The Impact of Chemotherapy and Radiation on Adult Survivors of Childhood Cancer:

Examining Their Impact on Adler’s Life Tasks

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Abstract

Adult survivors of childhood cancer who receive chemotherapy and cranial radiation for hematological and brain tumor cancers experience late effects from these methods of treatment. Physical, cognitive, and psychological effects in the lives of survivors have been most reported up to this point. This paper examines the influence of these effects through Adler’s life tasks: love, work, and community.
Outline

I. Most Common Types of Childhood Cancer
   A. Acute Leukemias
   B. Brain and Spinal Cord Tumors

II. Best Methods of Treatment
   A. Chemotherapy
   B. Radiation Therapy

III. Late Effects
   A. Physical
      1. Chemotherapy
      2. Radiation therapy
   B. Cognitive
      1. Chemotherapy
      2. Radiation therapy
   C. Psychological Late Effects

III. Adler’s Three Life Tasks
   A. Life Task of Love and Sex
      1. Task Defined
      2. Impact
   B. Life Task of Work
      1. Task Defined
      2. Impact
   C. Life Task of Community
1. Task Defined

2. Impact

V. Proposed Solutions

A. Support Groups

B. Direct Interventions and Prevention of Late Effects

C. Mental Health and Career-Based Interventions

1. Therapeutic services

2. Vocational training

D. Experienced After-Care and Comprehensive Follow-Up Services

VI. Significance in General Field

VII. Relevance in Future Practice

VIII. Most Salient Strengths

IX. Most Noteworthy Limitations

X. Areas of Future Study

XI. Conclusion
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“Just like kids who were in a big car accident or who were hurt in a flood, all children have events in their lives that affect who they become as adults. Having had cancer is one of those big events. It can play a part in how you view the world.” (Keene, 2002, p. 145).

The National Cancer Institute (2009) states that at least 270,000 of the more than 10 million cancer survivors alive in the United States today were diagnosed before the age of 21. Because of the amazing advances in cancer treatments over the years, “almost 80 percent of children diagnosed with cancer are alive at least five years after diagnosis” (National Cancer Institute, 2009, p. 1). “Survivors of childhood cancer often find that the illness and its treatment [has] changed their lives” (Keene, Hobbie, & Ruccione, 2012, p. 1). While common cancer treatments such as chemotherapy and radiation therapy have advanced significantly over the past 20 years, these treatments often do not distinguish between unwanted cancer cells and perfectly healthy cells. Keene, Hobbie, and Ruccione (2012) state that long-term side effects such as physical, cognitive, and psychological issues can accompany desirable results, impacting the survivor’s adaptation to a “normal” life after treatment.

There is a relatively extensive amount of research available on the presence of such issues within the adult population who are at least 5 years post-treatment. Some examples of common issues faced by this growing population are as follows. Physical late-effects in survivors can affect anything from an increased risk for obesity and infertility to changes in vision, dental abnormalities, and bodily growth depending on the method of treatment received (Friedman, 2003). Neurocognitive shortfalls reported by survivors who received cranial and neck radiation consist of processing speed, memory, and concentration problems (Kirchhoff, Krull,
Ness, Armstrong, Park, Stovall, Robison, & Leisenring, 2011). Those with a central nervous system (CNS) injury as a result of treatment for a brain tumor might experience difficulty “understanding social situations in the ways that other children understand them, inhibiting impulses or generating, evaluating, and selecting appropriate responses in social situations” (Kazak & Rourke, 2003, p. 142-143).

As typical life events and necessities occur such as seeking and maintaining employment, developing community relationships and love relationships, and independent living, these issues can and most likely affect the survivors’ psychological well-being (Kirchioff et al., 2011). Because of this, it is becoming increasingly important for research to continue to seek advances and solutions in this area and for services offering comprehensive medical and psychological support to these individuals to be made more readily available. In order to make this a possibility, professionals working in this area need to remain up to date on developing research regarding not only psychological advances, but also the biological and physical effects of current and past medical cancer treatments. Interventions recommended not only include post-treatment action, but suggest preventative methods such as psychoeducation and an established plan. These suggestions could provide effective assistance to these survivors.

As noted above, the adult childhood cancer survivor population is large and growing (Barr, Crockett, Dawson, Eves, Whitton, & Wiernikowski, 2001). It is an opportune area for those professionals with both experience and interest in the psychological and medical fields to merge services. It is also important to alert practitioners that in proportion to this increase in the childhood cancer survivor population, there is then a growing need for psychological support in dealing with the long-term effects of this trauma. While there are child life, mental health, and social work services available that are equipped and trained to work with patients and families
While in the midst of the shock of diagnosis and treatment, support once through the treatment process is often overlooked (Keene, 2002).

While it can be understood that, as with any trauma (divorce, death, abuse or neglect, etc.), there are psychological effects, the same stands for surviving a life-threatening disease such as cancer (Kazak & Rourke, 2003). However, not only are emotional and psychosocial effects present but there is often an existing fear that the cancer may return. This permeates through the entire family system. Keene, Hobbie, and Ruccione (2012) state that practices such as family counseling can aid in the transition from patient status to survivor status. Including parents and siblings in the survivor’s continuing development can offer the comfort of continued support.

An obvious necessity to collaborate across fields is then essential to success in working with these individuals. As it is important for parents and teachers to keep in contact in order to ensure care for the child is as consistent as possible, the same is true for counselors or therapists and involved medical professionals. While direct contact between pediatric oncologist and therapist may not always occur, to ensure treatment is effective it can be assumed that the therapist working with this population have at least a general medical case-by-case knowledge. This could take place by contacting the local children’s hospital or a clinical child psychologist.

Aside from psychological effects, the survivor will most likely face ongoing medical issues, and receiving care with the benefits of quality health insurance is imperative. Those with a medical history including cancer or leukemia are considered high-risk and these individuals are often declined for coverage or are only able to get coverage with a very high deductible (thus negating the success of gaining coverage) (Keene, Hobbie, & Ruccione, 2012). Often the solution is for adult survivors to be covered under their parent’s insurance as long as possible (Keene, 2002). The repercussions on these individuals without family support or the help of a
spouse or partner can be devastating and, in turn, cause psychological distress in itself (Keene, Hobbie, & Ruccione, 2012). While this is a difficult moral situation to face as a therapist, it must be understood that these issues are ever present in the lives of cancer survivors. Helping professionals must be able to hold to strong ethical practices, such as making appropriate referrals when the case extends outside of the professional’s scope of practice and advocating for the best interests of the client, while doing their best to offer effective interventions and treatment plans specific to each case.

Most Common Types of Childhood Cancer

Two of the most common childhood cancers are acute leukemias and brain and spinal cord tumors (Keene, 2002).

Acute Leukemias

Leukemia is a disease of the blood and affects bone marrow, the blood-forming tissues. It affects approximately 3,500 children in the United States each year (Keene, 2002). The two types of acute leukemia are Acute lymphoblastic leukemia (ALL) which accounts for 75% of all children with leukemia and Acute myeloid leukemia (AML) of which approximately 500 children are diagnosed with in the United States each year (Keene, 2003). Leukemia causes the bone marrow to produce “too many immature white blood cells that cannot perform their normal function of fighting infection” (Keene, 2003, p. 3). The production of red blood cells (the cells that carry oxygen) and platelets (those that form clots to stop bleeding) eventually slows and stops as the bone marrow fills with these abnormal cells. The blood then carries these leukemic cells to other organs in the body such as the lungs, liver, spleen, or kidneys (Keene, 2003). “The cancer can also cross the blood-brain barrier and invade the central nervous system or the brain and spinal cord” (Keene, 2003, p. 4). Some common signs and symptoms look like many
common childhood illnesses that can make a timely diagnosis challenging (Keene, 2003). Onset in children may be slow or quick, beginning with fatigue or the need to rest often. An “interest in eating gradually diminishes,” “parents usually notice pale skin and occasional bruising,” and “some children develop back, leg, and joint pain” (Keene, 2003, p. 1). Following a tentative diagnosis, children are often referred for further tests and treatment.

**Brain and Spinal Cord Tumors**

Brain and spinal cord tumors or Central Nervous System (CNS) tumors are “the most common solid tumor in children” (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 33). They affect “approximately 2,200 children younger than age 20” in the United States each year (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 33). Depending on the location of the tumor, individuals experience a wide variety of symptoms. Some of these indicating a tumor in the brain include headaches, dizziness, seizures, staring spells, double vision, unsteady walk, facial drooping, hearing loss, trouble swallowing, changes in school performance or behavior, or weakness in hands on one or both sides of the body. Those indicating a spinal cord tumor include back or neck pain, changes in bowel or bladder control, weakness or sensory changes in arms or legs, tilting of the head and upper spine to one side (torticollis), or a curvature of the spine resulting in leaning of shoulders to one side or a hump noticeable in the back (scoliosis) (Shiminski-Maher, Cullen, & Sansalone, 2002). Tumors may remain in the brain or spinal cord for long periods of time without growth or “dramatically increase in size in just a few days” (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 33). Again, these children are often referred to “a major medical center with expertise in treating children with tumors” following a tentative diagnosis (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 4).
It is important that these children be treated using a team or multi-disciplinary approach including professionals such as pediatric oncologists, neurosurgery, specialized surgeons and pathologists, radiation oncology, rehabilitation specialists, educational specialists, child life specialists, and social workers to ensure state-of-the-art treatment and the best opportunity for a cure and remission (Shiminski-Maher, Cullen, & Sansalone, 2002).

**Best Methods of Treatment**

Keene (2002) explains that normal, healthy cells are only produced by the body as they are needed and are “preprogrammed to die at a specific time” (p. 171.) Both cancer and tumor cells “reproduce uncontrollably and in unpredictable ways” (p. 171). Two of the most common methods of treatment used for both leukemia and brain and spinal cord tumors are chemotherapy and radiation therapy. These methods are often given in combination with others if needed, such as bone marrow transplant (BMT) or peripheral blood stem cell transplant (PBSCT) for the treatment of leukemia (Keene, 2002) and surgery, peripheral blood stem cell transplant (PBSCT), and observation for the treatment of brain and spinal cord tumors (Shiminski-Maher, Cullen, & Sansalone, 2002). The small differences in how each method is used to treat both leukemia and tumor cells are presented below.

**Chemotherapy**

“The word chemotherapy is derived from the combination of ‘chemical’ and ‘therapy’ or treatment. It means using drugs, singly or in combination, to destroy or disrupt the growth of cancer cells without permanently damaging normal cells” (Keene, 2002, p. 171). The drugs “work in some way to interfere with the ability of the cancer cells to live, divide, and multiply” (Keene, 2002, p. 172). It is important to note that not all chemotherapy drugs, as with any type of medication, are created equal. This means that each drug has its own set of short and long-term
side effects (Keene, 2002). Keene states those that are effective with both leukemia and tumor cells are alkylating agents which “poison cancer cells by interacting with DNA to prevent cell reproduction,” antimetabolites that “starve cancer cells by replacing essential cell nutrients,” antibiotics, alkaloids that “interrupt cell division,” hormones, and enzymes (2002, p. 172). Anti-angiogenesis agents which “have the ability to disrupt the blood supply to the tumor” (Shiminski-Maher, Cullen & Sansalone, 2002, p. 214) are added to the list of drugs used to treat tumor cells. These drugs can be delivered one of five ways in the treatment of leukemia including orally (liquid, capsule, or tablet form), directly into the bloodstream (intravenous or IV), directly into the cerebrospinal fluid (intrathecal or IT), injecting into a large muscle (intramuscular), and injecting into the soft tissues under the skin (subcutaneous or Sub-Q) (Keene, 2002). Shiminski-Maher, Cullen, and Sansalone add intracavitary for the treatment of tumor cells. This means the drugs are given “directly into a body cavity through a catheter” (2002, p. 214).

As with any drug, it is important to be aware of the potential side effects. Many of these side effects, states Keene (2002), are short-term and are likely to cease soon after treatment ends. Specifics regarding these side effects are discussed in a later section.

**Radiation Therapy**

Also known as radio therapy, radiation therapy uses high-energy x-rays to kill and destroy cancer and tumor cells (Shiminski-Maher, Cullen, Sansalone & Keene, 2002). All radiation treatment is given in doses measured in units known as centigrays (cGy). The use of radiation therapy differs slightly when treating leukemia and brain and spinal cord tumors.

During treatment of both types, children undergo a process called radiation simulation. It is then that a radiation oncologist or technologist outlines the treatment area while adjusting any machinery used to accommodate for the area needed to be treated along with marking the skin
with small, black dots (Shiminski-Maher, Cullen, & Sansalone, 2002). This process is essentially a preparation procedure before beginning any formal radiation therapy treatments.

The two main types of radiation used for leukemia treatment include radiation to the head, cranial radiation, and radiation to the whole body, or total body radiation (TBI). There is no pain in the preparation (radiation simulation) or administration of radiation therapy, but it is common that as many as 30 treatments are needed (Barr, Crockett, Dawson, Eves, Whitton, & Wiernikowski, 2001). Children treated using cranial radiation usually receive between 1800 cGy to 2400 cGy to the entire brain. Those treated using total body radiation usually receive 1000 cGy to 1200 cGy (Keene, Hobbie, & Ruccione, 2012). Because of the known long-term effects, which include changes in dental health, and IQ and academic decline, of specifically cranial radiation used to treat acute leukemia, when possible, chemotherapy is the preferred form of treatment (Mulhern & Palmer, 2003). As the dose of radiation therapy given increases, so does the risk of long-term effects later on in life.

The two most common types of radiation therapy used to treat brain and spinal cord tumors are external and internal radiation. The four types of external radiation are 3D conformal radiation therapy that “delivers high-dose radiation tailored to the precise area of the tumor, while delivering a lower dose to the normal tissue surrounding the tumor,” intensity modulated radiation therapy which “modified the radiation beam based on the shape of the target,” stereotactic radiosurgery that “directs radiation to a small, precisely defined target,” and proton beam radiation that “uses large, positively charged particles having a larger mass than standard proton-beam radiation” providing excellent beam definition (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 192). Internal radiation is not as commonly used as external radiation
therapy and involves “radioactive material [being] placed directly into tissue or applied to the surface of tumor sites” (Shiminski-Maher, Cullen, & Sansalone, 2002, p. 193).

Radiation therapy to the brain and spine, while effective in shrinking small tumors and even reducing pain, can cause “mild, short-term side effects, and sometimes permanent damage that may not be evident until months or years after treatment” (Keene, 2002, p. 236). The target area of the beam and the location of the body targeted all play a part, just as in the variety of chemotherapy drugs, in the types and intensity of these short or long-term effects (Keene, 2003). These long-term side effects are discussed in the next section.

**Late Effects**

Just as chemotherapy drugs and radiation therapy to different areas of the body produce alternate desired (or undesired) outcomes in treating the presenting cancer, so do chemotherapy and radiation therapy present varying long-term side effects in the bodies and lives of adult survivors of childhood cancers. These side effects are categorized by physical, cognitive, and psychological influence. According to Keene (2002), some of the most influential risk factors include type of leukemia or brain and spinal cord tumor, total dosage of individual drugs, combination of different types of chemotherapy, location and dose of radiation, and age at diagnosis. Shiminski-Maher, Cullen, and Sansalone state that long-term side effects in general can range from “none to severe” (2002, p. 435). The varying potential long-term side effects are described in detail below.

**Physical**

**Chemotherapy.** As explained above, “because children are still growing and developing, their bodies are much more susceptible to certain kinds of damage than adults” (Friedman, 2003,
Some of the areas of the body affected by chemotherapy treatment include teeth, ears, heart, and lungs.

In a study by Kaste, Goodman, Leisenring, Stovall, Hayashi, Yeazel, Beiraghi, Hudson, Sklar, Robison, and Baker, the authors found that “children who are aged <5 years when they are exposed to alkylating agents, particularly those who receive high doses, are at high risk for developmental abnormalities” such as missing or small teeth, lack of enamel, root stunting, or decreased joint mobility (2009, p. 10). Alkylating agents were defined in the sub-section titled Chemotherapy as drugs that “poison cancer cells by interacting with DNA to prevent cell reproduction” (Keene, 2002). Hearing loss that can potentially affect language reception and expression has been reported in older children or adults months to years following treatment, specifically those who received cisplatin or carboplatin (alkylating agents) as younger children (Friedman, 2003).

Long-term effects within the heart and lungs include serious symptoms such as shortness of breath, fatigue, wheezing, poor exercise tolerance, rapid heartbeat, and irregular heartbeat (Keene, Hobbie, & Ruccione, 2012). Miller, Lopez-Mitnik, Somarriba, Lipsitz, Hinkle, Constine, Lipshultz, and Miller report that of those survivors treated with doxorubicin, a chemotherapy drug known to cause shortness of breath and heart damage, “more than 12 years after completing therapy, have a significantly lower exercise capacity…[and] less endurance and a lower anaerobic threshold” (2013, p. 666). An increase in chronic fatigue was also reported by those diagnosed between the ages of 1 to 18 at 4 to 20 years after diagnosis (Jóhannsdóttir, Hjermstad, Moum, Wesenberg, Hjorth, Schrøder, Mört, Jónmundsson, & Loge, 2012). While the participants in this study were still adolescents at the time of assessment, they experienced “substantially elevated fatigue levels, relative to the general public” (Jóhannsdóttir et al., 2012, p.
While not all survivors experience these effects, these can all become dangerous with the addition of an increased risk for obesity in adult survivors as a result of cranial radiation. This will be discussed in the following sub-section.

**Radiation therapy.** There is some overlap between the physical long-term side effects as a result of chemotherapy and radiation therapy. Among those are hearing loss, changes and damage to dental health, and fatigue, as reported above (Friedman, 2003; Keene, 2002, & Shiminski-Maher, Cullen, & Sansalone, 2002). These effects are especially common in those adult survivors who received cranial and spinal radiation (Friedman, 2003). In addition to those already mentioned, obesity has been a researched long-term side effect in adult survivors by the Childhood Cancer Survivor Study (CCSS) (Green, Cox, Zhu, Krull, Srivastava, Stovall, Nolan, Ness, Donaldson, Oeffinger, Meacham, Sklar, Armstrong, & Robison, 2012). Green et al. states that comparisons between a 1995 National Health Interview Survey and CCSS showed that the “risk of obesity was increased 50% among adult female and 20% among adult male leukemia survivors” (2011, p. 1). Green et al. also found that “cranial radiation in a well-established risk-factor for obesity among adult survivors,” particularly those with a diagnosis of ALL (2011, p. 8). Coupled with symptoms accompanying chronic fatigue and poor exercise tolerance, older child survivors and adult survivors are at greater risk for developing common health problems such as high blood pressure and high cholesterol (Lenihan & Cardinale, 2012). There has also been evidence that cranial radiation, particularly in those survivors treated for brain tumors, causes a decrease in production of growth hormone resulting in shorter stature than typical counterparts. Cranial radiation has also been shown to cause infertility in a small amount of adult survivors and bring about an early or late puberty in those that received treatment prior to the onset of puberty (Shiminski-Maher, Cullen, & Sansalone, 2002). Lastly, vision loss, more
commonly the development of cataracts, in those survivors who received cranial radiation or two specific chemotherapy drugs has been reported. These cataracts may or may not prevent full vision but can cause difficulty in trying to discern against contrasting shades (light and dark) (Friedman, 2003).

All of these physical late and long-term side effects can create the need for additional medical attention and subsequent costs as well as serious and sometimes painful challenges for adult survivors and their families.

Cognitive

Chemotherapy. As defined by Mulhern and Palmer, cognitive late effects, are “problems with thinking, learning, and remembering [and] have become an important area of concern” especially in survivors of acute lymphoblastic leukemia (ALL) and brain tumors (2003, p. 101). The chemotherapy drug Methotrexate is the most reported to cause late effects in adult survivors. Methotrexate can be given in pill form by mouth, intravenously or intrathecally. This drug, also called Methotrex or MTX, “is an antimetabolite that replaces nutrients in the cancer cell” that then causes cell death (Keene, 2002, p. 185). Keene notes that it is documented to potentially cause “neurotoxicity which can cause learning disabilities” and “temporary or permanent nervous system damage” (2002, p. 184). The brain and spinal cord make up the central nervous system in the body. This is the first main part of the nervous system. The peripheral nervous system is a network of nerves throughout the body and these two parts “work together to monitor, coordinate, and control all activities of the body” (Keene, Hobbie, & Ruccione, 2012, p. 209). Any changes in the functioning of this system, say Keene, Hobbie, and Ruccione, can “profoundly affect both health and quality of life” (2012, p. 209).
Within the general area of learning disabilities, a wide range of issues and potential learning problems can be identified. These can begin immediately or several years after treatment. Kirchoff et al. (2011), as noted in the introduction, identified processing speed, memory, and concentration problems as being a few of these reported issues. Other more specific signs to be aware of are problems or changes in handwriting, spelling, reading or reading comprehension, understanding math concepts, remembering math facts, comprehending math symbols, sequencing and working with columns and graphs, auditory or visual language processing, attention deficits, short-term memory and information retrieval, planning and organizational skills, and social maturity and social skills (Keene, 2002). Many of these such as attention deficits and social maturity and social skills, can merge into late effects that are psychological, as well.

Argyriou, Assimakopouloa, Iconomou, Giannakopoulou, and Kalofonos (2011) report on a state they term “Chemobrain” or “Chemofog,” or “a relatively common adverse effect of chemotherapeutic agents typically administered to treat various types of solid tumors” (p. 2). Chemotherapy-induced cognitive impairment (CICI), “Chemobrain,” is “the impairment of patients’ memory, learning, concentration, reasoning, executive function, attention, and visuospatial skills during and after discontinuation of chemotherapy” (Argyriou et al., 2011, p. 2). They also report that these drugs, specifically cisplatin, cause damage to the central nervous system, periodically resulting in hormone changes. These in turn can affect the cognitive function of patients, specifically females, “because of decreased levels in the neuroprotective estrogen hormone” (Argyriou et al., 2011, p. 3). Keene, Hobbie, and Ruccione (2012) also identify cisplatin chemotherapy resulting in hormone deficiencies.
Gender is an identified factor that affects late cognitive effects and females have been shown to be at greater risk, especially those who received MTX for the treatment of ALL (Mulhern & Palmer, 2003).

**Radiation therapy.** Those survivors under the age of 5 and treated for a brain or spinal cord tumor with cranial radiation are at a higher risk for serious cognitive late effects than those treated for ALL (Keene, Hobbie, & Ruccione, 2012). Again, damage to the central nervous system is among the most reported in the bodies of adult survivors. Mulhern and Palmer found that “40 – 100% of long-term brain tumor survivors have some form of cognitive late effects, with impaired IQ found in nearly 90% of patients for medulloblastoma” which is a common childhood brain tumor (2003, p. 103). They also found that those who were treated for a brain tumor with cranial radiation therapy (CRT) compared to those who were not “consistently scored lower on IQ testing” and that the long term effects of CRT “may cause a continuing pattern of IQ and academic decline over time” (Mulhern & Palmer, 2003, p. 103). Greene-Schloesser, Moore, and Robbins (2013) identify verbal memory, spatial memory, attention, and novel problem-solving ability as additional possible areas of impairment related to learning disabilities in adult survivors. Difficulty with memory or changes in attention span, verbal fluency, and speed of information processing have been evident in many survivors years after treatment or immediately following treatment in many cases. Areas of academic difficulty most commonly reported are mathematics, reading and reading comprehension, and spelling (Shiminski-Maher, Cullen, & Sansalone, 2002).

Mulhern and Palmer (2003) also indicate age as an influential factor for developing late effects. It could be argued that the developing brain “can explain why younger children are more likely to have cognitive late effects [and] the immature, developing brain in young children
appears to be more fragile” (Mulhern & Palmer, 2003, p. 106). Shiminski-Maher, Cullen, and Sansalone (2002) state that those children treated under age 5 are at a high risk and those treated under age 2 are at the highest risk, especially if cranial radiation was given to large portions of the brain.

**Psychological Late Effects**

While there is a lack of evidence citing the direct effect of chemotherapy and radiation on adult survivors as cause for late psychological distress, there is enough information to support that the adult survivor of childhood cancer is at risk for experiencing a wide variety of psychological late effects (Kazak & Rourke, 2003). The literature does however, support a small distinction in the various late effects, psychological in nature, experienced by those survivors of leukemia as opposed to brain and spinal cord tumors (Zeltzer, Recklitis, Buchbinder, Zebrack, Casillas, Tsao, Lu, & Krull, 2009). Kazak and Rourke define these psychological late effects as “the long term influences of the cancer on feelings, thoughts, behaviors, and relationships of survivors and their family members” (2003, p. 137). Morasso, Leo, Caruso, Decensi, Beccaro, Berretta, Bongiorno, Cosimelli, Finelli, Rondanina, Santoni, Stigliano, and Constantini report that according to a recent national U.S. study “this population is almost twice as likely to report severe psychological distress as subjects never diagnosed with cancer” (2010, p. 1547). As can be understood, the fact that the disease itself and its treatment affect one’s psychological state not only impacts the survivor but the entire family as well. A short, not exhaustive by any means, list of the various psychological effects cited in current literature include depression, anxiety, somatization, a reduced quality of life, and symptoms of posttraumatic stress. A diagnosis of Posttraumatic Stress Disorder (PTSD) was reported in rare cases (Kazak & Rourke, 2003; Wakefield, McLoone, Goodenough, Lenthen, Cairns, & Cohn, 2010). There are also several
reported factors on the presence of psychological late effects such as present age of survivors, transition from “patient” to “survivor” status, educational level, and current level of social support following treatment (Morasso et al., 2010; Wakefield, McLoone, Goodenough, Lenthen, Cairns, & Cohn, 2010).

Zeltzer et al. found in their investigation of data published by the Childhood Cancer Survivor Study (CCSS) that both leukemia and brain tumor survivors “demonstrate elevated rates of psychological distress as compared to their siblings” (2009, p. 2398). While leukemia survivors were found to experience increased rates of depression, anxiety, and social-skills deficits, those survivors treated for brain tumors showed higher rates of impaired physical health as compared to those leukemia survivors (Zeltzer et al., 2009). Brain tumor survivors were also found to display depression, but differed from their counterparts in that they experienced somatization, “higher rates of impaired physical health,” and “more symptoms of fatigue and daytime sleepiness” (Zeltzer et al., 2009, p. 2398). Within their results, Zeltzer et al. (2009) also found a link between the presence of depression in adult survivors and the report of sleep disorders or increased daytime sleepiness. Overall it was found that “those survivors who rated their own health as poor also reported significantly more symptoms of depression, anxiety, and somatic distress” (Zeltzer et al., 2009, p. 2401). In addition to a link between physical health (impacted by chemotherapy and radiation treatments as indicated in previous sections), Zeltzer et al. (2009) note a correlation between psychological function and health behaviors as well. Smoking and drinking were among the two health behaviors reported. It was found that “17% [of survivors] were current smokers at the time of long-term follow up” but that “survivors were less likely to be current drinkers” (Zeltzer et al., 2009, p. 2401). Those survivors that did report drinking, “heavy drinking was more likely in those who reported poor health, depression,
anxiety, and somatic distress” (Zeltzer et al., 2009, p. 2401). According to this evidence, it can be assumed that there is a relation between the physical effects mentioned in the previous section and the reported late psychological effects.

Kazak and Rourke state that “survivors who have cognitive impairment as a result of their disease or treatment could have higher levels of [psychological] distress than others” (2003, p. 141). While this statement is not meant to draw a definitive link between cognitive impairment experienced by adult survivors and the presence of posttraumatic stress symptoms, it is made in an attempt to find a cause for the presence of these symptoms (Kazak & Rourke, 2003). Kazak and Rourke describe posttraumatic stress as “a term that describes reactions that people have after they experience a trauma” and seek to make the distinction between these symptoms and a complete diagnosis of PTSD (2003, p. 138). As with any of the other late effects identified, these posttraumatic stress symptoms could occur anytime immediately following the diagnosis to years later (Kazak & Rourke, 2003). The three kinds of posttraumatic stress symptoms that could potentially manifest are a “persistent re-experiencing of the traumatic event,” “increased anxiety,” and “isolation,” at least one of which has been shown in the results found by the Childhood Cancer Survivor Study (Kazak & Rourke, 2003, p. 139). Signs of increased anxiety seen in survivors, according to Kazak and Rourke (2003), can range from bouts of irritability, feelings of jumpiness, or constantly being on guard to trouble sleeping or concentrating. Simply hearing, smelling, or seeing something that reminds survivors of their treatment has the potential to bring about vivid nightmares or distressing images or thoughts. There is a chance that some survivors could develop symptoms in all three of these categories. If these then interfere with their daily lives and functioning, they can be diagnosed with Posttraumatic Stress Disorder. Young adult survivors are at a particularly high risk for developing PTSD post-treatment because
the realization could be made that they experienced losses or missed out because of their disease (Kazak & Rourke, 2003). For some, these losses could include the ability to reproduce, and any other cognitive or physical limitations. “During this time, [adolescents and young adults] are becoming increasingly more responsible for personal healthcare” and this has the potential to become “a phase characterized by psychological vulnerability” (Wakefield, McLoone, Goodenough, Lenthen, Cairns, & Cohn, 2010, p. 264). Those survivors that exhibit higher levels of isolation, who are treated for brain tumors, or have cognitive or learning issues resulting from their treatment may also experience social skills deficits. In general, those survivors who sustained any central nervous system damage as a result of cranial radiation or chemotherapy may have difficulty balancing their own needs with the needs and desires of others; understanding social situations as others understand them; inhibiting impulses; and generating, evaluating, and selecting appropriate responses in social situations. As increased isolation might result in these deficits, these deficits may also result in increased isolation in some survivors (Kazak & Rourke, 2003). While this will not occur in every survivor, it could be a challenging psychological effect impacted by many others.

In association with isolation and a deficit in social skills, “a higher ratio of distressed patients was observed among those with lower social support” (Morasso et al., 2010, p. 1545). More specifically, Morasso et al. observed higher proportions of psychological distress in females “with a lower overall social support” (2010, p. 1549). “Each of these kids is an individual, and probably some have more psychology trauma from their therapy, from being diagnosed with cancer from an early age, than others, depending on how they were supported,” states Dr. Donald Durden, research director in the division of hemotology/oncology at the Moores UCSD Cancer Center (Landau, 2009, p. 3). However Wakefield, McLoone,
Goodenough, Lenthen, Cairns, and Cohn (2010) found a positive effect to report among all the negative late effects mentioned above. They reported “that children who had recently completed treatment have high levels of global self-worth and good behavioral conduct [and] they demonstrated that overall psychosocial adjustment in their sample was similar to the general population” (Wakefield, McLoone, Goodenough, Lenthen, Cairns, & Cohn, 2010, p. 267). It could play to the hopes of all adult survivors of childhood cancer and their overall quality of life that this attitude perpetuates long after childhood.

**Adler’s Three Life Tasks**

The individual psychology of Alfred Adler, a medical doctor and psychotherapist from Vienna born in 1870, seeks to provide “a strategy of psychotherapy [and] a philosophical framework with which to interpret and comprehend information relevant to an understanding of human nature” (Mosak & Maniacci, 1999, p. X). The most basic of Adlerian concepts is that of social interest (Gemeinschaftsgefühl) “which encompasses the individual’s awareness of belonging in the human community and the cosmos of which it is a part, and an understanding of his or her responsibility for the way the life of the community is being shaped by his or her actions” (Griffith & Powers, 2007, p. 11). Not only does true social interest in an individual bring about an awareness of belonging, but to belong to the social world is “the strongest motivating force for the human being” (Griffith & Powers, 2007, p. 9). As Adler (1959) states, “no adequate man can grow up without cultivating a deep sense of his fellowship in humanity” (p. 38). Without this goal, the thought is that no movement would take place in the life of the individual or that one would act on the useless side of life. Adler believed that “people are affected by their perceptions of the facts, not the facts themselves” and therefore play a role in
the construction of one’s own life based upon how one interprets the “facts” he receives (Mosak & Maniacci, 1999, p. 31).

Rudolf Dreikurs, an American psychologist and practitioner of Adler’s individual psychology, described children as being “excellent observers” but “horrible interpreters” in their ability to attach meaning to the facts received (Mosak & Maniacci, 1999, p. 33). Adler put a name to the process of developing these perceptions: the lifestyle. (Mosak & Maniacci, 1999).

The lifestyle, which can also mean personality (Mosak & Di Pietro, 2006), “is the individual’s characteristic way of thinking, seeing and feeling towards life” (Mosak & Maniacci, 1999, p. 31). Because “people are seen in relation to their perceived environment,” individual psychology or Adlerian theory includes three tasks of life or “life tasks” (Mosak & Di Pietro, 2006, p. 15). The three life tasks are love and sex, work, and social and community.

Any of the late effects that have occurred inside the body of the adult survivor has and will continue to challenge and provide movement within the current perception of self and the convictions previously built. It is the purpose in the following sections to expand upon the function of each task itself and to examine the physical, cognitive, and psychological late effects and its evidenced or potential impact upon the individual within the concept of each task of life.

**Life Task of Love and Sex**

The life task of love and sex, also known as the sexual task, encompasses the simple fact that “humans come in two sexes” (Mosak & Maniacci, 1999, p. 103).

**Task defined.** Within this task, Adler identifies four subtasks. These subtasks are sexual sex role definition, sexual sex role identification, sexual development, and sexual behavior (Mosak & Maniacci, 1999). Sexual sex role definition means defining the roles of men and women or determining what it means to be each. This might have been demonstrated by the
parents during childhood and the individual might already have a pre-conceived perception of what makes a woman a woman and a man a man (Tuites & Tuites, 1997). Sexual sex role identification necessitates an established awareness of sex role definition and progresses to a personal measuring of how the individual fits into the established conception of either one. Simply, this means personally identifying with one sex role or the other. The subtask of sexual development includes the movement through and adaptation of each developmental milestone within the lifestyle. Finally, sexual behavior is about finding out what is socially appropriate sexual behavior (Mosak & Maniacci, 1999). However, Mosak and Di Pietro (2006) do emphasize the fact that the institution of marriage is about more than just sexual behavior. While one’s own personal perspective within the context of sexual development could include ideas of whom one should date and marry, it should be remembered that “marriage is a unique social relationship that should go much farther than, and not be measured only by, sexual intimacy” (Mosak & Di Pietro, 2006, p. 17). More specifically:

A married couple is seen in the light of Adlerian psychology as two separate individuals, each operating according to the guidelines of his/her basic convictions, intentions, and expectations, each striving to achieve his/her place in life, but at the same time, each also working to build a life with the other, and in the process using more or less courage, more or less selflessness, more or less positive cooperation. (Belove, 1997, p. 365)

These individuals must account for the potential complications of a chronic illness and the late effects it brings into the relationship.

**Impact.** Relative to the two other life task areas, less research was found that was directly related to the task of love and sex and on the topic of marriage. However, Zebrack and Landier state that “in general, survivors who were married/partnered, employed, of higher levels
of formal education and who earned higher incomes reported significantly better quality of life (QOL)” (2011, p. 1598). There also appears in the current literature to be much overlapping of marital status, employment status, and level of education in regard to perceived increased QOL among survivors. Zebrack and Landier found that “those not in a significant or committed [partnership were] significantly more likely to report distress and lower mental health” (2011, p. 1600-1601). This result was substantiated by survivor ratings in the areas of physical function, physical role, bodily pain, general health, vitality, social function, emotional role, and mental health indicating that each area played a role in the marital or relationship status in young adult survivors. Results of the study suggest, though, “that perception is a critical predictor of distress and QOL for young adult survivors of childhood cancer (Zebrack & Landier, 2011, p. 1601-1603).

Janson, Leisenring, Cox, Termuhlen, Mertens, Whitton, Goodman, Zeltzer, Robison, Krull and Kadan-Lottick (2009) compared data from the Childhood Cancer Survivor Study to the data collected from a sibling cohort as well as from the U.S. Census. They found “that survivors were 1.21 times more likely to be unmarried than the sibling comparison group and 1.25 times more likely to be unmarried than the U.S. Census population” (Janson et al., 2009, p. 2632). Overall, they found a history or cranial radiation, emotional distress, male gender, and younger age at diagnosis as having a direct effect on nonmarriage. “Cranial radiation has been associated with social difficulties in past studies A few of the physical, cognitive, and psychological factors cited as cause for this statistic are “cognitive processing difficulties and short stature, as well as poor physical function” or a disability (Janson et al., 2009, 2633). While short stature is a reported factor, more research is needed to determine why this is. Nina Kadan-Lottick, assistant professor at the Yale School of Medicine and co-author of the Childhood Cancer Survivor Study,
speculates if it is “whether it’s because people perceive shorter individuals as less attractive, or it’s that shorter men and women lack the social skills to overcome their stature” (Landau, 2009, p. 2). Janson et al. states that “diminished height is known to be associated with lower marriage rates and bachelors are significantly shorter” (2009, p. 2633). Dr. Kadan-Lottick mentions late effects, such as processing speed, “may be an indication …of being able to get your life in order…to live independently, to do things like get married and live your own life” (Landau, 2009, p. 3). Apart from any physical or cognitive issues, cancer can simply be an isolating illness (Keene, 2003).

As mentioned, chemotherapy has been reported to affect growth when used during puberty (Keene, 2002). While infertility is rare, it can occur in both males and females and weigh in on a couples’ desire to have children of their own. Keene, Hobbie, and Ruccione (2012) state that those at the highest risk to be infertile or to have impaired fertility are survivors who had high doses of alkylators and total body irradiation, boys who received direct radiation to their testes, and girls who received direct radiation to their ovaries. Children treated before puberty, particularly boys, have been reported to be at naturally higher risk than females or children treated after the onset of puberty (Keene, Hobbie, & Ruccione, 2012). As with any other developing teen and eventually adult, Keene (2002) emphasizes the importance on education about safe sex. Nancy Keene is one of the original developers of the Patient-Centered Guides series and has a daughter who was diagnosed with acute lymphoblastic leukemia at 3 years of age. While infertility is rare, it must be made clear that infertility does not protect from sexually transmitted diseases. Consequently, survivors might also fear the health of their offspring if they are able to and do decide to bear children. In general, Keene, Hobbie, and Ruccione state that, “children born to survivors are just as healthy as those born to people who never had cancer”
No special tests are recommended, but close monitoring is necessary for certain groups such as those who received drugs that can damage the heart (Keene, Hobbie, & Ruccione, 2012).

Because cancer and its late effects have the potential to change the survivor’s physical appearance, they could also change how the survivor views himself or herself (Keene, Hobbie, & Ruccione, 2012). Keene, Hobbie, and Ruccione state that “healthy adult sexual relationships have psychological, interpersonal, and physical parts,” and that “people with histories of cancer can view the body as a source of health concerns rather than sexual pleasure” (2012, p. 69-70). Many survivors may be coming out of or dealing with long periods of time in isolation from others for fear of physical appearance or hesitation to disclose information about their illness to others around them (Keene, Hobbie, & Ruccione, 2012). Some men and women have reported positive dating experiences following treatment that have boosted their self-esteem. However, not all have a positive experience.

Changes and shifts are taking place in the area of disability awareness though there are those that will stare, make rude or demeaning remarks, and act uncomfortable around these individuals (Keene, Hobbie, & Ruccione, 2012). “A lingering fear of recurrence,” according to Keene, Hobbie, and Ruccione, “makes some survivors hesitant to link their future to another” (2012, p. 76). Importance lies in survivors being able to come to terms with and communicate this fear to “incorporate love and companionship” into their lives (Keene, Hobbie, & Ruccione, 2012, p. 77). However, some survivors will use a relationship as a quick way to gain financial security or as a way to feel less vulnerable during a time of uncertainty. Others enter a successful relationship feeling that “cancer gave them maturity that helped them find a partner who shares their values” (Keene, Hobbie, & Ruccione, 2012, p. 77). Therefore, it could be speculated that it
is the psychological impact on self-esteem and confidence that affects the rate of marriage or partnership among childhood cancer survivors. As parallels have been made between survivors and their healthy counterparts, the cancer experience can be viewed as an experience that has shaped their self perceptions.

**Life Task of Work**

**Task defined.** Adler’s work task essentially incorporates the idea that if not for the act of social interest “very few of us, if any, could exist independently” (Mosak & Maniacci, 1999, p. 99). We, as humans, have a duty to cooperate in the facilitation of living dependently with each other or “the way in which a person contributes to the common welfare” (Mosak & Di Pietro, 1997, p. 16). The work task, according to Griffith and Powers, is “our continuing to live…made possible by the work of others, demands that we offer something in exchange” (2007, p. 64). Our work is, essentially, a personal contribution to the community in the interest of maintaining society.

This task can also be broken down into subtasks. These include vocational choice, vocational preparation, vocational satisfaction, leadership, leisure, and socio-vocational issues (Mosak & Di Pietro, 1997). In the quest to define a vocational niche, Mosak and Manicacci (1999) use the example of a common childhood question: “What do you want to be when you grow up?” For some, being truly well matched in vocation is easier than it is for others. Today’s world, stresses Mosak and Maniacci, often defines the individual by what he or she does and the lifestyle, or personality, “help[s] us define what we select as acceptable” (1999, p. 100). Preparation can begin as early as elementary school. With this fact in mind, children can be strongly influenced from an early age by parents, peers, and teachers to pursue any multitude of career paths. Therefore, Mosak and Maniacci say that “what we perceive as helpful in our
movements toward our goal we do more of [and] that which we sense as having no or minimal use, we do less of” (1999, p. 100). Vocational satisfaction entails simply that: satisfaction with one’s work. These issues of satisfaction are related closely to lifestyle goals. Some individuals find satisfaction on a daily basis, or in the form of immediate or short-term qualities (Mosak & Maniacci, 1999). This could include smaller details of the job such as working regular or flexible hours, being paid hourly or on salary, or working days or nights. Others, however, find satisfaction in working toward longer-term career goals, and “they can tolerate a great deal of immediate, daily dissatisfaction” (Mosak & Maniacci, 1999, p. 101). Mosak and Maniacci use the college student as an illustration. The typical student will strive for the attainment of a rewarding career in exchange for all the hard work and time dedicated to years of schooling. Lifestyle goals can also lend some individuals better to leadership roles than others. Consequently, those that do not lead, follow. Some may feel more comfortable leading others, some more comfortable following, or those that follow may simply lack the initiative to effectively lead (Mosak & Maniacci, 1999). The issue of leisure can easily point out the workaholic as “they work virtually all the time,” almost making leisure a non-issue (Mosak & Maniacci, 1999, p. 101). However, any other area of life that is not work related is considered leisure such as retirement, vacation, or hobbies (Mosak & Di Pietro, 1997). Finally, socio-vocational issues is “how a person deals with coworkers and the public” (Mosak & Maniacci, 1999, p. 16). This could include issues such as sexual harassment in the workplace to the formalities of our encounters with a non-preferred coworker.

**Impact.** “Work fulfills many needs for adults, including financial security, health insurance, and self-worth” (Keene, Hobbie, & Ruccione, 2012, p. 115). Many of the neurocognitive late effects are factors in childhood cancer survivors attaining and holding a
constant job (Kirchoff et al., 2011). However, Keene, Hobbie, and Ruccione (2012) report that survivors are employed in common career fields such as education, entertainment, sports, medicine, dramatic or expressive arts, law, reception or administration, and social services. Not surprisingly, those who are unemployed or are seeking employment report high levels of psychological distress (Kirchhoff et al., 2011). This, in turn, can influence the survivors’ continuum of care or ability to receive adequate long-term care, as most health insurance is available through employment, and “it seems unlikely that major reforms of the American health insurance system will occur in the near future” (Keene, 2002, p. 380). Health insurance is difficult enough to attain, and job discrimination bars many survivors from this important service. While there are now both federal and state laws that protect the employment rights of cancer survivors, “cancer history can still create barriers to finding, keeping, or changing jobs” (Keene, Hobbie, & Ruccione, 2012, p. 115). Keene, Hobbie, and Ruccione express the importance of survivors being honest about their skill and ability level during interviews and to look for employers who are covered by an anti-discrimination law such as the Americans with Disabilities Act (ADA). The ADA “prohibits discrimination based on actual disability, perceived disability, or history of a disability” and covers employers with 15 or more employees (Keene, Hobbie, & Ruccione, 2012, p. 118). Other federal and state laws include the Federal Rehabilitation Act and the Family and Medical Leave Act (FMLA). Those that are not covered under the ADA are covered under the Federal Rehabilitation Act, and FMLA protects the job security of workers in large companies (Keene, Hobbie, & Ruccione, 2012). Almost all states and the District of Columbia have laws protecting people with disabilities against discrimination. “Unless you have specific mental or physical limitations that affect your ability to do the type of
work you are applying for,” says Keene, Hbbie, and Ruccione, “your cancer history should
have no bearing on your qualifications for the job” (2012, p. 115).

Kirchhoff et al. (2011) found those survivors who were at higher risk for poor
employment outcomes also had lower levels of education. As has been briefly touched on,
because of significant processing and concentration problems, learning disabilities are present in
many survivors. This makes the early education process difficult, especially if much of the
treatment takes place during those developmental years. Children often end up missing
significant amounts of school in the formative years, most often while treatment is taking place.
They are then thrown back into the educational system post-treatment for additional training or
continued education (Copeland & Butler, 2003). Copeland and Butler state that “once children
have developed these problems, repeated failures at school result in low self-esteem and self-
confidence” (2003, p. 165). These problems can persist throughout childhood and into adulthood,
and potentially affect “the opportunities of survivors to participate fully in adult life roles,
including their ability to find or maintain employment” (Kirchoff et al., 2011, p. OF1).

Other deficits noted in a study relating physical, mental, and neurocognitive status to
employment includes emotional regulation and poor physical health. As can be true with any
disease inducing trauma, emotions themselves can become compromised. Examples included in
the study are becoming easily frustrated or upset and intense emotional outbursts. Ellenberg, Liu,
Gioia, Yasui, Packer, Mertens, Donaldson, Stovall, Kadan-Lottick, Armstrong, Robison, and
Zeltzer (2009) utilized the Childhood Cancer Survivors Study Neurocognitive Questionnaire
(CCSS-NCQ) in their investigation to determine if the “reported neurocognitive impairment”
(processing speed, memory, planning, and organization, aspects of task efficiency, and executive
functioning) “will be associated with poorer adaptive outcomes in adulthood as assessed by
lower achievement in education, full time employment and income, and less likelihood of being married” in individuals 16-34 years post-diagnosis (p. 706). Four reliable and valid factors identified in the examples listed above are labeled task efficiency, emotional regulation, organization, and memory in this 25 item questionnaire. Some items listed under task efficiency are “I am easily overwhelmed,” “It takes me longer to complete my work,” and “I have trouble prioritizing my activities” (Ellenberg et al., 2009, p. 717). Some of those listed under emotional regulation are “I get upset easily,” and “I get frustrated easily” (Ellenberg et al., 2009, p. 717).

This questionnaire was given to siblings as well as survivors because of greater similarities in the areas of ethnic group and education. Ellenberg et al. were able to conclude that “the current study indicates that adverse outcomes in indicators of successful adult adaptation (educational attainment, income, employment, marital status) were most likely in survivors who report neurocognitive dysfunction” (2009, p. 713). These, along with poor health conditions requiring long periods of time away from the workplace, can influence a survivor’s likelihood of working in a higher skill occupation.

Life Task of Community

Task defined. In its most basic sense, the social and community task accentuates Adler’s belief that “we need to get along with each other” (Mosak & Maniacci, 1999, p. 102).

Underlining the concept behind working together as discussed within the context of the life task of work, Mosak and Maniacci maintain that “without the community, without the support and cooperation of others, we would be extinct” (1999, p. 102). This striving for social interest, as Adler would say, can be seen in the very young child as he or she begins “his early search for tenderness, which leads him to seek the proximity of adults” (1959, p. 38). This demonstrates
that humans need each other (Adler, 1959). There are two main subtasks within the life task of social and community. Mosak and Maniaci (1999) identify these as belonging and transactions.

As mentioned during the introduction of Adler’s life tasks, Griffith and Powers (2007) classify belonging as “central to human motivation.” As a powerful part of being human, belonging then propels people to choose how they wish to belong. This will be guided by their own perceptions and convictions which fit into and have been developed by their own life styles (Mosak & Di Pietro, 2006). Questions such as “What kinds of behaviors does the person feel are necessary to gain the feeling that he or she belongs?” or “Is the person helpless, or dependent, or energetic, or belligerent, or whiny?” provide others with perspective on an individual’s behaviors (Mosak & Di Pietro, 2006, p. 16). According to Adler “we orient ourselves according to a fixed point which we have artificially created, which does not really exist, a fiction” and this point helps us to arrive at some conclusion and categorize sensations and sentiments (1959, p. 67).

The transaction subtask refers to how the individual interacts with others (Mosak & Di Pietro, 2006). Adler’s concept of inferiority feelings explains this concept. Inferiority feelings are essentially “those universal human feelings of incompleteness, smallness, weakness, ignorance, and dependency included in our first experiences to greater or lesser degree throughout adult life” (Griffith & Powers, 2007, p. 60). It is how individuals use these feelings and the “games people play” with others in attempting to move closer to their own goals that epitomizes transaction (Mosak & Maniaci, 1999). However, Griffith and Powers say that “to be human means to feel inferior” and people are able to find belonging through use of the patterns or complexes they develop (2007, p. 60). These inferiority feelings, as a source of constant motivation, also cause individuals to constantly grow and improve (Griffith and Powers, 2007). However, when the individual feels there is no hope or the inferiority feelings are so
overwhelmingly intense, one will tend to compensate for this feeling, possibly moving toward over-compensation. This can occur, for instance, when a child is born “into the world greatly crippled” or acquires and suffers from a serious illness during life causing an organ inferiority or physical compensation (Adler, 1959, p. 71).

Adler states that:

We understand that children with inferior organs will feel inadequate for the tasks of life and that the minus situation will be felt by the child with inferior organs more intensely than by the average child…The organic weakness does not necessarily function as a minus situation, but the child experiences the weakness of his organic equipment for average social tasks, and he feels impelled to reorganize accordingly. (Griffith & Powers, 2007, p. 76)

While there is emphasis upon the physical aspect of this task in being able to bridge that connection in an attempt to encourage societal belonging, Adler includes an element of psychological compensation in the successful achievement of this task.

**Impact.** “For those survivors still struggling…socially, recent reports indicate that the risk factors contributing to their distress are the same as those observed in the general population: female gender, lower household income, lower education attainment, and unemployment” (Zebrack & Lendier, 2011, p. 1595). This again draws attention to the fact that many struggles of the survivor can be similar to those faced by the general population and that all of these life tasks relate and create crossover in distress in other areas. Zebrack and Landier documented “avoid social activities” and “left out of friends’ lives” as potential negative impacts of cancer in the lives of survivors as evidenced by results collected from the *Impact of Cancer—Childhood Survivors (IOC-CS)* (2011, p. 1607). Keene, Hobbie, and Ruccione (2012) talk about
the benefit to survivors in having friends who are also survivors. Because young adult and adult survivors of an intense illness such as childhood cancer may not feel they are receiving the support and understanding from friends who do not or did not have the same experience, the shared experience may create the bond needed by this population. Keene, Hobbie, and Ruccione suggest seeking out people who are willing to listen without judgment, or those who respect a desire not to talk about their illness.

Social support was reported to be important to the distress level of survivors. As it is important for any individual, social support is proven important for maintaining a healthy level of psychological stability after the treatment process and on into survivorship. “The sense of community,” says Keene, Hobbie, and Ruccione, “can help dispel the isolation felt by too many survivors” (2012, p. 42). Not only can the support of others help dispel the isolation, but it has been reported to affect self-view and management of life after cancer (Keene, Hobbie, & Ruccione, 2012). However, social support of a negative kind can be detrimental to survivors’ already compromised health. Thompson, Gerhardt, Miller, Vannatta, and Noll (2009) report that “externalizing behaviors and substance use increase risk for a variety of negative outcomes…and risk for adverse consequences may be magnified for survivors” (p. 2). While the authors examined the “role of peer acceptance, social behavior, and medical factors in predicting later externalizing behaviors and substance use among survivors of childhood cancer,” it was found that patterns of externalizing behaviors, actions that direct problematic energy outward such as physical aggression or defiance, were comparable with peers (Thompson, Gerhardt, Miller, Vannatta, & Noll, 2009, p. 7). However, it was also found that “once survivors had initiated substance use, they may have used more frequently and in larger quantities than peers” (Thompson, Gerhardt, Miller, Vannatta, & Noll, 2009, p. 7). There was a negative association
between isolating behavior and later substance use. Higher rates of externalizing behavior and substance abuse were reported in those diagnosed later in childhood, even as late as adolescence. This is believed to be true because those “who were diagnosed later may have already begun experimenting” and “coping with a chronic illness…may encourage survivors to engage in behaviors that promote feelings of normalcy and acceptance” (Ellenberg et al., 2009, p. 8).

Another study by Robinson, Gerhardt, Vannatta, and Noll found that, though most of the participants still lived with their parents, “children begin to distance themselves from family in adolescence and rely more on peers for support” (2009, p. 29). Correlations suggest that “although parents perceived the family environment as related to young adult internalizing symptoms, youth did not” (Robinson, Gerhardt, Vannatta, & Noll, 2009, p. 29).

Michel, Taylor, Absolom, and Eiser (2009) purport that while cancer is a traumatic and life threatening condition, it is also an opportunity to find benefits and grow as a person. They utilize a technique called “benefit finding” which means exactly that: indentifying “potential benefits of the illness” (Michel, Taylor, Absolom, & Eiser, 2009, p. 125). They found higher levels of optimism and self-esteem among leukemia patients (not survivors) than in solid tumor patients as well as in younger patients overall. An assumption made is that treatment for leukemia extends over a period of years while treatment for solid and CNS tumors is often shorter (Michel, Taylor, Absolom, & Eiser, 2009). The study also had a limited number of participants who had or were diagnosed with a solid or CNS tumor compared to those with a diagnosis of leukemia.


Proposed Solutions

Support Groups

“In providing family support,” state Shelton and Stepanek (1994), “it is important not to overlook the needs of the child with a chronic illness or disability” (p. 72). While working with the family as a system and a constant in the life of the child, they state that it is important not to forget about the needs of the individual child as well. These children, as well as survivors of the illness, need a safe place to share their own experiences with others going through similar situations, without fear or worrying their parents or judgment from others (Shelton & Stepanek, 1994). Davitt and Hicks (2009), certified child life specialists (CCLS), who work with typical and special needs children and their families within the hospital setting, state that “coping skills can be strengthened and knowledge increased or reinforced through a support group” (p. 276). These groups are a method for which to strengthen social support in the life of the survivors and negate feelings of isolation.

Direct Interventions and Prevention of Late Effects

Ligibel (2012) states that “lifestyle factors have increasingly been identified as potential means to impact cancer outcomes and improve quality of life in survivors” (p. 3697). Factors such as body weight, physical activity, diet, alcohol consumption, and smoking have been previously discussed and have been shown to link to cancer prognosis as well as potentially impact lifestyle changes in cancer survivors (Ligibel, 2012). The majority of the studies used in this article utilized breast cancer survivors. However all of the interventions suggested could be utilized with survivors of childhood cancer.

Physical activity has been reported in some studies to improve “prognosis for individuals with several common cancers” including decreased risk of cancer recurrence, and others suggest
“that individuals who increased physical activity after cancer diagnosis appeared to have a better prognosis than individuals who maintain or decrease levels of physical activity” (Ligibel, 2012, p. 3699). Many of the studies reported walking at a moderate-to-brisk pace for anywhere from 90 minutes to 3 hours a week was enough to show results (Ligibel, 2012). Because late-effects include challenges such as shortness of breath, poor exercise tolerance, and rapid or irregular heartbeat, it would be wise for individuals experiencing any of these to consult a physician before making any changes in their level of activity.

Modification of diet has also been shown to impact disease recurrence (specifically breast cancer) and prognosis. Studies such as the Women’s Interventional Nutrition Study (WINS) and the Women’s Healthy Eating and Living (WHEL) examined the impact of dietary intervention, specifically emphasizing an increase in consumption of fruits, vegetables, and fiber and decreasing fat intake (Ligibel, 2012).

Ligibel (2012) also reports that, as has been previously stated, smoking and regular alcohol consumption during and after treatment are risk factors for many malignancies and increased risk of many cancers. Therefore, both the American Cancer Society and the American College of Sports Medicine have issued “lifestyle guidelines” for cancer survivors (Ligibel, 2012, p. 3702). These include incorporating daily moderate-intensity physical activity, attaining and maintaining a healthy weight, and eating a healthy diet with at least five servings of fruits and vegetables daily. The healthy diet guidelines also include limiting consumption of processed food as well as consumption of alcoholic beverages and smoking cessation if one has not already done so (Ligibel, 2012). Ligibel states that “interventional studies have demonstrated that… individuals who are able to lose weight, exercise more, and improve their diets experience
Additional sources report potential benefits in the use of attention-deficit hyperactivity disorder (ADHD) medication post-treatment to address memory, attention, and behavior problems in children who undergo radiation and chemotherapy that target the CNS (McBride, 2011). Penkman (2004) defines “attention” as “a person’s ability to direct, focus and sustain their attention to a particular stimulus in the environment” and can be thought of as a ‘supportive’ or ‘core’ cognitive function (p. 111). McBride details a study of 122 children who “developed attention and learning problems after successful treatment for brain cancer or acute lymphoblastic leukemia” (2011, p. 24). The children were given the drug methylphenidate (Ritalin) for 1 year and showed “greater improvement in attention, behavioral problems, and social skills than those who did not take the medication” (McBride, 2011, p. 24). Copeland and Butler (2003) have also found methylphenidate effective in improving attention abilities in this population but advise it be given at a lower dose than to healthy children with ADHD. The use of this medication, however, as with its use for treatment of those children with ADHD, is only one component in an approach that includes a multitude of interventions. In regards to attention deficit, “the efficacy and advisability of stimulant medication is always an issue in discussion” (Copeland & Butler, 2003, p. 171). Further research is needed to continue to provide safe and up to date information on the effectiveness and necessity of the use of Ritalin in adult survivors.

Another program recommended for those who experience cognitive difficulties as a result of treatment to the central nervous system is cognitive remediation (Copeland & Butler, 2003). Mulhern and Palmer define this same concept as cognitive rehabilitation or “interventions intended to restore lost cognitive functions or to teach the child skills to compensate for
cognitive losses that cannot be restored” (2003, p. 107). The Cognitive Remediation Program was designed “to improve survivors’ abilities to attend, remember, and learn” and specifically “attempts to counteract the cognitive effects of irradiation or chemotherapy to the central nervous system” (Mulhern & Palmer, 2003, p. 165). The program involves three parts: massed practice (practice where there is little or no rest between skill performances), learning strategy for increasing attention, and psychological intervention activities. Participants engage in at least 20 2-hour weekly sessions with a therapist. The therapist tailors the sessions to each participant and his or her individual needs. The goal is to not only increase effectiveness in each of the three areas of the program, but for each participant to successfully complete activities and improve their self-esteem and self-confidence. The three of parts of the Cognitive Remediation Program were derived from three disciplines: brain injury rehabilitation, educational psychology/special education, and clinical psychology (Copeland & Butler, 2003).

The Sohlberg/Mateer model, developed by two clinician-researchers in brain injury rehabilitation, focuses on a concept called cognitive flexibility. This model “regards attention as the capacity for the brain to focus on an object over time and to be flexible in processing the information” (Copeland & Butler, 2003, p. 167). Sohlberg and Mateer also depict four types of attention and specific exercises to improve each type. These four types include sustained, selective, alternating, and divided. The exercises are meant to become gradually more complex as students gain more competence and increase level of achievement. Psychological interventions within the Cognitive Remediation Program involve cooperation of the entire family in recognizing the child’s need for more opportunities for independent functioning and encouragement toward independent organization, judgment, and decision-making (Copeland & Butler, 2003).
Some concerns regarding the Cognitive Remediation Program are expense because of the intensity and frequency of required sessions, maintenance of gains made during the program, and how soon Cognitive Remediation should be introduced. The program has been offered to children who are at least a year post-treatment and show signs of attention deficit. Medical insurers are split in their view of Cognitive Remediation. Some regard it as a medical condition, while others are adamant that it be covered by mental health insurers (Copeland and Butler, 2003). These are all areas requiring more research and willing participants.

**Mental Health and Career-Based Interventions**

**Therapeutic services.** As previously discussed within the goals of the Cognitive Remediation Program, “interventions that achieve cognitive reframing of the cancer experience may be of benefit” (Zebrak & Landier, 2011, p. 1605). “Opportunities for survivors to re-frame,” such as approaches like Cognitive Behavioral Therapy (CBT) … the context of cancer in their lives may offer a potential to facilitate social (re)-engagement, normalization, and successful accomplishment of developmental tasks like finding a job … or dating” (Kazak & Rourke, 2003, p. 1605). Kazak and Rourke (2003) mention the use of CBT for reducing posttraumatic stress symptoms and to prevent a full PTSD diagnosis. Research has also been done regarding the effectiveness of CBT used with the entire family in a group intervention setting. Psychoeducation about the cognitive and mental health effects is a key part of this type of intervention, “helping families build a shared understanding of the cancer/survivorship experience” (Kazak & Rourke, 2003, p. 148). Social skills training is another potential intervention, offering services to those survivors affected by cognitive deficits to promote “adaptive social development” (Kazak & Rourke, 2003, p. 148). These programs, specifically aimed at populations treated for brain tumors, are conducted in a group setting and are being
offered at an increasing number of pediatric centers across the country. Parents and survivors can contact their own hospital or brain tumor organizations to find out about availability and location.

**Vocational training.** The intervention suggested includes vocational rehabilitation or training. Specifics were not elaborated upon, but an option always available and recommended is for a plan to be made with involved care professionals before beginning treatment (Zebrack & Landier, 2011). Side-effects should be outlined and made clear, and recommendations could be made to begin working on potential problems. Keene, Hobbie, and Ruccione outline a public vocational rehabilitation system, “which trains and places adults with disabilities into jobs” (2012, p. 98). Within this type of program, survivors often work with a job coach who might accompany the individual to work and help him or her learn work skills and how to handle workplace stresses. Students with an established disability should receive vocational counseling. This is likely to include aptitude testing, a discussion of their interests and abilities, and information about work possibilities. The Federal Rehabilitation Act requires every state to offer minimum services through a vocational rehabilitation agency. These services include an evaluation of potential for rehabilitation, counseling, placement services, and physical accommodation. The act also requires these agencies to work with schools to provide transitional services for those youth with disabilities transitioning from high school to the workplace. Some states may also have access to vocational rehabilitation scholarship money that can be put towards vocational training (Keene, Hobbie, & Ruccione, 2012).

**Experienced After-Care and Comprehensive Follow-Up Services**

Keene, Hobbie, and Ruccione state that “people cope better with transitions if a period of planning occurs before the change happens” and “the transition from cancer patient to survivor
should be acknowledged by all healthcare providers” (2012, p. 5). This can be a frightening and stressful time for patients and their families, and the knowledge that they will have a safe and experienced network of support after treatment is reassuring.

A large component of the long-term care of survivors of childhood cancer is comprehensive follow-up programs and clinics (Hieb, Ogle, & Hobbie, 2003). Before 1996, there were no established guidelines for the care of childhood cancer survivors. It was not until then that the International Society of Pediatric Oncologists developed guidelines for care and “stressed the importance for psychological support and the education of patients about a healthy lifestyle” (Keene, Hobbie, & Ruccione, 2012, p. 18). Their goal was to “promote long-term physical, psychosocial, and socioeconomic health and productivity, not merely to maintain an absence of disease or dysfunction” (Keene, Hobbie, & Ruccione, 2012, p. 18). The Institute of Medicine then published a book in 2003 on the subject of childhood cancer survivorship, and finally the Children’s Oncology Group published follow-up guidelines in 2004. That same year, the American Academy of Pediatrics also published its own guidelines for pediatric cancer centers (Keene, Hobbie, & Ruccione, 2012).

Sadak, DiNofia, and Reaman (2013) report on previous studies detailing patient perspectives “on what is most important for optimal transition” as part of a long-term follow-up program (p. 1). Out of the 141 participants in the study done by Sadak, DiNofia, and Reaman, 86% stated they understood the need for long-term follow-up care, and only 56% stated that they were aware of their risks for specific long-term side effects, with 39% stating they were “somewhat” aware (2013, p. 2). Information regarding personal medical histories, psychosocial support, and social advocacy were among the top three most desired by young adult survivors of childhood cancer, specifically those treated for leukemia, lymphoma, and CNS tumors (Sadak, DiNofia, & Reaman, 2013). In addition, “comprehensive survivorship
care was the most beneficial part of the long-term follow-up program” (Sadak, DiNofia, & Reaman, 2013, p. 1365). Other important components reported by survivors were issues related to insurance, clinical team composition, services offered, scheduling, and “knowing that they were not alone and having opportunities to network with other survivors” as well as access to comprehensive health insurance (Zebrack & Landier, 2011; Sadak, DiNofia, & Reaman, 2013, p. 1365).

Hieb, Ogle, and Hobbie define successful follow-up programs as having the following components: “a dedicated medical team” that includes a medical director, nurse practitioner, clinical psychologist, school liaison, and social worker; “a group of sub-specialty health care providers … who are interested and experienced in caring for survivors of childhood cancer”, and “financial and philosophical support from the cancer center” (2003, p. 155). The most effective survivorship programs include the mentioned components as well as focus on the areas of clinical care, education, and research (Hieb, Ogle, & Hobbie, 2003). Within the scope of services offered by health care providers, screening survivors for physical, psychosocial, and educational effects is necessary to determine level of developmentally appropriate care. In addition to offering education and guidance for survivors and their families, “survivorship programs also emphasize health promotion and maintenance” (Hieb, Ogle, & Hobbie, 2003, p. 156). A part of education also includes a detailed summary of their disease, treatment and follow-up guidelines. It is important that every survivor have an up to date, detailed summary in order to provide this information for any follow-up program and subsequent health care providers (Hieb, Ogle, & Hobbie, 2003). In a continued effort to provide survivors with up to date information and follow-up guidelines for potential late effects from treatment, the research goals of comprehensive follow-up programs should investigate new areas of potential long-term
or late effects, use of current data to provide clinical care for survivors, update and validate survivorship healthcare guidelines, “identify the impact of the aging process on the organ system(s) already affected by previous disease and treatment,” and provide late effect prevention options while maintaining current survival rate (Hieb, Ogle, & Hobbie, 2003, p. 157).

According to Keene, Hobbie, and Ruccione, some general questions that survivors and families should ask when considering a follow-up program include:

- How do you provide follow-up for childhood cancer survivors?
- Who is in charge of the program (i.e., doctor, nurse practitioner)?
- What is your experience in treating the late effects of childhood cancer?
- Which other professionals are part of the team?
- What is a typical follow-up visit to the clinic like?
- What transition services from child to adult care do you provide?
- Are there support groups or mentoring programs available? (2012, p. 20)

**Significance in General Field**

As has been recognized and stated by many sources reporting on this topic, the population of young adult and adult survivors of childhood cancer is large and increasing as advances in treatment services are made. Sadak, DiNofia, and Reaman state that “overall survival rates for children with cancer now approach 80% [and] it is estimated that there are over 325,000 survivors of childhood cancer living in the United States” (2013, p. 1365). Not only does this pose a unique challenge for medical programs such as long-term follow-up care and recurring tumors or relapse in cancer patients, but the field of psychology faces the needs of those who have experienced or are experiencing a very specific trauma.
Relevance in Future Practice

Many sources have identified the need for survivors to have access to and receive some form of skills training or psychotherapy to address any potential psychosocial and psychological long-term or late effects from treatment of the trauma related to the disease itself. As stated in the introduction, this also means collaboration between mental health and medical professionals in working with this population to provide the most effective and consistent care (Cline & Greene, 2007). Zebrak and Landier state that, “we acknowledge that QOL or distress may conversely influence self-perception, thereby suggesting that psychotherapeutic or psychopharmacological interventions aimed at reducing distress symptoms may lead to changes in one’s perceptions of how cancer has affected their lives” (2011, p. 1604-1605). This is evidenced by suggestions that the common ADHD drug, Ritalin, has been effective in addressing attention and behavioral problems and social skills. With the additional use of Adlerian concepts such as lifestyle and social interest and without underestimating the impact of encouragement in the lives of these survivors, professionals can “make a difference in how well and how long” survivors live (Cline & Greene, 2007, p. xxv). A small number of resources report cognitive behavioral therapy as an effective method to help survivors re-frame the effects of their experience. Merging the practice of these two theories to guide survivors to change their perceptions of these physical and cognitive effects throughout their love, work, and social lives could create a strong foundation upon which professionals can tailor strategies for each individual survivor.

Most Salient Strengths

In a review of the current literature, there appears to be an agreement across sources that late effects impact the areas of cognitive and physical development in adult and young adult survivors of leukemia and brain and spinal cord tumors. Many sources also emphasize the
psychological impact in the lives of survivors as a result from either the trauma of living through such an illness and its treatment or battling the challenges of long-term effects sustained from chemotherapy and radiation (Kazak & Rourke, 2003; Keene, Hobbie, & Ruccione, 2012).

Positive outcomes from both the corroboration of research as well as being an individual having survived a life-threatening illness, such as leukemia or a CNS tumor, have been reported. Researchers such as Wakefield, McLoone, Goodenough, Lenthen, Cairns, and Cohn report finding positive psychosocial outcomes in regard to “high levels of global self-worth and good behavioral conduct” as well as a level of psychosocial adjustment comparable to that of the general population (2010, p. 267). Aside from positive statistical results, Keene, Hobbie, and Ruccione discuss simply “a renewed appreciation for life and an awareness of the value of each day” (2012, p. 46). Survivor stories have been shown to touch the hearts of those around them and can leave a lasting, positive impact on family and friends as well as the survivors themselves.

**Most Noteworthy Limitations**

There is a discrepancy in the literature about the cause of post traumatic stress symptoms or a full Post Traumatic Stress Disorder diagnosis in the lives of childhood cancer survivors, as well as what researchers are labeling actual PTSD or only posttraumatic stress symptoms (PTSS). Stuber, Meeske, Leisenring, Stratton, Zeltzer, Dawson, Kazak, Zebrack, Mertens, Robison, and Krull (2011) used participants from the Childhood Cancer Survivor Study (CCSS) “to determine the relative predictive ability of the total number of PTSSs and the severity of total symptoms in the prediction of functional impairment and/or clinically significant distress” in survivors of childhood cancer (p. 348). They found that marital status and employment were shown to impact posttraumatic stress symptoms in survivors. However the level of impairment
impacted by these symptoms within the areas of marital and employment status varied. Kazak and Rourke report that it was not “those survivors who endured more difficult treatments, or whose diagnoses had worse prognoses” who were more likely to develop PTSD or symptoms of posttraumatic stress (2003, p. 141). Neither is treatment intensity, diagnosis, or age at time of treatment shown to relate to developing posttraumatic symptoms. Risk for developing these symptoms, state Kazak and Rourke, is more related to what people believe about their illness, treatment, and current medical status. Therefore, Stuber et al. state that “these results raise interesting questions about what operational definitions of PTSD is best used in studies of childhood cancer studies” (2011, p. 352).

Zebrack and Landier state that “future studies utilizing more representative samples of the population of childhood cancer survivors are still needed” (2011, p. 1603). Most of their participants are survivors of hematological (blood-related) cancers and lack of response from survivors of brain tumor cancers is a result of severe cognitive impairment (Zebrack & Landier, 2011).

**Areas of Future Study**

While many sources such as the National Cancer Institute (2009) and Thompson, Gerhardt, Miller, Vannatta, and Noll (2009) generally utilize a population of survivors 5 years out of treatment as a baseline for study, others make no such distinction. Some sources identify an age range, such as 18-25, as the transition phase from adolescence to adulthood and therefore “an important developmental period” from which to evaluate the impact of late effects (Robinson, Gerhardt, Vannatta, & Noll, 2009, p. 23). Wakefield, McLoone, Goodenough, Lenthen, Cairns, and Cohn state that “there is currently little consistency in the terminology used to describe cancer patients who have recently completed treatment and are awaiting transition to
long-term survivor status” (2010, p. 273). Essentially, further research or clarification of patient status between immediately following completion of treatment but prior to reaching survivor status is needed. Wakefield, McLoone, Goodenough, Lenthen, Cairns, and Cohn also indicate a need for further research “examining the variability in the psychological impact of different types of cancer treatments…and the location and the severity of the cancer” with the hope of better preparing patients and families for successful completion of treatment (2010, p. 273).

Despite the efforts of and guidelines put into place by the International Society of Pediatric Oncologists, the Children’s Oncology Group, and the American Academy of Pediatrics, Earle and Ganz (2012) state that “the evidence base for survivorship care remains weak” (p. 1). There is little surveillance of current comprehensive long-term follow-up programs, yet there has been an expectation created and presented to patients and their families that there will be a plan in place following treatment. While it is common protocol for the medical team to continue to watch for relapse in patients, the same is not often said for such scrutiny in other areas comprised under a comprehensive follow-up program (Earle & Ganz, 2012). In an effort to improve in this area of care, Earle and Ganz say “don’t let the perfect be the enemy of the good” (2012, p. 4). Simple and attainable goals must be set, such as screening for new cancers, coordination of care, health promotion education, symptom management, and palliative care (Earle & Ganz, 2012).

**Conclusion**

Survivors of leukemia and brain and spinal cord tumors, despite those being the most common types of childhood cancer, make up only a small portion of the population of survivors. Other significant types of childhood cancer include Ewing’s Sarcoma, Neuroblastoma, Wilm’s tumor, and non-Hodgkin’s lymphoma. In addition, those challenges and effects reported in this paper do not take into account other chronic and terminal childhood illnesses such as sickle cell
anemia or diabetes. However, all of the areas affected by the drugs used to treat these illnesses seem to cross-over and affect others, such as with Adler’s tasks of life. A comprehensive form of follow-up care seems to be the most effective type for providing these survivors and their families the long-term service so desperately needed. This includes the help of mental health professionals and a thorough knowledge of how this illness impacts individuals and families. While it is obvious that further research is needed to improve the execution of the lofty guidelines set by the various groups and institutions invested in the successful care of this population, underlying it all is social interest and the encouragement of these individuals.
References


