated for cancer so that now about 77% survive for five years or more (American Cancer Society, 2006a). It should be noted that the length of time the child may be out of school will vary from a brief period of time to a significant amount of time (American Cancer Society, 2006b; Chai Lifeline, n.d.). However, experts recommend that children return to school immediately after diagnosis and continue in school during treatment if at all possible. The reason for this immediate return is that "children have a sense of purpose in school and receive the clear message that they have a bright future and potential for a full recovery from cancer" (American Cancer Society, 2006a, p. 1).

Although the return to school may occur easily for some children, others may have physical, emotional, and cognitive changes which may make their return difficult (Parlikar, 2008). Children are often afraid to return to school as Susan Nessim, cancer survivor stated:

> I know the fear that kids with cancer feel when they 'check back' into school… They want to be treated just like everyone else, but often teachers and friends are uncertain how to act around them. (Bafile, 2000, p. 1)

Table 3

Types of treatment and their side effects

Treatment	Side Effects	Delayed/Late Effects*
Surgery	***Physical & Emotional*** pain, weakness, depression, behavioral changes ***Academic*** speech-language, visuo-spatial changes	***Physical & Emotional*** scarring, sadness, depression ***Academic*** memory
Chemotherapy	***Physical & Emotional*** hair loss, nausea, vomiting, anemia, fatigue, susceptibility to infection, excessive bruising or bleeding, upset stomach, pain, weight gain or loss, incontinence, cataracts, slowed growth	***Physical & Emotional*** delayed onset of puberty, growth retardation ***Academic*** learning disabilities, memory issues, attention, distractibility, language delay, spatial memory,

	Academic fine motor issues, memory, attention, distractibility	nonverbal skills especially mathematics
Radiation Therapy	***Physical & Emotional*** hair loss, nausea, vomiting, anorexia, skin burns, mouth sores, headaches, apathy, seizures, blurred or double vision, body marks, ear infections, dizziness ***Academic*** learning disabilities, motor dysfunction	***Physical & Emotional*** hyperpigmentation, sterility, necrosis, seizures, cataracts, hypothyroidism, growth hormone deficiency, hearing loss, heart problems, respiratory problems, precocious puberty, bone fragility ***Academic*** cognitive deterioration (IQ score reduction of

		10-20 points), fine motor processing, distractibility, visuospatial problems, learning disabilities, memory loss

*The younger the age of the child when treatment occurred, the area of the body involved, and the higher the actual dosage given are linked to greater risk for late effects.

In fact, Kline, Silver, and Russell (2001) state "children with cancer experience numerous obstacles to school attendance and academic performance" (p. 36). These obstacles include (a) increased absenteeism because of medical appointments and illness as a result of treatments; (b) changes in social interaction with peers and adults in the school, also known as social stigma, and (c) the cognitive changes that may be occurring or have occurred. Bafile (2000) maintains that returning the child to the school environment can provide that child with a feeling of "normalcy" during and after treatment.

ROLE AND RESPONSIBILITIES OF EDUCATORS

It is essential that educators "learn to facilitate healthy emotional, social, and intellectual development during and after a child's treatment" (Bessell, 2001, pp. 345-346). In order for teachers to support the child with cancer who is returning to school there are a number of issues of which they must be aware (see Table 4).

First, teachers working directly and indirectly with the child must acquire information on the type of cancer that the child has, the treatment that is occurring or has occurred, the prognosis, and the possible side effects that may result including any late effects that may impact on the child's school performance (see Table 5 for a selected list of resources to assist teachers in

Table 4

Checklist for Educators: Preparation for Teaching a Child with Cancer

If a student in your classroom has cancer and is returning to the classroom during or after treatment, you will need to prepare yourself, the other students, and the physical environment. The following questions will help you focus on issues of which you should be aware and may need to further your knowledge.			
Question	Yes	No	Comments
Is my classroom climate accepting of difference?			
Do I have adequate knowledge about the type of cancer that the student has and the treatments that may occur?			

Do I know and understand the type of physiological and cognitive effects the treatment may have on the student?			
Have I identified academic and social accommodations that I may need to implement to support the student?			
Have I planned how to address the classroom curriculum for a child who has frequent absences?			
Have I developed an assessment plan in order to evaluate the changes in the student's academic skills that may occur as treatment progresses?			

Am I prepared to address the emotions of the child's peers (including fear, anxiety, and anger)?			
Am I prepared to respond to the emotions of the child with cancer (including fear, anxiety, rejection, and anger)?			
Do I know how, and am I ready, to deal with the issue of death of a child?			

gaining further knowledge). Before the child returns to school, the child's teachers will need to understand the physical, social, and psychological difficulties that the child may experience. Specifically teachers will need to know the treatment effects on the skills needed for learning and on the strength and vitality of the child. In addition, teachers will need to determine the child's need for emotional support as a result of the child's feelings of anxiety, frustration, and even behavioral outbursts. Thus, teachers will need to prepare themselves and the students for the child's return to school during the child's absence so as to facilitate the child's return.

Second, teachers of the child must determine or assess their attitude toward the diagnosis of cancer, their fears and anxieties, and their expectations for children with this diagnosis. Appropriate expectations should be maintained with the needs of the child impacting on accommodations that may need to be implemented in the classroom (Deasy-Spinetta, Spinetta, & Kung, 1999). On the other hand, teachers must also guard against attributing all of the child's school problems to the effects of the illness. If possible, a base level of

Table 5

Internet Resources

American Cancer Society
http://www.cancer.org

Cancervive, Inc.
http://www.cancervive.org

Candlelighters Cancer Foundation
http://www.candlelighters.org

KidsHealth
http://kidshealth.org

Lance Armstrong Society
http://www.livestrong.org/

The Leukemia and Lymphoma Society
http://www.leukemia-lymphoma.org/

Pediatric Oncology Resource Center
http://www.acor.org/diseases/

Planet Cancer
http://www.planetcancer.org

The Starbright Foundation
http://www.starbright.org

The Ulman Cancer Fund for Young Adults
http://www.ulmanfund.org

the child's educational and social development should be completed as early as possible to serve as a guideline for assessing future concerns. If the child has received treatment earlier the teacher should be aware of any late effect changes that may be attributable to the earlier treatment.

Third, teachers should consider their role as a conduit of information among the school personnel, parents, and health care providers. Teachers will be spending a significant amount of time with the child and should be ready to identify problems when they arise early so that they do not become major obstacles to school success (Kline, Silver, & Russell, 2001). As Best, Heller, and Bigge (2005) state:

> As they do for all students with chronic conditions, teachers and others must maintain consistency in educational programming, while assisting the student to cope with missed school time, social and academic reintegration after hospitalization, or altered appearance as a result of treatment and/or disease progression. (p. 70)

SUMMARY

Children with cancer and children who are cancer survivors have a number of distinct challenges which must be met if they are to be successful in an educational setting. Assisting students in meeting these challenges is the charge given to today's educators. First, educators must study childhood cancer to learn about the cancer, its treatment, and the potential effects of the treatments on the classroom performance of the child. Second, educators must reflect on their attitudes, beliefs, and fears of cancer and compare their expectations to current research findings. Inconsistencies must be examined and actions taken based on the compilation of current research. Finally, educators should assume the role of information repository and be ready to share pertinent information concerning cancer, educational recommendations, and the needs of the student and his/her family with others in the school, the family, and health care providers. Teaching students with cancer or cancer survivors cannot be seen as an easy task, but these students need the normalcy provided within the daily routine of schooling.

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