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The Psychological Effects of Experiencing Pediatric Oncology

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The Psychological Effects of Experiencing Pediatric Oncology

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CANCER. It is a word that strikes fear into people and is something that completely changes their lives. As much as we try to ignore it, cancer is still a reality in our world, and the effects of cancer touch everyone involved. It is sometimes hard to think about infants and children being diagnosed with cancer, but this too is a reality. Cancer is the number one cause of death due to disease in children aged one through adolescence (MacDougal 1). One of each one-thousand adults at age 20 is a survivor of childhood cancer (Granowetter 9). Before the age of 19, one in every three hundred-thirty children in the United States will develop some form of cancer. Being afflicted with cancer is an extremely intense, dangerous, and overwhelming experience for any child and his or her parents. From the time of diagnosis, issues such as pain management, nausea and vomiting, return to school, neuropsychological impact of treatment, and death and dying, are part of the situations dealt with by the child and family (Powers 323). As a result of treatment, there is no doubt that children suffer from diverse and severe psychological late-effects such as depression, post-traumatic stress, and academic struggles. These effects sometimes emerge right after treatment, while some do not become apparent until 3 or more years after the end of the treatment. In a survey of childhood survivors, 51.5% described themselves as changed as a result of the cancer experience (Stuber and Seacord 217). With these possible late-effects occurring in children, it is important to find the causes and interventions to help these children cope with the, for the most part, irreversible psychological deficits.

Before there can be a discussion on the psychological late-effects of childhood cancer, it is necessary to look at what cancer is, the different varieties, and the treatments as a result of the different diagnosis. The general definition of cancer is abnormal,
uncontrolled proliferation of cells, which can occur in any organ system of the body (Granowetter 10). The abnormal and uncontrolled growth of cells turns into a tumor, which can be benign or malignant. Benign tumors have a better diagnosis because the cancer does not spread throughout the body. However, malignant tumors will start in one centralized location and then move to other parts of the body, making it more difficult to treat. For many childhood cancer cases, the cause is unknown. There have been studies linking increased risk to prenatal exposure to ionizing radiation, to certain parental occupations such as work in the petroleum fields, and to a variety of other environmental exposures (11). This field needs more research to determine the causal factors.

The most common form of childhood cancer is leukemia, followed by brain tumor, and then lymphoma. Other typical childhood cancers are Wilm’s tumor, neuroblastoma, and a variety of solid tumors, for example, rhabdomyosarcoma, bone, and liver (9). Acute lymphoblastic leukemia (ALL) is the most common pediatric malignancy. It affects the bone marrow, specifically white blood cells called lymphoblasts. Abnormal lymphoblast growth in the bone marrow ultimately causes failure to produce other normal bone marrow elements. Children are brought to the doctor because of symptoms such as unexplained persistent fever, infection, bone pain (caused by the expansion of the bone marrow filling with leukemia cells), easy bruising, bleeding, or enlarging of lymph nodes, liver, or spleen. The duration of these symptoms can range from a few days to weeks (22). Treatment for ALL includes chemotherapy and radiation. Systematic chemotherapy used to be the only treatment given; however, radiation therapy to the head and spine was added due to the tendency for ALL to invade the central nervous system and systemic chemotherapy does not always reach the nervous
In contrast to leukemia, solid tumors are tumors that occur in an organ system or soft tissue. They cause harm by excessive local growth or by metastasis. For example, brain tumors cause symptoms based on the location of the tumor. There may be headache and vomiting, changes in personality, cognitive function, motor control, increased intracranial pressure, or visual changes (24). Brain tumors are the second most common malignancy and account for nearly 2.5 children in 100,000 per year (Mahajan & Jenney 272). Most brain tumors require a multimodal approach including surgery, radiation, and chemotherapy. Surgical procedures are used to obtain local control and usually the initial therapy. If the tumor is not completely removed, then the next step is radiation and chemotherapy to try to decrease the tumor size and to prevent the spread of the tumor (Granowetter 16). Effectiveness of treatment depends on the location and severity of the tumor.

The non-Hodgkin’s lymphomas (NHL) are cancers which originate in lymph node-bearing areas. The major problem with NHL is that the tumor is never in a single area because the lymph nodes are made up of lymphatic cells that move throughout the body. Symptoms of lymphoma include enlarged lymph nodes, difficulty breathing because of enlarged lymph nodes in the chest, an abdominal tumor, fevers, weight loss, and lethargy. Lymphomas often metastasize to bone, bone marrow, and the central nervous system (CNS). Therefore, treatment programs include chemotherapy given directly into the spinal fluid to protect the CNS. If the patient already has CNS disease, then cranial or craniospinal radiation is necessary (Granowetter 25-26). A similar lymphoma to NHL is Hodgkin’s lymphoma, which is also a cancer of the lymph nodes.
The difference is that Hodgkin’s has a slower onset, an orderly progression, and involves nearby lymph node areas. When the cancer is localized in one or two lymph nodes areas and the patient is fully-grown, radiation therapy can be used as the only treatment. However, for most children chemotherapy is also required for eradication (26).

Wilm’s tumor is located in the kidney and affects one child out of ten-thousand. It is usually symptom-free; parents normally notice a lump or mass in the child’s abdomen. This tumor was the first pediatric solid tumor shown to be responsive to chemotherapy. Normal treatment is chemotherapy followed by surgical extraction. Only in severe causes is radiation therapy needed (27).

Neuroblastoma develops in the tissue of sympathetic nervous system. The most common sites are in the abdomen, the chest, and rarely the neck or pelvis. If the children are diagnosed at a young age, the prognosis is better; however, for older children the outcome is not as favorable. Unfortunately the majority of children presented with neuroblastoma have advanced causes where the tumor has metastasized to the bone, bone marrow, lymph nodes, and less commonly the skin (27). For children ranked as low stage, only surgery is necessary to remove the tumor, but for the other stages, chemotherapy increasing in intensity is required.

Osteosarcoma is the most common malignant bone tumor. It is not sensitive to radiation; consequently, surgery is the primary method of treatment. Chemotherapy is usually given before and after the surgery to make sure the tumor is under control. Even with the advances in surgery, many patients still require amputation. The other option is a variety of limb-saving techniques. Although some patients are able to keep their limbs, they have a higher risk for recurrence, functional deficits, and cosmetic defects. The
second most common bone tumor, though quite rare, is Ewing’s sarcoma. It occurs in the bone and requires intensive chemotherapy that lasts for about one year. This can significantly interfere with school and normal activities (28).

After the diagnosis, treatment is started as soon as possible. Treatment is often a horrifying, scary, and painful series of events for everyone involved. Events range from losing hair, to feeling nauseous, to experiencing repeated, painful, and invasive procedures. There are four major forms of treatment available to eradicate cancer: chemotherapy, surgery, radiation therapy, and bone marrow transplant. Leukemias are mostly treated with only chemotherapy. Most solid tumors require a multimodal therapy that includes chemotherapy in combination with surgery and radiation therapy (18).

The first step of treatment is the induction phase. In this phase the goal of treatment is remission or to obtain a state where there are no cancerous cells. Remission for leukemia patients, for example, is defined as having an appropriate blood count, normal bone marrow, and a spinal fluid with no leukemia cells. The length of this step is determined by the tumor. The next step in treatment is the maintenance, which continues for two or three years. This step is used to help the child heal and watch for the possibility of relapse, which is the reoccurrence of the disease during or after therapy. Death due to relapse or complications of therapy occurs in about 40% of childhood cancer patients (15-16). Patients that relapse will receive more aggressive therapies (Mulhern 109).

The backbone of most cancer treatment programs is chemotherapy. Medication given systemically can fight the cancer at the site of its origin and throughout the body (Granowetter 18). Most chemotherapeutic agents work by stopping the increase of
rapidly growing cells. Some chemotherapy is given by vein, by mouth, by injection into a muscle, or directly into the spinal fluid. About 70% of ALL patients are cured with only chemotherapy. Most children receive a 3-drug combination over four to six week intervals, followed by another thirty months of chemotherapy with additional drugs. With some cancers, if the cancerous cells are in the brain and spine, specific therapy is directed at the central nervous system (CNS) to destroy those cells. Effective CNS therapy includes chemo with or without cranial radiation therapy (CRT). CRT reduces the likelihood of relapse and mortality; however, it carries increased risk of late neurotoxicities, which cause neurological function problems afterwards. Other side effects of chemo are reversible hair loss, nausea, vomiting, malaise, mouth sores, changes in appetite, inability to eat, or short and long term damage to internal organs (19).

Radiation is a requirement when surgery and/or chemotherapy cannot completely remove the tumor, when surgically removing the tumor is known to be associated with relapses, or when after the tumor is removed there are still residual microscopic tumors. For a very few tumors, radiation or radiation and surgery are the only type of treatment required. Most radiation treatments are a form of external beam radiation, which means that the radiation is delivered from a machine to the outside of the patient’s body. The treatment takes only minutes and it is not painful. Even though there is little pain, radiation must be delivered to a completely still patient so young children may require strong sedation or anesthesia. Radiotherapy causes a variety of effects, including reddening and irritation of the skin areas receiving radiation, loss of appetite, and malaise (19). A specific type of radiation is cranial radiation therapy (CRT). CRT is directed at the brain; it causes DNA damage and cell death within the first or second attempt at
division which puts rapidly growing cells more at risk. If CRT causes damage to the normal tissue of the CNS, this may manifest as cortical atrophy, vascular damage, or white matter destruction. The severity of these effects is associated with the volume of brain irradiated and dose size (Mulhern 103).

Despite response to chemo and radiation therapy, which are used to control or shrink the tumor, sometimes surgery is necessary to remove solid tumors. Most brain tumors and primary bone tumors require removal of all or most of the tumor after initial therapy (Granowetter 20). The goal of surgery is to remove as much tumor as possible without sacrificing function. Some brain tumors, for example, those in the brain stem, cannot be removed because of their vital location. Other tumors are treated successfully with surgery alone. Many tumors cannot be completely removed. For these, radiation has been the most important element of therapy after surgery. Many patients and parents feel that removing the cancer by surgery is the single most important aspect of treatment (24).

Another treatment for leukemias, because the cancer is originated in the bone marrow, is bone marrow transplantation (BMT). The basic approach of BMT is to give near-lethal doses of chemotherapy and/or total body irradiation in an effort to destroy tumor cells and/or diseased bone marrow then provide the patients with healthy marrow from a donor (Powers 315). There are 6 stages to BMT (315-317): (1) donor search and initial evaluation of disease and organ status, (2) preparative treatment, (3) bone marrow infusion, (4) severe neutropenia, (5) initial period of engraftment, (6) intermediate and long-term follow-up. In the first stage, the children undergo a series of studies of their current disease status and functioning of organ systems to determine if they are transplant
candidates. Then there is a search for a suitable donor. There are two kinds of donors, autolous BMT, where patients serve as their own bone marrow donors. The other is allogeneic BMT, which uses marrow from a sibling, parent, or unrelated person that has shown to have genetically compatible bone marrow. Umbilical cord blood stem cells are another alternative source of stem cells in patients lacking a suitable donor (Elhasid et al 248). The second stage is the preparative treatment where near-lethal doses of chemo and/or radiation are given to the children to kill tumor cells, eliminate existing bone marrow, and limit the ability of the patients’ immune system to reject the donor marrow. In the third stage bone marrow injection occurs the day after preparative treatment is complete. The transplantation of the marrow is not a surgical procedure; it is given to the patients intravenously. The donated marrow enters by vein, finds its way to the bone marrow, and repopulates the marrow with the cells necessary to regenerate all the blood-forming elements (Granowetter 20-21). The fourth stage is “neutopenia”. The patients are at greatest risk because for a minimum of two to four weeks, the patients have no functioning marrow. During this period the children are extremely susceptibility to infection; consequently, protective isolation is maintained to minimize the possible contact with diseases until a safe level of bone marrow function has returned. The average length of hospitalization is about one month (Elhasid et al 249). The fifth stage is the observing to make sure the marrow is not rejected by the patients’ body. The sixth and final stage is the continuation of check-ups. The outpatient process to assess and treat continuing immune system recovery is lengthy, taking about one to two years. Thus restrictions may be put in place for many months, for example, no school.

Despite all these treatments and possible “cures”, a question still lingers: When is
cancer really completely cured? Even if the disease itself is eradicated, there may still be effects left with which to deal. Most of these effects are psychological; therefore, the patients are not entirely cured until the psychological damages are healed. The psychological impact of having had childhood cancer can continue long after treatment ends for survivors and their families. However, most survivors appear to have a reasonable level of psychological adjustment. Kazak (1994) acknowledges that “the data are clear in stating that most childhood cancer survivors do not have clinically significant psychological difficulties and most function well. However, a troubling subset of survivors do have significant difficulties, which we do not presently understand very well.” This adjustment is dependent on a number of variables (Mahajan and Jenney 266). The age at diagnosis, level of academic functioning and family cohesiveness are major determinants in childhood and adolescence cancer patients (267). The conditions of psychological difficulties include anxiety and pain, inhibited and withdrawn behavior, fear of trying new things, low emotional expressiveness, behavior problems, intense stress, post-traumatic stress disorder, peer relationship difficulties, worry about future in relation to career and relationships (MacDougal 5). Length of time following completion of treatment also appears to significantly affect overall psychological adjustment. Only three factors were identified which were associated with an increased risk of maladjustment: older patient at follow-up, greater number of relapses, and presence of severe functional impairments (Mahajan and Jenney 271).

After being diagnosed with cancer, treatment starts almost immediately. Unfortunately, the positive effects of most treatments have unavoidable negative side effects. Many of these procedures cause psychological problems because they include
painful invasive procedure, repeated hospitalization, complications after treatment, traumatic stress, and separation from the child’s family. Varni, Katz, Colegrove, and Dolgin (1994) said “the chronic strains of childhood cancer, such as treatment-related pain; nausea and vomiting; visible side effects such as hair loss, weight gain or loss, and physical disfigurement; and repeated absences from school and peers, interact to negatively impact social and psychological adjustment” (MacDougal 5). All of these problems observed are caused by the procedures that are necessary in eradicating the cancer. Chemotherapy has shown signs of causing late psychological effects. Brown et al (1996) study showed that patients receiving chemotherapy in their CNS had poorer academic achievements (6). Children receiving intrathecal and/or systemic methotrexate chemotherapy had long term neurobehavioral abnormalities (Kadan 35-36). Even though chemotherapy has shown to have psychological effects, these effects are significantly less than chemotherapy in combination with radiotherapy. Studies suggest that radiotherapy with chemotherapy results in long-term effects on the brain and subsequent neuropsychological functioning (Powers 313-314). Most at risk for neuropsychological problems are those treated with high doses of radiation and chemotherapy to the CNS and the younger children, with the most commonly noted affect being learning difficulties (Kadan 41). Younger children are at a higher risk because the CNS is still developing anatomically and functionally (Mulhern et al. 28).

Radiotherapy alone also causes psychological damage. In fact, neurocognitive and psychosocial defects are an accepted consequence of the use of radiotherapy. Studies have demonstrated significantly lower IQ in irradiated compared to non-irradiated patients (Mulhern 105). It has been found that 35% of children under five years with
leukemia, which were treated with cranial irradiation, developed learning disabilities (Marina 1031). Specifically, CRT causes neurobehavioral impairments which are associated with significantly reduced IQ and academic failure. The deficits did not surface until four to five years after diagnosis and were worse for children under the age of six. In particular, children with ALL that receive CRT are more likely to be in special education services and possibly achieve a lower level of secondary education in comparison to their siblings (Kadan 38-39). These results are consistent with Mulhern et al's (1998) study, which says that age and dose of CRT has significant affect on the psychological effects. In this study, younger children with standard CRT dose had IQ median of 70, but younger children with reduced CRT dose had median IQ of 85. Older children with standard CRT dose had median IQ of 83, while with reduced CRT the IQ was 92 (Mulhern et al. 27). In looking for a cause of cognitive declines in children treated with intensive CNS therapies, it is shown that these treatments cause white matter injury in the brain (22). In a cross-sectional study of medulloblastoma survivors, IQ was positively correlated with white matter volume in the brain and inversely correlated with age at CRT (32).

With bone marrow treatment, the major psychological effect is psychosocial impairments, which deals with how the child adjusts to society and social environments. However, studies also show that the effects seem to be reversible by proper psychosocial interventions. Phipps and Mulhern (1995) examined the psychological adjustment of survivors of pediatric BMT. From their finding, the parents said that most of the children did not think back about BMT with anxiety, but many preferred not to talk about it with their parents, 41%, or friends, 50%. Twelve months after BMT, most of the children
(80.8%) improved in their psychological state and were reintegrating into normal life. However, compared to healthy children, BMT survivors showed more disturbed behavior in the academic, social, and emotional domains even twelve months after transplant, 35% as compared with 15% in the control (Elhasid et al 259).

Neurocognitive and academic effects from childhood cancer are one of the most prominent consequences, effecting 40-100% of long-term survivors of CNS tumors (Mahajan and Jenney 272). Neuropsychological difficulties include difficulties with higher conceptual abilities, memory functioning, visual-motor functioning, visuographic abilities, and fine motor skills, as well as signs of ADHD, distractibility, impulsivity, and concentration problems. The most commonly used psychological index of neurological damage is the IQ score displayed by survivors (MacDougal 5). In Mulhern’s experiment comparing the neuropsychological status of survivors, it was found that children treated for ALL had significantly lower mean IQ, poorer performance of visual and auditory memory, lower achievement in arithmetic, and greater frequency of special education interventions (Mulhern 107). Even though survivors of ALL have significant damage, patients treated for malignant brain tumors tend to have a greater number of potential sources of brain insult, more severe overall impairment as measured by IQ loss, and a greater number of specific neuropsychological deficits (Mulhern et al 32). Age is also a factor in cognitive effects. A study by Smedler shows that twelve to seventeen age group had normal neurodevelopment while the three to eleven age group had slight difficulties especially in perceptual and fine motor skills and in the less than three age group, clear delays in sensorimotor development were found (12). According to Jannoun and Bloom’s (1990) study on age of patients and ultimate IQ, they show that five years and
younger had the greatest risk, six to eleven ages had intermediate risk, and eleven years and older were normal (27). These findings of decreasing in IQ and performance are proposed by Mulhern and Palmer to be a secondary effect resulting from changes in the children's ability to attend to and process new information. Through studies of children with medulloblastoma, it has been shown that the decrease of function is not due to the loss of information from missing it during hospitalization; rather, it is the failure to acquire new info once they are done with treatment (Kadan 41). As many studies show, childhood cancer survivors tend to show greater impairments in speed of info processing, and they have lower scores when measured for attention and concentration. Brouwers and Poplack (1990) asserted that attentional deficits play a central role in encoding of memory and learning deficits. From this study, it is concluded that attentional deficits are a major factor in the learning impairments and intellectual decline in ALL patients (Powers 312). With these neuropsychological deficits combined, these impairments can create serious problems in a classroom setting.

While most survivors do well academically, some do not. Kazak et al (1994) report that 25% of their sample of long-term cancer survivors received special school services related to learning problems (MacDougal 6). There are numerous long-term effects on preschool/early school age children. The most crucial impairments at this age are related to language and motor skill development. Fundamental reading skills, writing, and arithmetic are also vital to long-term academic success (Giammona 1071). In a childhood cancer survivor study, it is shown that, compared to siblings, survivors of CNS tumors and leukemia have the greatest educational differences and are significantly less likely to finish high school (Kadan 41). Difficulties in school can be seen through
many different behaviors ranging from difficulties in learning the alphabet, recalling
reading materials, memorizing math facts, poor reading comprehension, forgetting
directions for assignments, to relating an incident that occurred on the playground
(Powers 318). Greenberg and Meadows showed the psychological effects impair
academic functioning. They reported a significant association between fewer academic
functioning, physical impairments and lower levels of distress in a group of cancer
survivors in the first few years following completion of treatment (Majahan and Jenney
269). These numerous difficulties in the school life of childhood cancer survivors
suggest a need for ongoing monitoring and appropriate intervention for any problems that
appear.

Once childhood cancer fighters become survivors, they have to reenter the world
and as joyous as this thought may seem, sometimes it is dampened by psychosocial late­
effects acquired during their experience. Anxiety is probably one of the first and
common response to the uncertainty of cancer diagnosis and prognosis, as well as to
various aspects of treatment. The recurrent body intrusions, pain, and hospitalizations, are
particularly difficult for younger children, who sometimes can not grasp why treatment is
necessary. Even though the anxiety usually never reaches the psychiatric level, the
response can reach the level of a phobic anxiety disorder for some children and
adolescents. Sometimes the children’s anxiety can lead to conditioned responses to
aversive aspects of treatment, but they are not limited to anxiety symptoms. There have
been numerous clinical reports of conditioned nausea in response to certain foods, which
had become associated with chemotherapy. Some children also exhibit anticipatory
anxiety where the children vomit in the car on the way to and from the clinic for
treatment. These symptoms need to be evaluated and intervention set because they are distressing to everyone involved (Stuber and Seacord 213). Other than anxiety, other psychosocial difficulties the children face are dealing with society. Sometimes the children have trouble responding appropriately to social cues. This difficulty is believed to occur because cognitive impairments have caused the children to have problems understanding how to react. Difficulties in verbal fluency and lower IQ are significantly related to difficulties with attention, inhibition, and social functioning (Rourke 299).

Koocher and O'Malley (1981) reported that half of survivors, although able to lead somewhat normal lives, experienced psychological problems with anxiety and interpersonal relationship difficulties (Mahajan and Jenney 271). This study shows that childhood cancer survivors have more difficulty in having close friendships and romantic relationships, and this has been confirmed by other studies as well. These results make it easy to see why survivors, overall, are rated as more socially isolated and having few best friends than other children. Consequently, these children participate in fewer than half as many normative peer related activities (Rourke 299). Specifically, studies of children with brain tumors identify difficulties in social competence and communication with peers (Mahajan and Jenney 269), while Celli et al showed that nearly one-third of the sample of childhood Hodgkin's disease survivors were maladjusted in social incompetence and poor interpersonal relationships, and a more recent study of adult survivors of childhood ALL and Wilms' tumor showed that they had significant long-term problems with interpersonal functioning and day-to-day coping (271). In regard to survivor's relationships, 32% reported being married, 6% being divorced or separated, 62% having never been married. This is much lower than general population and
survivors of CNS tumors were even less likely to be married (272).

Adolescent cancer survivors have to cope with fear of relapse, insecurity of the future, damage to self-esteem, loss of autonomy, and sometimes distorted appearance and body image; therefore, it is not surprising that normal progression through adolescence is difficult (269). A study was done specifically to evaluate the behavioral reputation and social acceptance of BMT survivors. The findings showed that they had fewer friends and were described as more socially isolated by their peers. They were also described as physically less attractive and less skilled in sports, which showed that they lack things that are considered socially desired (Elhasid et al. 256). Survivors also tend to feel that their bodies and own self are fragile in such a way that they have to stick to the safety of their family resulting in loneliness (Oppenheim 117). In general, a poor body image is associated with self rankings of academic, social and psychological impairment, low self-esteem, and symptoms of depression. A study showed that the more the subject perceived that his or her appearance was affected by cancer, the worse he or she tended to rate social adjustment, which included feelings of loneliness and social anxiety (MacDougal 4). In infants, bonding is extremely important, but a long term issue faced by infants affected with cancer is a disruption in the early bonding with parents and family. This fact makes them at high risk to develop separation anxiety, which is defined as an excessive anxiety concerning separation from home or from those to whom the individual is attached. They are also bombarded with noises, bright lights, changing routines, and prolonged hospitalizations (Giammona 1067-68). These children may experience nightmares about separation from their parents and home, be terrified that something horrible will happen to them or a loved one as a result of the separation, and
experience physical symptoms such as headaches or nausea (Stuber and Seacord 214). It is important for the parents and family to bond with their child, develop age-appropriate boundaries, and help their child meet and cross developmental milestones (Giammona 1066). If the separation anxiety persists, then it is likely that these feelings will manifest into school phobia. Through school phobia the child may express somatic complaints, which the parent responds to and let the child stay home, and soon this pattern of getting away with missing school will become a cycle where the child ultimately refuses to attend any school (MacDougal 7). “It is possible that this prolonged absenteeism from the school coupled with deficiency in socially desirable characteristics may lay the groundwork for social difficulties that could impair the children’s social and emotional quality of life” (Elhasid et al 256). Reports from teachers and peers have confirmed this statement. When compared to their peers, children with cancer are perceived as being less sociable and more socially isolated and withdrawn. Survivors even reported having fewer friends, greater loneliness, and isolation, despite the fact that there were no significant differences in popularity, number of friends, or self worth (Mahajan and Jenney 268).

The degree of psychosocial deficit and social competence among survivors appears to be closely associated with status of the children, parental education, and family functioning. Following the end of therapy, the interactions of the children and family assume an important role. So much so that Kupst et al reported that positive association was made between the coping and adjustment in survivors and their mother’s adjustment (269). Another finding is that higher levels of family cohesion are related to better quality of life in survivors. Thus family connectedness has an extremely important
role in the prevention of stresses characteristic of the post-BMT period (Elhasid et al. 260). Other factors that have been found to be involved for better adjusted survivors are a resilient personality, emotionally adjusted parents who experienced marital satisfaction, and parents that were able to provide the children social support.

As seen from much research about the psychosocial effects, many of the childhood cancer survivors experience loneliness and feel like outsiders. These feelings subsequently lead to depression. About one-fourth of young adult survivors reported higher than average levels of psychological distress, with a concerning percent reporting thoughts of suicide. These high levels of psychological distress were not limited to the psychologically poor-functioning survivors, but were also seen in survivors with good overall functioning and high quality of life (Rourke 296). When looking at all survivors, intensive chemotherapy seems to relate to symptomatic somatic distress scores (Zebrack 47). Depression does not only have to be on a verbal level, there is also a nonverbal level that is seen in many childhood cancer patients. Nonverbal levels of depression include looking sad, crying even when staying still, and usually demonstrating withdrawal from playing activities with their favorite toys (Postovsky and Weyl Ben Arush 96). Researchers found that newly diagnosed children reported increased emotional distress such as anxiety or depression. Looking at a longitudinal study increased negative emotions such as anxiety, depression, insomnia or somatic and social dysfunctioning were seen shortly after diagnosis (Last and Grootenhuis 313-314). The characteristic pattern of depressed children over the age of five included decreased interest in enjoyable activities, fears of disease recurrence, emotional detachment from parents and friends, and difficulties in concentration, as well as eating difficulties and temper tantrums. The
characteristics for children under five years of age included lethargy, eating problems, and social difficulties, with a tendency for regression in self-help skills (Elhasid et al. 255). During treatment, it is extremely important for the parents to provide the emotional and physical needs of the children, despite how the parents, themselves, are feeling. In the preschool age children, if emotional and physical needs are not met, despair and hopelessness can result, which leads to anxiety and depression. School age children can also become withdrawn and isolated, and if left unattended, will lead to depressive symptoms (Giammona 1071). Sometimes characteristics of depressed children are confused with the normal actions and feelings as a result of the stress of treatment. To resolve any doubt about the children’s state, a brief trial with antidepressants helps clarify whether the children is actually suffering from depression (Postovsky and Weyl Ben Arush 97).

The effect of cancer treatment on the brain can also cause neurobehavioral problems. Neurobehavioral functioning is believed to be progressive with deficits becoming more pronounced as time after treatment increases (Kadan 43). Behavioral problems can also result in school age children because of their feelings of socially isolation, feeling inferior, and frustrations due to inability to perform work and play (Giammona 1072). Brouwers says that neurobehavioral outcomes may be influenced by a number of factors, which are divided into mediator and moderators. The moderators include age at insult, time since insult, age at testing, gender, and socioeconomic/family factors and affect the direction and strength of relation between the mediator and outcome. These moderators have been shown to affect neurobehavioral outcome after brain insult. Mediators are factors that specify how or by which mechanism an effect
occurs and are comprised of therapy exposures (Kadan 42). An example is a therapy exposure to BMT, which has been shown to cause an increase in behavioral problems. The findings show that 15% of children had these problems pre-BMT, but post-transplant 40% of children had problems. This rate is higher than the normal population, which is 15% (Elhasid et al. 255).

From the psychological late-effects already presented, it can be understood that it is relatively difficult to find a clear psychological diagnosis. An alternative to help in this situation is to view cancer as a traumatic event, which leads to post traumatic stress (Rourke 296). Symptoms of post-traumatic stress disorder (PTSD) have been observed in some children with cancer. A third of the adolescent survivors met criteria for the lifetime PTSD, which is greater than the population (Last and Grootenhuis 313). Since PTSD is, by definition, only diagnosable four weeks after the traumatic event, it could be argued that children and adolescents, who are on active treatment, could only be diagnosed with post-traumatic stress syndrome (PTSS), and not PTSD (Stuber and Seacord 214). Whichever one is used, they are both still associated with anxiety and psychological distress that may interfere with achievement of development milestones. Symptoms include anxiety, avoidance, depression, and recurrent nightmares. This reflects the perspective of the children towards the cancer and treatment. According to the diagnosis of PTSD, an event must be experienced as life-threatening, and produce a response of intense fear, helplessness, or horror to generate the full complex of symptoms of PTSD (214). There is research documentation of higher levels of PTSS and PTSD in cancer survivors. In one study 50% of adolescent survivors reported re-experiencing symptoms and 29% reported increased physiological responses when reminded of their
experience (Rourke 297). Self-reports from forty adolescents and young adults showed they had PTSS by documenting denial of distress, higher levels of intrusive memories, and avoidance (Stuber and Seacord 215). Yet another study showed that when three-hundred survivors, ages eight to twenty years, were compared to two-hundred-and-twenty children without significant medical history, over 10% of survivors reported moderate and approximately 3% reported severe PTSS related to the cancer and treatment experience (217). There were two predictors of PTSS found in a study examining one-hundred-and-eighty survivors: time since end of treatment and gender. Females reported more symptoms than males and symptoms appeared to decrease over time. From this study, participants that met criteria for PTSD reported higher appraisal of current life threat, had more intense treatment histories, and reported higher levels of psychological distress when compared to the non-PTSD survivors (218-219). In a more recent study of fifty survivors, 22% met criteria for PTSD. They also reported poorer quality of life, with the greatest differences reported in social functioning, emotional wellbeing, and none of them were married (219). Another factor that contributes to PTSS is facing medical late-effects or relapse. For young adult survivors, the ratings of medical late-effect severity were related to higher levels of PTS. These symptoms of PTSS can significantly impede development. For example, an adolescent who is very upset when reminded of her experience may feel uncomfortable socializing with friends or dating. PTSD appears to be even more prominent for childhood cancer survivors during young adult with 15-21% reporting PTSD. There are three types of PTS symptoms that tend to emerge in this age group: persistent re-experiencing of traumatic parts of cancer/survivorship, actual or considered avoidance of cancer or survivorship related
situations, and strong physiological responses when reminded about cancer. 75% of young adult survivors report re-experiences, nearly 50% reported increased physiological reactions, and 25% attempted to or want to avoid cancer-related topics (Rourke 297). From these findings it is shown that there is a necessity to recognize these symptoms and intervene as soon as possible so that there is no lasting effects to the children's social and neurological life.

Death is sadly one of the unfortunate outcomes for many of the children diagnosed with cancer. About 40% of children with cancer will die as a consequence of treatment complications of the cancer itself and more frequently occurs after medical treatments have been ineffective (Granowetter 17). Not only do these children have to deal with their own possible death but they also come to know children their own age who die during the years they are on active treatment (Stuber and Seacord 213). A widely known description of the development of awareness of death is offered by Bluebond-Langner (1978). Stage one is defined as "seriously ill" and is the children's experience of admission to the hospital, the ensuing medical treatments, and the changed caring attitude assumed toward them by the adults. The majority of their fears are of the unknown instead of the prognosis. The next stage is "seriously ill and will get better" where they experience a remission and rapid recoveries of cancer related symptoms. They begin feeling better and notice that people treat them in a normal way; therefore, they conclude they will eventually get better. Stage three is "always ill and will get better". In this stage the children have been through the relapse-remission cycle. They are afraid of recurrence, but believe they can fight the cancer. Stage four is the "always ill and will never get better" which sets in after more relapses, pain, and drug
complications. The children become aware that they are getting weaker, that they can only plan short terms, and start grieving about the things they will miss in the future. The last stage is the "dying" stage that usually follows a death of another child in the ward. They begin to compare their disease and treatments to the other child and realize that they themselves are dying. It is in this stage that they begin expressing their awareness of death verbally and symbolically. This new awareness may cause children to decrease communication with adults and by lowering cooperation with medical procedures that have not helped in the past (Kreitler and Krivoy 395). The children's ability to understand the concept of death and dying plays a role in treatment and varies depending on age and cognitive ability. By adolescences, children fully understand the concept of death including the inevitability and its permanent state. This enhances their fear and anxiety which leads to depression (Postovsky and Weyl Ben Arush 97). This description of steps is a slowly developing process that is fed by the children's personal experiences of cancer and by information from the adults. Throughout these processes, the children's bodies go through dramatic changes that lead to a loss of their own identity. They no longer recognize themselves, nor do they know who they are at the moment. These feelings bring about extreme loneliness and depression (Oppenheim 127). In a sense they are dying psychologically as well physically. The children lose interest in many things, give up plans for the future, do not look forward to holidays, and become absent and distant to loved ones. However, the children can be helped to overcome this dreadful situation by discussions and explanations of death without terrifying descriptions. The explanations should focus on the children's personal issue and should be an ongoing process (Powers 323). This helps the children continue to have faith in themselves,
parents, and caregivers, and they know that their life has been worth living, that their parents do not regret their birth, that they will not be left alone facing death, nor be forgotten if death does eventually and unfortunately take place (Oppenheim 128). If these explanations are brief and treated adequately, the children are less terrified by the idea of their own possible death.

It is important to recognize that to minimize the incidence of psychological maladjustment in the long term, constant efforts must be made to reduce the incidence of medical and cognitive problems. One way to attempt to minimize neuropsychological impairment impact is by direct intervention with cognitive rehabilitation, pharmacotherapy, and/or through indirect approaches involving manipulations of the patient’s environment. Cognitive rehabilitation is a term that describes interventions that intend to restore the lost cognitive functions or to teach the patient skills to compensate for the unrecoverable losses. There is only one program in the USA that has a system of cognitive rehabilitation for ALL and brain tumor survivors funded by the National Cancer Institute (Mulhern et al. 33). Some researchers feel that a combination of psychological and pharmacological interventions is the best approach. A study done by Kazak showed that the addition of psychological intervention made a significant difference in decreasing the children’s procedural distress. Some of these treatments are filmed modeling, breathing exercises, imagery/distraction, incentives, rehearsal, and therapists coaching during medical treatments. This kind of treatment is called cognitive-behavioral and results in less child distress during the procedure and effective in reducing PTS. Hypnosis is another technique that has been extremely effective in reducing the child’s distress (Stuber and Seacord 221). One of the most frequently used intervention
is the elimination of CRT, delay of CRT until the patient is older, or lower CRT dose and volume to spare more normal brain function (Mulhern et al 33). This has made possible by systemic chemotherapy and has been shown to make profound improvements in quality of life for survivors without reduction in survival rates (Mahajan and Jenney 274).

Since there are many neurological late-effects, childhood cancer survivors have difficulties when it comes to their academics. Returning to school can be a difficult time for children, but there are early indications that this can be eased with intervention. A proportion of survivors are likely to have some neurocognitive impairments. It is essential that these are recognized and addressed within both the medical and educational systems for the children (275) especially since 75% of survivors reported that their education suffered as a result of their illness (Tadmor and Weyl Ben Arush 417). The objectives of most intervention programs are to open channels of communication between the child, parents, hospital staff, school personnel and peers; to safeguard academic progress and peer relations; to facilitate a smooth return to school; and to prevent delayed psychosocial difficulties (423). Cognitive strategies stress the importance of knowing what to do and when to do it. This may include verbal self-instruction, problem-solving steps, rewards, and modeling (Powers 318). Interventions for attention difficulties often focus on avoiding distractions and imposing structure on the learning task and academic environment. Memory impairments may be due to the inattentiveness, but can be remediated by teaching mnemonic strategies that can be verbal, visual, or associative. Other programs have been directed more specifically at helping children with cancer acquire the social skills to cope with school life. Peer support is consistently and significantly associated with psychological adjustment measures at a greater magnitude
than other perceived social support domains. Peer support also helps with return to school (Tadmor and Weyl Ben Arush 420). Maintaining friendships and engaging in routine interactions with peers is essential to normal psychological development (Powers 318-319). The higher perceived classmate social support predicted lower depression symptoms, lower anxiety, lower social anxiety, and lower internalizing and externalizing behavioral problems (Stuber and Seacord 222). It is shown that returning to a normal routine as soon after diagnosis as possible is crucial for children, because it has a significant effect on the children’s general adjustment and self-esteem. Parents not only facilitate a return to the normal routine, but they also show the child that they have an optimistic expectation that the child will survive. The teacher also has a very important role in the transition. In cases where neurological and psychological deficits could impair the children’s ability to function in a classroom environment, routine communication between the cancer treatment center and the patient’s school should be the standard of care (Mulhern et al 34). They should be aware of the psychological effects of cancer and be prepared to deal with issues such as anxiety, behavior problems, emotional difficulties, peer relationship difficulties, and frustration related to school difficulties (MacDougal 6-7). These are preventive interventions and should be introduced as soon as the children are diagnosed. Without intervention, these issues may have negative, long-lasting effects; therefore, it is crucial that an intervention plan to reintegrate the children into school involves the family, peers, the teachers, and the school psychologist (10).

The coping process is extremely important for the children and parents of children with cancer. The way survivors of childhood cancer cope with their disease, experience, and late-effects, greatly affect their psychosocial lives. A popular intervention is to use
the cognitive-behavioral approach, because if there is an understanding about the reasons behind the actions the children are portraying, then there are ways for them to adjust. This discussion is provided by Last and Grootenhuis (315-323). People evaluate events in their life through cognitive appraisal. The components, which are important to the appraisal of the situation for children with cancer and their parents, are uncertainty, uncontrollability of the situation, responsibility, the restriction of freedom, and the long duration of the situation. Indications pointing to a remission of the disease contribute to a feeling of hope and trust, while indications of a relapse or recurrence of the disease evoke feelings of fear that all efforts will be unsuccessful. Feelings of uncertainty about the future and fear of a relapse are often reported by parents of children with cancer. Also, after diagnosed with cancer determination of the controllability of the situation determines whether individuals feel insecure or confident. There is a sense of uncontrollability over the situations about to come, which evokes feelings of helplessness. Children and parents cannot influence the disease or the treatment process. The children have to undergo many painful medical procedures while parents stand by helplessly. In reaction, children can easily develop avoidant and/or resistant behavior. Long duration of the threatening situation is associated with feelings of exhaustion and depression if the children or parents do not perceive an end to the suffering.

Cognitive appraisal and reappraisal is the first stage in coping. How a person deals with a stressful situation is called coping. One’s perceptions, or cognitive appraisals, are important elements in regulating distress, emotion-focused coping, or managing the problem causing the distress, problem-focused coping. Problem-focused coping involves direct efforts to reorganize the problem causing the distress whereas
emotion-focused coping is directed towards regulating affects surrounding a stressful experience. People do not only have emotions, they also handle them. Regulations refer to all methods that have the function of modifying other processes induced by a given stimulus situation. Parents of children with cancer have few possibilities to regulate events, but they have the ability to regulate appraisal. The appraisal of a situation can be regulated by selective attentive and self-serving cognitive activities. One of the best known appraisal regulations is the use of denial. Individuals facing a life-threatening illness often go through a phase of denial. Another area which has received attention in the research on coping with cancer is the importance of turning to others or social support. Social support affects coping in several ways. Social resources can reinterpret the meaning of the situation so it seems less threatening, or it may influence the use of other coping strategies.

There are four types of control strategies that can describe the reactions of children with cancer and their parents: predictive, vicarious, illusory, and interpretative. Strategies of primary predictive control are gaining knowledge about the expected course of the disease and of the side effects of treatment. In predicting events, a feeling of control over the situation is created. Secondary predictive control is used in attempt by children or parents to predict events to avoid disappointments. Most striking in this way of coping are parents who react with "anticipatory mourning" while the treatment of their child is still curative. They feel they are preventing feelings of shock and pain from an unexpected death by acting this way. Secondary predictive control can manifest itself in two ways. On one hand, parents can protect themselves against disappointments by expecting the worst, but on the other hand, they can also protect themselves by having
positive expectations. By living optimistically children and parents may try to control their emotion. This manifestation of secondary predictive control can also be considered as forms of healthy denial or attempts to interrupt the situation in a positive light. A study found that persistent hopefulness proved to be the major predictor of positive emotional outcome for parents of children with cancer.

Vicarious control can be exercised through its primary form by trying to imitate or manipulate powerful people in their lives or through its secondary form by attempts to associate with them. Children with cancer and their parents are highly dependent on doctors. Their attempts to influence the doctor's choices can especially be seen when treatment is not successful. Parents may try to convince the doctor not to terminate treatment and even to use experimental therapies to avoid an inevitable death. The secondary form is demonstrated by attributing special power to the doctor. In this case, a sense of control is derived from the perception that the medical caregivers can exert control.

Illusory control is used to attempt to influence chance-determined outcomes or as a secondary process, to associate with chance. Attempts to influence the chance-determined outcome of the illness can be sought in changes in lifestyle, eating habits, or alternative healthcare. These actions offer children and parents the possibility to do something themselves, and thus promote a sense of control. Secondary illusory control is present in children and parents when they take the side of fate, admitting that fate is more powerful, but create the illusion that fate will be kind to them. Examples are hoping for a miracle, wishful thinking, or attributing special characteristics to the child as proof that the child is one of the survivors.
Primary interpretative control is focused on understanding problems so that the parents and children are able to solve them. Gaining information about the disease and the different treatments is often seen in children and parents and is very obvious around the time of the diagnosis. Research confirms that a majority of older children prefer to be informed about their disease and treatment. Secondary interpretative control refers to the search for meaning and understanding. Finding an answer to questions like “what caused cancer in my child?” and “why did this happen to me?” serves the process of acceptance and helps children and parents to find meaning in the cancer experience.

In the behavioral approach all behavior is conceived as learned stimulus-response relationships. The process of learning is governed by principles of classic conditioning, operant conditioning, and imitation. The use of these learning principles underlying the behavioral approach has shown to be beneficial to children with cancer, particularly in handling anxiety and pain provoking treatment procedures. Some of the major techniques used are: Pre-exposure, which helps children from aversive conditioning, Positive Reinforcement, where cooperative behavior is encouraged, Breathing and Relaxation Exercises, and Systemic Desensitization, which is a step by step exposure for children who have developed extreme avoidant behaviors. Besides improvements in using anesthetics and nausea reducing drugs, the application of behavior therapeutic techniques remains important in many cases.

As the cognitive-behavioral model shows, children and parents use the various control strategies to cope with stressful situations. Psychosocial intervention is indicated if control fails and subsequently, children and/or parents need support in rebuilding their defenses or to reduce or eliminate unpleasant behavioral reactions. This intervention
emphasizes the importance of the characteristics of the situation, the main primary and secondary control strategies, and the history of learned behavioral reactions. These aspects are involved in analyzing the emotional and behavioral reactions of children with cancer and their parents.

Another approach is group therapy. These therapies have been useful when targeted towards the impact of social isolation, dependency, and the cosmetic and social effects of treatment. Groups provide opportunities for identifying common problems and reality testing about the types of problem experienced with others who have had similar experiences. Mutual problem solving and the creation of a temporary support system are the strategies that appear to be effective. The typical group sessions focus on the developmental tasks of adolescence and the impact of the illness upon achieving individuality. Groups discuss a wide variety of topics, including the impact of the illness upon serious relationships, how to cope with physical appearance issues, conflicts with others, and concerns about the future. However, the most successful groups occur within the context of a social event, such as a pizza party or camp. The uniting issue for all is cancer. Yet, they are not brought together just to talk about cancer, which many view as unappealing, but to have fun. Cancer camps allow children who would not otherwise be able to get away from their parents to go to a safe place, and do “normal” things such as swim. They are also among others who have had similar experiences, so it becomes easy to go without a cover on a bald head or to remove a prosthetic limb (Stuber and Seacord 222).

To be diagnosed with cancer is a traumatizing experience for everyone. For the unfortunate children that are forced to suffer through this difficult journey, there are life
long reminders that are with them every single day. From neurological deficits to psychosocial problems to educational difficulties, some children have an uphill battle even after they are through with their treatment. Even though many of childhood cancer survivors are fortunate enough to live normal lives after the eradication of their disease, there are quite a few that continue to deal with psychological problems. It is necessary for the medical staff, doctors and nurses alike, the parents, teachers, and peers to help the children in their return to normal life and as long as needed after treatment is over. There are some wonderful interventions that are helping these children have an easier transition, but there needs to be more ways found. As more children survive cancer, awareness and research is finding new and innovative ways to help. One day these children will not have to suffer with late-effects, but until that day comes, we need to do the best we can in helping them on their way to recovery.


References


