Beyond the Cure

~ Information Book for Child Life Specialists about the Long Term Effects of Childhood Cancer ~
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**Introduction**

**What this book offers...**

This book is created for Child Life Specialists (CLSs) who work with children/teens who have experienced childhood cancer. Children/teens who are under treatment for childhood cancer experience enormous distresses until the completion of cancer treatment; however, many childhood cancer survivors also experience physical long term effects and social or emotional difficulties after cancer treatments. These long term effects sometimes affect the child’s entire life including marriage, fertility, and occupation. By utilizing skills and knowledge of Child Life, CLSs can provide psychosocial supports for children/teens who are suffering from long term effects. Although psychosocial supports for childhood cancer survivors have not been developed yet, Child Life services can be offered in cancer follow-up clinic or Hematology/Oncology unit. In order to implement efficient services, it is essential for CLSs to have understanding of physical and cognitive long term effects, psychological and social difficulties that childhood cancer survivors go through. This book covers information of physical, cognitive, psychological, and social long term effects of childhood cancer. It also includes how childhood cancer experience affects children in each developmental stage. In addition to the information, this book focuses on the role of CLSs for childhood cancer follow-up care including Child Life interventions, and ideas for support groups. At the end of this book, there is a resource guide section so that CLSs can gather more information for a particular topic.
Overview of Childhood Cancer

Childhood cancer is divided into several categories depending on where the cancer is located in the body. The major categories of childhood cancer are leukemia, cancers of central nervous system, sarcomas, lymphomas, liver cancers, cancers of kidney, and others.

- Leukemia
  - Acute Lymphoblastic Leukemia (ALL)
  - Acute Myelogenous Leukemia (AML)

- Cancers of the central nervous system
  - Brain tumors
  - Neuroblastoma

- Sarcomas
  - Bone cancers
    - Osteosarcoma
    - Ewing sarcoma
  - Soft tissue sarcomas
    - Rhabdomyosarcoma

- Lymphomas
  - Hodgkin disease (Hodgkin’s lymphoma)
  - Non-Hodgkin lymphoma

- Liver cancers
  - Hepatoblastoma
  - Hepatocellular carcinoma

- Cancers of kidney
  - Willms tumor (Nephroblastoma)
  - Clear cell Sarcoma

- Other types of cancers
  - Retinoblastoma
  - Germ cell tumors

(CureSearch Children’s Cancer, 2011)
Overview of Long Term Effects of Childhood Cancer

When children have childhood cancer, they go through a variety of treatments. Because of advances in treatment, childhood cancer is no longer a fatal disease in many cases. However, because of strong treatment, the treatments that allow children to live cancer also cause health problems, which are called side effects. Most side effects appear during or just after the cancer treatment, and these side effects go away a short time later. However, some problems may not go away or may not show up until months or years after treatment. These long-last problems are called “long term effects”. Long term effects can involve more than one part of the body or more than one organ system and can range from mild to severe. That is, some children who completed childhood cancer treatments may not experience any long term effects although others may experience severe long term effects. Research about long term effects of childhood cancer is a still new field; nobody knows what kind of long term effects can happen to what kind of patients with childhood cancer (American Cancer Society, 2010).

The causes of long term effects are chemotherapy and radiation in most cases. Less commonly major surgery also can be the cause of long term effects of childhood cancer. The American Cancer Society (2010) described the relationship between childhood cancer treatments and its long term effects:

- Cancer treatments like radiation therapy, chemotherapy, or stem cell transplants kill cells that grow quickly, such as cancer cells. But in a child, many health cells in organs throughout the body are growing fast, too. Treatment can damage these cells and keep them from growing and developing the way they should (para 7.).

In addition to types of cancer treatments, the following factors also affect a child’s risk of having long term effects (American Cancer Society, 2010).

- The type of cancer
- Where the cancer was in the body
- How old the child was when treated
- The child’s overall health before the cancer
- The child’s genetic make-up (inherited risk for certain health problems)
Chapter 1:

Long Term effects of Childhood Cancer ~ Physical ~

This chapter provides long term effects of childhood cancer in terms of physical aspects. After the completion of cancer treatment, childhood cancer survivors will experience a variety of long term effects. The causes of these aftereffects can be from cancer treatments including chemotherapy, radiotherapy, and transplantation. Also, the history of having a cancer will increase the risk of second cancer. This chapter clarifies physical aftereffects of childhood cancer.
The Side Effects of Cancer Treatment

The treatments for childhood cancer can vary depending on the child's age and type of cancer; however, there are mainly three treatments that most children with childhood cancer experience: chemotherapy, radiotherapy, and surgery. These treatments are quite effective to treat childhood cancer, but they are accompanied by many side effects.

Chemotherapy

When children with childhood cancer receive chemotherapy, their cancer cells will be killed by drugs, but their healthy cells will be destroyed as well. The chemotherapy causes both short term and long term side effects. The level of side effects can be determined by the length of time of treatment and the doses of medicine that are used for the treatment. The more and longer children with childhood cancer receive, the more they experience a variety of side effects (American Cancer Society, 2010).

Cancer cells are quickly growing and dividing compared to most healthy cells; chemotherapy works effectively on these quick growing and dividing cells. However, some healthy cells, which are in the bone marrow, the mouth and stomach, and hair follicle, also quickly grow and divide. Therefore, these healthy cells are likely to be destroyed by chemotherapy along with cancer cells. Because of this fact, children with childhood cancer experience side effects during treatment including low blood cell counts, nausea, diarrhea, or hair loss. These side effects usually last short term, and they will disappear after cancer treatments (American Cancer Society, 2010).

On the contrary, as the body of the child who experienced childhood cancer is growing, long term effects of chemotherapy can happen years after the completion of cancer treatment. When children receive high-dose and strong chemotherapy, treatment damages healthy cells and keeps children from growing and developing the way they should (American Cancer Society, 2010).
**Radiation**

Radiation treatment is also commonly used for the treatment of childhood cancer. It can be the main treatment for childhood cancer or used before and after surgery to remove tumor. The purposes of radiation treatment are to destroy cancer cells and shrink tumors by using high-energy rays. Children with childhood cancer receive radiation treatment from either outside of the body or radioactive materials placed into or next to the tumor. As well as chemotherapy, radiation therapy also strongly affects not only cancer cells but also healthy cells. The long term effects of radiation treatment can be determined depending on the dose of radiation, the area of the body that is being treated, the child’s age, and the child’s genetic makeup (American Cancer Society, 2010).

**Surgery**

Surgery is also an effective treatment for childhood cancer; tumors and areas that are affected by cancer cells can be removed through surgery. The type of cancer and its location in the body can determine the level of surgery children will have. If children have minor surgery, they may have nothing more than a scar. However, in many situations, children receive more extensive surgery. It may require removing part or all of an organ or even a limb (American Cancer Society, 2010).
The Late Effects of Childhood Cancer on Each Part of Body

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Eyes and Ears

Eyes

The type of childhood cancer that most affects eyes is retinoblastoma; many children used to have their eyes surgically removed due to the cancer. Now, as medical treatments progress, most retinoblastoma can be treated by radiation (Hobbie, Keene, & Ruccione, 2006).

As for the late effects on eyes caused by cancer treatments, the eye can be damaged by surgery, radiation, or treatment with steroids. Mainly, there are four most common problems of the eye or their bony sockets after treatment for childhood cancer which are cataracts, loss of vision, dry eye, and hypoplasia (Hobbie et al., 2006).

Cataracts, the condition through which the lens of the eye becomes opaque, are a frequent long term effect of radiation treatment. The younger the child is treated, the more severe the cataracts appear. Also, the higher dose of radiation is used, the more severe and shorter the cataracts would appear (Hobbie et al., 2006).

Loss of vision can be led by cataracts; it also can result from the damage to the retina or optic nerve from radiation. When children with childhood cancer have brain surgery, it may be a trigger of losing vision (Hobbie et al., 2006).

Mild to severe dry eye may happen when children receive certain amount of radiation. The symptoms of dry eye includes irritation, burning, pain, blurred vision, sensitivity to light, and the feeling that a foreign body is in the eye (Hobbie et al., 2006).

The orbit, bony structures in the skull that protect the eye, can be damaged by high dose radiation; late effects on the orbit because of radiation are slowed bone growth, poor growth of soft tissue, flattening of the bridge of the nose, and contracture of the eye socket (Hobbie et al., 2006).

Other possible long term effects on eyes due to childhood cancer treatments are watery eye, discolored sclera (white part of the eye may be a different color), poor night vision, and drooping eyelid (American Cancer Society, 2010).
Ears

Radiation, chemotherapy, and some antibiotics for treating childhood cancer can impact ears and hearing. Particularly, nasopharyngeal carcinomas, parameningeal sarcomas, brain stem gliomas, medulloblastomas, and ependymomas are common childhood cancers that can affect the ears. Children and teens with head and neck tumors treated with high dose radiation often develop hearing loss (Hobbie et al., 2006).

In addition to hearing loss, chronic ear infections are also common long term effects from high dose radiation; they are caused by drying out and thickening the external ear canal and ear drum (Hobbie et al., 2006).

Children may increase the risk of having hearing loss or other ear problems due to cancer treatment if they have the following factors:

- Young age at the time of treatment
- Poor kidney function
- Tumors in the central nervous system
- Surgery to the parotid gland or the parietal region of the brain

(Hobbie et al., 2006)

Other long term effects of radiation, chemotherapy, and antibiotics are:

- Ringing in the ears
- Trouble hearing words when background noise levels are high
- Dizziness
- Hard, crusty earwax

(American Cancer Society, 2010).
Immune System

Hobbie (2006) described what the immune system is:

The immune system is the body’s defense against harmful organisms and substances. It is made up of a variety of cells, organs, and systems, ranging from individual white cells to the entire lymphatic system. One of its primary functions is to fight infectious disease such as influenza or the common cold. It identifies foreign substances and neutralizes, eliminates, or breaks them down into harmless components. (p.341)

Childhood cancer treatments including chemotherapy, radiation, stem cell transplantation, and removal of the spleen can cause decreased immune function and decreased production of blood cells (Hobbie et al., 2006).

Spleen and Lymphatic System

The lymphatic system is a body wide network of vessels and organs. The tonsils, thymus, and spleen consist of lymphoid tissue. Removal of the spleen or high dose radiation to the spleen can affect the body’s immune system. In this case, the body becomes vulnerable to infections. Especially, viral infections including chicken pox and shingles are common infections among children whose spleen is affected by treatment (Hobbie et al., 2006).

Lymph Nodes

The lymphatic system is composed of vessels, nodes and organs. Lymph vessels are delicate tubes that branch into all parts of the body; lymph and white blood cells are carried through lymph vessels. When children and teens have tumors, they have multiple lymph nodes removed for biopsy. Less likely, this removal can cause permanent late effects such as hydrocele, lymphedema, impotence, and ejaculation problems (Hobbie et al., 2006).
Bone Marrow

Bone marrow is the spongy material filled in the long bones and is a blood forming tissue. Bone marrow produces red blood cells, white blood cells, and platelets. Decreases in cell production can lead to lowered immune function, anemia, or bleeding problems (Hobbie et al., 2006).

Radiation to the bone marrow can disturb production of blood in the bone marrow, which can last for a long time. Children with Hodgkin’s disease who received total nodal radiation can sustain long term bone marrow damage (Hobbie et al., 2006).

In addition to radiation, chemotherapy also can affect bone marrow and its function. Some children who received chemotherapy may have problem with low blood counts for years after treatment (Hobbie et al., 2006)

Lungs

When patients with childhood cancer had radiation treatment to the whole body or especially to the chest, they are likely to develop lung problems. In many cases, chemotherapy is used along with radiation treatment; the usage of chemotherapy and radiation it increase the risk of possible lung problems (American Cancer Society, 2010).

The followings are major possible late effects on lungs due to radiation treatment and chemotherapy.

- Decreased lung volume, which enables lungs to hold enough air
- Shortness of breath
- Chronic or ongoing dry cough
- Scarred and thickened lung tissues which is called pulmonary fibrosis
- Inflamed lung tissue which will be the cause of trouble breathing
- Increased risk of lung infections
- Increased risk for lung cancer later in life

(American Cancer Society, 2010)
Hormone-Producing Glands

Hormone which is some glands produce substances are released in tiny amounts, but they travel throughout the body to orchestrate complicated processes including growth, puberty, reaction to stress, temperature regulation, and urine output (Hobbie et al., 2006).

Among type of glands, hypothalamus, pituitary, thyroid, testes, ovaries, and adrenal are sensitive to treatment for childhood cancer (Hobbie et al., 2006).

Hypothalamus & Pituitary

Hypothalamus and pituitary are located deep inside the brain. They work together to control all the other glands in the endocrine system. Normally, chemotherapy does not affect hypothalamus and pituitary; however, abnormalities are commonly seen after radiation to the brain, face, or neck. The level of damage can be different depending on the amount of radiation and age of the child (Hobbie et al., 2006).

The most common long term effect on hypothalamus and pituitary is hormone deficiency, which mostly worse over time. That is, children who received radiation around their brain are likely to display short adult height. Because of the characteristic of treatments, children with brain tumor are at high risk of having a short adult height. In addition, children treated for leukemia with whole brain radiation, children who were treated with total body radiation prior to a bone marrow transplant, children who enter puberty before age 8, and children who had spinal radiation are likely to have a short adult height as well (Hobbie et al., 2006).

Thyroid

The thyroid is a small butterfly-shaped gland located in front of the trachea in the neck. It enlarges and becomes more active during puberty, pregnancy, or times of great stress. The thyroid’s functioning can be disrupted by radiation to the gland itself or to its regulator. Children or teens who had total body radiation, mantle radiation for Hodgkin’s disease, or head and neck tumors are at the high risk for a malfunctioning thyroid. The common impacts on thyroid because of radiation treatment are:
Primary hypothyroidism
Secondary hypothyroidism
Compensated hypothyroidism
Hyperthyroidism
Thyroid cancer

(Hobbie et al., 2006)

Testes

The testes are the male reproductive organs. Testes contain hundreds of densely coiled tubes which are called seminiferous tubules. Semineferous tubules contain spermatogonia which are cells that produce sperm. They are damaged by radiation, chemotherapy, or surgery (Hobbie et al., 2006).

Radiation

Spermatogonia are very sensitive to radiation. When children receive a certain amount of radiation, radiation can cause a temporary drop or stoppage of sperm production. If children receive high dose and long period of radiation treatment, children may become permanent sterility. The groups which are likely to receive high dose and long term radiation treatment are

- Boys treated for testicular leukemia
- Recipients of bone marrow transplants whose conditioning included radiation
- Boys or teens with Hodgkin’s disease treated with “inverted-Y” radiation
- Boys or teens with soft tissue sarcomas in the thigh, groin, or abdomen

(Hobbie et al., 2006)

Chemotherapy

Chemotherapy can be devastating to the production of sperm, although sperm production may resume months to years after chemotherapy ends. Not every drug that is used for chemotherapy affects testes; some types of drugs have strong influence on testes. The higher the dose of certain drugs for chemotherapy, the more damage may
occur to the sperm-producing cells. Also, the long term effect of chemotherapy seems to be age-related. That is, children treated before puberty usually have a normal puberty whereas children treated during adolescence can have testes problems (Hobbie et al., 2006).

**Surgery**

Surgery also can affect sexual functioning in the male childhood cancer survivors. For example, children who had an abdominal lymph node dissection may become impotent or may experience inability to ejaculate in adulthood (Hobbie et al., 2006).

**Ovaries**

Ovaries are the main reproductive organs of the female. Normal ovarian function is crucial for optimal growth, puberty, and fertility. Younger girls are more able to tolerate ovarian damage compared to older teens. However, ovaries contain a finite number of eggs, so any damage to them is irreparable (Hobbie et al., 2006).

**Radiation**

The treatment that has the most effect on ovaries is radiation treatment. Children or teens who received radiation to abdomen for the treatment of Wilms tumor, Ewing’s sarcoma, or lymphoma or total body irradiation are at high risk for primary ovarian failure. The effect of radiation on ovaries can be different depending upon the dose of radiation and the age of the child. When their ovaries were affected by radiation (the dose of up to 1000 cGy), older girls may stop having their periods but periods most likely resume their normal cycles months to years after treatment ends. However, children who received total body irradiation prior to bone marrow transplant may have ovarian failure; young girls may not start puberty and teens past puberty may stop having periods. In some cases, female who had bone marrow transplant never develop secondary sexual characteristic including breasts and pubic hair (Hobbie et al., 2006).
Chemotherapy

Ovaries have more resistance to chemotherapy rather than radiation treatment. It takes a very high dose of drugs to cause damage to ovaries. Some teens who received high dose drugs for chemotherapy may have ovaries problems or experience early menopause (Hobbie et al., 2006).

Many female survivors of childhood cancer are worried if they are able to have a healthy baby. Many researches reassure that “the children of vast majority of female survivors are just as healthy as those of the general population” (Hobbie et al., 2006, p.255).

Adrenal Glands

There are two adrenal glands on top of each kidney. This organ is durable to abdominal radiation; however, brain irradiation may occasionally disrupt the functioning of the adrenal glands (Hobbie et al., 2006).
Liver, Stomach, and Intestines

The liver, stomach, and intestines are part of the body’s gastrointestinal system, which is also called GI system (Hobbie et al., 2006).

Liver

The liver is located beneath the rib cage in the upper-right part of the abdomen, and it is the largest and most complex internal organ. Among childhood cancer survivors, inflammation of the liver used to be a common long term effect of childhood cancer treatment. Inflammation of liver can happen because of infection by viruses and damage from radiation and/or chemotherapy drugs. The condition of inflammation of liver is called hepatitis; there are three types of hepatitis: hepatitis A, hepatitis B, and hepatitis C. In addition to hepatitis, a small number of survivors of childhood cancer develop liver fibrosis (scarring of the liver). It can happen to those who received more than 4500 cGy of radiation to the liver, those who received strong chemotherapy, and those who received bone marrow or stem cell transplantation (Hobbie et al., 2006).

Stomach & Intestines

As for the long term effects on stomach and intestines, long term GI problems are not common in survivors of childhood cancer. However, some cancer survivors have fibrosis and enteritis. “Fibrosis is excessive formation of scar tissue, which can interfere with normal function of the intestines” (Hobbie et al., 2006, p.334). Also, “enteritis is inflammation of the lining of organs in the GI tract” (Hobbie et al., 2006, p. 334). These issues can be caused by radiation, abdominal surgery, chemotherapy, chronic graft-versus-host disease, and infection. When children have either fibrosis or enteritis, they may have adhesions, obstruction, ulcers, diarrhea, constipation, lactose intolerance, and mal absorption problems (Hobbie et al., 2006).

In addition to fibrosis and enteritis, some children can develop slow emptying of the stomach and reflux of food back into the esophagus. These problems are likely to happen after radiation or in survivors who had long term problems with vomiting while on treatment (Hobbie et al., 2006).
Brain and Nerves

Keene, Hobbie, and Ruccione (2006) explained the definition of nervous system in the body:

The nervous system in the body has two main parts: the central nervous system and the peripheral nervous system. The central nervous system is composed of the brain and the spinal cord. The peripheral nervous system is a network of nerves throughout the body. The central nervous system and peripheral nervous system work together to monitor, coordinate, and control all activities of the body. Changes in the functioning of the brain or nerves can profoundly affect both health and quality of life (p. 208).

Brain

The brain of children with childhood cancer can be damaged by tumor growth or treatments including chemotherapy, radiation, and surgery. Especially, treatment for leukemia, brain tumors, and tumors of the head and neck such as rhabdomyosarcoma can affect the brain with a high risk (Hobbie et al., 2006).

Chemotherapy

Chemotherapy, especially for leukemia, can damage children’s brain and be the cause of learning disabilities. The learning disability caused by chemotherapy is usually milder than the one caused by radiation. Since their brains are still developing, children less than 5 years old are at higher risk of brain damage caused by chemotherapy (Hobbie et al., 2006).

Radiation

The brain and the tissues of the brain are sensitive to radiation; therefore, radiation treatment strongly affects the brain of children with childhood cancer. The long term effects of radiation therapy on brain can be different depending on the dose and location of radiation, the child’s age, gender, and his/her vulnerability. Those who are at the highest risk are children under the age of 2; children between ages of 5 to 8 are relatively...
at high risk of being affected by radiation. As for gender consideration, girls are more likely to be sensitive to radiation than boys (Hobbie et al., 2006). Many children who received high dose radiation on their brain display cognitive long term effects including learning disabilities. The chapter 2 will explain more about cognitive long term effects of childhood cancer.

In addition to cognitive long term effects, children who received radiation on their brain may develop:

- Problems with balance and coordination
- Impaired growth
- Early or delayed puberty
- Second cancers
- Permanent hair loss or thinning hair
- Dental problems
- Hearing loss
- Cataracts
- Seizure disorders (can also be caused by chemotherapy and surgery)

(Hobbie et al., 2006)

**Surgery**

“Surgery to the brain can cause a host of late effects. The body system and amount of damage depend on the part of the brain that was operated on, the amount of healthy tissue that was removed, and complications after surgery” (Hobbie et al., 2006, p. 214).

Some statistics show that children who had surgeries near the brain stem had balance and vision problems. They also lost the ability to write with their dominant hands (Hobbie et al., 2006).
Nerves

The following descriptions are about long term effects on nerve systems caused by childhood cancer treatment.

- Children who received cranial radiation are likely to have chronic problems with strength and coordination. Children who had chemotherapy or radiation have long-lasting problems with sensation or motion.
- Survivors of brain tumors who were treated by high-dose radiation can develop various problems with the nerves months to years after treatment.
- Children with Hodgkin’s disease were used to be treated by high-dose radiation. Some of these children displayed neuropathies that affect sensation and function.
- Although it is not caused by treatments, children with some forms of tumors may have motion and function problems because tumors directly give nerves pressures.
- Chemotherapy often causes acute peripheral neuropathies that are characterized by foot drop, problems with balance, winging out of lower legs when running, and poor coordination.
- Some surgeries can cut nerves; therefore, they affect function or sensation. Late effects can be different depending on the place of the surgery. For example, children who received spinal cord surgery or urinary tract surgery may become unable to control urination or bowel movement.

(Hobbie et al., 2006)
Head and Neck

The head and neck are affected by tumors that grow around this area and by the treatments that destroy tumors. The parts of bones that are likely to have long term damage from cancer treatment are bone, soft tissues, sinuses, teeth, mouth, taste, esophagus, and vocal cords (Hobbie et al., 2006).

Bone growth

Many children who are treated by radiation experienced that their bone growth including the skull, face, and jaw stopped or slowed. Especially cranial radiation can inhibit normal growth and expansion of the skull. If children receive a certain amount of radiation on their jaw, they may experience underdevelopment of the mandible. In addition, children with retinoblastoma or rhabdomyosarcoma often have an altered appearance because they receive radiation near their eyes, and it causes the sockets to stop growing (Hobbie et al., 2006).

Soft tissues

When children have rhabdomyosarcoma, nasopharyngeal carcinoma, or sarcomas of the head and neck, they often have soft tissue damage as well as underlying bone damage in the irradiated tissues. Such injuries can slow down healing in the area and weaken bone by disrupting its blood supply. In addition, children with Hodgkin’s disease who were treated by mantle radiation are at high risk of having underdevelopment of the structures (Hobbie et al., 2006).

Sinuses

It is a common side effect of chemotherapy or/and radiation therapies that children or teens have acute damage to the mucous membranes in the nose and mouth. Specifically, many children and teens experience severe ulcerations or mouth sores during the treatment, which cause severe pain and make it difficult for children and teens to eat and drink. Usually, these conditions go away after the childhood cancer treatment; however, some childhood cancer survivors persistently have mucus membrane changes.
In addition, some children and teens under cancer treatments have scarring in the nasal passages, which can interfere with normal mucus production and result in chronic sinus infections (Hobbie et al., 2006).

Teeth

The radiation therapy and chemotherapy can affect both appearance and development of teeth. Radiation has a great impact on teeth when it is given in high dose to young children. The common long term effects of radiation and chemotherapy on teeth are: short or thin roots, absent teeth, abnormally small teeth, small crowns, poor bite, poor enamel, incomplete calcification, frequent cavities, enlarged pulp chambers, and baby teeth that don’t fall out at the usual time during a child’s development (Hobbie et al., 2006).

Mouth & Taste

Dry mouth and decreased amount of saliva are common long term effects on mouth among childhood cancer survivors. Saliva is a mix of secretions produced from the parotid gland, sublingual gland, and submandibular gland. These glands can be affected by a certain amount of radiation. Children with head or neck soft tissue sarcomas are at high risk of having trouble with their saliva production. The results of dry mouth and decreased amount of saliva are inability to taste food, teeth riddling with cavities, bad breath, and bone decay. In addition to radiation, very high dose of chemotherapy can also affect saliva production (Hobbie et al., 2006).

Decreased saliva production can affect a child’s sense of taste. In addition, since radiation can destroy the microscopic structures of the taste buds, children are likely to experience changes in taste as long term effects of childhood cancer treatments. In many cases, children are fond of foods high in salt and sugar which lead to problems with nutrition and dental health (Hobbie et al., 2006).

Esophagus

The esophagus is in charge of carrying food and liquids from the mouth to the stomach. When children are treated by radiation including mantle radiation and direct radiation
to the chest and neck, their stomach acid can flow up into the esophagus and can cause a burning sensation and tissue irritation. Furthermore, it causes swelling of esophagus and an inflammation, which make children have extreme pain and lose their appetite. In addition, Barrett’s esophagus and esophageal stricture can happen to children and teens after childhood cancer treatments (Hobbie et al., 2006).

Also, some children and teens have trouble with swallowing because of the damage from a tumor, prolonged vomiting from chemotherapy that damaged the esophagus, or complications from surgery or a tumor (Hobbie et al., 2006).

Vocal cords

When children receive a high dose of radiation, it can change their voices to high and thin. Children who received radiation to the neck are likely to develop voice change (Hobbie et al., 2006).
Heart and Blood Vessels

Heart, blood vessels, heart valves, and pericardium can be affected by certain types of radiation and drugs for chemotherapy, which occur during the treatment or months to years after completion of treatments (Hobbie et al., 2006).

The Heart

“The heart is a four-chambered and muscular organ that pumps blood throughout the body” (Hobbie et al., 2006, p. 286). The muscles in the heart consist of cells called myocytes. Chemotherapy drugs, especially anthracyclines, sometimes impact or destroy myocytes. Since the number of myocytes is finite, the myocytes destroyed by chemotherapy drugs cannot be recovered. In this case, the remaining cells enlarge and stretch to try to compensate for the damage, which causes thin and stiff ventricular walls and reduce the heart’s ability to contract effectively. In addition to chemotherapy drugs, irradiation, gender, and age can increase the risk of having myocytes issues (Hobbie et al., 2006).

In addition to myocytes issues, a certain chemotherapy drug called antharacyclines can interfere with the rhythm of the heart and on how signals are carried through the heart to make it beat regularly. The condition of irregular heart beat is called arrhythmia (Hobbie et al., 2006).

As well as chemotherapy, radiation treatment can affect the heart. “Children or teens who received high-dose spinal radiation of more than 3000 cGy, chest radiation, left flank radiation, or radiation directly to the heart are possible at risk” (Hobbie et al., 2006, p. 289). The long term effects of high dose radiation are restrictive cardiomyopathy and arrhythmias. Also, valves in the heart can be damaged by high dose radiation. Restrictive cardiomyopathy is the condition when the heart muscle becomes stiff and cannot adequately fill (Hobbie et al., 2006).

Blood Vessels

There are three types of blood vessels: arteries, veins, and capillaries. Among these three types of vessels, arteries are large vessels that carry blood away from the heart. Arteries
branch into smaller arteries and then go into arterioles. Usually, inside healthy blood vessels are flat and smooth; however, radiation and chemotherapy drugs can roughen the inside of blood vessels. These rough spots provide a site for fatty deposits called plaques and that is where plaque develops. This condition causes various problems. For example, the fatty deposits narrow the blood vessels and reduce flow of blood. Also, layers of plaque decrease the strength and elasticity of the arteries. Plaques roughen the lining of the vessel, allowing platelets to form clots in the rough spots. These clots can block flow in narrow arteries, reduce or stop the supply of oxygen to the body (Hobbie et al., 2006).

Heart Valves

The valves that control the flow of blood in the heart can become stiff or leaky after radiation (Hobbie et al., 2006).

Pericardium

As for the impact on pericardium because of childhood cancer treatments, pericarditis can be happened among children who receive chemotherapy and radiation. Pericarditis is an inflammation of the sac surrounding the heart. Children may have the condition during cancer treatment or the first year after treatment. This condition can be treated within a few months to years (Hobbie et al., 2006).
Skin, Breasts, and Hair

Skin, breasts, and hair are part of the integumentary system of the body. The roles of the integumentary system are to protect the body by keeping fluids in and foreign organisms out, to insulate the body and help regulate body temperature (Hobbie et al., 2006).

Skin

Skin is divided into two main layers: the epidermis and the dermis. Some types of chemotherapy, graft-versus-host disease, and higher doses of radiation can change the color of the skin. Also, some children and teens treated with certain medicine can develop darkened areas of the skin and nails. Pressure from trauma can also result in darkened streaks in the traumatized areas. However, these changes usually disappear over time. In addition to change of the skin color, the following effects can happen to the skin:

- Moles (children and teens who received radiation therapy)
- Scars
  - Extensive scarring from tumor removal surgery (children and teens who had solid tumors)
  - Scars from central line insertion and removal (children with leukemia and lymphomas)
  - Permanent tattoos and small black dots (most survivors treated with radiation)
- Stretch marks (children who gain weight because of the usage of steroids to treat childhood cancer)
- Radiation injuries (children who received high dose radiation)
  - Dry skin
  - Dark and/or light areas on the skin
  - Thinning of the skin
  - A spidery pattern of capillaries visible in the skin
- Ulcers on the skin
- Fast aging skin

- Damage to sweat glands, sebaceous glands, and hair follicles (can be permanent)
- The risk of skin cancer

(Hobbie et al., 2006)

Breasts

Radiation has impacts on breast especially on the developing breast among young women. As for childhood cancer survivors treated before puberty, their breasts may not grow well because their breasts were irradiated. Also, the breast bud is quite sensitive to radiation. High dose radiation can decrease breast development in the radiated area. In addition to development of breasts, children and teens may increase the risk of having breast cancer if their breasts were irradiated (Hobbie et al., 2006).

Hair

The treatment that has the most impact on the hair of children with childhood cancer is chemotherapy. It usually causes hair to fall out. In most cases, the hair grows back again but can be of a different color or texture than it was before the diagnosis and treatment. Children and teens who take cyclosporine for extended period of time may have excessive hair growth.

Although it is less likely severe compared to chemotherapy, radiation also damage the hair, especially the hair follicles. The higher the doses of radiation children receive, the more risk of permanent damage children have. For example, those who had over 1800 cGy may have permanently thinned hair, and the hair may not grow back (Hobbie et al., 2006).
Kidneys, Bladder, and Genitals

Kidneys and bladder are in charge of cleaning waste in the body.

Kidneys

In most cases, children who experienced childhood cancer have healthy kidneys in spite of receiving radiation and chemotherapy. However, some long term effects of radiation on kidneys develop among few cancer survivors including nephritis, renal artery damage, and tubular necrosis. Also, some types of chemotherapy also damage the kidneys (Hobbie et al., 2006).

Bladder

The bladder is a muscular bag located in the lower pelvis. The vast majority of childhood cancer survivors have a healthy function of bladder. However a few childhood cancer survivors may develop the following long term effects:

- Hemorrhagic cystitis
- Fibrosis
- A abnormal sized bladder
- Scar (children and teens who had tumors in the bladder or pelvic area)

(Hobbie et al., 2006).

Genitals

Genitals are human reproductive organs. The female organs include the ovaries, uterus, and vagina. The male organ includes testes (Hobbie et al., 2006).

Female

When children and teens have tumors in the pelvic area (which is very rare) including rhabdomyosarcoma, Ewing’s sarcoma, and osteosarcoma, they may get high dose radiation that can affect the growth and development of the vagina and/or uterus. Girls or teens who received more than 4000 cGy of radiation to a field that included the
vagina can also develop fibrosis and diminished vagina development. These conditions can alter sexual function and the ability to deliver babies vaginally (Hobbie et al., 2006).

**Male**

As for boys and men, those who had rhabdomyosarcoma, Ewing’s sarcoma, or osteosarcoma to the pelvis and received high dose radiation are likely to develop the risk of having damages to the prostate gland and the nerves that control sexual functioning. Also, children with testicular cancer or relapsed leukemia in the testes may need to remove a testicle and irradiate the area. Low dose of radiation may slow or stop the development of genitals (Hobbie et al., 2006).
Bones and Muscles

Long term survivors of cancer may have a number of complications to their bones and muscles. Radiation and chemotherapy can change both appearance and function of any part of the body (Hobbie et al., 2006).

Bones

There are approximately 206 bones inside the human body, all held in place through connective tissues such as ligaments and tendons. Since the structure of bones changes as children grow, cancer treatment may have strong effects on bones’ growth. Radiation, chemotherapy, and surgery are the major three sources of long term effects on bones (Hobbie et al., 2006).

Amputation

When children and teens develop a malignant tumor that extends to vital structures including major nerves and blood vessels, amputation of a limb may be inevitable. When children and teens experience amputation, they need a variety of support to cope with the situation and get used to the altered physical functions. Also, some survivors may experience phantom pain in the missing limb and develop problems with calluses or pain in the stump (Hobbie et al., 2006).

Limb radiation

High dose radiation and/or surgery to a limb to treat a solid tumor can cause bone growth to slow or stop. When only one part of the body is affected by cancer treatment, the discrepancy in length of limbs can happen. Also, survivors who had radiation to a limb may get fractures in the irradiated area if the bone weakened (Hobbie et al., 2006).

Spine radiation

Some children and teens receive radiation on only parts of the spine, which sometimes causes scoliosis (a sideways curvature of the spine). While the damaged part of spine stops growing, the undamaged part continues to grow; the spine curves like a bow.
Radiation to the whole spine can stop or slow the growth of the spine. Spinal shortening is best identified by measuring the sitting height of the survivors. Spinal shortening often happens among brain tumor survivors (Hobbie et al., 2006).

**Osteoporosis**

Some childhood cancer survivors have thinning of their bones and low bone density. Having this condition, children are likely to have broken bones and may develop osteoporosis. Osteoporosis is a disease of the skeleton that results from too little new bone formation or too much loss of bone tissue (Hobbie et al., 2006).

**Osteonecrosis**

Osteonecrosis is a condition caused by the death of the small blood vessels that nourish the bones. When children receive high dose radiation or long term use of high dose steroids, they tend to experience osteonecrosis. Children treated by bone marrow transplant or children with bone sarcomas are at high risk of having osteonecrosis (Hobbie et al., 2006).

**Osteoarthritis**

Osteoarthritis is a type of degenerative joint disease characterized by pain with activity. When children receive radiation to joints, they increase the risk of having osteoarthritis (Hobbie et al., 2006).

**Muscles**

There are more than 650 muscles in the human body. These muscles are connected each other by connective tissues including tendons and cartilage. Mainly, there are three types of muscles including skeletal muscle, smooth muscle, and cardiac muscle (Hobbie et al., 2006).

Radiation treatment may prevent health cells from growing in muscles, soft tissues, and bones. Muscle underdevelopment called hypoplasia is one of the common long term effects on muscles after radiation treatment. The weakening of muscle increases along with age and can severely affect survivors’ quality of life (Hobbie et al., 2006).
In addition, when children and teens have radiation to one side of the body while they are growing, they may have less muscle and fat tissue in the areas that were irradiated. This asymmetry body may alter their appearance (Hobbie et al., 2006).
Chapter 2:

Long Term Effects of Childhood Cancer ~ Cognitive ~

In this chapter, the focus is on long term effects of childhood cancer in terms of cognitive issues. After the treatment of childhood cancer, many cancer survivors experience some form of cognitive issues such as learning disability or memory disorder. Childhood cancer survivors are likely to have unique issues and these issues can affect their educational background. This chapter aims to clarify the cognitive issues of childhood cancer survivors and understand its uniqueness.
The Sources that Cause Cognitive Issues on Childhood Cancer Survivors

Considering the sources that have effects on children with childhood cancer in terms of cognitive issues, they can be broadly divided into two parts:

- Cancer treatments including chemotherapy, radiation, and surgery
- The length and high-frequency of hospitalization

(Keene & Oeffinger, 2001)

In addition to these sources, Sumpter (2005) described the additional factors that may place children and teens at increased risk for difficulties in school:

- Diagnosis of cancer at a very young age
- Numerous or prolonged school absences
- A history of learning difficulties before being diagnosed with cancer
- Cancer treatment that results in reduced energy levels
- Cancer treatment that affects hearing and vision
- Cancer treatment that results in physical disabilities

(p. 2)

Although it has not been proved yet, young girls are more vulnerable to lingering cognitive problems than boys (Sumpter, 2005).

De Haan, Grootenhuis, Langeveld, Last, Ubbink, and Voute (2003) found the relationship between childhood cancer treatment and educational achievement among childhood cancer survivors throughout their research:

The education achievement level of survivors with the history of childhood cancer was apparently lower than the people without the history of childhood cancer; female survivors of childhood cancer reported they were less likely to complete their high-school or attain advanced graduate degrees; and there were significantly differences between cancer survivors and the comparison group in terms of following normal elementary secondary schools, and many cancer survivors needed to be enrolled in learning disabled programs (p. 215).
The Long Effects of Cancer Treatments on Cognitive Development

The cognitive long term effects of childhood cancer treatments include the changes in the way children or teens think, remember, and learn. The common childhood cancer treatments that can affect children’s cognitive development are brain radiation, certain types of chemotherapy (intrathecal methotrexate & high dose systemic methotrexate), and brain surgery. Also, when children have a growing brain tumor, it may have an impact on children’s cognitive ability (Hobbie et al., 2006).

Among childhood cancers, leukemia, brain tumors, and tumors of the head and neck such as rhabdomyosarcoma tend to be at the high risk of having cognitive problems after the treatments. Since their brains are developing and growing, very young children, less than five and particularly less than two, are at higher risk compared to older children or teens (Hobbie et al., 2006).

Radiation

The tissues of the brain are very sensitive to radiation. Most children with leukemia receive either 1800 cGy or 2400 cGy radiation to the whole brain in order to avoid spreading leukemia. Also, many children who are going to have bone marrow transplant or stem cell transplant receive radiation to their brain. Children who received 1200 to 1800 cGy radiation often develop learning disabilities. It usually becomes evident gradually, beginning a year or two after the radiation treatment and continuing to develop up to 5 years after the radiation treatment. Learning disabilities include mathematics, spatial relationships, memory, problem solving, attention span, and concentration skills. Having learning disabilities may change children’s or teens’ learning style as well as social behaviors. When children at a very young age receive cranial radiation, it can affect children’s growth of the skull. It may leave children with a smaller head than they would otherwise have had. The smaller brain they have, the slower children have processing speeds. Slow processing speeds can have impacts on the ability to make good judgments (Hobbie et al., 2006).

Furthermore, high doses of radiation can cause slower brain processing speeds and greater drops in IQ scores (Hobbie et al., 2006).
Chemotherapy

Some types of chemotherapy drugs have impact on the brain. Intrathecal methotrexate and high dose methotrexate can cause learning disabilities that are sometimes subtle. As well as radiation therapy, younger children whose brains are developing and growing have higher risk of having learning disabilities rather than older children and teens (Hobbie et al., 2006).

Surgery

Surgery possibly affects children’s cognitive abilities. The body system and amount of damage can be determined depending on the part of the brain that was operated on, the amount of healthy tissue that was removed, and complications after surgery (Hobbie et al., 2006).

Typical Problems of Possible Learning Disabilities

When children or teens have learning disabilities due to childhood cancer treatments, they may display problems in terms of:

- Handwriting and spelling
- Reading or reading comprehension
- Understanding math concepts, remembering math facts, comprehending math symbols, sequencing, and working with columns and graphs
- Remembering and coping shapes
- Learning to ride a bike or tie shoes
- Auditory or visual language processing including trouble with vocabulary, blending sounds, and syntax
- Attention deficits, either inattentive or hyperactive or both
- Short term memory and Information retrieval
- Social maturity and social skills
- Recognizing faces and understanding facial expressions or gestures
- Understanding deceit, cunning, or manipulation
- Planning and organization skills (Keene et al., 2001)
The Effect of the Length and Frequency of Hospitalization

Although schools are the primary place where children learn and develop their cognitive skills, children under treatment of childhood cancer are likely to be absent from school. Children who receive bone marrow transplant or stem cell transplant need to be hospitalized for a long term; children who receive chemotherapy need to be frequently in and out of the hospital. Even when they complete all cancer treatment and go back to school, they may not be able to behave the way they used to. Since their body is still vulnerable and weak, they may not feel good enough to participate in the class or may feel fatigued due to the late effects of childhood cancer treatment.

In addition, children and teens that completed cancer treatment and go back to school may not be able to attend particular classes, especially physical education classes and club activities because their physical functions have not fully recovered from cancer treatment.

Children and teens are able to receive additional education supports during hospitalization. Also, various legal services can be available for children who have troubles with learning after the treatment of childhood cancer. However, it is challenging for them to catch up with classes and learning. They may need to drop classes or cannot go to the next grade.

In this case, communication between children, their parents, and teachers is essential. According to Hodder & Keene (2001), the parents and teachers need to share the following information for the better educational supports for children after the treatment of childhood cancer:

- The student’s health status and its probable effect on attendance
- Whether the child will attend full or half days
- Whether the child can attend unrestricted general physical education classes, general physical education with restrictions, or Adaptive Physical Education for disabled children
- How much recess is allowed
- A description of any changes in the child physical appearance
- The child’s feelings about returning to school
- Any anticipated behavioral changes resulting from medication or treatment
- The possible effects of medications on the child’s academic performance
- When any medications or other health services need to be given at school
- A reminder to never give any medication, especially aspirin, which can cause uncontrollable bleeding, without parental admission
- Any special considerations such as extra snacks, rest periods, extra time to get from class to class, use of the nearest restroom, and the need to leave for the restroom without permission
- Dietary restrictions
- Concerns about exposure to communicable disease
- A list of signs and symptoms requiring parent notification
- A reminder that the teacher’s job is to teach, and the parent and nurse will take care of all medical issues

(Para. 6)
This chapter focuses on psychological issues that childhood cancer survivors are likely to experience. Even though children and teens successfully complete their cancer treatment, it does not mean they are free from all the stress associated to cancer. Childhood cancer survivors have different types of emotions from children under treatment of childhood cancer.
The Long Term Effects of Childhood Cancer Treatment: Psychological Issues

During childhood cancer treatments, children and their families experience a variety of emotions and distress including fear of painful treatment, frustration of being separated from their home, and anxieties whether the cancer can be cured or not. When children with childhood cancer complete their cancer treatments, they become free from some stressful emotions; however, completion of childhood cancer may give children and their families, different types of psychological issues. “No matter what age a child is during treatment, potentially long-lasting emotional effects may occur” (American Society of Clinical Oncology, 2011, para.6). It does not mean that all cancer survivors have long lasting emotional issues, but there are several common issues among childhood cancer survivors in spite of their developmental age. The following are common psychological issues children with childhood cancer and their families may encounter after the treatment:

- Fears of recurrence
- Anniversary reactions
- Grief and loss
- Anger
- Anxiety and depression
- Survivor’s guilt
- Post traumatic stress

The occurrence of these psychological issues can be determined by several factors including:

- Possibility of recurrence of childhood cancer
- Dealing with physical changes that result from the cancer or its treatment
- Understanding from others including friends, classmates, coworkers, and families
- The child’s developmental age
No one chooses to have childhood cancer; however, in many cases, having an experience of childhood cancer may have positive effects on childhood cancer survivors. They are likely to mentally strong because of the series of hard cancer treatments and the incident that they have a life-threatening illness. At the same time, they do feel emotional distress, and sometimes those emotional distresses seriously affect the childhood cancer survivor’s life.

**Fears of recurrence**

Even though the treatments for childhood cancer have improved, and many children with childhood cancer are able to recover from the condition and lead a normal life just like other people without the history of childhood cancer childhood cancer survivors always have to think about the possibility that cancer might relapse. After the treatment of childhood cancer, children and their families may return to the normal life that they used to have before cancer; however, anxiety towards relapse cannot be separated from their mind. “Many feel anxious when an anniversary date approaches or it is time for a medical checkup. After many years of the treatment, childhood cancer survivors may still have nightmares or anxieties”(Hobbie et al., 2006, p. 27). The feeling towards recurrence is unstable; sometimes childhood cancer survivors may be obsessed with fear towards recurrence, but they may not think about it at all some other time. In many cases, childhood cancer survivors tend to increase their fears when their annual follow-up is coming. When childhood cancer survivors increase their fears extremely, some mental supports are needed for them such as support group or counseling (Hobbie et al., 2006).

**Anniversary reactions**

Anniversary may mark the last day of treatment, the date of the diagnosis, or the 5 year remission date. The reaction towards anniversaries is different depending upon the family. Many families stated that anniversary is a time for pain or joy. No matter how they celebrate anniversaries, they tend to bring up a variety of emotional reactions. Some families may appreciate that their child has been healthy without further recurrence of cancer; other families may think of the time while their child was under treatment for cancer. If childhood cancer survivors do not have any long term effects
from their cancer treatment, they and their families may forget the anniversaries or may not celebrate. Children and their families who are struggling with a lot of long term effects may think each day is celebrated blessing and needs to be celebrated. In addition, some families dare not to celebrate anniversaries because they do not want to remind their child of memories of hard time. On the other hand, others decide to remember the anniversaries and give thanks for their life and health. The ways families deal with anniversaries need to be respected, and it is important for health care professionals to recognize families have their own way to celebrate anniversaries (Hobbie et al., 2006).

Grief and loss

Hobbie et al., (2006) state “Losses come in all shapes and forms and may emerge or continue to exist for many years, or even a lifetime” (p. 33). Children who experienced childhood cancer and their families are likely to experience both relief and loss. The relief from cancer and its treatment is the universal feeling among childhood cancer survivors and their families; however, the sense that the world is a safe place is the most common loss as well. Usually, children think that they never die before parents and have a happy life without having any life-threatening condition. However, childhood cancer robs these beliefs from children. Once this belief gets lost, it is hard for childhood cancer survivors to make up for it; they may constantly need to think their life may change or they may die before their parents. Also, many childhood cancer survivors start to believe that their life is so fragile that can easily be changed (Hobbie et al., 2006).

In addition, childhood cancer and its treatment can cause a variety of physical loss including loss of abilities, life prospects, skills, or body parts. As introduced in previous chapters, some children with osteosarcoma may experience amputation of leg, and some children with brain tumor may have trouble with their memory due to their cancer treatments. These physical losses affect children’s development. For example, even though children in school age are usually expanding their relationship from their family to peers, childhood cancer may limit opportunities to develop friendship among children with childhood cancer. Also, physical changes can strongly affect teenagers’ body image. These mental losses can be count as loss. The
grief and loss children experience can be changed as they get older; some loss will fade but other loss may become deeper. It is important for health care providers and families not to assume childhood cancer survivors do not have any problem since several years have passed since the end of cancer treatments (Hobbie et al., 2006).

_Anger_

Anger is also a common feeling childhood cancer survivors have. Many childhood cancer survivors and their families experience strong feeling of anger because their normal life was robbed by childhood cancer. Even after treatment, they have anger for a long term and they may ask “how did this happen to me?” or “when will I be free from fear of recurrence?” Although excessive anger might cause problem to childhood cancer survivors, it is important to recognize that feeling of anger is normal for them as well. What is most important for them is to allow anger to manifest itself instead of keeping it stored. Also, just like grief and loss, childhood cancer survivors feel anger differently as they get older. They may feel anger for different reasons; for example, some childhood cancer survivors may have strong anger when they found out they are not able to have a baby because their reproductive system was affected by cancer treatment. If their anger is too strong to handle, it is recommended to ask professional help including counseling or peer support group (Hobbie et al., 2006).

_Anxiety and depression_

Anxiety and depression are considered as similar emotions, but they are actually completely different. As for anxiety and depression that childhood cancer survivors are likely to experience, these two feelings can be seen as two sides of the same coin. Hobbie et al., (2006) described that “Anxiety is fear related to losses that may occur in the future, while depression is sadness related to losses that occurred in the past” (p. 37). When childhood cancer survivors deal with their emotions, both anxiety and depression can be common for them (Hobbie et al., 2006).

One of the most common anxieties that childhood cancer survivors tend to have is related to the fear of a relapse or fear of long term effects. When childhood cancer
survivors have high level of anxiety, they may become afraid of knowing their condition; some of them may stop going to cancer follow up clinic or become embarrassed or ashamed of their concerns towards their body and health. Generally, young adults are not worried if they have cancer or not; therefore, some young adults who experienced childhood cancer become tired of having concerns about their health condition. They may keep thinking that they are different from other healthy young adults. One important thing that health care providers need to keep in mind is that there can be a gap between doctors and childhood cancer survivors. Doctors may think their patients do not have any concerns because patients recovered from cancer years ago; whereas many childhood cancer survivors may increase their concerns along the way. If healthcare providers do not respect their patients’ concerns, childhood cancer survivors may hesitate to share their concerns with them in order not to be seen as complainers. It is important for health care providers to become sensitive to their patients’ feelings (Hobbie et al., 2006).

When it comes to depression, depression can be clearly distinguished from sadness. Sadness can be normal a feeling, but depression is more serious and can take over sadness. Childhood cancer survivors who have strong depression may think their life is worthless and may not be able to find the meaning of life. This feeling can prevent them from seeking or receiving appropriate care from health care professionals. Both health care providers and families of childhood cancer survivors need to carefully observe how much depression childhood cancer survivors are experiencing so that they can offer support immediately (Hobbie et al., 2006).

Survivor’s guilt

Some emotions are common among childhood cancer survivors and children who are currently fighting childhood cancer; however, survivor’s guilt is a typical emotion among childhood cancer survivors. Even though the survival rate of childhood cancer has been rising year after year, some children with childhood cancer are still not able to recover from cancer. When children lose their peers, they may feel strong survivor’s guilt and ask themselves why they survived while their friends did not.
This survivor’s guilt makes them think that life is going to be quite short; they may start pushing themselves hard.

Another type of guilt is related to long term effects of childhood cancer. Some childhood cancer survivors have a variety of long term effects including physical ability or cognitive ability. In order to maintain their life, they need assistance from their family members. In that case, they may feel strong guilty to limit their family member’s daily life (Hobbie et al., 2006).

*Post traumatic stress*

When children are under cancer treatment, they do their best to defeat the cancer. Once they finish their cancer treatment, they come to realize there is also an emotional price to pay. They somehow become burn out and have various unsolved emotions. The harder children fight against childhood cancer, the more they may have unsolved emotions. These unsolved emotions do not vanish with time, but they may grow stronger and then erupt. This condition is called post traumatic stress disorder (PTSD) (Hobbie et al., 2006).

Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) provides the definition of PTSD:

PTSD always follows a traumatic event which causes intense fear and/or helplessness in an individual. Typically the symptoms develop shortly after the event, but may take years. The duration for symptoms is at least one month for this diagnosis. Symptoms include re-experiencing the trauma through nightmares, obsessive thoughts, and flashbacks. There is an avoidance component as well, where the individual avoids situations, people, and/or objects which remind him or her about the traumatic event. Finally, there is increased anxiety in general, possibly with a heightened startle response (American Psychiatric Association, 2004, para. 2).

The prognosis of PTSD is varied, but PTSD can be treated completely. The assistance from healthcare providers is necessary for the treatment of PTSD (Hobbie et al., 2006).
*Posttraumatic growth*

Although a variety of negative emotions were still present with childhood cancer survivors, these individuals also reported that the cancer experiences changed their point of view on life and strengthen them mentally.

Alderfer, Barakat, and Kazak (2006) researched posttraumatic growth symptoms among adolescent survivors of cancer and their mothers and fathers by conducting self-report measures. A majority of adolescents and their mothers and fathers reported posttraumatic growth. The greater they perceived treatment as severe and life-threatening, the more they became aware of posttraumatic growth.
Chapter 4:

Long Term Effects of Childhood Cancer

~ Social ~

The main focus of this chapter is social long term effects of childhood cancer. After the treatment for childhood cancer, the relationship or social interaction with others may change among childhood cancer survivors. Those changes include the relationship with parents, siblings, and friends. Also, marriage, job, and education can be affected by childhood cancer. This chapter clarifies how childhood cancer affects survivors’ social relationships.
The Long Term Effects of Childhood Cancer Treatment: Social Issues

As the previous chapters described, there are a variety of long term effects of childhood cancer; the cancer history and its treatment can strongly affect the life of childhood cancer survivors both physically and emotionally. However, in addition to these issues, social aspects and relationships need to be taken into consideration as well. Because of cancer experience and its long term effects, childhood cancer survivors may realize that the relationship with their loved one is no longer the same as it was before having cancer; jobs, marriages, and education might be affected by the cancer as well. However, many childhood cancer survivors reported that cancer experience gave them benefits to some extent. Some survivors could find out the meaning of life and realized how human life is precious. Also, some of them chose their future career by reflecting on their cancer experience. Although childhood cancer experiences can have positive effects on childhood cancer survivors, it is also important to understand that many childhood cancer survivors have trouble in terms of social aspects and are struggling with maintaining healthy relationships with their loved ones after cancer treatment. The following is the topics that cancer survivors are likely to be worried about.

- Relationship with parents
- Relationship with siblings
- Relationship with friends
- Dating and marriage
- Fertility
- Returning to school and education
- Job opportunities and workplace
Relationship with parents

Childhood cancer is a life-changing experience for both children and their families. During the cancer treatment and after the treatment, family dynamics and their daily life inevitably change. Most of the times, parents play the main role of caretaker to their child during and after the cancer treatment; therefore, parents may struggle to balance taking care of their ill child with their family’s daily routine (Hobbie et al., 2006).

Thinking about the relationship between parents and childhood cancer survivors, one of the most common issues is parents’ over-protectiveness. Since children who just finished cancer treatments are physically weak, they need attention from adults, especially from their parents. Parents may pay extra attention to their child’s diet, interaction with peers, and school life; they especially worry about situations when they cannot observe their child such as during school. However, just like children without any history of cancer are getting independent from their parents, childhood cancer survivors need to be independent from their parents as they grow. This is a natural process of child development. If parents excessively protect their child, the child may have trouble with social skills and interaction.

Childhood experiences among teenagers may have strong influence on their sense of independence. “At a time when they are gradually withdrawing from the family and beginning to function autonomously, they suddenly become dependent upon medical personnel to save their lives and on their parents to provide emotional and physical support (Hobbie et al., 2006, p. 52)”. It can be quite stressful for teenagers because they encounter conflict between being independent and being dependent on their parents. Some teenagers may become rebellious but others may become extremely obedient because they feel bad towards their parents who gave all the energy to their child’s care (Hobbie et al., 2006).

See “Chapter 6” for more information about family members’ feelings and Concerns towards childhood cancer and its late effects.
Relationship with siblings

As well as parents, siblings of childhood cancer survivors are strongly affected by the cancer experience. When they find out that their sibling has cancer, they surely are worried about their brother’s or sister’s condition. However, at the same time, they may have more complicated feelings towards the situation, which are different from feelings parents have. “Childhood cancer survivors themselves often have strong feelings about the effect their cancer had on family functioning and the long-range effects on siblings” (Hobbie et al., 2006, p.59).

Some childhood cancer survivors mentioned that they felt strong guilt towards their brother/sister because they brought disruption to their family and received all attention from their parents. This feeling of guilt may not be appeared while they are fighting cancer; they realize how this experience affected their siblings after the treatment. Also, childhood cancer survivors sometime have not rebuilt the relationship with their siblings after the treatment. Siblings may be confused how to get along with their family member who just finished childhood cancer treatment. Childhood cancer survivors are also struggling with solution for the feeling of guilt. In this case, support from other family members, especially parents, is necessary. In addition, family therapy can be effective in exploring and working out ways to communicate well to support one another (Hobbie et al., 2006).

See “Chapter 6” for more information about family members’ feelings and Concerns towards childhood cancer and its late effects.
**Relationship with friends**

- Losing friends

After treatment of childhood cancer, many survivors encounter the conflict with friends they have known since before having cancer. Some cancer survivors feel different from their peers. Some feel more mature or more empathetic and understanding of others. Other cancer survivors may feel that their concerns, interests, values, or perspectives have changed after the cancer treatment. Because of these changes, many childhood cancer survivors feel disconnected from their peers or even stop contacting them. Losing friends or changing friends can happen not only because of changes of children with childhood cancer but also because of friends’ emotional changes. Many friends may move on to other friendships while the child is under treatment for childhood cancer just because they are not able to spend time with the child. Also, some friends are so confused about how to communicate with the child with childhood cancer that they may try to avoid contacting the child. Many childhood cancer survivors reported having feelings of rejection or betrayal. To make matters worse, some childhood cancer survivors receive teasing from their peers in the classroom (The National Children’s Cancer Society, 2011).

It can be a natural matter that childhood cancer survivors lose their friends and make new relationships with other people. However, if childhood cancer survivors lose their friends because of ignorance about childhood cancer, some types of interventions are effective by teachers, parents, or other healthcare professionals. In this case, having same level of understanding among teachers, parents, and health care professionals and cooperating with each other are essential. It is healthcare professionals’ and parents’ responsibility to tell teachers about what they want the child’s classmates to know about the child’s condition. Based on the information from parents or healthcare professionals, teachers have to explain their students about the child with cancer in order to not only protect the child but also help students understand the child’s condition and develop compassion (The National Children’s Cancer Society, 2011).
Children’s age can determine whether childhood cancer survivors lose their friend or not. The friends’ relationship of children around preschool or early school age is mostly determined by what classroom they are assigned to or whom they share their daily life with. These types of relationships can strongly be affected by the environment; thus, it is hard for childhood cancer survivors to keep such a relationship once they are separated from the environment. When it comes to middle school-age children, friendships often dissolve. In this age group, children are forming social groups and feel high peer pressure all the time; therefore, compassion is often a temporary casualty of puberty. Teasing is a typical behavior among this age group. As they get older, they become more mature and understand the situation of the child with childhood cancer. Among adolescents, friendships remain or even become stronger throughout the treatment (Hobbie et al., 2006).

- Making new friends

As the previous section explained, the experience of childhood cancer can change the child’s value and perspectives. “Some feel that they are rejected socially due to their cancer history, while others feel mature beyond their years because of what they have experienced” (Hobbie et al., 2006, p.65). This change creates differences between survivors and their peers, and childhood cancer survivors start looking for the new relationship that matches their values and perspectives (Hobbie et al., 2006).

In some cases, childhood cancer survivors find it difficult to make friends with others or seek for new relationship because of several reasons. One of the reasons is that some childhood cancer survivors are so mature compared to their peers that they can be disappointed when nobody is as mature as they are. Some may worry about making new friends because they do not want to cause their friends pain in the event cancer returns. Others can be disrupted in making friends due to physical long term effects that change their appearance such as hair loss, short height, amputation, or thinness. In addition to physical long term effects, sometimes cranial radiation can affect children’s social skills; children may have trouble communicating with their peers (Hobbie et al., 2006).
When children experience conflict to develop new relationships, it is recommended for parents to have the child participate in the new opportunities such as a community interest groups, clubs, and recreational activities. These opportunities can be helpful for childhood cancer survivors to build new relationships with others who have same interests as them (The National Children’s Cancer Society, 2011). In addition, peer support groups are usually great help for childhood cancer survivors. The most beneficial aspect of these groups is that the participants can listen to the experience childhood cancer survivors have without any judgment because most participants have somehow had the same experience related to childhood cancer. In these support groups, childhood cancer survivors are treated as normal like other children without the history of childhood cancer. Children can share their feelings with others who have same experiences; children can create strong and long-lasting bonding through the support group. Since some childhood cancer survivors avoid participating in the group in order to forget childhood cancer experience and live a life like other healthy children, it is important for parents to respect what children want to do in terms of their peer relationships (Hobbie et al., 2006).

**Dating**

- **Body image**

No matter what level of long term effects they have, many adolescents encounter challenging times when they are going to be young adult. The experiences of childhood cancer make them struggle with identity and self-esteem including appearance and body image. As they worry more about how they are different from others, they increase anxiety towards sexual interest and puberty. Cancer treatment including chemotherapy and radiation therapy may have various long term physical effects including weight loss or gain, surgical scars, and any change in their appearance. Also, radiation therapy can damage their reproductive systems; female may not have periods. These physical long term effects may strongly affect their self-esteem and make them uncomfortable in terms of dating and sexual relationships (The National Children’s Cancer Society, 2011). Even if they have no
physical scars, they may have an altered sense of their own appearance. When adolescents consider themselves unattractive, they may find it difficult to convince themselves that someone they want to date might think they are. “Many single cancer survivors avoid dating because they fear being rejected” (Cancer.Net, 2011, para. 2).

As for the relationship, there are two common types of sexual relationship among childhood cancer survivors. First, “some young adults rush into relationship while they are feeling vulnerable and uncertain of who they are or what they want” (Hobbie et al., 2006, p. 77). On the other hand, some childhood cancer survivors mentioned that having cancer made them mature and this maturity helped them find a partner they can share feelings with (Hobbie et al., 2006).

- Disclosure and Communication

When childhood cancer survivors find their possible future partners, they encounter the problem of how to disclose their condition to their partner. Some cancer survivors may think that talking about their diagnosis and treatment is too personal to share with someone. Some may worry that the experience may scare away the potential partner. However, in the meantime, they have feelings that not telling about cancer feels dishonest or insincere. The time when to tell about the cancer experience can be different depending on individuals; however, it may be better for both cancer survivors and their partner to wait until both of them develop a mutual level of trust and caring, and the relationship become serious. Although it will be one of the most difficult times for childhood cancer survivors, sharing their experience with others whom they want to trust is unavoidable in order to build a trusting relationship. The information childhood cancer survivors may need to share is: the possibility of recurrence, their ability to have children, and whether their life expectancy is shortened. To support childhood cancer survivors to communicate with their partners, they might need help from healthcare providers such as counselors or social workers (Cancer.Net, 2011).
Marriage and Fertility

Just like other people without history of childhood cancer, marriage is one of life’s major events for childhood cancer survivors. Long term effects of childhood cancer or feelings coming from the experience may make survivors hesitate to link their future to another (Hobbie et al., 2006). In fact, “adults who are childhood cancer survivors are 20 to 25 percent less likely to marry compared with their siblings and the American population. The trend held across all age groups over 25 years old” (Landau, 2009, para. 4). Even when childhood cancer survivors find their partner and get marry, they encounter challenging situations.

Among childhood cancer survivors, one of the biggest issues is fertility issues; childhood cancer survivors may choose not to marry because of this issue or may struggle with this issue after marriage. Although evidences indicate that cancer survivors are not at a greater risk of being unable to have babies or having children with disabilities, many childhood cancer survivors are worried whether they are able to have babies without disabilities. The nature and degree of fertility are determined by various factors: types of cancer, the location of cancer, the types of therapies, gender of the survivors, and age at diagnosis. It is strongly recommended for female cancer survivors to pay attention to their periods. They may need to contact their doctors or other healthcare providers if their periods become irregular or completely stop. Since fertility can decline even with regular periods, childhood cancer female survivors should not rely on their periods as evidence of fertility; they can ask doctors to check their hormone levels. Whether they are able to have babies or not, physical and emotional long term effects of childhood cancer impact desire to have children. One of the common emotions that affect their desire to have babies is fear that their cancer might relapse. Some childhood cancer survivors are afraid of having babies because they do not want their children to encounter the situation that their parent has cancer. It is important for healthcare providers to encourage childhood cancer survivors to talk about periods or other concerns related to fertility even though they may be uncomfortable topics for childhood cancer survivors. Some of them may hesitate to open the discussion especially when their doctors are different gender; therefore, healthcare providers need to cooperate with other professionals.
who provide psychosocial supports in order to create comfortable environment for childhood cancer survivors. Also, healthcare providers need to inform childhood cancer survivors to use birth control despite of the condition that they are able to be pregnant. Even though they are told by doctors they are infertile because of cancer treatments, they may find out that they are not infertile after becoming pregnant unexpectedly. In spite of the ability, educating usage of birth control is encouraged for childhood cancer survivors, especially among teenage groups. In addition, some childhood cancer survivors feel they lost support from their family once they found out they are infertile. Lack of support related to fertility issues strongly affects their self-esteem; they may have hard time to admit not to be able to have children. Healthcare providers who are in charge of psychosocial supports can play important role for these emotional issues (Hobbie et al., 2006).

In addition to fertility issues, childhood cancer survivors often worry about the health of their future children. They are afraid that their baby might be born with serious or life-threatening conditions due to cancer treatments, or their cancer may be passed on to their babies genetically (Keene et al., 2006). However, not every type of cancer can be passed from parent to child genetically. If they are extremely worried if their cancer passes on to their child or not, they may be able to take a genetic counseling and genetic tests (Hobbie et al., 2006).

**Education and Returning to School**

Experience of childhood cancer may lead unique needs among childhood cancer survivors. After the long-lasting treatments and frequent hospitalization, many children and family have a major concern about returning to school smoothly. The treatments of childhood cancer including chemotherapy, radiation therapy, and surgery can affect children’s school performance physically and cognitively. Numerous and lengthy hospitalization also make childhood cancer survivors feel difficult to return to school. Since either their body has not been fully recovered or has been affected by cancer treatments, many childhood cancer survivors may still have fatigue, hearing loss, or gross/fine motor impairments. Also, some particular
treatments such as cranial radiation may affect children’s brain that causes learning disability, trouble of memory, or social difficulties (See chapter 1 & 2 for detailed information).

When childhood cancer survivors and their parents encounter difficult situations related to school issues, they will find it helpful to understand which laws protect childhood cancer survivors. In the United States, there are mainly three public laws that can protect the rights of students who have experienced childhood cancer and have special educational needs.

- The Rehabilitation Act of 1973 – Section 504
  “All childhood cancer survivors in the United States are eligible for accommodations under this law, and all educational institutions receiving federal funding are required to comply” (CureSearch, 2008, p. 3). This accommodation includes curriculum and the environment.

- The Individuals with Disabilities Education Act (IDEA)
  “The IDEA legislation requires that public school provide free and appropriate education in the least restrictive environment for disabled students between the ages of 3 and 21 years of age” (CureSearch, 2008, p.3). Childhood cancer survivors who have particular long term effects including learning disability, traumatic brain injury, or other health impairment can qualify under this law. If the child was notified that he/she was qualified under this law, the child receives individualized plan, which is called Individual Educational Plan (IEP), to meet the identified specialized educational needs. It includes, specialized classroom placements, psychological services, adaptive physical education, physical occupational and speech/language therapy, and transportation services.

- The American with Disabilities Act (ADA)
  “The ADA law protects against discrimination in employment, transportation, communication, government and public accommodations for people with disabilities” (CureSearch, 2008, p3). Under this law, childhood cancer survivors are guaranteed that they have right to access to public spaces, events, and opportunities just like other healthy children.
As long as childhood cancer survivors are protected by the law, they have rights to receive appropriate supports from school in order to deal with their learning problems. Teachers can modify their curriculum and environment depending on the child’s needs. These strategies are available to meet the child’s special educational needs: seating near the front of the classroom, minimizing the amount of written work required, use of tape-recorded textbooks and lectures, use of a computer keyboard instead of handwriting, use of a calculator for math, modification of test requirements, assignment of a classroom aide, extra help with math and reading, access to an elevator, extra time for transition between classes, and duplicate set of textbooks to keep at home (CureSearch, 2008).

In addition to those supports for the childhood cancer survivors with special educational needs, people who support the child need to consider the relationship between the child and other classmates. Whether the child has healthy social interaction or not can determine the child’s motivation to go to school. As this chapter describes the relationship between childhood cancer survivors and their friends, the relationship between friends can be changed by the childhood cancer. The younger they are, the more their relationship is affected by the environment; it means that children who have been hospitalized for a long period have hard time to keep the relationship with their friend because they are not able to spend time with friends. In order to encourage children to go back to school after treatment of childhood cancer, cooperation between family, healthcare providers, and school is essential. Even though the child does not have much health issues that qualifies them as students with special needs, it is important to give enough information about the child’s condition to school. Healthcare providers need to inform the school what the child’s condition is and what attentions are needed to support the child. Family, especially parents, is responsible to discuss what they want school to do for their child’s school life. Then, school and teachers are in charge of providing additional supports for the child based on needs and helping other students to understand the child’s condition (The National Children’s Cancer Society, 2011).
Job Opportunities & Work Place

Along with the improvement of childhood cancer treatment, the number of childhood cancer survivors is increasing; thousands of childhood cancer survivors have been staying healthy, entered college, and graduated. Now, 1 in every 450 young adults will be childhood cancer survivors. The condition of childhood cancer survivors can vary; some of them have a variety of long term effects or others have no long term effects and live just like other healthy peers. However, many childhood cancer survivors come to realize that their cancer history still affect their life even over years later when they try to get jobs. Since most childhood cancer survivors get all kinds of jobs, some survivors have hard time to find a job or encounter job discrimination. Getting a job and working can fulfill various needs for adults: financial independence, financial security, health insurance, self-esteem, and self-confidence. By working in the society, people feel they are part of the society and contribute to the society as one mature adult. Supporting childhood cancer survivors to find a job is important in order not only to encourage them to be financially independent but also to keep their dignity as human beings (Hobbie et al., 2006).

One of the main factors that keeps childhood cancer survivors from getting job or working is various long term effects of childhood cancer or its treatment. Chapter 1 introduced a variety of physical long term effects after childhood cancer treatments. Treatments for childhood cancer including chemotherapy, radiation therapy, and surgery can affect patients’ body physically and cognitively. Childhood cancer survivors who have fatigue due to cancer treatments may be having a hard time to find a job that fit their condition. Some cancer survivors have problem for their memory due to cranial radiation; it makes them difficult to find a job. Some male childhood cancer survivors mentioned that they have a hard time to find a job that requires less physical labor such as desk works or indoor jobs. Even though these jobs are appropriate for them, there are still prejudices that these jobs are for females, and males who want these job are considered unusual (Hobbie et al., 2006).

Regardless of long term effects of childhood cancer, the history of childhood cancer can still create barriers to finding, continuing, and changing their job. Some
childhood cancer survivors are declined to the job because they told the company about their history of childhood cancer in the job interview. Some of them may be confused whether they should conceal the history of childhood cancer or reveal it. They are afraid that the company may have a negative impression of them due to their health history. Even if they are able to get job, they may receive job discrimination from their coworkers. (Hobbie et al., 2006).

In order to deal with these situations, it can be helpful for them to know their rights and understand how to protect themselves. Considering laws that protect people from discrimination, the history of childhood cancer should not be a barrier to getting jobs or working unless childhood cancer survivors still have specific mental or physical limitations that can affect the type of work they are applying for. Many U.S. laws including federal and states defined that an employer who is relevant to the law cannot treat a childhood cancer survivor differently from other employees. The following laws are important for childhood cancer survivors to know to protect their own rights and prevent them from being discriminated.

- The Americans With Disabilities Act
- The Family Medical Leave Act of 1993
- The Genetic Information Nondiscrimination Act of 2008

Also, it is recommended for cancer survivors to consider asking the doctor for a letter stating their ability to work and to seek counseling from a professional or support from other cancer survivors (Cancer Net, 2011).
This chapter focuses on children’s developmental aspects. There are many common long term effects of childhood cancer despite the child’s age. However, children have different types of issues depending on their developmental age. In order to support children who are suffering from long term effects of childhood cancer, it is essential for healthcare providers to have the knowledge of child development. This chapter gives the information of children in each developmental stage and their stressors towards hospitalization and long term effects.
Infants & Toddlers

Developmental Tasks

According to Erikson’s child development, infants are in the stage of “Trust vs. Mistrust”. They are dependent on adults and are building a concept of trust when their needs are met by parents or caregivers. Also, in Piaget’s developmental theory, infants are in the stage of “Sensorimotor”. In this stage, infants explore the physical self and the environment, and they are acquiring a sense of cause and effect. When it comes to toddler, based on Erikson, they are in the stage of “Autonomy vs. Shame and Doubt”. They are developing their cognitive abilities and start seeking for their autonomy. In Piaget’s theory, toddlers are categorized as either “Sensorimotor” or “Preoperational”. They start utilizing symbols, and can hold and recall images. Also, it is typical for them to have a highly egocentric perception of world (Ahman & Rollins, 2006).

The following is major developmental tasks among infants and toddlers:

<Infants>

- Develop a sense of trust
- Attach to parent
- Learn through sensori-motor experiences
- Begin to develop a sense of separateness from parent

<Toddlers>

- Develop autonomy
- Master locomotor and language skills
- Learn through sensori-motor experience, beginning preoperational thought

(Ahman & Rollins, 2006)
Stressors

- Being separate from parents and caregivers
- Changing routine
- Being their needs unresolved
- Environment with over stimulation
- Lack of stimulation
- Lack of activities which stimulate their senses
- Receiving painful procedures/treatments
- Being around strangers
- Being exposed in the unfamiliar environment
- Lack of autonomy
- Lack of contact with peers

Potential Effects of Childhood Cancer and Its Treatments

<Infants>

☆ Delayed because of separation, parental grief for loss of “dream” child, parental inability to accept the condition, especially a visible defect
☆ Increased dependency on parent for care
☆ Over-involvement of parent in care
☆ Multiple caregivers and frequent separations, especially if hospitalized
☆ Deprived of consistent nurturing
☆ Limited contact with environment from restricted movement or confinement
☆ Increased exposure to more painful experiences than pleasurable ones

<Toddlers>

☆ Increased dependency on parent
☆ Limited opportunity to test own abilities and limits
☆ Increased exposure to painful experience

(Ahman & Rollins, 2006)
Preschool

Developmental Tasks

Preschoolers are, in Erikson’s words, in the stage of “Initiative vs. Guilt”; they increase muscular, mental, and language abilities. They are more active and are likely to have lots of questions and filled with curiosity. In Piaget’s theory, preschoolers are in the preoperational phase. They are in the transition period between depending solely on perception and depending on truly logical thinking. They are better able to see more than one factor at a time that influences an event (Ahman & Rollins, 2006).

The following is the major developmental tasks among preschoolers:

- Develop initiative and purpose
- Master self-care skills
- Begin to develop peer relationships
- Develop sense of body image and sexual identification
- Learn through pre-operation thoughts (Magical thinking) (Ahman & Rollins, 2006)

Stressors

- Separation from caregivers
- Fear of loss of control, sense of own power
- Frightening fantasies
- Immobility or restriction
- Forced regression
- Loss of routine and rituals
- Being restricted their activities due to physical late effects of childhood cancer
- Being in pain
- Lack of interaction with peers
- Lack of understanding from others including families, friends, and teachers
Potential Effects of Childhood Cancer and Its Treatments

- Limited opportunities for success in accomplishing simple tasks or mastering self-care skills
- Limited opportunities for socialization with peers; may appear “like a baby” to age-mates
- Protection within tolerant and secure family may cause child to fear criticism and withdraw
- Awareness of body may center on pain, anxiety, and failure
- Sex role identification focused primarily on mothering skills
- Guilt (thinking he or she caused the disability, or is being punished for wrong-doing)

(Ahman & Rollins, 2006)
School Age

Developmental Tasks

When children turn to be school age, they expand social relationships including friends, school, and neighbors. In Erikson's theory, they are in the stage of “Industry vs. Inferiority”; they are concerned with academic performance. If they are praised for doing their best and encouraged to finish tasks then work enjoyment and industry may result. According to Piaget's theory of child development, they are in the “Concrete Operations”, which means they are increasing their ability to think logically in the physically concrete realm. Also, they understand the meaning of series of actions, of order and sequencing (Ahman & Rollins, 2006).

The following is the major developmental tasks among school age

- Develop a sense of accomplishment
- Form peer relationships
- Learn through concrete operations
- Increase language skills, interest, and acquiring knowledge
- Improve concept of time
- Increase self-control
- Strive for industry

(Ahman & Rollins, 2006)
Stressors

* Being different from others
* Being separated from families and friends
* Being absent from school
* Lack of independence
* Lack of control
* Loss of industry
* Immobility and restriction
* Being in pain
* Lack of understanding
* Lack of interaction with peers

Potential Effects of Childhood Cancer and Its Treatments

* Limited opportunities to achieve and compete (e.g. many school absences or inability to join regular athletic activities)
* Limited opportunities for socialization
* Incomplete comprehension of the imposed physical limitations or treatment of the disorder
* Decreased self esteem

(Ahman & Rollins, 2006)
Teens

Developmental Tasks

As for teens, they are in “Identity and Repudiation vs. Identity Diffusion” according to Erikson’s theory. They are seeking for who they are and are trying to be themselves. Also, according to Piaget’s theory, they are in the stage of “Formal operation”, which means they are deductive and possess abstract reasoning, and they can imagine the conditions of a problem, including past, present, and future, and develop hypotheses about what might logically occur under different combinations of factors. They are extremely worried about their body image and sexuality (Ahman & Rollins, 2005).

The following is the major developmental tasks among teens:

- Develop personal and sexual identity
- Achieve independence from family
- From heterosexual relationships
- Learn through abstract thinking and reasoning
- Increase conscious of appearance
- Strive for independence
- Develop new peer relationships

(Ahman & Rollins, 2005)
Stressors

* Lack of self-control
* Lack of independence
* Being in pain
* Body image
* Being different from peers
* Lack of interaction with others
* Having restrictions or limitations
* Lack of self-esteem
* Having concerns about future

Potential Effects of Childhood Cancer and Its Treatments

* Increased sense of feeling different from peers and less able to compete with peers in appearance, abilities, and special skills
* Increased dependency on family; limited job or career opportunities
* Limited opportunities for heterosexual friendships; fewer opportunities to discuss sexual concerns with peers
* Increased concern with issues such as why he or she got the disorder, whether he or she can marry and have a family
* Decreased opportunity for earlier stages of cognition may impede achievement
* Having a distorted body-image and a low self-concept, which can affect their social competence, dating and sexual behavior
* Limit the skills necessary to fulfill normal needs and desires that teenagers have
* Decreased sexual expression, adequate information about sexual issues
* Decreased interaction with those who are unfamiliar with childhood cancer; they may communicate with only their acquaintance

(Ahman & Rollins, 2005)
Chapter 6:

Long Term Effects of Childhood Cancer

~ Family ~

This chapter’s main focus is family including mothers, fathers, and siblings. Childhood cancer can affect the entire family and may cause a variety of long term effects on the family. The family’s concerns are unique and are somehow different from childhood cancer survivors. This chapter gives information about the family’s emotions and their needs related to childhood cancer.
Parents

As well as childhood cancer survivors, parents whose child is a cancer survivor experience a variety of emotions even after the treatment and discharge. Chapter 3 covered psychological long term effects of childhood cancer among childhood cancer survivors, which include fears of recurrence, anniversary reactions, grief and loss, anger, anxiety and depression, and post traumatic stress. These feelings can be all applied to parents as well, because experiences related to childhood cancer can affect not only patients but also their family members. There are several different types of emotions and concerns that parents of childhood cancer survivors are likely to have.

Confusion

One of the common topics families concern is how to return to normal life after treatment of childhood cancer. Most families do not really know what normal is any longer because their life has changed due to the activities that related to the cancer's experience such as frequent contact with hospital, constant medications, change of the routines, and extra attention to their child’s health. At first, many families are at a loss on how to get their life back to normal and how to get used to these changes. Parents and their child need to discuss at length how to deal with the issue (Hobbie et al., 2006).

Fears and Anxieties

In addition, parents usually have strong fears and anxieties related to their child’s cancer after treatment. The causes of these feelings are varied: fear of recurrence, anxieties if they can keep their child in good shape and condition, worries that their child may be teased by their peers, questions about how much they should pay attention to their child’s health when the child is grown up, and concerns about who can take care of their child after they pass away. Some parents can be over protective towards the child; this may cause conflict between parents and their child, especially teenagers (The National Children’s Cancer Society, 2011).
Guilt

Additionally, the typical concern among parents of childhood cancer survivors is how to deal with both their child with the history of cancer and their other siblings; parents cannot help but paying extra attention to the child who experienced cancer rather than their other children. Sometimes, siblings feel isolated and become rebellious toward the parents. It can be challenging for parents to support all children equally. Since some families have genetic forms of cancer that can be passed to their children, some parents have strong feelings of guilt that their genes are the cause of their child’s cancer (The National Children’s Cancer Society, 2011).

Emotional Conflict

As children become older, they develop independency and may have different views on what life after cancer should be like. Whereas many parents are likely to be protective to keep their child from having any risk that may cause relapse, some children, especially teens, want to leave the cancer behind and move on with their new lives. Although such parents try to keep connection with cancer related communities, those children may not have contact with friends who experienced childhood cancer or cancer communities. If parents have a hard time to accept their child’s decision in terms of the lifestyle after cancer treatment, conflict may occur between children and their parents. On the other hand, some children still want to keep strong relationships with other cancer survivors or people in cancer community whereas parents may want their children to pretend that their child never had a cancer and may force their child to move on (Hobbie et al., 2006).

The different point of view on cancer between parents and children can weaken cohesiveness and level of expressiveness between family members. Inada, Mantani, Nakagawa, Ogata, Okamura, Ozono, Saeki, Ueda, and Yamawaki (2010) hypothesized that family’s functioning appear to be a predictor of psychological distress among childhood cancer survivors and their family members. Therefore, they studied to identify distinct clusters of families that include childhood cancer survivors, and to measure differences between the clusters with respect to anxiety, depression, and post-traumatic stress symptoms. As a result, although the majority
of families displayed high cohesiveness, high expressiveness, and low conflict, about 30% of family reported low cohesiveness, low expressiveness, and high conflict. Also, those families with high levels of conflict tend to develop anxiety and depression.

**PTSD**

As it is described in chapter 3, some childhood cancer survivors develop PTSD due to the cancer related experiences. However, some parents are also at risk of having PTSD because of their child’s cancer experiences. Although this topic still has not been proved enough, there is one study that showed how the levels of anxiety in mothers of younger survivors are higher than in school-aged and adolescent survivors themselves (Barakat, Christakis, Kazak, Meadows, Meeske, Penati, & Stuber, 1997).

Alderfer, Annunziato, Cnaan, & Kazak (2005) interviewed 98 couples parenting adolescent childhood cancer survivors to find out whether parents suffered from PTSD or not and what patterns of PTSD parents had. After the interview, researchers identified most parents experience symptoms of PTSD to some extent, and their patterns could be divided into five categories: minimal Post Traumatic Stress (PTS) and parents had below average scores on PTS; mothers elevated high scores of PTS; parents did not display symptoms of PTS but elevated cognitive and emotional avoidance of cancer experiences; fathers elevated high scores of PTS; and both mothers and fathers displayed high scores of PTS. Most parents who participated in this study reported that they do not have high level of PTS, but mothers are likely to have higher levels of PTS compared to fathers.
**siblings**

Childhood cancer can affect not only patients and parents but also siblings; the effects of childhood cancer can last among siblings even after cancer treatment. Typically, siblings of childhood cancer survivors are considered as “forgotten child” since parents’ attention is most likely towards childhood cancer survivors. This fact can cause emotional distress among siblings. In addition, siblings may feel unsure about how to treat their brother/sister who completed cancer treatment. Childhood cancer survivors may need to change their lifestyle including physical activities and education because of cancer treatment; therefore, sometimes siblings think how they can adapt themselves to the new situation that childhood cancer survivors experience. When considering the siblings’ reaction towards childhood cancer survivors, it is important to take their developmental stage into consideration. Siblings’ reaction towards childhood cancer can usually be determined depending on their age, temperament, and other family’s support (Hobbie et al., 2006).

**Jealousy/Resentment**

Cancer related experiences including diagnosis, treatment, and aftermath may all create conflicting feelings in and among siblings. Siblings are mostly concerned about their brother or sister, but they also usually resent the turmoil the family has been thrown into. Many siblings feel jealous of the gifts and attention given to a child with childhood cancer (Hobbie et al., 2006). Many siblings resent the fact that a child with childhood cancer does not have to do chores and go to school (American Society of Clinical Oncology, 2011).

**Guilt**

Among siblings of childhood cancer survivors, jealousy and resentment are common feelings; however, at the same time, many siblings feel guilty for having these ugly emotions. Younger siblings, especially preschool children, also feel guilty because they misconceive that something they did caused their brother or sister’s cancer (Hobie et al., 2006). In addition, when siblings encounter the situation that their brother or sister is suffering from severe long term effects of childhood cancer, they
may experience guilt for not being the sick one. They may feel guilty for saying mean things, having bad thoughts about their ill sibling, or for having emotions such as anger and jealousy (American Society of Clinical Oncology, 2011).

Anger

Siblings may get upset with their parents and the cancer survivor for not having time for siblings anymore. As well as having feeling of jealousy, they may also be angry because all their parents’ attention is paid to the child with childhood cancer. They may be angry when they have to do all chores while their parents are taking care of the child with childhood cancer (American Society of Clinical Oncology, 2011).

Siblings can also get upset for the fact their brother/sister has cancer. It is hard for siblings to accept that their brother/sister has a life-threatening illness, which can lead to strong anger among siblings. Even after treatment, siblings still have strong anger and questions why their brother/sister had to have cancer (Hobbie et al., 2006).

Fear and Anxiety

The younger siblings are likely to have misconceptions because their cognitive level has not developed yet; therefore, they may experience strong fear that they caused cancer or they might catch cancer like the flu. They are also anxious whether the same occurrence will happen to their other siblings in the future. Since they have realized that they are not able to predict what tomorrow is going to be due to the cancer experience in their family, siblings have strong fear of what will happen to the family in the future. If the patient is not stable yet, siblings experience a heightened sense of fear that the child with cancer may die. Furthermore, in cases where parents do not include siblings into treatment process, siblings may become anxious about things they do not understand (American Society of Clinical Oncology, 2011).
Loneliness/Feeling of abandonment

While children are under cancer treatment, parents are likely not to stay in their own house as they take care of their sick child in the hospital. Even after treatment, parents need to take care of their sick child. These facts may cause feelings of loneliness among siblings. Siblings often feel left out and at the same time feel that they have just lost the support and friendship once provide by the sibling with cancer. Siblings may miss the time with friends when their parents cannot take them to after-school activities or to a friend’s house to play (American Society of Clinical Oncology, 2011).

For younger children, absence of parents and lack of attention from parents can cause feelings of abandonment; that is, younger children think that they are less important than the sick child (Hobbie et al., 2006).

Sadness and Grief

Just like some siblings feel strong anger for their ill brother/sister and their parents, many siblings feel sad for the terrible things that happened to their brother/sister. They also may feel sad that everything seems to have changed. Grief does not always mean “death”; even though the child with childhood cancer was treated well, siblings may be struggling with the feeling of grief due to the loss of normal family life and a carefree childhood (American Society of Clinical Oncology, 2011).

Positive effects

Siblings of childhood cancer survivors also reported a variety of positive effects coming from childhood cancer experiences. Siblings learn about compassion, sharing, and coping skills; they increase the knowledge about health and disease, increase empathy for the sick or disabled, increase sense of responsibility, enhance self-esteem, develop great maturity, and increase family closeness. Those positive effects, which can also be called as posttraumatic growth, can be seen among siblings of childhood cancer survivors (Hobbie et al., 2006).
This chapter looks at Child Life supports and interventions for childhood cancer survivors and their families. Although supports for childhood cancer survivors from Child Life perspective have not been developed yet, there are a variety of needs that CLSs can support by utilizing Child Life theories and practices. This chapter identifies how CLSs are able to work with childhood cancer survivors and their families.
Where can CLSs possibly work to support childhood cancer survivors?

Currently, CL interventions for childhood cancer survivors have not been established yet. As one of the professions in multi-disciplinary team, CLSs play major roles to support children and their families while children are under treatment for childhood cancer. However, once children complete their cancer treatment and are discharged from the unit, it is hard for CLSs in Hematology/Oncology unit to follow up each patient and provide psychosocial supports. As the previous chapters described, childhood cancer survivors still experience long term effects of childhood cancer treatment and face strong emotions along with the long term effects. In order to support these children who are struggling with long term effects of childhood cancer treatment, there are several work places that CLSs could be possibly able to work.

*Cancer clinic*

When children/adolescents complete cancer treatment and are discharged from a hospital, they start visiting cancer clinics for check-ups on their conditions. The frequency of clinic visit will be less as time goes by and children/adolescents get into remission. However, follow up visits are quite important for childhood cancer survivors in order to investigate whether they have any symptoms of relapse or not, or to give childhood cancer survivors and their families opportunities to ask questions. In some cases, children/adolescents may need to have procedures such as lumbar puncture, blood draw, peg injection, and bone marrow aspiration. In the cancer clinic, CLSs would contribute by providing distraction during procedures, teach coping techniques to children/adolescents, educate them about their condition, and offer other emotional supports.
Cancer survivors’ support group

Support groups can be extremely helpful for children/adolescents affected by life-threatening illnesses and long term effects of childhood cancer. The type of support group ranges from closed ended to open ended and from informal support groups to more structured therapy groups. The purpose of support group specifically for childhood cancer survivors is a sense of universality. Children who experienced childhood cancer often feel that their friends can never understand what they are facing and thinking; therefore, support group where childhood cancer survivors get together are a great opportunity for them to express their feelings with someone who has had a similar situation. Groups can consist of children/adolescents with the same diagnosis or of the same age. CLSs with knowledge of Child Development and awareness of long term effects of childhood cancer can be great facilitators (Davitt, & Hicks, 2008).

Nonprofit organizations

In the United States and worldwide, there are many nonprofit organizations which provide support for childhood cancer survivors and their families. The activities and concepts are different depending on the organization; however, these organizations would offer extra help for childhood cancer survivors and their families, or support that hospitals do not provide. In many cases, these nonprofit organizations introduce and publish resources related to childhood cancer, conduct support groups, run message boards for childhood cancer survivors and their families, create education tools about childhood cancer, and introduce emotional supports. Some nonprofit organizations are established to help parents, and some other nonprofit organizations specifically support siblings of childhood cancer survivors. If CLSs get opportunities to work in nonprofit organizations, they can provide information from CL’s perspectives. Also, CLSs implement some activities that are helpful for children/adolescents to cope with their feelings.
Camp programs

Camp experiences for children who experienced childhood cancer can have profound life-long effects. Just like support groups, camp programs give children a sense of normalcy. Within the group of children who have same experiences, children are treated as “a normal child”. In the supportive environment of camp, children can develop mastery and may acquire new skills. In addition, through communication with others who also experienced childhood cancer, children can increase their understanding towards their medical condition and can improve their attitudes towards their illness. By working on some tasks with others, children also improve their social skills (Davitt & Hicks, 2008). As facilitators, CLSs conduct the camp program. They give children opportunities to express concerns and ask questions about life after childhood cancer. Also, CLSs facilitate activities that are aimed to help children cope with their feelings and express themselves.
In which situations childhood cancer survivors need supports from CLSs?

☞ When children/adolescents have questions about their previous diagnosis...
  o In most cases, children/adolescents understand their diagnosis and treatment for childhood cancer while they are under cancer treatment. However, children/adolescents who have been treated at a young age do not remember their diagnosis. Also, their knowledge of diagnosis and treatments may be the same as when they were diagnosed. As children develop their cognitive level, they may seek for more information about what exactly happened to their body.

☞ When children/adolescents are having a hard time to adjust to new situations...
  o After the treatment of childhood cancer, children/adolescents and their families need to change their life style; children/adolescents find it difficult to get used to new life when they have obvious physical change due to cancer treatment. Even though children/adolescents do not have any physical change, they may have to follow various rules to keep themselves healthy including healthy diet, cessation of smoking, regular exercise, medication, and infection control. Children/adolescents may have hard time to change their life style after treatment.

☞ When children/adolescents are struggling to cope with their emotions related to childhood cancer experiences...
  o As chapter 3 and chapter 6 describe, just like children/adolescents who experienced childhood cancer, their parents and their siblings also experience a variety of emotions not only during the cancer treatment but also after the treatment. Common emotions they tend to have are: fear of relapse, anxiety towards future, feeling of loss of normalcy, and anger of long term effects of cancer treatments. They may need professional supports to cope with their feelings related to childhood cancer experiences.
When children/adolescents return to school after cancer treatment...

- For school age children, teenagers and their parents, returning to school after cancer treatment can be a major stressor. Although most children and their families are glad to go back to school, they have to deal with various problems: children who lost their hair may be worried about their body image; parents are likely to worry about their child being able to catch up with the class after a long absence of school; and teenagers may be confused that their relationship with friends have changed during the absence. Also, many teenagers reported that they felt like they are much older than their classmates and did not know how to rebuild the relationship when they returned to school. In addition, classmates and teachers may be confused about how to treat the child who returns to school after cancer treatment.

When children/adolescents are in transition period...

- Transition period indicates a passage from one stage to another. For childhood cancer survivors and their families, major transitions could be “the end of treatment”, “return to normal life”, and “change from child to adult”. During these periods, children/adolescents and their families experience new anxieties and require adjustment. Hobbie et al., (2006) identified that “people cope better with transitions if a period of panning occurs before the change happens. The transition should be acknowledged by all healthcare providers, and psychosocial and educational aspects of survival should be addressed” (p.5).

When children/adolescents are in pain due to the late effects of childhood cancer treatment...

- Depending on what kinds of long term effects children/adolescents have, childhood cancer survivors may experience pain to some extent. In addition to pain medication, some non-pharmacological pain management techniques could be useful to ease their level of pain.
☞ When children have a conflict with their siblings who did not experience childhood cancer...
  o As the chapter 6 describes, many siblings experience different types of emotions from childhood cancer survivors. Some children feel jealous about the extra attention given to a sick child, and other children are confused about how they can treat their brother/sister who was discharged from a hospital. Just like childhood cancer survivors, siblings also need opportunities to share their concerns and ask somebody their questions.

☞ When children/adolescents are suffering from “survivor's guilt”...
  o Survivor’s guilt is one of the typical reactions among most childhood cancer survivors. “Some survivors feel guilty that they survived when so many others did not. Sometimes they feel that life is going to be short, so they must push themselves very hard” (Hobbie et al., 2006, p. 39). When childhood cancer survivors increase strong survivor’s guilt, they may need professional supports to release their emotions.

☞ When children/adolescents are looking for friends who can share their feelings with...
  o After the treatment of childhood cancer, many children/adolescents reported that their perspectives and values have changed because of such a traumatic and life-threatening event. They may be no longer able to get along with their friends because they became much more mature compared to kids in their same age group. Also, some children/adolescents may be looking for friends who have same experiences so that they can share their concerns, or others may seek for friends who are not related to the cancer community at all.
How can CLSs support childhood cancer survivors and their families?

Education

One of the major roles of CLSs is to educate children/adolescents about their diagnosis, treatment, and procedures in the way children/adolescents can understand. CLSs are trained professionals with a sound knowledge of Child Development. When CLSs support childhood cancer survivors, they still have opportunities to educate children/adolescents about their diagnosis. Since children/adolescents who were diagnosed with cancer at quite young age, they might have not been taught anything about their medical condition.

For those who have questions about their medical condition, CLSs can provide education so that children/adolescents understand what exactly happened to them before. When educated on their medical condition, children/adolescents will be able to understand the importance of clinic visits for check-ups, become more positive to follow rules to maintain their health, and have more responsibility to take care of themselves.

Also, education provided by CLSs can be beneficial to siblings as well. In most cases, siblings are given information about their sick brother/sister. However, siblings sometimes do not receive enough information about their brother’s/sister’s condition because they are too young to know everything or their parents want to hide what is happening to the sick child. Even after the treatment, CLSs can support siblings and teach them about their brother’s/sister’s condition if siblings want to know about it.

When CLSs provide education to children/adolescents, they usually use some visual props including pictures, books, dolls, and videos, and they may provide activities to enhance learning such as “blood soup” activity. Also, they are trained to use soft language and developmentally appropriate language for children in each developmental stage. These techniques give correct and clear understanding to children/adolescents.
School Services

Returning to school can be a difficult and stressful situation for children and their families as this is a great milestone in treatment. In order to help children return to school smoothly, CLSs can provide education and presentation about the child who completed cancer treatment in the classroom. Based on the assessment and discussion between CLSs, patient, and his/her families, CLSs decide what they should talk and should not talk to classmates. The purposes and benefits of school service are:

- To help students and teachers understand what the child has experienced and provide opportunities to learn about the illness and the hospital experience.
- To offer the child the chance to “be the expert” and talk about his or her experience and answer questions (if the child is comfortable doing this).
- To clear up misconceptions and rumors as well as encourage classmates to be supportive.

By using developmentally appropriate language and utilizing visual props, CLSs offers presentations to children. Age group is from preschoolers to school age children (sometimes, teenagers). As well as educating classmates about childhood cancer the patient had, CLSs may explain how the patient was brave and was working hard to beat his/her cancer. If the patient and his/her parents are comfortable, CLSs may ask them to bring something from hospital so that classmates can imagine how life in the hospital looks like.

(C, Campo, personal communication, October 4, 2011)
Coping & Problem-solving

Coping, within the framework, is viewed as “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Goldberger, Luebering, & Thompson, 2008, p.162).

Children who experienced life-threatening illnesses and have long-term physical effects of treatment may encounter various stressful situations over long periods. They have to cope with psychological aspects of the condition itself and with the prognosis. For those patients, the establishment of coping skills is extremely significant. CLSs studied and practiced teaching coping techniques and providing activities that help children cope with their emotions. Coping activities can be either direct actions or cognitive strategies. Direct actions include the use of behavioral methods, relaxation, distraction, and imagery, and cognitive strategies can be positive self-talk, cognitive reframing, and thought stopping. In addition to these practices, rehearsal and practicing of coping skills are important as well (Davitt & Hicks, 2008).

In addition to teaching coping techniques to children, teaching problem-solving skills is also beneficial for childhood cancer survivors. “All children benefit from the development of problem-solving skills. For children with chronic conditions it can be especially empowering as they will be cast into many situations in their lives that may require effective problem solving” (Hicks & Davitt, 2008, p. 274). Learning problem-solving skills enable childhood cancer survivors to adjust to chronic conditions. When CLSs teach problem-solving skills, they help children/adolescents create a sense of autonomy. They encourage children/adolescents to think how they resolve the situation independently so that children/adolescents are able to acquire appropriate problem-solving skills (Davitt & Hicks, 2008).
Encouraging children/adolescents who experienced childhood cancer to express their feelings related to their life after cancer treatment is a major role of CLSs. As the chapter 3 describes, childhood cancer survivors may have a variety of fears, anxieties, concerns, and thoughts, and they sometimes find it difficult to externalize their inner feelings. In this situation, CLSs utilize various means to give children/adolescents opportunities to express their feelings. When CLSs plan and implement activities that aim to help children/adolescents to express their feelings, CLSs would focus on non-threatening, developmentally appropriate, and safe ones. The contents and means of self-expression activities can be different depending on the patient’s developmental age group. The next page provides suggestions for self-expression activities in each developmental stage.
<table>
<thead>
<tr>
<th>Infants</th>
<th>Toddlers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Literature</strong></td>
<td><strong>Literature</strong></td>
</tr>
<tr>
<td>- Books with various emotional faces and voices</td>
<td>- Storytelling (self)</td>
</tr>
<tr>
<td>- Books of feelings and colors</td>
<td>- Books of feelings and colors</td>
</tr>
<tr>
<td>- Storytelling</td>
<td><strong>Art &amp; Music</strong></td>
</tr>
<tr>
<td><strong>Art &amp; Music</strong></td>
<td>- Gentle or classical music</td>
</tr>
<tr>
<td>- Gentle music</td>
<td>- Scribbling</td>
</tr>
<tr>
<td>- Coloring</td>
<td>- Dancing</td>
</tr>
<tr>
<td><strong>Toys &amp; Tools</strong></td>
<td><strong>Toys &amp; Tools</strong></td>
</tr>
<tr>
<td>- Rocking</td>
<td>- Play dough</td>
</tr>
<tr>
<td><strong>Activities &amp; Games</strong></td>
<td>- Puppets &amp; finger puppets</td>
</tr>
<tr>
<td>- Imitating</td>
<td>- Toy phones</td>
</tr>
<tr>
<td>- Gesture game</td>
<td><strong>Activities &amp; Games</strong></td>
</tr>
<tr>
<td></td>
<td>- Role play</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Preschoolers</th>
<th>School Age Children</th>
<th>Teenagers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Literature</strong></td>
<td><strong>Literature</strong></td>
<td><strong>Literature</strong></td>
</tr>
<tr>
<td>- Self storytelling</td>
<td>- Journal</td>
<td>- Poetry (reading or creating)</td>
</tr>
<tr>
<td>- Picture books with</td>
<td>- Self storytelling</td>
<td>- Self storytelling</td>
</tr>
<tr>
<td>emotions</td>
<td>- Poetry</td>
<td>- Journaling</td>
</tr>
<tr>
<td><strong>Art &amp; Music</strong></td>
<td><strong>Art &amp; Music</strong></td>
<td><strong>Art &amp; Music</strong></td>
</tr>
<tr>
<td>- Gentle music</td>
<td>- Healing music</td>
<td>- Drawing emotions</td>
</tr>
<tr>
<td>- Drawing feeling</td>
<td>- Drawing their feelings</td>
<td>- Dancing</td>
</tr>
<tr>
<td>pictures</td>
<td><strong>Toys &amp; Tools</strong></td>
<td>- Gentle music</td>
</tr>
<tr>
<td><strong>Toys &amp; Tools</strong></td>
<td>- Puppets &amp; finger puppets</td>
<td>- Finger painting</td>
</tr>
<tr>
<td>- Play dough</td>
<td>- Play dough</td>
<td><strong>Activities &amp; Games</strong></td>
</tr>
<tr>
<td>- Puppets &amp; finger puppets</td>
<td></td>
<td>- Feeling balloons</td>
</tr>
<tr>
<td>- Small dolls and maps</td>
<td></td>
<td>- Scrapbookking</td>
</tr>
<tr>
<td><strong>Activities &amp; Games</strong></td>
<td><strong>Activities &amp; Games</strong></td>
<td>- Genga</td>
</tr>
<tr>
<td>- Balance game</td>
<td>- Feeling balloons</td>
<td>- Card games</td>
</tr>
<tr>
<td>- Feeling balloons</td>
<td>- Scrapbooking</td>
<td><strong>Activities &amp; Games</strong></td>
</tr>
<tr>
<td>- Role play</td>
<td>- Genga</td>
<td>- Feeling genga</td>
</tr>
<tr>
<td>- Dancing</td>
<td></td>
<td>- Card games with feeling</td>
</tr>
<tr>
<td>- Walking</td>
<td></td>
<td>- Playing instruments</td>
</tr>
<tr>
<td>- Cooking</td>
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</tr>
</tbody>
</table>
Grief Support

When children/adolescents experience grief, CLSs usually provide emotional support to help them cope with the loss. As for childhood cancer survivors and their families, they also experience various losses even though they survived from cancer treatment. Treatment for childhood cancer can result in the loss of abilities, life prospects, skills, or body parts. Also, while they were hospitalized, childhood cancer survivors experienced the loss of normal development opportunities such as missing the time to spend with peers. Although this type of loss is not related to death and dying, it has significant effects on childhood cancer survivors and their families (Hobbie et al., 2006).

When childhood cancer survivors and their families are in the grief process, CLSs would be able to offer some interventions to help their process. There are several types of grief activities.

* Memory interventions

Memory interventions are designed for children/adolescents and their families to recall their memories of their cancer treatment in positive ways. Overcoming childhood cancer treatment is a great achievement for both children/adolescents and their families, and this achievement should be honored. By recalling the memories and achievement during the treatment, children/adolescents and their families may be able to cheer up when they are struggling to adapt to the new life after cancer treatment. The ideas of memory interventions are as follows:

- Memory box
- Scrap booking
- Video message from people who supported the family during cancer treatment
- Collage
- Memory book
Education about the loss

When children/adolescents experience loss of abilities, body parts, and skills due to childhood cancer treatments, it is important for CLSs to provide children/adolescents with education about the loss. Understanding the loss without misunderstanding enables children/adolescents to cope with the loss and to think what they can do even though they lost part of their abilities. Books and pictures are great tools for CLSs to educate especially younger children about the loss. The following books are all about differences:

- “What It’s Like to Be Me” by Helen Exley (ages 3 and up)
- “Little Squire Head” by Peggy O’Neil (ages 3 and up)
- “What I Like about Me” by Allia Zobel Nolan (age 3 and up)
- “Only One You” by Linda Kranz (age 4 and up)
- “The Don’t Give Up Kid” by Gehret (First grade and up)
- “The Tree with No Limbs” by Christine Marie (First grade and up)

Coping activities

The focus of coping activities is to help children/adolescents cope with their feelings towards losses. The coping activities enable them to heal their emotions and deal with their emotions in positive and non-threatening ways. The coping activities include learning coping techniques which help them to reduce stress level. It can be simple and easy techniques such as deep breathing, punching pillow, meditation, Yoga, journaling and so. Children/teens choose their preferred coping techniques based on their interests. Coping activities are not only for individuals but also for group of children. The benefit of coping activities for individuals is that children/adolescents face the emotions they have towards their loss in depth, whereas coping activities in a group give them opportunities to discuss their feelings with peers who have had the same experiences.
The following is examples of coping activities:

▷ Punching pillow
▷ Screaming
▷ Burning incense
▷ Mediation
▷ Tearing toilet papers
▷ Exercising
▷ Clay sculpting
▷ Smashing play dough

* Expressive activities

Expressive activities are offered to children/teens so that they can express their feelings related to their loss. By engaging in these expressive activities, children/adolescents are able to feel they are accepted and supported. These feelings are important steps in the process to deal with their loss.

Expressive activities do not have to be discussion or counseling. Children are likely to show their hidden feelings through drawing. Also, some teenagers may want to do journaling privately. Since each grieving style is different (inward/outward, private/social, and intuitive/instrumental), expressive activities need to be carefully chosen to meet one’s own grieving style. The following are the ideas of expressive activities:
- Journaling
- Writing poems
- Role play
- Drawing/Scribbling
- Painting
- Storytelling
- Playing music
- Writing stories
Non-pharmacological Pain Management

When children/adolescents are having pain due to long term effects of childhood cancer treatment, CLSs can help them by providing non-pharmacological pain management techniques.

Non-pharmacological pain management therapies can be provided by other medical professional including nurses, Physical Therapists, or Occupational Therapists. However, CLSs may be able to offer effective therapies for children/adolescents. Among the different types of occupations in hospital setting, CLSs are the ones who do not provide any medical care (procedure, examination, and administration of medication). Thus, children/adolescents are more comfortable to get involved in the pain management therapies because they understand CLSs do not hurt children/adolescents.

The non-pharmacological pain management techniques can be useful not only for children/adolescents who are in pain but also for families. Parents/caregivers may have strong emotional pain because of their child’s condition; therefore, these pain management therapies would be helpful for them to release their stressful emotions and improve their emotional pain.
The following chart displays components of the multidimensional model of pain with the treatment components (Janette, Seville, & Ahles, 2002).

<table>
<thead>
<tr>
<th>Model component</th>
<th>Treatment Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological</td>
<td>• Guided imagery</td>
</tr>
<tr>
<td></td>
<td>• Progressive muscle relaxation</td>
</tr>
<tr>
<td></td>
<td>• Breathing strategies</td>
</tr>
<tr>
<td></td>
<td>• Meditation</td>
</tr>
<tr>
<td>Sensory</td>
<td>• Active pacing</td>
</tr>
<tr>
<td>Affective</td>
<td>• Challenging negative thoughts</td>
</tr>
<tr>
<td></td>
<td>• Increasing pleasurable activities</td>
</tr>
<tr>
<td>Cognitive</td>
<td>• Education about illness/injuries, medication, and pain</td>
</tr>
<tr>
<td></td>
<td>• Distraction</td>
</tr>
<tr>
<td></td>
<td>• Challenging negative thoughts</td>
</tr>
<tr>
<td>Behavioral</td>
<td>• Activity pacing</td>
</tr>
<tr>
<td></td>
<td>• Exercise</td>
</tr>
<tr>
<td></td>
<td>• Working with family members to ignore pain behaviors and reinforce well behaviors</td>
</tr>
</tbody>
</table>
Peer Support

Peer support is extremely effective and important particularly for school age children and teenagers. Sharing concerns and questions with others who had same experiences can be a great help for them. In the support group setting or camp setting, CLSs can conduct peer support opportunities and provide some activities in the group.

When CLSs conduct either support groups or camp programs, it is important to determine what they want children/adolescents to focus on each time. Instead of discussing random topics, it would be more effective for children/adolescents to pick one topic and talk about it. The following are ideas of discussion topics in either support groups or camp programs. CLSs may need to get other professions involved in the discussion depending on the topic, such as Social Workers, Dietitians, Doctors, Psychologists, Physical Therapists, and Occupational Therapists.

▷ Late effects of cancer treatment
▷ Sexuality
▷ Nutrition /Healthy diet
▷ Exercising
▷ Emotions
▷ Survivor’s guilt
▷ Anniversary reaction
▷ Returning to school
▷ Grief/Loss
▷ Transition to adult care
▷ Adjustment to life after treatment
▷ Relationships with parents/siblings/friends/boyfriend/girlfriend
Chapter 8: Bibliography & Web Resources

This chapter includes bibliography and web resources that CLSs can utilize when they support children who experienced childhood cancer and their family members.
Life after cancer treatments

Beyond the Cure: the Mountain You Have Climbed- A Teen’s Guide to Childhood Cancer Survivorship
- The National Children’s Cancer Society
- This is a practical guide for teenagers who have completed childhood cancer treatment.

Childhood Cancer Survivors: A Practical Guide to Your Future
- Hobbie, W., Keene, N., & Ruccione, K.
- ISBN-10: 0596528515
- This is a comprehensive guide for childhood cancer survivors and their families about their life after childhood cancer treatment.

Beyond the Cure: the Mountain You Have Climbed: A Young Adult’s Guide to Childhood Cancer Survivorship
- This guide is designed to answer questions and address issues related to cancer survivorship for young adults ages 18 and up.

Cancervive
- www.cancervive.org
- This website helps cancer survivors face and overcome the challenges of survivorship.

National Cancer Institute
- www.cancer.gov
- This website provides a nationwide telephone service for people with cancer, their families, friends, and the professional who treat them.

ACOR’s Site for Families of Survivors of Childhood Cancer
- www.acor.org/ped-onc/survivors
- This website provides information of life after childhood cancer treatments.

Children’s Oncology Group’s Long-Term Follow-Up Guidelines
- www.survivorshipguidelines.org
- This guideline provides comprehensive information about late effects of childhood cancer treatment.
National Cancer Institute
  o  www.cancer.gov/cancertopics/pdq/treatment/lateeffects/patient
  o  This website is for patients who want to get information about the late effects of childhood cancer.

Long term effects & Health issues

Beyond the Cure
  o  www.beyondthecure.org
  o  The childhood cancer survivorship web site sponsored by the National Children’s Cancer Society.

Candlelighters
  o  www.candlelighters.org
  o  This website provides the information about education, support and advocacy for childhood cancer survivors, families, and professionals.

Cure Search – National Childhood Cancer Foundation
  o  www.curesearch.org
  o  This website includes information on various childhood cancer and treatments, educational issues and legislation.

Pediatric-Oncology Resource Center
  o  www.acor.org/ped-onc
  o  This website is more for parents of children with cancer. The website provides support and information on survivorship, education and cognitive long term effects.

Education

American Cancer Society
  o  www.cancer.org
  o  This website covers issues related to returning to school and college scholarships for survivors.
- The Leukemia & Lymphoma Society
  - www.LLS.org
  - This website provides materials on educational needs.

- Grouploop
  - www.grouploop.org
  - This is a professionally mentored, online support groups and discussion board for educational and informational purposes.

- Monkey in My Chair Organization
  - http://www.monkeyinmychair.org/
  - This organization support children who are going to return to school after treatment of childhood cancer. This site and services provided by this organization are helpful to support pre-school and elementary aged children.

**Healthy lifestyle**

- American Cancer Society
  - www.cancer.org
  - This is a guide to quitting smoking. Also this website has information for proper diet and activity necessary to maintain a healthy weight, as well as on cancer survivor scholarships.

- The Foundation for a Smokefree America
  - www.tobaccofree.org
  - This website offers tips to quit smoking and motivates youth to stay tobacco free.

- American Institute for Cancer Research
  - www.aicr.org
  - This website supports research on the role of diet and nutrition in the prevention and treatment of cancer.

- Cancer Nutrition Info
  - This is a website for cancer patients and survivors; it includes information on keeping yourself healthy before, during and after cancer treatment.
Sexuality

Sexuality and Fertility after Cancer
  o Schover, L
  o ISBN-10: 0471181943
  o This book is about sexuality and fertility information for childhood cancer survivors.

Pregnancy outcome in long-term survivors of childhood cancer.
  o Blatt, J.
  o Medical and Pediatric Oncology, 33, 29-33
  o This is an academic research about pregnancy outcome in long-term survivors of childhood cancer.

Emotional supports

2bMe
  o www.2bme.org
  o This site is for teens with cancer. Teens can get the scoop on medical issues they are wondering about.

Cancer Care
  o www.cancercare.org
  o It provides free professional-support services to anyone affected by cancer.

Planet Cancer
  o www.planetcancer.org
  o This is a community of young adults with cancer that share insights and laughs and explores fears. A safe place for teens with cancer to build on an online community and find support.

Teens Living with Cancer
  o www.teenslivingwithcancer.org
  o This is a website for teens with cancer who have a lot of living to do. Teens can connect with others who may have same questions and concerns.
Service Organizations

- Cancer Care
  - [www.cancerfree.org](http://www.cancerfree.org)
  - A nonprofit organization to help people with cancer and their families.

- Candlelighters Childhood Cancer Foundation
  - [www.candlelighters.org](http://www.candlelighters.org)
  - This organization provides support, education, and advocacy for children and adolescents with cancer, survivors of childhood cancer.

- National Coalition for Cancer Survivorship
  - [www.canceradvocacy.org](http://www.canceradvocacy.org)
  - This organization addresses the needs of long-term cancer survivors and advocates for changes in healthcare to maximize survivors’ access to optimal treatment and support.

Parents & Siblings

  - Dietz, W., & Stern, L.
  - ISBN-10: 0375754873
  - This is a comprehensive guide to making peace at the table, feeding your baby, and creating healthy eating habits for the whole family.

- Men Don’t Cry. Women Do.
  - Martin, T., & Doka, K.
  - ISBN-10: 0876309953
  - This book offers a refreshing change from the popular gender stereotypes of grief.

- Diamonds or Dust: Keeping Your Marriage Together When Your Child Fights for Life.
  - Raiess-Dana, D.
  - This book is about tips on how to keep people’s marriage together when their child has life-threatening illness.
Healthy Eating & Physical Activity Across Your Lifespan: Helping Your Child Tips for Parents

- This website contains information and tips about healthy eating habit after treatment of childhood cancer.

National Cancer Institute: Young People with Cancer: A Handbook for parents

- This is a guide book for parents whose child completed childhood cancer treatment.

The Mountain You Have Climbed: A Parent’s Guide to Childhood Cancer Survivorship

- This guide is designed to address issues from the time of diagnosis through completion of treatment and beyond.

### Academic Research

**Families Surviving Childhood Cancer: A Comparison of Posttraumatic Stress Symptoms with Families of Healthy Children.**
- Barakat, L., Kazak, A., Meadows, A., Casey, R., Meeske, K., & Stuber, M.
- *Journal of Pediatric Psychology, 22*(6), 843-859.

**Infertility and Premature Menopause in Childhood Cancer Survivors.**
- Byrne, J.
- *Medical and Pediatric Oncology, 33*, 24-28.

**After the Cancer-Adolescent and Young Adult Survivors’ Psychological Experiences.**
- Jones, B.
- *Association of Pediatric Oncology Social Workers, 28*, 4-5.

**What Do Childhood Cancer Survivors Know about Their Past Diagnosis.**
- Kadan-Lottick.
- *Journal of American Medical Association, 287*, 1832-39
Cognitive Late Effects in Leukemia Survivors
  o Keene, N., & Oeffinger, K.
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