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## The Effects of Childhood Cancer

Kenny Tiffany Grand Valley State University

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#### Introduction

In 2007 there were 10,400 children under the age of 15 diagnosed with cancer. In fact, pediatric cancer is the highest cause of death by disease in children under 15 (National Cancer Institute, 2012). However, the survival rate from cancer has increased drastically over the years. In the 1960s the survival rate was at only 25%, now recently in 2010, the survival rate was close to 80% (Griffiths, Schweitzer, & Yates, 2011; Quillen, Crawford, Plummer, Bradley, & Glidden, 2011). Due the drastic decrease of children dying from cancer there are many more childhood cancer survivors.

Unfortunately childhood cancer survivors are not completely safe from further complications after treatment. There are many physical effects from cancer treatment, both acute and long term effects. There are a variety of physical effects than can affect childhood cancer patients based on what treatments the child is receiving and where the patient is receiving the treatments. Along with physical effects many childhood cancer patients also suffer psychological.

Studies show that childhood cancer survivors are at a much higher risk of neurocognitive impairments, neuropsychological problems, social withdrawal and many other psychosocial problems. Parents with children with cancer also are shown to have a decrease in mental health due to stress and burdens. The treatment itself is known to contribute to most of these problems. Some of the problems childhood cancer survivors face do not appear for a few years after their treatment is over, so knowledge of the risks is important be aware of, in order to prevent future problems. Acute Lymphoblastic Leukemia (ALL) is the most common type of childhood cancer followed by other types of leukemia and brain tumors. More than half of children diagnosed with

cancer have leukemia or a type of brain tumor (Herrmann, Thurber, Miles, & Gilbert, 2011). So, the focus will be mostly on ALL, other leukemias and brain tumors.

Unfortunately, through the treatment process and following treatment, childhood cancer can have an effect not only on the patient. The family can be significantly affected as well. Childhood cancer can affect the family system, the parents' marital relationship, as well as the family members individually. They can suffer psychologically, financially, emotionally, and even physically. This paper will discuss the many different effects to the patient as well as the family. In addition, some interventions will be discussed that have been found beneficial in helping avoiding possible effects as well as dealing with the effects.

## **Physical Effects**

There are many late effects of childhood cancer treatments. These effects include secondary malignant neoplasms as well as many non-malignant effects to the body. Most of the effects are directly proportional to the amount of dose the patient receives during their treatments. The higher the dose the patient receives, the higher the risk of acquiring a late effect. In a recent study among 10,397 survivors between the ages of 18-48, 62.3% had at least one chronic condition and 27.5% had a life threatening condition. The survivors that received their diagnoses at an older age were more likely to have a serious health condition (Kolb, 2009). This study is also supported by the Institute of Medicine, which reported in 2003 that as many as 2/3 of childhood cancer survivors will experience some type of late effect, with 1/4 experiencing a severe or life threatening effect (McNeil, 2006).

Incidence of cancer in children under the age of 15 has been increasing by approximately 1% each year, while the cure rate has been increasing by 1.4% each year (Ward, 2000). Due to the increased amount of childhood cancer survivors, it is expected that 1 in 450 will be long-term

cancer survivors in the near future. In 2007, 1 in 640 between the ages of 20 and 39 were childhood cancer survivors (Dickerman, 2007).

Thanks to large databases of late effects, it is been made possible to figure out what doses of which treatments affect which patients. From these databases, as well as other studies, I have put together a brief description of the most common late effects from childhood cancer treatments. These late effects include secondary cancers, cardiovascular disease, growth retardation, neurocognitive problems and many more.

## **Secondary Neoplasms**

After being diagnosed with cancer during childhood the risk of developing a second cancer increases three- to sixfold, increasing as the childhood cancer survivors get older (Bhatia & Landier, 2005; Ward, 2000). Three to twelve percent will most likely develop a secondary cancer within the first 20 years following their primary cancer treatments (Ward, 2000). The type of secondary cancer and the risk depends on what cancer the patient was diagnosed with first, the type of therapy used, and genetic conditions (Bhatia & Landier, 2005; Ward, 2000). Childhood cancer survivors of Hodgkin's disease or acute lymphoblastic leukemia (ALL) are at a higher risk for secondary cancers (Ward, 2000). The most common secondary malignancies are breast cancers, bone cancers, thyroid cancers, therapy-related myelodysplasia, and acute myeloid leukemia (AML). Most frequently, the younger the child is when treated for their primary cancer, the higher the risk of a second cancer. However, the opposite is true for myelodysplasia and AML, the older the child is when treated, the higher the risk. The female sex has a higher risk for secondary cancers due to the higher incidence of breast and thyroid cancer in females (Bhatia & Landier, 2005).

In terms of radiation, the risk for developing cancer due to radiation is greatest at a younger age and a higher dose. Cancer usually develops in the treatment field used during radiation therapy for the primary cancer. Some common tumors associated with radiation are breast, lung, thyroid, brain and osteosarcoma (Bhatia & Landier, 2005). Radiation induced leukemia has a latent period of 7 years, while radiation induced solid tumors have a 10-15 year latent period (Ward, 2000). In terms of chemotherapy, alkylating agents are associated with myelodysplasia and AML (Bhatia & Landier, 2005).

Now let us get into the specifics. Secondary skin cancers are most likely the result of a decrease in immunosurveillance, as a result of radiation and chemotherapy along with sun exposure. Thyroid cancer is caused by radiation to the head, neck, or thorax. The risk of developing a secondary thyroid cancer is highest at 20-29 Gy. Above 30 Gy the incidence starts to decrease, most likely due to the killing effect of the radiation. Also, children younger than 10 years of age have a much higher risk of developing a secondary thyroid cancer as a result of an increased susceptibility of the thyroid at a younger age (Dickerman, 2007).

It has been found that when children receive thoracic radiation for cancer treatment, particularly for Hodgkin's disease, there is a significant risk for developing breast cancer later in life. With each Gy of radiation absorbed into any breast the excess relative risk of breast cancer increases by 0.13. Thankfully, it has also been found that there is no elevation in risk when the dose is less than 26 Gy and no more than 26 Gy is normally used (Dickerman, 2007).

Secondary leukemias have most often been found to be caused by alkylating agents in chemotherapy. Sarcomas of the bone or connective tissue are more common after radiation therapy, especially combined with the use of alkylating agents. The risk of developing brain tumors from cranial radiation is highest when the patient is younger, but the secondary malignant neoplasm does not usually appear for 9 to 10 years after treatment for the child's primary cancer (Dickerman, 2007).

Secondary malignant neoplasms are only a small portion of the late effects from cancer treatment for childhood cancer survivors. Table 1 gives a nice visualization of possible late effects than can occur after receiving certain treatments. In addition to the secondary malignant neoplasms there are also many non-malignant late effects. Late effects from cancer treatments can show up in any region. This depends on where the patient is treated and how the patient is treated, along with

| Type of Treatment          | Late Effect(s)                       |
|----------------------------|--------------------------------------|
| Radiation therapy          |                                      |
| Cranial radiation          | CNS                                  |
|                            | Neurocognitive defects               |
|                            | Panhypopituitarism                   |
|                            | Seizures<br>Strokes                  |
|                            | Strokes<br>Brain cancer              |
|                            | Growth and development               |
|                            | Obesity                              |
|                            | Short stature                        |
|                            | Teeth and gums                       |
|                            | Defective dentition                  |
|                            | Increased caries                     |
|                            | Root abnormalities                   |
|                            | Periodontal disease                  |
|                            | Eye                                  |
|                            | Cataracts<br>Keratoconjunctivitis    |
|                            | Thyroid                              |
|                            | Hypothyroidism                       |
|                            | Hyperthyroidism                      |
|                            | Cancer                               |
| Thoracic radiation         | Heart                                |
|                            | Coronary artery disease              |
|                            | Valvular disease                     |
|                            | Pericardial disease                  |
|                            | Arrhythmias                          |
|                            | Lung<br>Fibrosis                     |
|                            | Restrictive-obstructive lung disease |
|                            | Interstitial pneumonitis             |
|                            | Cancer                               |
|                            | Thyroid                              |
|                            | Hypothyroidism                       |
|                            | Hyperthyroidism                      |
|                            | Cancer<br>Skeletal                   |
|                            | Abnormal chest wall development      |
|                            | Breast                               |
|                            | Cancer                               |
| Abdominal/pelvic radiation | Gastrointestinal tract               |
|                            | Gastrointestinal obstruction         |
|                            | Cancer                               |
|                            | Spleen<br>Asplenia                   |
|                            | Kidney                               |
|                            | Nephropathy                          |
|                            | Cancer                               |
|                            | Bladder                              |
|                            | Fibrosis                             |
|                            | Cystitis                             |
|                            | Dysfunctional voiding<br>Cancer      |
|                            | Gonads                               |
|                            | Ovarian failure                      |
|                            | Testicular failure                   |
|                            | Cancer                               |
|                            | Muscle                               |
|                            | Atrophy                              |
|                            | Cancer (sarcoma)<br>Skeletal         |
|                            | Osteopenia                           |
|                            | Osteoporosis                         |
|                            |                                      |

Table 1. Select late effects from radiation therapy and chemotherapy. (Dickerman, 2005)

| Type of Treatment                     | Late Effect(s)   |
|---------------------------------------|--|
|                                       | Avascular necrosis   |
|                                       | Spinal deformities   |
|                                       | Cancer (sarcoma)   |
| Any radiation                         | Skin   |
|                                       | Melanotic nevi   |
|                                       | Nonmelanotic skin cancer   |
|                                       | Melanoma   |
| Chemotherapy                          |  |
| Alkylating agents                     | Gonads   |
| Nitrosourea                           | Infertility  |
| Dacarbazine                           | Hypogonadism   |
| Cytarabine                            | Bone marrow  |
| Cyclophosphamide                      | t-AML/MDS  |
| lfosfamide                            | Bone   |
| Chlorambucil                          | Cancer<br>Bladder  |
| Carmustine<br>Lomustine               |  |
| Thiotepa                              | Cystitis (cyclophosphamide, ifosfamide)<br>Fibrosis (cyclophosphamide, ifosfamide) |
| Procarbazine                          | Dysfunctional voiding (cyclophosphamide)   |
| Procarbazine                          | ifosfamide)  |
| Melphalan                             | Cancer   |
| Busulfan                              | Lungs  |
| basailari                             | Fibrosis (carmustine, lomustine, busulfan,   |
|                                       | cyclophosphamide)  |
|                                       | Kidney   |
|                                       | Nephrotoxicity (ifosfamide)  |
|                                       | Eye  |
|                                       | Cataracts (busulfan)   |
| Cisplatin                             | Ear  |
|                                       | Sensorineural high-frequency hearing loss  |
|                                       | (exacerbated by ifosfamide and cranial   |
|                                       | radiation)   |
|                                       | Kidney   |
|                                       | Nephropathy  |
|                                       | CNS  |
|                                       | Neuropathy   |
| Methotrexate                          | Liver  |
|                                       | Cirrhosis  |
|                                       | Skeletal   |
|                                       | Osteoporosis   |
| 6-Mercaptopurine                      | Liver  |
| araapsapatiita                        | Cirrhosis  |
| Vincristine                           | CNS  |
| · · · · · · · · · · · · · · · · · · · | Neuropathy   |
| Anthracyclines                        | Heart  |
| Doxorubicin                           | Left ventricular dysfunction   |
| Daunorubicin                          | -  |
| Idarubicin                            | Cardiomyopathy   |
|                                       | Arrhythmias  |
| Epirubicin<br>Mitaurataan             | Bone Marrow  |
| Mitoxantrone                          | Leukemia (?)   |
| Bleomycin                             | Lung   |
|                                       | Fibrosis   |
| C                                     | Interstitial pneumonitis   |
| Corticosteroids                       | Eye  |
|                                       | Cataracts  |
|                                       | Skeletal   |
|                                       | Osteopenia   |
|                                       | Osteoporosis   |
| Topoisomerase 2 inhibitors            | Bone Marrow  |
| (etoposide, teniposide)               |  |
|                                       |  |

Table 1. Select late effects from radiation therapy and chemotherapy (continued). (Dickerman, 2005)

other factors, like age or genetic factors. Just like secondary cancers.

#### Neurocognitive

Later after childhood cancer patients receive their cancer treatments, cognitive and neurological problems can develop. This is most often the result of whole brain irradiation or chemotherapeutic agents such as high-dose methotrexate, cytarabine, or intrathecal methotrexate. Children with primary cancers such as brain tumors, ALL, or non-Hodgkin's lymphoma are most likely to have a late cognitive or neurological effect (Bhatia & Landier, 2005). Other risk factors include younger age, higher dose, being treated with radiation combined with chemo, and being female. The reason females are at a higher risk is because the female brain develops rapidly during early childhood, so they are at a greater risk for a drop in IQ when treated with cranial radiation at a young age. Children that experience neurocognitive late effects tend to have problems with receptive and expressive language, attentional concentration, and visual and perceptual motor skills. This is usually not experienced until 3

or more years after treatment (Bhatia & Landier, 2005; Dickerman, 2007; Ward, 2000).

Cognitive impairments are thought to be caused by vascular and biochemical changes that are caused by radiation therapy and chemotherapy, however other factors, like social factors, may also contribute (Ward, 2000). Radiation or chemo-induced destruction of white matter and atrophy may be the explanation for intellectual and academic achievement deficits. Many commonly experience reading, language and math difficulties and some may experience drops in their IQ. Reading and math performance is often 2 grade levels below normal (Bhatia & Landier, 2005; Ward, 2000). Other effects may include psychological maladjustment, moodiness, behavior problems, somatic distress, unemployment, and post-traumatic stress disorder (PTSD) (Dickerman, 2007).

#### Cardiovascular

Cardiovascular function can also affected by childhood cancer treatments. Chronic cardiotoxicity most often appears as cardiomyopathy, pericarditis, and/or congestive heart failure (Bhatia & Landier, 2005; Ward, 2000; Dickerman, 2007). Anthracyclines are known to cause the death of myocytes, which is the cause of late cardiovascular problem (Bhatia & Landier, 2005; Ward, 2000). A Children's Cancer Survivorship Study by Dr. Aplenc showed that variations in genes that control the metabolism of anthracyclines and others that control the elimination of oxygen free radicals were associated with higher risks of congestive heart failure when treated with anthracyclines (McNeil, 2006). Unfortunately, around 60% of pediatric patients are treated with anthracyclines (Dickerman, 2007). These late effects often show up much later during pregnancy, during exertion such as weight lifting, or randomly (Bhatia & Landier, 2005; Ward, 2000). Receiving radiation to the heart can often cause coronary artery disease, left ventricular

dysfunction, pericarditis, and thickened or leaking valves (Ward, 2000; Dickerman, 2007). This is why the heart is always avoided as best they can when planning radiation treatments.

## **Pulmonary**

The lungs are another critical structure that is avoided as much as possible. Lung tissue is fairly radiosensitive. Pulmonary fibrosis with loss of lung volume, inflammation of the lung tissue, and delayed interstitial pneumonia is often caused by radiation to the lungs (Bhatia & Landier, 2005; Ward, 2000; Dickerman, 2007). Five to fifteen percent of patients who receive 30 Gy of fractionation to more than half of the lung present with inflammation of the lung tissue with cough, fever, or shortness of breath (Bhatia & Landier, 2005). Radiation can also cause incomplete development of the lung (Ward, 2000). Thoracic radiation combined with chemotherapy agents can cause lung inflammation at low doses and also increase risk for pulmonary disease in long-term survivors of childhood cancer (Bhatia & Landier, 2005; Dickerman, 2007). Other risk factors may include having an established infection, having an underlying lung disease (e.g. asthma), smoking, respiratory toxicity, chronic graft-versus-host disease and reaction to a tumor (Bhatia & Landier, 2005).

#### Musculoskeletal

There are many childhood cancer survivors that report musculoskeletal and other related issues. One-third report disabilities involving bone, teeth, muscle, and other soft tissues (Bhatia & Landier, 2005). Bony abnormalities include scoliosis, atrophy or hyperplasia, bone cell death due to lack of blood supply, osteopenia and osteoporosis. Bone density often is decreased in younger patients and especially in ALL patients (Bhatia & Landier, 2005; Dickerman, 2007). Avascular necrosis (AVN), bone cell death due to lack of blood supply, most often occurs in the femoral heads during treatment, however the latent period can be as long as 13 years (Bhatia &

Landier, 2005). Skeletal problems are most often caused by radiation to the bone or cranium, steroids, and chemotherapy agents such as cyclophosphamide and ifosfamide. These chemo agents cause gonadal damage resulting in ovarian and/or leydig cell dysfunction with loss of bone mass (Dickerman, 2007). Delayed tooth development has been seen when children receive at least 18 Gy of cranial radiation, while chemo has been seen to cause cavities and gingivitis (Bhatia & Landier, 2005).

## **Growth and Development**

In relation to skeletal problems, other late effects from childhood cancer treatment are growth and other developmental problems. Cranial radiation in ALL patients can cause short stature (Dickerman, 2007). Short stature is more often a late effect in females. Short stature can also be caused by tumor location, surgery, spinal radiation, malnutrition, corticosteroids, or radiation damage to the hypothalamic-pituitary axis (Ward, 2000). Following 30 Gy or more to the hypothalamus or pituitary gland, severe growth retardation has been found in more than 50% of pediatric patients with brain tumors. Severe growth retardation, when the height is less than the fifth percentile, has been found to affect as many as 30-35% of survivors of childhood brain tumors and in 10-15% with anti-leukemia regimens (Bhatia & Landier, 2005).

An increased risk of being obese has been observed in many childhood cancer survivors. A genetic change in the leptin receiver gene is associated with an increased risk of obesity among childhood ALL survivors, especially among those who received radiation to the cranium (McNeil, 2006). Ranging from 16-56% of ALL survivors experience obesity caused by cranial radiation, steroid therapy, along with physical inactivity and increased eating (Dickerman, 2007).

## **Gastrointestinal and Hepatic**

Childhood cancer survivors that were treated with abdominal radiation therapy frequently suffer from fibrosis and enteritis. These are associated with obstruction, ulcers, and malabsorption syndromes (Bhatia & Landier, 2005; Ward, 2000; Dickerman, 2007). The majority of effects to the liver is reversible and resolve after therapy, so there are not many late effects of the liver. However, low dose chemotherapy over a long period of time has a greater risk of liver damage in comparison to intermittent high dose chemotherapy (Ward, 2000). The chemo agents that are most often linked to liver damage are methotrexate and 6-mercaptocurine (Dickerman, 2007). Patients treated with a hepatectomy, methotrexate or radiation therapy to the liver should be warned about high risk behaviors such as excessive alcohol (Bhatia & Landier, 2005).

## **Renal and Urologic**

Radiation or chemotherapy agents, like ifosfamid, have been associated with kidney damage as well as bladder damage. Radiation to the kidney may sometimes lead to inflammation of the kidney or glomerular and/or tubular damage (Ward, 2000; Dickerman, 2007). In addition, cyclophosphamide has also been associated with bladder damage. In relation to the bladder; hematuria, cystitis, fibrosis, and an inability to completely empty the bladder, are a few common late effects from pediatric cancer treatments (Dickerman, 2007). Hemorrhagic cystitis is the most often observed urologic result from chemotherapy treatments (Ward, 2000).

#### **Thyroid**

Adolescents are at highest risk of having any late effects of the thyroid. Also, females are at a greater risk than males. Hypothyroidism is common when treated with radiation to the head and neck, most often when treating for brain tumors (Bhatia & Landier, 2005; Ward, 2000).

Hyperthyroidism can also result from thoracic, cranial, or neck radiation (Dickerman, 2007). Chemotherapy does not have much of an effect on the thyroid; radiation is almost always what causes hypothyroidism.

#### **Auditory and Ocular**

In some occasions, tinnitus or hearing loss can result from acute intoxication or long-term chemotherapy. These effects can sometimes be reversible (Ward, 2000). Ototoxic agents that are most often associated with hearing loss include platinum-based chemotherapy, ominoglycoside antibiotics, loop diuretics and radiation. Patients under the age of 4, that have diagnoses of CNS neoplasms, and that are treated with multiple ototoxic agents are at the highest risk of hearing loss. Cataracts are the most common ocular late effect and are most often a result of total body irradiation, radiation to the head or brain, or corticosteroids (Bhatia & Landier, 2005). However, the eye rarely receives much radiation thanks to eye blocks and multi-leaf collimators that shape the beam to avoid treating the eye.

#### Gonadal

Unlike the majority of late effects experienced by childhood cancer survivors, many gonadal late effects are less common in younger children (Ward, 2000). Testicular and ovarian damage may be caused by radiation to the gonads or the brain, or alkylating agents (Dickerman, 2007). The survival of fertility is uncertain; however, we do know that younger patients are more likely to regain their fertility than older patients. Male patients are also more likely to regain their fertility, even though male patients' fertility is also more sensitive to radiation therapy and chemotherapy (Ward, 2000). Sperm cells, along with lymphocytes, are the most radiosensitive cells of the human body. In adolescent and young adult patients, fractionated doses of 730 Gy to the testes may induce leydig cell failure in about 50% of cases (Bhatia & Landier, 2005). The

fractionation allows the sperm cells to quickly recover from the radiation. If surgery is used to treat cancer in the male gonads, it can lead to impotence, retrograde ejaculation, or partial or complete removal of organs in the pelvis (Bhatia & Landier, 2005). However, improvements in technology, including minimally invasive robotic surgeries, have improved results from surgery on the male gonads.

Ovaries, before puberty, are relatively radioresistant. In pre-pubertal female patients, doses of 12-50 Gy, in comparison to 4-7 Gy in women older than 40, result in ovarian failure in almost all patients. Ovarian failure has also been linked to chemotherapy agents, such as alkylating agents (Bhatia & Landier, 2005). Female pediatric patients are at a higher risk than the rest of the female population to have miscarriages and low-birth weight babies. These effects are often due to lower uterine vascularity or uterine fibrosis. The offspring of childhood cancer survivors could inherit genes that led to their parent's cancer or they could acquire new gene line mutations that were induced in the parent by the cancer therapy (Ward, 2000).

#### **Conclusion**

As you can see, practically every form of cancer treatment for any form of pediatric cancer has a chance of late effects after treatment. Unfortunately, life will not be the same for many childhood cancer survivors. They are at risk for developing secondary cancers as well as inheriting one or more non-malignant effects from their cancer treatments. It is very important to have many follow-up visits to talk to their doctors on how to prevent or at least control these late effects. Having resources to help them along this journey can also be beneficial, which should be mentioned to the patient before, during and following the completion of treatments. The family should also be informed so they can provide social support throughout the child's life and

encourage the child to use the resources available in order to improve the quality of life of the childhood cancer survivor.

## **Psychological Effects of the Patient**

In addition to physical effects from cancer treatments there are many psychological effects that can affect the patient during and especially after treatment is complete. Cancer treatment can cause cognitive effects as well as many psychosocial and behavioral effects. There are many interventions that can be implemented in order to help the child go through the cancer process and help deal with any late effects after treatment as well. These interventions can range from yoga to video games to social networking cites. Different interventions can be used based on how the patient is coping with having cancer or being a cancer survivor.

## **Cognitive Effects**

In treating ALL and brain tumors there is a special treatment that is directed at the central nervous system (CNS). When this CNS treatment is combined with other treatments or done separately it is known to have negative effects on cognitive functioning. One neurological problem known to appear from CNS treatments is called leukoencephalopathy. This is calcifications or damaged white matter in the cerebral subcortex (Herrmann et al, 2011). Herrmann et al (2011) performed a case study of a 7-year old girl with ALL that has bilateral leukoencephalopathy. Through IQ tests the girl showed above average IQ before treatment while after treatment showed a 25 point drop in overall cognitive functioning (full-scale IQ before treatment of 113 and 88 after treatment). IQ deficit is typically 5 to 20 points after treatment which can last for years, but this does not always appear immediately after treatment (Herrmann et al, 2011). Through this evidence we can see that the treatment can cause neurological

problems that can cause drastic negative effects on cognitive functioning. More, larger studies may need to be done to confirm this thesis.

Neurocognitive functioning of childhood cancer survivors is also vulnerable to the effects of fatigue and sleep disruption in adulthood. As it turns out childhood cancer survivors have shown rates of sleeping problems as high as 90% compared to 45% of the general population (Clanton, Klosky, Li, Jain, Srivastava, Mulrooney, et al., 2011). Sleep is important for recovery after brain injury. As a result, if childhood brain tumor survivors have problems of fatigue and sleep deprivation, this can cause an increase in the degree of neurocognitive impairment.

Disruption of REM sleep is associated with memory impairment in aging adults. Higher dosages of cranial radiation also showed greater memory impairment along with decreased task efficiency and emotional regulation (Clanton et al., 2011). Sleep is necessary for everyone in order to keep from losing cognitive function as we age. Sleep is especially necessary for childhood cancer survivors because they are at a greater risk for cognitive impairments.

## **Psychosocial and Behavioral Effects**

Childhood cancer survivors, in particular leukemia and CNS tumor survivors, are at much higher risk for psychological problems. Eilertsen, Rannestad, Indredavik, & Vik (2011) did a study on psychosocial health in children and adolescents that survived cancer and determined through a case-control study of 50 children and adolescents that childhood cancer survivors had more emotional problems and lower academic performance than their peers (Eilertsen et al, 2011). Psychological problems during adolescence also increase risk for obesity and poor health behavior in adulthood. This poor health behavior can also lead to an increased risk for chronic health conditions and the return of cancer (Krull, Huang, Gurney, Klosky, Leisenring, Termuhlen, et al., 2010). Krull et al (2010) found the same higher rates of psychological

problems due to childhood cancer, consisting of attention deficit, emotional problems, externalizing behavior and social withdrawal, as well as adding how these psychological problems are associated to later health issues in adulthood.

Relating to the psychological problem of social withdrawal, when children finish cancer treatments their relationships with their best friends may be compromised in some areas compared to healthy children. Due to being kept out of school for hospitalization during treatments children with cancer spend less time with their friends. When childhood cancer survivors go back to school they are seen to engage in less social activities and are more socially withdrawn. Katz, Leary, Breiger, & Friedman (2010) did a study to find out if cancer survivors have problems interacting with their best friends as well. They found that interactions with their best friends are less likely to be highly engaged and are more disengaged (Katz, Leary, Breiger, & Friedman, 2010). This shows that when childhood cancer survivors return back to school and get back together with their best friends their relationship interaction will be less intimate resulting in more contribution to the cancer survivors' feelings of isolation.

Some childhood cancer survivors feel a loss of identity due to less interaction with their peers during treatment. Children need relationships for healthy development. This is shown in Griffiths, Schweitzer, & Yates' (2010) analysis of experiences that children have during and after treatment. Through interviews of childhood cancer survivors they were able to observe how children feel towards the experience. One of the themes they pulled out from the interviews they did was how important relationships were during treatment. They appreciated all the gifts they received and all the friends they made at the hospital. It helped them cope with the pain of treatment and the anxiety of being away from home (Griffiths, Schweitzer, & Yates, 2010). When they return home and have a higher risk for psychological problems it is important for

them to receive support from their peers. Otherwise, they may become socially withdrawn from their peers and even their best friends.

#### **Interventions**

Around two thirds of childhood cancer survivors will have some type of long-term affect from their treatment and experiences, such as cognitive or adjustment problems, infertility, secondary malignancies, growth problems and organ damage, to name a few (Bingen, & Kupst, 2010). Due to all the possible problems it is important for childhood cancer patients to receive all the care and information they need to help them during and after treatment. During treatment it is important for them to receive help coping. This is due to all the anxiety from being away from their home, family and friends. Going through treatments can cause anxiety as well. Depression can be fairly high in children who are going through cancer treatments. Social support is very important during and after treatment. After treatment their problems are not over and they still need social support just as much as during treatment, if not more. The following are a few possible interventions, which are often called complementary therapies, for during treatment, transferring back to school after treatment, and later in life, dealing with any long-lasting problems from the cancer treatments and experience.

Some coping strategies are useful for children with cancer during and after treatment.

This can help children deal with the anxiety and fear of going through treatments and help them to come out of the treatments with less psychological problems, even if some problems cannot be prevented completely, due to neurological problems from cancer treatments. Hildenbrand, Clawson, Alderfer, & Marsac (2011) completed research on the stressors and coping strategies of childhood cancer survivors. One thing to notice is that most of the distress experienced is due to the treatment rather than the cancer itself. Most of the stressors dealt with the pain and anxiety of

treatments. Also to be noted is the stress of being away from home, friends and family. These stressors were also noted by the parents. Some of the coping strategies include relaxation, seeking social support, expressing feelings, and distraction (Hildenbrand, Clawson, Alderfer & Marsac, 2011). Coping strategies can be very beneficial for children going through cancer treatment. Having a good attitude can always be helpful in the healing process.

Depression is a problem for many children who are going through treatments. There was a study done in China were they used virtual reality computer games to minimize anxiety and reduce depression. After doing the study on 122 children they found some promising results. The experimental group showed a significant decrease in depression symptoms after a weeklong trial period, while the control group showed slightly more depression since the study began (Li, W., 2011). This intervention shows how important it is for children to have playtime in order to take their minds off their treatments and deal with their depression.

Another complementary therapy intervention would be yoga. Yoga calms the mind and relaxes the nervous system using slow, deep breaths. The meditation involved in yoga allows a heightened awareness of what is causing anxiety by slowing down any anxious thinking (Thygeson, Hooke, Clapsaddle, Robbins, & Moquist, 2010). In the background research of Thygeson et al, they found that yoga for adults going through cancer treatments shows promising decreased fatigue, insomnia, mood and stress causing an improvement in quality of life. It was also found that children with cancer have shown distress related to pain, nausea, fatigue, anxiety, sleep disturbance, muscle weakness and lack of balance. Parents also have their own distress from worrying about their child's future as well as distress over their child's suffering. Parents of a child with cancer can have levels of anxiety comparable to a person hospitalized with an

anxiety disorder (Thygeson et al., 2010). Putting these facts together it shows that children with cancer, along with their parents, could use a complementary therapy to reduce their distress.

Thygeson et al. (2010) conducted their study to find out if yoga is beneficial in reducing this distress. In their study 11 children, 5 adolescents and 33 parents chose to participate in a yoga class. This yoga class was found to be reasonable for children and adolescents with cancer as well as their parents. After the participants filled out an open-ended questionnaire all responses were found to be positive about the class. There was a significant decrease in anxiety experienced by adolescents and parents; however children anxiety levels remained the same. The children with cancer started out with a normal anxiety level before the yoga class, so even though their anxiety level did not decrease it was still normal. This study was fairly small and a convenience sample was done so the participants may not be a great representation of the population, but the study shows that yoga has a promising decrease in anxiety for participants who started out with higher anxiety and also has a highly positive rating from all participants in this study.

After treatment is over it is very important for continued social support. Bauman (2011), a professional school counselor, discusses in her article how school counselors can make child cancer survivors' transition back into school go smoothly. Bauman discusses how counselors need to "reconceptualize the cure". They need to understand that the cure of the disease goes beyond just the cancer treatments. Most children develop many late effects from their treatments. This is where the counselors come in, to work with the child's medical team to provide a smooth transition and getting them the best resources and education with his/her issues. The transition back to school can be a difficult time for a childhood cancer survivor. Especially in adolescence when they are trying to understand their identity.

Neuropsychological recommendations from nurse practitioners can be very helpful in improving cognitive functions after going through cancer treatment that impair brain development in children. The research of Quillen, Crawford, Plummer, Bradley, & Glidden (2011) shows how neuropsychological recommendations can be very helpful. Of the thirty parents in the study, 51% said that the recommendations were extremely helpful in improving their child's quality of life (Quillen et al, 2011).

Ocampo (2010) conducted a case-study of a childhood cancer survivor. This study gave a good representation of how resources can help improve the quality of life of a childhood cancer survivor. Paul was diagnosed with a brain tumor at 4-years old. After undergoing surgery, 2 months of radiation therapy and 9 months of chemo Paul received counseling and other therapy to improve his depression and physical and cognitive problems. Through all the therapy and through his family providing full support to help him cope, Paul made an almost complete recovery. He can now walk independently, can handle 4 hour school days without fatigue and is performing well academically, only two grades behind in reading and writing levels. Socially, Paul is very socially active with his peers (Ocampo, 2010). This case-study shows the importance of family support and the use of therapy and counseling resources. However, this is only one case, so larger studies will need to be done to observe how counseling and support from the family can help the population of children with cancer.

Another small study was done to try to improve cognitive effects from treatments. They found that attentional deficits, like ADHD, are very common in childhood cancer survivors. As a result, Hardy, Willard, & Bonner (2011) created a computerized cognitive training program called *Captain's Log* to try to improve their cognitive abilities. After testing this program on 9 childhood cancer survivors, they found that their program may be a feasible mechanism for

improvement in working memory and attention. It was a small sample size but it is a good start at empirical evidence that training programs like these can improve cognitive abilities of childhood cancer survivors.

Interventions can be done much later in life as well. A study done by Bingen & Kupst (2010) found that many childhood cancer survivors have limited knowledge of their risk of late effects and do not receive proper after treatment care. Bingen & Kupst put together a conference for childhood cancer survivors to attend so that they can learn more about their risks. After the conference they discovered from reviews they had the participants fill out, that the majority would have a high likelihood of attending more programs like this and/or join a social group. This shows that conferences like these would be a good way to educate childhood cancer survivors of their risk of late effects and increase awareness of social groups. This would hopefully lead to a healthier, longer and happier life for childhood cancer survivors.

Social networking cites can help childhood cancer survivors connect with other cancer survivors and receive more social support. The social network created by McLaughlin, et al. allows childhood cancer survivors to share their stories and learn the stories of other survivors. Plus, if they had any questions on how to better cope with late effects they could connect with their friends on this site to receive advice. The researchers found that the people who were most likely to use the site had lower social support at home (McLaughlin, et al., 2011). This study shows the great need childhood cancer survivors have for social support after treatment. Children do need social support, especially from friends and family, during treatment, but it is just as important after treatment is over and later into life when they have to deal with late effects.

#### **Conclusion**

There are many psychological effects that can affect a childhood cancer survivor, from cognitive to social effects. Many interventions have been found to benefit children going through the cancer process and after treatment. However, it is important to know that these interventions can impact childhood cancer survivors differently and will not help every patient. A psychological assessment should be done before implementing an intervention to figure out what the child needs and what intervention would help improve the patient's coping strategies in order to improve the patient's quality of life. Social support is always beneficial for all childhood cancer survivors. Support from family and friends can be the greatest benefit in coping with cancer and being a childhood cancer survivor.

## **Family Effects**

Due to the improvement in childhood cancer survival there has been a shift in research from coping with a fatal disease to gaining an understanding of how the child, parents, and family adapt and recover during and after cancer treatment (McCubbin, et al., 2002). Sometimes the family can be affected just as much, if not more, psychologically than the child with cancer. Not one of the family members will go unscathed from having a child/sibling with cancer. Having a child with cancer will affect parents emotionally, psychologically, physically, and financially. The effects are different from one family to another. It all depends on their coping strategies, family cohesion, communication, past events, and many more factors. For some parents having a child with cancer will hurt their marriage, but for others it can bring them closer. The same goes for the whole family. Siblings do not go unaffected either. The parents will tend to give the majority of their attention to the ill child so their other children may feel

neglected in the process. Having a child with cancer will affect the family as a whole, the parents' relationship, as well as the mother, the father, and the siblings individually.

## **Family System Effects**

The life threatening nature of illness, invasive treatment, distressing side effects, uncertainty about survival, repeated hospitalizations that disrupt normal family routines, and change in roles and responsibilities have repercussions not only for each individual family member, but also for the whole family system (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998) Koch (1985) explains five patterns of response to the diagnosis of cancer. The first pattern of response described was the experience of increased negative emotions. The family will worry that the patient might die and feel sad about the impact the cancer has had on the patient. A sibling of a cancer patient described her feelings, "Sometimes when I'm in there with him taking shots, I'll just say, 'Why couldn't it be me instead of him?' Cause he's so little and so young, that I probably could take shots better than he could" (Koch, 1985, p. 66). Many family members have similar feelings to this sibling. They would rather it would have been them who got the cancer instead of their innocent little child that has to endure all the treatments and physical effects from the disease.

The second pattern of response to diagnosis is rules prohibiting emotional expression. Many families will go through months or even years of denial and suppress their emotions. Normalization of emotional changes can help the family cope with these emotions and express themselves better (Koch, 1985). Suppressing these emotions will cause greater stress and can cause even greater problems within the family. When one or more family member is stressed out from withholding their emotions it can be taken out in anger and other negative emotions on other family members.

The third pattern of response to diagnosis is health and behavior problems following diagnosis. There are different problems in different family members. In Koch's study (1985) she found that problems seen in fathers included alcoholism, extramarital affairs, and increased severity of kidney stones, and vertebral disk problems requiring surgery. Problems in mothers may include attempted suicide, gall stones requiring surgery, allergic reactions requiring medical intervention, and miscarriages. Finally, problems seen in siblings of children with cancer of Koch's (1985) study included hepatitis requiring hospitalization, multiple knee injuries requiring multiple knee surgeries, emotional symptoms requiring psychiatric help, fighting and other disruptive behavior at school, and a death resulting from an automobile accident (Koch, 1985). These health and behavioral problems are from a small study and do not generalize the health and behavioral problems for all family members and they may not even be only resulting from having from having a child with cancer in the family. However, there is no way to control other factors and this just gives possible examples of problems that can occur as a response to the diagnosis.

The fourth pattern of response to diagnosis is role changes within the family. Parents will focus their attention primarily upon the patient, families will need to focus on their emotional caretaking, and siblings will often need to mature more quickly than other children in order to take on more responsibilities that their parents do not have time for (Koch, 1985).

Koch (1985) found that the last response to diagnosis for families in her study was increased family closeness. One parent describes how the diagnosis affected their family closeness, "At first, it tore each of us apart, everyone in the family, individually. But, because of it, we've gotten a little closer" (p. 68). In this study the author found that the whole cancer

process brought the family closer in the end, however this can differ greatly from family to family depending on their coping strategies and other factors.

The resiliency of a family to the effects from having a child with cancer depends on many variables. These variables include internal family strengths of rapid mobilization and reorganization, support from the healthcare team, support from the extended family, support from the community, and support from the workplace (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002).

A family needs to mobilize quickly at diagnosis and be able to tolerate living as a split family. As one parent said, "You really have to change gears really fast...I think you gotta kind of jump in and do it" (McCubbin, et al., 2002, p. 105). Support from the health care team is very important for the family. Support from the health care team can include reassurance and realistic hope, accessibility for information and assistance, and respect for the parents. One parent explains the importance of the health care team, "You have to understand that the parent kind of feels like...they're lost at sea or something like that and the doctors are the only ones with life preservers" (McCubbin, et al., 2002, p. 106). Support from the extended family can include providing respite for the parents, taking care of the other children, transportation, emotional support, and instrumental support (providing meals). The community can support the family during this difficult time by providing child care, financial aid through donations, home maintenance assistance, and emotional support. Workplace support is another important factor in family resiliency. A flexible schedule, time off to be with the child and job assurance can be a big difference in how the family is affected by having a child with cancer (McCubbin, et al., 2002).

In order to anticipate their adjustment, identify potential problems in coping, and provide the proper intervention to the pediatric patient and their family, a psychological assessment is essential. Adams-Greenly (1986) provides a multi-dimensional perspective including stage of disease, socioeconomic vulnerability, degree of psychopathology and coping capacity, family cohesion and communication, and personal/family history. Interventions can include patient/family education, community outreach and the provision of practical resources, support groups, and various therapeutic modalities. Therapeutic modalities can include crisis intervention, behavioral techniques, ego-supportive counseling, and insight-oriented psychotherapy (Adams-Greenly, 1986). Although this is an older study it is still currently relevant and the ideas are not outdated.

At the stage of diagnosis, education about the medical facts is important. In order to help the family express and understand the emotions they are feeling a crisis intervention can be helpful. If the patient will not survive the cancer, interventions for the stage of terminal illness will be most appropriate. This can include ego-supportive counseling for the patients, parents and siblings as they struggle to handle their pending loss while maintaining their sense of family. Other interventions that may help in this stage, as well as the stage of survivorship, include home care, transportation, and babysitting for siblings, especially when the family is struggling financially. In the stage of survivorship, education of long-term effects of treatments and community outreach from the school to help with re-entry can be helpful (Adams-Greenly, 1986).

Very few families can go through treatment and not have some economic stress. This is why socioeconomic vulnerability is another important variable in assessing a family for possible interventions. Some studies have shown that families with a lower socioeconomic status have a

more difficult time adjusting psychologically. Cultural factors may make it more difficult to accept assistance from the community. Culture can also cause problems in communication and differences in gender roles. Work-related issues are also important. It could cause worrying about sick-leave to be with their child, insurance staying while on leave, and being unable to move up in the business for fear of insurance changing and not covering their child's medical bills (Adams-Greenly, 1986).

The experience of childhood cancer is a profound stress for any family. This stress can result in serious immediate and long-term mental health issues. However, the hospital staff should always be cautious in applying psychiatric labels to family members of the patient that are undergoing severe stress. In order to assess the psychopathology and coping capacity of family members they should know the history of psychiatric illness or evidence of a current thought or behavior disorder, coping skills utilized previously, and adaptiveness of defense mechanisms currently in use. Ego-supportive or insight-oriented interventions can help the family build on existing coping skills and find ways to use the experience to help them grow further (Adams-Greenly, 1986).

Family cohesion and communication is another very important variable to assess.

Although adults may go to great lengths to shield their children, they are often relatively informed from observation, non-verbal communication, eavesdropping, and talking with other patients. It is often better for the parents to keep their children informed and keep open communication with them. Open family communication has been found to be related to better psychological adjustment. The patient's level of anxiety and feelings of isolation as well as sibling guilt have also been found to be related to family patterns of communication. Open family communication is one of the major aspects of family cohesion. Another aspect is

synchrony of coping styles. One parent may cope by seeking information, asking questions, and freely expressing emotions, while the other is reserved. This could come across as lack of empathy but it is actually just a difference in coping styles. Support groups, self-help groups, and psychotherapy can be useful for family members or a whole family who may address issues in communication, closeness, or differences in coping styles (Adams-Greenly, 1986).

The last variable that Adams-Greenly (1986) says should be assessed is personal/family history. Past experience with cancer or other serious illness may affect a family's ability to be hopeful or to trust in the hospital staff. During diagnosis, feelings about previous separations or losses may be reactivated. This reactivation of feelings could interfere with their ability to cope with the present crisis. Previous problems at work could strongly affect a parent's ability to balance work, home, and hospital responsibilities. Previous problems with peer relationship and/or academic performance can influence the patient's ability to re-enter the school life. The meaning of the child to the family before cancer can affect how much effect the illness has on the family. Ego-supportive or insight oriented psychotherapy can help family members or the family as a whole with integrating past experiences with the present situation (Adams-Greenly, 1986).

## **Marriage Effects**

Having a child with cancer can take a toll on the family as a whole and especially take a toll and the parents. Even after treatment is complete, many parents have feelings of uncertainty and loneliness and they continue to be concerned about the physical and mental development of their child and potential fewer future opportunities (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998). Family cohesion has often been found to be strengthened by childhood cancer, but as hospitalization increases marital quality and spousal support declines (McCubbin, et al., 2002). Having a child with cancer is very stressful and spouses will often take it out on each other

(Fletcher, 2010). The stress and burdens of caring for a child with cancer can also cause a decreased quality of life for the parents. From the research done by Litzelman, Catrine, & Gangnon (2011) it can be seen that this is indeed true. They found that by putting stress and burden of the parents into account for the decreased quality of life of parents that have children with cancer, any other relationship between having children with cancer and the low quality of life of parents disappeared (Litzelman, Catrine & Gangnon, 2011).

Hoekstra-Weebers, et al. (1998) conducted a study to find out how marital dissatisfaction is related to having a child with cancer. How it affects the parents differs from one couple to another. Studies have shown that family coping is directly related to the quality of the marital relationship. Marital difficulties can arise when parents utilize different coping strategies or use coping strategies in a dyssynchronous way. A discrepancy in emotional-focused coping was found to be a risk factor for marital dissatisfaction for both parents. Symmetry in emotion-focused coping is associated with higher marital quality. When faced with a stressful situation of the child's cancer, some fathers may react with intense, emotion-focused coping. This reaction is unusual and upsetting both for the fathers and for their partners. The partner may not be able to provide the emotional support that the father needs, which may affect their marital satisfaction (Hoekstra-Weebers, et al., 1998).

The level of marital dissatisfaction reported by both parents in this study was found to increase significantly in the year following diagnosis, although this was not consistent throughout all couples, some showed an increase in marital satisfaction. Almost half of the couples showed more discord over time. However, even though there was an increase of dissatisfaction, the level of dissatisfaction was still comparable to the control group.

Psychological distress was found to predict marital dissatisfaction overtime and especially after a

year, but not right after diagnosis. For fathers, acute psychological distress was found to be a predictor for later marital dissatisfaction. This could be from feelings of isolation and exclusion early on when the mother was more actively involved. This could lead to tension and the father may miss the emotional support from his wife (Hoekstra-Weebers, 1998). Brody & Simmons (2007) found that fathers tend to be more positive than mothers regarding their marital relationship. This could be from the fact that husbands are often expected to provide emotional support to their wives in difficult times. For example, fathers might bring their child to medical procedures that are too difficult for the mother to handle (Brody & Simmons, 2007).

There are many more factors beside psychological distress and coping styles, so more research needs to be done on marital satisfaction in relation to childhood cancer. Other factors may include the child's response to treatment, the child's psychological adaption and coping, family cohesion before diagnosis, disruption of family life, or differences between parents personalities or ideas of how to raise a child with cancer. What is certain is that cancer in a child is not a life event that can be dealt with individually. Parents must cope together as a couple (Hoekstra-Weebers, 1998).

#### **Mother Effects**

All parents, regardless of whether their child survives or does not, must try to maintain some sense of normalcy for the family unit, while at the same time trying to cope with the situation at hand. There are many costs of caring for a child with cancer for a mother. Fletcher (2010) conducted a study interviewing mothers of children with cancer. From these interviews she found that the costs of having a child with cancer may include financial and work issues, health of the family, upheaval of family life, and a life lost (Fletcher, 2010).

The first cost of having a child with cancer in the point of view of mothers is the financial and work issues. Mothers had to alter work schedules, take unpaid leave, or even quit their jobs. Some of their husbands had to quit their jobs as well or at least decrease hours in order to focus on the child. One mother described fear of losing their house and how they had to sell both of their cars to make ends meet. After treatment is done some mothers found it difficult to go back to work. It took them awhile to get back in the swing of things (Fletcher, 2010).

The next cost of having a child with cancer is the health of the family. Some mothers described changes in weight. Some gained weight from eating at the hospital cafeterias because they did not have time to make their own food and they spent so much time in the hospital taking care of their child. While others lost weight from their eating habits getting messed up from being so busy. Sleeping habits were also disrupted allowing some mothers to only sleep 3 hours a night. One mother complained of bad migraines, tension headaches and back problem, while another mother said she was exhausted, depressed and went through an emotional rollercoaster. Psychological health was significantly affected as well as physical health. After treatment, some mothers experienced anxiety and depression that consisted and fear of relapse. They carried the worry and memories that haunted their sleep (Fletcher, 2010). PTSD in mothers has been found to range from 6.2% to 54% for lifetime PTSD in mothers of survivors (McCubbin, et al., 2002). For mothers that lost their child, grief and aguish was almost unbearable at times. Some mothers feel that her other children do not have their parents back and they feel that they cannot give them what they need anymore (Fletcher, 2010).

The upheaval of family life was found to be the next cost having a child with cancer.

With taking care of the ill child, working, and possibly taking care of other children, there is little family time. A lot of time goes into appointments and taking care of the child with cancer. One

mother told how her and her husband spent only 2 nights together while the child was being treated. She worked days and her husband worked nights so they could trade shifts of taking care of the child. Travel to the children's hospital can be over an hour long, which eats up even more time. After treatment many mothers described how it can be difficult for the family to get back together again and learn to be a family all over again (Fletcher, 2010).

The final and most difficult cost of having a child with cancer is a life lost. The death of a child is the greatest cost endured by all family members. A child cannot be replaced. The death rate has decreased drastically in the last few years, but there are still many deaths from cancer. Thinking about the lost child can bring great unbearable grief to a mother. One mother explained how when others talk about their sons it makes her think about what the child would have been like if he was still alive and how she will start crying and they have no idea what brought on the tears. She also mentioned that her other children have been robbed of a caring big brother and now have parents that have been changed. Some mothers said that their other children fear being an only child and fear that their parents will die as well (Fletcher, 2010).

#### **Father Effects**

There are not as many studies on how fathers are affected by having childhood cancer; however Brody & Simmons (2007) conducted a study to find the father's perspective on how having a child with cancer can be costly. Fathers, compared to mothers, may find it difficult to find support throughout their child's cancer process. Social support plays a key role in resilience, especially from the health care team. Without support outside the hospital fathers have difficulty obtaining support. Social support from extended family can be very helpful. They can help take care of the other children and sometimes help financially. Fathers also appreciate support from the community. They can help financially through donation, instrumentally through meals, and

emotionally by talking about things other than their child's cancer. One father mentioned how his faith got him through the crisis, "I couldn't have made it without the Lord through this. And I wouldn't have wanted to either" (p. 161). Some fathers get support from their workplace, including flexible schedules, opportunities to take time off, and reassurance that the job will still be available when the parent is able to return to work (Brody & Simmons, 2007).

Work is a factor that can cause problems or sometimes be beneficial. In order to earn income many fathers must keep working, this can make them frustrated because they are unable to provide continual physical and emotional support to protect their children from the effects of the illness. Fathers are often the provider of the family and often experience role conflict between working to earn money and staying at home or in the hospital to be with their ill child. On the other hand, work can be beneficial for some fathers. For one, it helps financially. Also, work can be an outlet for fathers to put aside the stressors of taking care of their child with cancer. Fathers are better able to keep their focus, mentally and emotionally, on the task at hand, while mothers often experience the effects of having a child with cancer in all aspects of life. As a result, fathers can often still keep their focus while at work and put aside the stress (Brody & Simmons, 2007).

Fathers may have increased stress from suppressing their emotions. Fathers often feel that expressing their emotions is a sign of weakness so they often find it hard to find gender-accepted ways to express themselves. Many fathers are in denial of the seriousness of the illness and feel a sense of responsibility to lift the spirits of others (Brody & Simmons, 2007). How a father deals with his emotion will differ from one father to another. In Fletcher's (2010) study a mother told of how her husband would not go back into the hospital after their child died from cancer. Their

other child had an appointment at the hospital but the father would not go in because there were too many painful memories inside (Fletcher, 2010).

Communication is extremely important to fathers, especially in regards with receiving and providing information on their child's diagnosis and treatments. Many fathers want doctors to be straight forward, provide continual information on treatments and progress of their child's condition, and to be willing and able to answers questions. Sometimes healthcare workers will be biased and talk more to the mother assuming she is the primary caretaker, while sometimes the father is the primary caretaker and wants to be talked to more directly. Fathers will often have to relay the information to the immediate family, extended family and friends. One father used different color paint in order to explain what was happening to their child who was diagnosed with cancer. He used red, white, and blue paint to represent different cells, telling his child that the blue cells are what is wrong and that the doctors are trying to fix it (Brody & Simmons, 2007).

There are many effects of the cancer experience on the father. One positive effect is that many fathers learn to adjust to their circumstances given the resources available to them. Maintaining a positive attitude is crucial to being able to adjust and adapt. Spending time with their children becomes more important because they know how quickly their lives can change. Changes in personality and parenting style after diagnosis can be a positive effect as well. Fathers can become more lenient or supportive and understanding. The negative effects on fathers can include becoming emotionally and mentally drained from feeling unsure about all the information of the child's condition, fearing relapse after treatment, and struggling to remain positive while watching child undergoing treatment (Brody & Simmons, 2007). A quote from a distressed father sums up how it can make a parent feel:

I'm afraid of nothing that walks or breaths, nothing...this does not walk nor breathe. This is living, this is something that lives inside my son, and there is nothing I can do about it. And I can't stand it. If it was a person or an object I could move it or do away with it, but it's not...it's a living nightmare. I just want him to grow up. I want him to be normal, but that'll never be. (Brody & Simmons, 2007, p. 164)

## **Sibling Effects**

Not only are just the parents affected by having a child with cancer. Siblings can be affected greatly as well. Malone & Price (2012) discuss the effects of childhood cancer on siblings. Sibling adjustment and adaption is first discussed. There are many variables that can affect a sibling's adjustment. These variables may include family size, stage of treatment, perception of support available and gender. Other factors may include parental depression, family income, support in the neighborhood and community, parent-sibling communication, and length of time since diagnosis. They found that families with larger families experience more adjustment difficulties. This could be because the parents do not have time for all the children while taking care of the ill child. The adaptation model shows that during the adjustment stage, how vulnerable the sibling is to the child having cancer depends on the actual stressor (in this case cancer), any previous strain the family has had to face (e.g. sibling being bullied), existing resources in the family to deal with the situation, and how serious the sibling perceives the stressor to be. During the adaption stage, how well the sibling adapts depends on the perceived strains on the family, how the family deals with the stressor, and how the family members perceive the crisis. In order to help the sibling adapt they need strong support (Malone & Price, 2012).

Having a sibling with cancer will most often have an emotional impact. In fact, emotional problems are the most common issue in siblings of children with cancer. They can experience feelings of sadness, loneliness, anxiety, anger, jealousy, and guilt. Some siblings will experience a sense of loss of themselves in the family unit. They may feel that their suffering is not justified and that it should have been them diagnosed with cancer on not their sibling (Malone & Price, 2012). Some often worry that they will contract a life-threatening illness and die. One sibling explains how she felt sometimes:

I used to think I had all kinds of things...I used to sit and think, oh no, what if I have...I really thought I had something. I was afraid to tell anybody cause they'd think I was silly...But it was very real to me for awhile. (Koch, 1985, p. 67).

In the long term, having a sibling with cancer can sometimes have a positive emotional effect. It can create increased empathy and sensitivity towards others, respect for their ill sibling, better self-concept, increased maturity, and a greater appreciation for life. Siblings found that time spent with their parents alone was special, even if it is only a short period of time, and this made them feel less lonely when they were away. Studies show that siblings with high social support have lower levels of depression, anxiety, and fewer behavioral difficulties. It has also been found that adolescent girls more commonly show depressive symptoms than adolescent boys (Malone & Price, 2012). Siblings can become emotionally scarred and need counseling (Fletcher, 2010). In order to reduce siblings' anxiety and post-traumatic stress, psychological intervention programs such as summer camps can be beneficial (Malone & Price, 2012).

Having good coping strategies can make a very significant difference in how a sibling handles having a sibling with cancer. Some siblings will use negative coping strategies such as wishful thinking, attention-seeking behaviors, and solitary play. Interventions to help siblings

implement good coping strategies can include support groups or sibling camps. Support groups in the hospital can help them express their feelings to those in similar situations. Regular meetings may allow siblings to develop trust in one another and discuss recent changes in their siblings' condition. Sibling camps provide an environment for them to relax from the daily stresses and strains from being alongside cancer. Camps can help improve self-esteem, quality of life, and social and emotional functioning by reducing levels of anxiety and post-traumatic stress, by talking with the counselors and mixing with peer groups. Before implementing any support services an assessment should be done. This is important because some studies have shown camps having no effect or even causing high levels of post-traumatic stress for some siblings. Play therapists can also help siblings turn negative coping strategies into more positive coping strategies (Malone & Price, 2012).

Many siblings feel that they have unmet needs, they feel that their needs are not met because they had less communication with their parents than before, lack information about ill sibling, had limited opportunities to visit sibling, and had few opportunities to help with care (Malone & Price, 2012). Siblings can get little to no attention because their parents have no time for them (Fletcher, 2010). In order to help siblings adapt, communication between siblings and parents is very important. Most sibling want accurate information about their ill sibling but they are often given incomplete age-appropriate information. Having the sibling actively involved in the treatment process can be beneficial. It can help meet many of their needs that they feel are unmet. They will be able to observe the gradual physical change, become more familiar with the hospital and staff, maintain contact with ill sibling, gain information about the illness, and help them to feel as they are still part of the family (Malone & Price, 2012).

#### Conclusion

As more and more children diagnosed with cancer are surviving their cancer there is greater need to know how cancer can affect the patient and family during and especially after treatment. These effects can include physical effects such as secondary neoplasms or non-malignant neoplasm, psychological effects such as cognitive or social effects, and psychological, emotional, financial, and physical effects of the family. In addition to knowing the possible effects, anyone involved in the cancer process needs to know possible interventions to suggest to the pediatric patient and their family as well. These interventions may include virtual video games to help the patients deal with anxiety, marital counseling to help parents going through the crisis, sibling camps to help siblings cope with having a sibling with cancer, and many more.

As a future radiation therapist I could be working with pediatric cancer patients. One of the main factors in how well the child copes through their cancer treatments is social support. Radiation therapists can be a source of social support for the children going through their treatments. Radiation therapists need to make the process fun for the pediatric patients and make them feel comfortable so they will not be scared to come get their treatments. Laughter can be the best medicine and children need their playtime, especially when diagnosed with cancer. Radiation therapists and pediatric nurses should also know all the possible effects of cancer treatments, from physical to psychological. They should also know how it can affect the family, so they can talk to the families about what can be expected and suggest possible interventions based on how the patients and families are handling the situation. Childhood cancer is something nobody wants to go through, including the patient and the family; it is the job of the healthcare team to make the process as tolerable as possible.

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