Coping With Pediatric Cancer

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Coping With Pediatric Cancer

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Coping With Pediatric Cancer

Abstract

Cancer is a life altering experience, and is the leading cause of death between infancy and fifteen years of age. This thesis explored coping, stress, and pain management of the individual and family throughout the lived experience of pediatric cancer. The participants in this study included three individuals ages one to seventeen from Montana. This research was qualitative and was based on the phenomenological method which has an emphasis on everyday lived experiences with pediatric cancer. Themes from this study included the following: (a) seeking a diagnosis, (b) remaining hopeful throughout treatment, (c) feeling exposed and vulnerable, (d) family support and coping, (e) nurses impacting care, and (f) individual growth through the experience. The findings of this study can help nurses gain a better understanding about the coping process of the individual with cancer and his or her family. Participants in this study recommended that nurses communicate, advocate, and genuinely care about their patients to facilitate a better healing environment.
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Chapter 1

Coping with Pediatric Cancer

Cancer is the leading cause of death between infancy and fifteen years of age (Bunin, Ries, & Percy, 2007). The National Cancer Institute estimated that 10,400 new pediatric patients would be diagnosed with cancer in the year 2007. In the United States, 34,500 pediatric cancer deaths were reported between 1990 and 2004 (CDC, 2007). This equates to an average of 2300 childhood cancer deaths per year. Childhood cancers often involve the hematopoietic system, the nervous system, or connective tissue (Porth, 2007). Of childhood cancers, the leading subtype is leukemia, followed by central nervous system cancers (Bunin, Ries, & Percy, 2007). The diagnosis of cancer in a young child can have immense physical and psychological effects not only on the child, but on the child’s loved ones as well. Cancer is life altering, and every individual and family affected by it undergoes the experience differently. This thesis will examine the coping, stress, and pain management of the patient and life adjustments throughout the course of pediatric cancer.

Etiology and Risk Factors

The etiology of cancer is unclear and is often multi-causal. A few rare types of pediatric cancer can be inherited genetically. The child gets this type of cancer when he or she inherits the cancer gene as a single-gene inheritance, polygenic inheritance, or chromosomal aberrations (Porth, 2007). Cancers that are inherited generally appear at an earlier onset of age. Environmental factors have also been proven to influence the appearance of cancerous cells. X-rays and environmental radiation could potentially
cause leukemia and other cancers (Office for National Stats, 2004). Those subjects exposed to electro-magnetic fields (EMF) and pesticides showed increased risk for cancer as well. Other contributors are bacterial and viral infections, inhalation of radon, hormones, weak immune system, excess sunlight, and tobacco smoke (Office for National Stats, 2004). Cancer is often preventable in the adult population, but with pediatrics, formulation of cancer is often unpredictable and acute. When a child develops cancer, his or her siblings have a two-fold risk to develop cancer as well (Porth, 2007).

Higher rates of pediatric cancer occur in the Caucasian population in comparison to African Americans, Asians, Hispanics, and American Indians (Office for National Statistics, 2004). The Office for National Statistics reported that leukemia and Hodgkin’s disease are more prevalent among those of higher socio-economic status. More childhood cancer incidences arise in males in comparison to females with males having a twenty percent greater chance of developing cancer (Bunin, Ries, & Percy, 2007). Children with other pre-existing inherited disorders have an increased risk of cancer occurrence (Porth, 2007).

**Pathophysiology**

Cancer can develop from almost any cell or organ throughout the body, and Porth (2007) states, “Cancer is a disorder of altered cell differentiation and growth. The resulting process is called neoplasia and a neoplasm” (p. 435). Cancer develops when cells fail to go through the cycle of cell proliferation and differentiation in a normal manner. Neoplasms can develop when there are mutations in the differentiation process resulting in high or low malignancy depending on the timing of the mutation in the process (Porth, 2007). Malfunctions in the DNA replication cycle lead to the formation of
cancer. Neoplasia occurs when the tumor suppressor genes are inactivated, the growth-promoting oncogenes are activated, the DNA repair is insufficient, or there is an alteration in cell apoptosis. These entire cell processes result in unregulated cell differentiation and growth. When a proto-oncogene is mutated, hyperactive cell growth occurs. When tumor suppressor genes are inactivated, the cancerous cells are able to over-actively proliferate (Porth, 2007).

Cancerous cells can either develop into benign or malignant tumors. The benign tumors are well differentiated cells that are slow growing and do not invade surrounding tissues. Malignant tumors have increased growth rate and size and have decreased differentiation. Malignant tumors invade the surrounding tissues and metastasize by use of the lymphatic system. Many childhood cancers are malignant, placing the child in an acute health state that requires immediate attention. Cancer affects the entire body and can cause inflammation, compression, bleeding, poor healing, cachexia, and tremendous pain (Porth, 2007). When caught early, quick steps can be taken to control the vast proliferation and reproduction of cancerous cells.
Chapter II

Review of Research

Throughout the following section current research regarding pediatric cancer is addressed.

Family Coping

Pediatric cancer causes significant stress on the patients and their families, specifically their parents. Each member of the family may cope with the disease process in a different manner. The level of family functioning can be challenged by the increased levels of stress and “the increase in burdens and stressors present formidable challenges for parent and family functioning” (Pai, Lewandowski, Youngstrom, Greenley, Drotar, & Peterson, 2007, ¶ 1). Through meta-analytic technique, 79 subjects were analyzed for family adaptation and family conflict. Both mothers and fathers were found to exhibit higher levels of stress at the initial diagnosis than twelve months following. Mothers were also found at times to display higher levels of stress than their male counterparts due to their more active role in the treatment process, accompanying the child to appointments, and increased levels of daily care (Pai et al., 2007).

Mothers of children with cancer tend to perceive a higher level of family conflict in comparison to mothers without children with cancer. Each person copes with the family conflict in a different manner and may need individualized stress management and it was found that, “Further understanding of how perceptions of parent and family functioning change during specific periods of the illness course is critical to developing specific and effective psychological interventions with families of children with
cancer" (Pai et al., 2007, p. 32). Psychological stress is very predominant in the first year of treatment and diagnosis, so support must be given to the family. The overall family functioning could take a turn for the worse if role changes and healthy adaptation to the new stressor, cancer, are not established (Pai et al., 2007).

Not only are the parents of the child with cancer affected, but the siblings are vastly affected as well. A study utilizing the method of grounded theory was conducted and examined the health related quality of life of siblings of cancer patients after they attended a summer camp. It was shown that these 77 children exhibited statistically significant improvement in their quality of life post-camp. This study supported that not only did the children with cancer need psychological support, but that their siblings did as well; and the children benefitted from positive emotional and social interactions at the summer camp as a means of psychological interventions (Packman et al., 2005).

**Familial Stress**

Dealing with the life changes involved with pediatric cancer poses significant stress for the family. One hundred sixteen parents of children who were treated for cancer were evaluated in a study to determine the level of stress in their lives as it related to family functioning. Streisand, Kazak, and Tercvak (2003) examined parents using the PIP and FAD scales. PIP stands for pediatric parenting stress which is a self-report, 42-item rating scale related to everyday stress involved with caring for a child with cancer. The FAD is a 60-item self-report scale of family functioning. The Cronbach’s alpha value in this study was 0.78. Frequency and regression analysis of the stress study results were also analyzed (Streissand et al., 2003). The study concluded that parental stress levels in pediatric cancer were related to the current status of treatment and the child’s level of
functioning. This in turn influenced whether or not the parents experienced stress and disruptions in daily life. The more complex and life-threatening the treatment process the higher the levels of stress, and therefore decreased levels of family functioning (Streissand et al., 2003).

**Family Communication**

Communication is a crucial factor in coping with the cancer, for the family to function and to provide the best healing environment for the child. Cohen, Friedrich, Copeland, and Pendergrass (1989) conducted a study that analyzed the effectiveness of communication between the parent and the child with cancer. This study utilized two instruments, the COMSIB and the COMILL, which are the parent-child measure and the parent-sibling measure. This study included 129 families and resulted with alpha scores of 0.78 and 0.76 (Cohen et al., 1989). The research concluded that there was a presence of increased communication with the sick child specifically during times of increased illness and side effects. The communication that occurred was seen as a direct result of the families’ thoughts and feelings regarding the cancer. This article highlights that it is very important for nurses to emphasize communication to enhance coping and healing. Through communication, parent-child bonds can be strengthened and more effective treatment can take place (Cohen et al., 1989).

**Diagnosis**

The diagnosis of cancer can be a very difficult process, especially in pediatrics. The diagnostic process can take an extended period of time, so nurses and healthcare professionals need to provide emotional support for the patient and family. There is no body system left unaffected by cancer (Porth, 2007). The signs and symptoms that occur
in childhood cancer differ from adult cancer. Children may experience swelling, unusual masses, paleness, loss of energy, frequent headaches, vomiting, unexplained fever, weight loss, changes in vision, easy bruising, and sudden persistent pain (Thompson, 2003). Cancer is much more difficult to diagnose in children due to the mesodermal germ layer being deeper than the epithelial layer, so early palpable abnormalities are less recognizable. Nursing assessments should focus on detection of unusual signs and symptoms (Thompson, 2003).

Extensive diagnostic testing may be utilized to determine if cancerous cells are present. X-rays, endoscopic procedures, urine and stool tests, blood tests, bone and tissue biopsies, ultrasounds, MRI, and CT scans are commonly used. When these samples are collected, they are then examined for the presence of abnormal cells and tumor markers. Once the subtype of cancer is determined, tumor staging and grading are used to classify the differentiation, tumor size, and level of differentiation (Porth, 2007). Once the diagnosis process is complete, a treatment regimen can be developed.

Treatment

Cancer treatment is often a lengthy expensive process that is difficult for many children to endure. Many of the treatments have extensive side effects and can be very painful. Surgery may be utilized for diagnosis and staging of cancer, but is also used for removal of tumors along with adjuvant therapies. The type of surgery depends on the state of the patient, the invasiveness of the cancer, the location, and structures involved (Porth, 2007). Radiation therapy is a primary form of treatment for localized cancers. It can be curative, palliative, and is often used in oncologic emergencies. Ionizing radiation is a subtype of treatment that causes cellular damage and can cause immediate cell death,
thus minimizing cancerous growths and shrinking the number of cells (Porth, 2007).

Other forms of radiation include high-energy photons, electron beams, and proton and neutron therapy. Radiation works most therapeutically with rapidly proliferating and poorly differentiated cells. It therefore may cause side effects including infection, bleeding, nausea, and vomiting (Porth, 2007).

Radiation therapy also can be classified into external beam radiation and internal radiation therapy. The family and patients may be concerned about being radioactive and what precautions need to be utilized after therapy. Children who receive external beam radiation are not radioactive and have no specific post-radiation precautions to implement. Children who receive internal radiation, temporary implants and permanent implants need to take special precautions. With a temporary implant, the child will be radioactive, and the amount of time spent in the room by visitors and nurses must be limited until the implant is removed. A temporary implant is a much weaker form of radiation. As a precaution the patient must avoid contact or limit for a few days because each subsequent day the implant loses energy (American Cancer Society, 2008).

Radiation is very difficult to undergo. It has numerous side effects and often leads individuals to being isolated, feeling alone, and possibly depressed.

Chemotherapy may also be used as a primary treatment. It is used when the cancer is systemic. There are more than fifty types of chemotherapeutic agents being utilized, and they are used either in combination or alone. Combination therapy has been proven to be more effective because the drugs have different mechanisms of actions and onsets of action (Porth, 2007). Chemotherapy does affect both cancer cells and normal rapidly proliferating cells causing side effects. The most commonly experienced side
effects include nausea, vomiting, bleeding, stomatitis, and anorexia. Every patient can respond differently to treatment, and individualized care must always be utilized (Porth, 2007). Children receive a much higher does of chemotherapy in proportion to their body surface area in comparison with adults (Thompson, 2003). With all cancer treatments, the patient’s nadir must be considered, and he or she must be monitored for neutropenia.

Side Effects of Treatments

Chemotherapy often renders patients multiple side effects, one of which is nutritional deficits. Height, weight, arm circumference, and skinfold thickness measurements were acquired from 54 children with cancer under the age of 18 in a study conducted by Ikeda, Collins, Alvaro, Marshall, and Garg. Fifty of the 54 patients reported nutritional side effects related to their treatment and only approximately 50% of the children had been consulted by a dietician or had carried out nutritional interventions (Ikeda et al., 2006). This signifies that as nurses it is important to regularly evaluate the nutritional status of the children with cancer to ensure that they are getting adequate calories to meet the bodily needs. Education and adapting nutritional needs specifically to the child are crucial in promoting healing and comfort. Also mouth care and antiemetics need to be taken into consideration to promote appetite. Culminating this study, “Many side effects are temporary and reversible; however, their nutritional consequences may persist for long periods leading to a negative impact on health and wellbeing and may lead to longer hospitalization, decreased response to the treatment and reduced clinical outcome” (Ikeda et al., 2006, p. 235). These researchers recommend that all pediatric patients with cancer should receive dietician consults to optimize treatment and decrease the amplitude of side effects of treatment.
Eating During Treatment

Chemotherapy often renders one with nausea and fatigue that may decrease appetite leading to weight loss. Nutrition is an integral part in keeping the body healthy during treatment and to aid the body with everyday functions. The Thomson Healthcare Company states, “Your diet during cancer treatment should have enough calories and protein to repair and build new body tissues” (2008, ¶2). Often foods that were not incorporated into the young child’s diet may be utilized during treatment, which can be a difficult task in itself in a healthy child. If adequate amounts of calories cannot be met through food sources, nutritional supplements may be used as well. If the child is still having problems receiving enough calories, products high in protein and calories can be added to daily meals. Some examples include butter, milk, cheese, sour cream, honey, and yogurt (Thomson, 2008).

Effective ways to combat the nausea from chemotherapy are to eat small frequent meals every few hours and eating when the patient feels best during the day (Thomson, 2008). Foods that are spicy, greasy, or high in fat usually are not beneficial to include because they may increase nausea. Another key is to avoid favorite foods during treatment because nausea may deter the child from wanting to eat this food again. When vomiting and diarrhea occur, it is necessary to rehydrate. Caffeine should be avoided as well as artificial sweeteners. Patients may also experience mouth sores, changes in taste, and dry mouth. Small frequent meals and proper oral hygiene can help decrease these side effects (Thomson, 2008).
Fever

A child with cancer who presents with a fever is an imminent concern. Neutropenia also can increase the severity of the fever and its effects on the body. Immediate interventions must be taken to ensure that infection is not present in the child with cancer. Tests that may be utilized in diagnosing infection included a chest radiograph, blood cultures, and urine cultures to determine the presence of any new organisms. CT scans may also be used in children with fever and accompanying respiratory symptoms (McAlister et al., 2005). The etiology of fever can be diagnosed through a history, physical, and laboratory test. Fever is often also indicative of sepsis in pediatric patients and neonates so it must be addressed promptly (McAlister et al., 2005).

Fatigue Related to Treatment

Cancer treatment is an extended process that may have many side effects including fatigue. Fatigue is not only caused by treatment but is a result of the disease process itself as well. In a study conducted by Gibson, Mulhall, Edwards, and Ream (2005), the method of phenomenology was utilized to discuss the effects of fatigue on adolescents who have cancer. This study was a small sample study with only eight subjects in a pediatric oncology unit. Semi-structured interviews were conducted using 11 open-ended questions. It was found through this study that adolescents with cancer struggle to find a sense of normalcy when they are faced with daunting, persistent fatigue and emotions surrounding their disease process. Fatigue had a significant effect on these children’s lives and activities of daily living in every dimension (Gibson et al., 2005).
This study utilized the Moustakas method which was a modification of the Stevick-Colaizzi method.

Tape recorded interviews took place and were reviewed by the researchers. “In accordance with the principles for qualitative research, the study was assessed for credibility, auditability, and transferability” (Gibson et al., 2005, p. 654). In nursing all professionals must take into consideration that adolescents with cancer are coping with extreme fatigue and treatment, and care needs to be personalized so as to provide the best care possible. Continuity between normality and the treatment process for these adolescents is very important and must be considered when providing holistic care for individuals with cancer. Nurses must remember that fatigue is only one of the many daunting effects cancer has on the young life, and appropriate rest should be encouraged.

Skin Care in Pediatric Oncology

The skin serves as a primary defense mechanism for infection, and children with cancer are increasingly susceptible to skin breakdown, so therefore are at a greater risk for infection. In a study of 347 acute care pediatric patients, the Starkid skin scale was utilized to determine the prevalence of skin breakdown. Eighty patients were found to have skin breakdown by the Starkid scale during this study. The most common areas of breakdown included the buttocks, perineum, and occiput areas. The Starkid was an adaptation to the Braden Q scale. The Starkid scale was found to be an effective means for accurately assessing and prevention of breakdown of skin in pediatric patients while in the hospital. The study also took into consideration the location and duration of breakdown and the treatments that were utilized (Suddabay, 2005). Skin should be
examined per shift or as needed to ensure protection from breakdown and further infections.

*Hopefulness during Treatment*

Every individual copes with illness in a different way. Adolescents were studied by Hinds, Quargnenti, Fairclough, Bush, Betcher, Rissmiller, Pratt, and Gilchrist (1999), and many were seen to take the approach of hopefulness in the beginning of their diagnosis with cancer. Hopefulness is defined as “the degree to which adolescents possess a comforting or life-sustaining, reality-based belief that a positive future exists for themselves or others” (Hinds et al, 1999, p. 602). “Hopefulness in the face of life-threatening illness has a protective function in adolescents, preventing the experience of overwhelming despair and facilitating tolerance of situations in which some of all of the adolescent’s needs are not met” (Hinds et al. 1999, p. 601). Hopefulness can be indicative of wellbeing and commitment to treatment, both of which can increase the treatment outcome. The dynamism of hopefulness and degree of hopefulness were assessed in this study, and it was found that the adolescents newly diagnosed with cancer had high levels of hopefulness and were focused on the immediate and short-term positive expectations of their treatment. Hopefulness has been influenced directly by the attitudes and behaviors of those surrounding the adolescent (Hinds et al., 1999). So the nurses, family, and friends must all be conscious of their outlook and behaviors involved in the disease process as well. These individuals need constant positive support from their loved ones to facilitate coping and healing.
Reducing Anxiety and Pain during Procedures

Children undergoing cancer treatments have to cope with numerous side effects and painful procedures that can cause anxiety and pain and, "Young patients consider painful procedures to be the most difficult part of having cancer" (Liossie, White, & Hatira, 2006, ¶1). In a study conducted by Liossi, White, and Hatira (2006) the use of EMLA cream and hypnosis before invasive procedures was analyzed in a sample size of 45 pediatric patients with cancer. The ability of children to perform hypnosis independently was also analyzed. The instrument used to evaluate the levels of anxiety and pain related to procedures and pre-treatment utilizing EMLA cream and hypnosis were the Wong-Baker FACES Pain Rating Scale, The Procedure Behavior Checklist, and The Stanford Hypnotic Clinical Scale for Children.

The Wong Baker Faces Pain Rating Scale “is a self-report measure and was used to assess anticipatory anxiety and procedure-related pain and anxiety. It is a 6-point faces rating scale in which Face 0 represents no pain (no anxiety) and Face 5 represents as much pain as the child can imagine” (Liossie, White, & Hatira, 2006, ¶10). The Procedure Behavior Checklist “requires observers to document the presence and rate the intensity (on a 1–5 scale) of discomfort reactions to pain or anxiety during an invasive procedure” (Liossie, White, & Hatira, 2006, ¶11). It was utilized for children ranging from six years of age to eighteen years of age. The reliability and validity of this instrument were good, and the possible scores ranged from zero to twenty-four. The Stanford Hypnotic Clinical Scale for Children is a twenty-minute, 7-item scale in which the scores are based upon the assessment of behavior and experience (Liossie, White, & Hatira, 2006). This is scored on a scale from zero to seven (Liossie, White, & Hatira,
2006). Before the painful procedures, children were asked to rate their pain and anxiety using the Faces scale and to complete the Procedure Behavior Checklist. Five minutes after the procedure, each child was asked to re-rate his or her pain using these scales. All of the scales utilized in this study had high reliability and validity ratings. All the scales utilized in this study also included scoring ranges and procedures related to scoring. No subscales were associated with the instrument. The reliability coefficient for the Procedure Behavior Checklist had an R value of 0.98. Little difference was seen between children who had EMLA cream and hypnosis and children who just received EMLA cream and attention due to children all responding differently to hypnotic stimuli (Liossie, White, & Hatira, 2006). To benefit nursing practice, patients who receive local anesthetic and/or hypnosis before painful procedures experience remarkably less procedure-related pain and anxiety. This then coincides with more effective healing and comfort (Liossie, White, & Hatira, 2006).

Kuppenheimer and Brown (2002) also analyzed different forms of decreasing pain during procedures through various interventions. Cognitive behavioral interventions, pharmacological interventions, and a combination of the two were utilized. It was previously believed that pediatric patients experienced pain in a completely different manner than the adult population. It was said that they experienced, or had the perception of, less pain during procedures than their adult counterparts, but this has now been proven to be untrue which led to new protocols for procedural pain management (Kuppenheimer & Brown, 2002).

Cognitive-behavioral therapy (CBT) is utilized to decrease stress from procedure pain, but this is limited in decreasing levels of anxiety. Pharmacological interventions
work well in conjunction with CBT and other forms of anesthetics. Some commonly used medications include the following: Demerol, Phenergan, Thoarazine, Flunitrazepan or Valium. Local anesthetics may also be used in pain management. It may either be conscious sedation or short-acting anesthesia (Kuppenheimer & Brown, 2002). CBT has been shown to decrease healing time and increases the young child’s sense of self-efficacy. This decreases further procedure-related anxiety and pain for the pediatric patient. (Kuppenheimer & Brown, 2002).

Pharmacological interventions are not used as much in the pediatric population as a form of pre-procedure medications. The research in this area is limited, and often pharmacological interventions are more prone to causing side effects. The Pediatric Oncology Group did a survey and found that only 68% of institutions occasionally utilized pharmacological interventions before painful procedures. Various forms of anesthetics are utilized in pediatric treatments. EMLA cream or lidocaine is often utilized before intravenous therapy. They aid in decreasing localized pain related to the procedure but have been shown to not have a significant effect on anxiety, so in turn they would be more beneficial if utilized with CBT (Kuppenheimer & Brown, 2002). Conscious sedation is the most commonly used form of decreasing procedure-related pain and distress in pediatric cancer patients. Conscious sedation is a controlled state of depressed consciousness and is seen as the new standard of care in pediatric oncology (Kuppenheimer & Brown, 2002).

\textit{Pain Management Interventions}

Pain management in children with cancer is a pivotal part of their treatment and care. Decreasing pain allows for quicker healing times, decreased distress, and increased
comfort in the patient. A primary form of managing pain is through medications. Micromedex (2008) addressed acute cancer pain management as a primary form of improving quality of life through reoccurring pain assessments, individualized treatment goals, and ongoing assessments of pain. A primary medication given for pain is morphine sulfate. Others included oxycodone, fentanyl, ibuprofen, ketorolac tromethamine, and naproxen. An important nursing consideration for patients on narcotics and pain medications is that of constipation. Children on narcotics most likely will experience the side effect of constipation, so they may be given stool softeners or laxatives to relieve abdominal discomfort and to increase regularity. Other side effects include sedation, respiratory depression, and nausea (Cancer Pain Management, 2008). Narcotics may function best along with adjuvant therapy as well. Adjuvants may include caffeine, neuropathic medications, and drugs that decrease itching.

National Treatment Guidelines

Nursing practice focuses on providing Evidence-Based Practice interventions that are the most effective and personalized for the needs of the individual patient. All children who are newly diagnosed and are suspected to have cancer are to be referred to a pediatric cancer center. This will allow the child to get the best prompt care possible to also begin individualized diagnostic tests and treatment. The treatment should be headed by a board-certified pediatric hematologist or oncologist. All team members should be knowledgeable in this area of expertise. The patient, however, may continue to have basic treatment and care within a qualified facility at a convenient location (Corrigan & Feig, 2004). Pediatric cancer is a very complex disease process with many aspects to consider.
Palliative Care

Cancer is often a terminal disease process, which requires advanced palliative care planning to provide the most individualized treatment for the patient while meeting his or her wishes. This is an especially difficult process in pediatric medicine. All palliative care planning should begin early on in the disease process to establish education and answer any questions the patient and family might have about this sensitive subject. Consultations may be necessary, and if that service is unavailable, primary care providers can initiate palliative planning ("Palliative Care," 2008). Early palliative care planning can help to ease the stressors of dealing with death in the final days of one’s life. Advance directives and goals for care should be established at the beginning of treatment. Nurses must always remember to establish a therapeutic relationship and take a holistic approach because they are an important advocate during the grieving process ("Palliative care," 2008).

When assessing the need for palliative care interventions, the treatment team must take into consideration culture, personal preferences of the patient and family, values, psychological, spiritual, and social aspects. "Good palliative care, as part of any good health care provision, requires continual reappraisal of the benefits and burdens of therapies. For patients to make informed choices regarding palliative care, it is important for both the patient and providers to have a realistic understanding of the options available" ("Palliative care," 2008, ¶ 2 #4 key point). The assessment of palliative care is ongoing and may change throughout the course of the child’s disease process. As the plan of care is readdressed, expectations and goals for care and life should be readdressed with
the patient and family. The patient’s preferences should always be put first when possible (National Guidelines Clearinghouse, 2008). In the case of very young children their parents or primary caregivers are in the decision making role for preferences of care.

The Initiative for Pediatric Palliative Care or IPPC focuses on education and improving quality of life through family centered care for children with cancer. The key concepts that the IPPC addresses are engaging children and families in care, relieving pain and distressing symptoms, end-of-life decisions, bereavement, and strengthening relationships with family (National Guidelines Clearinghouse, 2008). Nurses must continue to reassess the psychological dimension throughout the disease. It is important to understand how the family and patient are coping with this debilitating illness and if there is any more support that the nurse could provide.

Resources

Many resources can be utilized to find valuable information regarding pediatric cancer. There is a free internet program that can be utilized as well that determines if sites are HON accredited and have non-biased information. This website is www.hon.ch. The internet is a vast and quick tool to find information, but the sites are not always accredited. The first ten search results on pediatric cancer on the Google site were non-accredited. Some valuable accredited sites include PubMed, WebMD, Medline, www.stjude.org, The National Cancer Institute, and www.pcfusa.org. The American Cancer Society also provides a plethora of information and can assist with finding a treatment center near the patient’s area. Many internet sites provide resources to contact to join various support groups for cancer survivors and clients who currently have active cancer.
Chapter III

Methodology

Phenomenology is defined as qualitative research that is applied to phenomena influencing the health profession and nursing. Phenomenology describes lived experiences (Russell, 1999). “Phenomenology is both a philosophy and a research method that explore and describe everyday experiences in order to generate and enhance the understanding of what it means to be human” (Russell, 1999, p. 220). This method was applied to understanding the experience of the child and family coping with pediatric cancer.

“To uncover the meaning in human experience, phenomenologists use an analytic-explicating method that is unlike most philosophy methods...” (Russell, 1999, p. 221). Through phenomenology one can uncover the meaning in human experience and the focus is on the inner world of human beings (Russell, 1999). This research method is rigorous and systematic and is very descriptive and retrospective (Russell, 1999).

Participants in this study were from the Midwest area. The number of participants in this study was three. The age range of the children was 1 to 17. The study included both male and female participants, and included one parent and two teenagers.

Participants

Participants included three pediatric patients ages 1 to 17 years who had been diagnosed with cancer. Two female participants and one male were included in this study. Participants were chosen from the Midwest area. Participants in the research study included family members of the child who was diagnosed with cancer as well as the
individual with cancer, as this will relate to the different coping mechanisms utilized by those affected by pediatric cancer. Participants were interviewed in person and/or telephone at their choice of setting. Audio taping was used with the consent of the interviewee. Confidentiality was maintained throughout the study and the study for IRB approved.

Data Collection

This research study was qualitative and was based on the phenomenology framework which has an emphasis on everyday lived experiences. The intention of this study was to gain an understanding of the lived experience coping with pediatric cancer within the family. Expanding on the category of phenomenology, Giorgi’s method of phenomenology was applied to this study. Utilizing this method, the study included three individuals who have coped with the lived experience of pediatric cancer. The data were gathered through interview regarding the subject. General questions included the following: how has this illness affected their daily life; what has been effective in helping them to cope with the disease process; what was the initial reaction to the diagnosis; what roles have the nurses played in helping cope with the cancer experience. A questionnaire is included in the appendix.

Data Analysis

Gathered data were analyzed by Giorgi’s method. The data were transcribed and read through to obtain a general sense of the responses and then were reread and analyzed for the essences of the lived experience (Russell, 1999). Once the information was read, it was examined for meaning, clarification, and elaboration. The data were reflected upon, and the essence of the experience was extrapolated for each subject. Data was reviewed
and analyzed with faculty to follow the methodology to maintain the integrity of this study. Finally a description of the meanings of the lived experiences was formulated for all experiences of the study. It is important to avoid any personal biases or preconceived notions about the topic or individuals being addressed. Bracketing is defined as the “identification of any previous knowledge, ideas, or beliefs about the phenomenon under investigation” (Fain, 2004, p. 219). In order to avoid bias in this research study, bracketing was used before any contact was made with interviewees. All interviews were conducted in a manner that was free from any judgment or bias from the researcher. Limitations of this included the small sample size and limited demographic. It cannot be generalized to be applied to all patients. Theses interviews were conducted by phone and personal interviews in which each participant was asked the same questions from the questionnaire included in the appendix. Interviews were audio-taped and kept confidential.
Chapter IV

This thesis examined the coping, stress, and life adjustments of the patient and family throughout the course of pediatric cancer. It included three individuals ages one to seventeen from Montana. Two teenagers, and the father of one child participated in an in-depth interview with a questionnaire. Each individual was of a different age, cancer type, prognosis, and treatment; however, each of the experiences was interrelated through common themes. Themes from this study include (a) seeking a diagnosis (b) remaining hopeful throughout treatment (c) feeling exposed and vulnerable (d) family support and coping (e) nurses’ impact on care (f) individual growth through the experience.

Seeking a Diagnosis

Each individual in this study went through a lengthy diagnostic process. Each had a delayed diagnosis that presented atypically. In order to be sufficiently diagnosed, he or she had to seek consultation from more than one physician. Each participant went through diagnostic tests including MRIs, CT, and X-rays.

Pain. Along with the initial diagnostic process, pain was a primary factor in seeking treatment. One participant who was very active in sports and extracurricular activities stated, “I was in a lot of pain and was hardly sleeping. I could hardly walk as well so they decided to do an MRI.” Another individual stated, “I got the lump on Jan 1st on my neck and it was really sore and big and it hurt to touch it.” Each sought out treatment for different forms of pain that was interfering with everyday functioning.

Reoccurring doctor visits. During the process of being diagnosed with cancer, it took multiple visits to determine the actual cause of the pain and discomforts that each participant was
experiencing. Lack of prompt diagnosis was interrelated to the atypical presentation of each participant’s cancer. One participant stated...

I was trying to get in shape for basketball season in November; the previous March I had pulled my hamstring in softball and they kept trying to treat it and it just wasn’t getting better. I was back and forth to doctors all summer, and it was one thing and then another and they couldn’t quite figure out what was going on.

This also can lead to financial stresses due to the increasing costs of healthcare. Another child had problems with vital functioning from his first days of life. His father stated, “They discovered after his second day of life that he wasn’t getting proper amounts of blood to his body because he was getting gray and so they didn’t know what was wrong with him.”

Another participant stated, “I was a really strange case and the reason it took them so long to diagnose me was that in Hodgkin’s Lymphoma usually the signs and symptoms are fever, loss of appetite, and weight loss and then you get the lumps.” She, however, presented with the lump first along with pain. Increased complexity and new knowledge of a vast array of new types of cancer leads to increased diagnosis time and often frustration for the patients going through the lengthy process of adequately diagnosing their disease process. It was important for all these individuals to remain hopeful throughout this process.

*Diagnostic tests.* There are a vast number of diagnostic resources available to medical staff in our generation to adequately visualize the body to search for abnormalities and malignancies. Each individual in this study underwent multiple forms of diagnostic tests to classify the disease process. A participant’s father stated, “Through x-rays and CAT scans they eventually discovered that it was a tumor attached to his liver.” Another stated:

I was going to physical therapy and I was trying to work out and run, and stretch and get things to heal and it didn’t seem to work. Around this time last year we went back to my doctor and decided something else needed to be done because there was obviously something more wrong than what they had found. She ordered an MRI and after she
ordered the MRI she went back and looked at some previous x-rays she had taken and one of the views of my pelvis.

She then was referred to a larger hospital: “I was off to Seattle to do a biopsy, because they didn’t want to operate on it in Butte.”

Often one source of scanning is not sufficient for diagnostic purposes, so other scans are completed. One participant went through different forms of tests; she stated:

They tested me for mono and strep throat and they thought that I just had swollen lymph nodes. And then they tested me for cat scratch fever; the results came back not positive but not negative either so it was undeclared . . . . So I had to wait a week and they had to test me again and by that time it had come back negative and it had been six weeks and they did a biopsy of the lymph node.

Final diagnosis. Each individual had a different diagnosis in this study. One participant said, “They completed a biopsy on the hip and determined that the tumor was malignant. It took them awhile to find the name and to determine exactly what it was because it had bone involvement and soft tissue involvement. So the final name they called it was malignant nixoidfibroitissiocytoma (MSH); it’s basically a type of sarcoma which is linked to osteosarcoma and Ewings sarcoma.” Another child’s final diagnosis was a hemangioma of the liver. And the other participant was diagnosed with Hodgkin’s Lymphoma. Even though they had vastly different disease processes, they each had to endure the difficult process of properly diagnosing their condition. Once a definitive medical diagnosis is declared, patients experience a multitude of emotions ranging from relief, shock, fear, and anger.

Initial reactions. Being diagnosed with cancer is a process that is life changing. Fear, shock, and uncertainty often accompany the initial response to diagnosing. One individual stated, “I was really scared; I didn’t know a whole lot about things like that; no one in my family had had cancer before. I didn’t know what to think, and when I heard the word tumor, I immediately thought of cancer and then after that I had a feeling that it wasn’t good.” Cancer is a
complex disease that carries with it a burden and a negative connotation of morbidity. There is hope for a cure or remission from the disease process, however. Another participant stated, “I just remember my dad looking at me and taking a deep breath, and I kept asking him, “dad what did they say?” He said it’s malignant sweetheart, and I was just numb. I didn’t know really what to feel. I didn’t know if I was scared, mad, or shocked.” Another participant stated:

It took over a month to diagnose me and once they finally did, I think I was more in shock. I didn’t really know what was happening. I knew that I had cancer, but I guess it just didn’t really click. I knew that it was bad and everything, but I didn’t have any idea of what I was going to go through.

*Coping with the diagnosis.* Dealing with the process of cancer is different for each individual. One participant stated, “I think you get to know your body and I knew I just had a feeling that I was going to be ok. So I guess that feeling I had about being okay was real but I just didn’t realize what it was going to take to be ok.” Reoccurring throughout the interviews was remaining initially hopeful following a diagnosis, but the main challenge with primary diagnosis was lack of knowledge about the disease process. One individual in the study stated:

I tried as much as possible not to deal with it. I dealt with it but I tried to forget about it as much as I could. So anytime I was home, I would try to go be with my friends and did what they were doing. I never realized I think it was harder on my parents and my family then it was on me. I was trying to be as normal as I could, and they really knew how sick I was.

The participant with the hemangioma stated, “I was really scared, I didn’t know a whole lot about things like that. . . . I knew that if it wasn’t growing that they could probably treat it.” Coping with cancer is an ongoing process even after a cure or remission. It is a life altering event for each individual who endures it.

*Family member reactions.* This study found family to be a significant form of support throughout the disease process. Family members care deeply for their loved one being diagnosed
and the diagnosis of their child having cancer can render them fearful, uncertain, and helpless. One individual stated, “I went in and they were shaking and crying, and I went in and was like guys it’s going to be fine. I think you get to know your body and I knew I just had a feeling that I was going to be ok.” This individual gave family members strength even though she was fearful herself. Another participant felt helpless because there was no impact he could make on the diagnostic process. He stated, “I had to put my son’s life in the hands of doctors and trust that they would take care of him. I second guessed everything that they did cause I knew I couldn’t do anything myself.” Many times parents feel helpless watching their children struggle when they had dreams and wishes for their children to live normal lives. A participant stated, “I didn’t actually see his eyes open until he was 2 months old. It was really hard to take; he just looked like a flaccid baby and he was on a ventilator. He just looked dead.”

Treatments

The treatment process for each individual was a different experience and included various medications and procedures. Treatment in each of the participant’s situations was aimed towards a cure. Chemotherapy, radiation, and surgery are common forms of treatment in cancer. Each participant sought treatment right away after the diagnosis. Often chemotherapy regimes are intense, lengthy processes, and one participant stated, “I started on November 7th with chemotherapy called cisplatin and doxorubicin. . . . So I was on doxorubicin for three days and then I was off of chemo for 22 days, and then I went back in for a drug called methotrexate.” Once the physicians discovered tumor growth, they switched her to a different treatment protocol and she stated, “Then they put me on the protocol for Ewing’s sarcoma which is called iphosphamide and etoposide.” The vast number of chemotherapeutic agents available to our society today allows multiple options for treatment if one course fails. Another individual with Hodgkin’s Lymphoma stated:
I just had seven medications and my main treatment chemotherapy which was the first two weeks of every month IV, and then every third week I did oral medications, and in the fourth week I had off for my blood to rebuild and to recover; then I started over again. The form of chemotherapy she received was vincristine, and she was on prednisone as well.

Another individual in the study received vincristine as well; his father stated, “He did chemotherapy after the steroids and after the biopsy.” The reason for the biopsy was, “He was very oddly shaped and his hemangioma was the size of my fist. They cut him from his sternum to his groin.” Not only did they do chemo but he underwent surgical intervention as well as a diagnostic tool for better diagnosis and treatment. The father stated, “He also wasn’t producing adequate amount of blood cells on his own. Then after that they decided to put him on steroids (prednisone) and it didn’t help at all so he basically had a blood transfusion every day, packed blood cells and plasma” Each individual had to endure the chemical hardships of treatments all while sustaining a positive attitude.

*Hopeful outlook towards treatment.* The treatment process was a mentally and physically challenging experience for the participants. One participant felt she coped better with treatment due to, “they always say being naïve about something is bad, but in my case being naïve about what was going to happen and how I was going to feel the side effects and everything was very beneficial.” Taking the process day by day and fighting through the pain and fatigue helped her in coping with the process and also observation of others’ strength around her inspired her to remain hopeful through treatment:

I was on the pediatric ward and I was an older peds patient cause I was 15 and a lot of the little kids there were so much younger than me, and it was just amazing to me and I look back on it and I would lay in bed and get my chemo and here five and six year olds were running around playing tag with their chemo back packs, and in that way they kind of helped me realize that no matter how bad things get, someone always has a worse case.
They had no idea why they were there, and they still had an amazing outlook on life, so I think they helped me keep a positive attitude.

Another participant experienced extreme weight loss during her treatment process, and she found it hard to maintain weight with all the treatment side effects but she stated, “So I was determined not to get a feeding tube, so I lost all that weight and had to backtrack to try to gain a whole bunch.” Another method of coping with treatment employed by this individual was communicating with her peers at the Ronald McDonald house: “I was waking up every day fighting for my life, and I got to know other people that were going through the same thing that were my age, and I could kinda talk to them and be normal.”

*Side effects.* Side effects from cancer agents are inevitable, and at some point each individual undergoing treatment will encounter side effects. The participants in this study all had life-altering side effects that they will cope with for the rest of their lives. One participant stated:

They told us that the side effects would be hair loss, bone and joint pain, which made me really sad cause I thought he had already been through enough but it was what we had to do. . . . They had him on low doses and over the first few months, we didn’t see any side effects and mostly the main side effect was that other 4 month old babies were much more active than he was; he kind of just laid there. He was very stiff.

It was particularly hard for this father to cope with his child appearing lifeless and not like a normal baby. The vincristine has lifelong effects on joints as well, so the father was concerned with his son having physical limitations in the future. Chemotherapy and radiation have a high emetic potential in many individuals, and one participant stated regarding her treatment:

The worst part I think was radiation for me as far as side effects. . . . I got pretty sick the first few treatments [chemotherapy] a lot of nauseous and vomitty sick. . . . I would just get really tired and, I was sleeping a lot and I had really bad headaches and stomach aches and I couldn’t eat.
Side effects of treatments can linger and appear years down the road after primary treatment, and another individual stated, “One of the major drugs that I was on was prednisone and that drug was one of the hardest that I had to take, and it is one of the side effects that I’m still trying to overcome today. It’s horrible on your joints and your bones, and at the time I gained 45 pounds of water weight. It just makes you really puffy and uncomfortable.” She also underwent chemotherapy:

Then I had hair loss from the chemo drugs, and I got bad chancre sores in my mouth because it kills the fast growing cells so everything in my mouth and my taste buds were raw. Vincristine affected my major joints and all other joints and it affected my jaw joint, and I had times I wouldn’t be able to open my mouth so I would be in the hospital so I could get food through my IV. The first treatment of the month I would get sick. (We traveled to Spokane every time.) I started at Sacred Heart, so my first week of treatment I didn’t get sick until the next day so we started planning it out to where we would drive there and drive back right after my chemo, but it got to where on my second treatment I would get sick right away.

Not only did she have to cope with experiencing the side effects, but compounding the issue was traveling to seek efficient treatment and traveling to reach her comfort zone of her home. Various forms of medication are also given to oncology patients undergoing treatment to combat the emetic effects and pain before the treatment process. One participant had a longer acting antiemetic that assisted her in regulating nausea: “I was on a lot of anti-nausea medicines and I wore a scopolamine patch behind my ear the whole time I was getting treatments.” Another participant stated about her nausea control, “I took a lot of Zofran.” The treatments that these individuals endured had incredible effects on their bodies that left them in a different psychological state than that of a normal child. Fatigue was another reoccurring side effect, and a disease characteristic among the children, and they battled that every day and sustained their treatments to overcome cancer.
Exposed and Vulnerable

Having cancer put the individuals in a vulnerable state. Everything about their bodies was changing and they felt as though their sense of control was gone. Each individual had to put his or her trust in their nurses and physicians to do the right thing for them. Compounding the situation was changing body image, fertility issues, traveling, seeking normalcy, and feeling alone and helpless.

Hair loss. Chemotherapeutic agents and radiation physiologically affect rapidly dividing cells in the body leading to hair loss. This is particularly a difficult part of the treatment process for most all individuals. Two participants were teenage girls who valued normalcy and body image, and their treatment process took most of their control away. One stated:

Definitely losing my hair was the hardest thing I dealt with. Being a teenage girl anyways appearance is a huge thing, and my hair has always been a big thing for me and I took a lot of pride in what I looked like. Losing my hair I kind of felt exposed and really vulnerable. Especially losing my eyelashes and eyebrows, I didn’t feel like a girl; I couldn’t look in the mirror.

She also attended a school dance during her treatment process: “I got to the dance and I was in so much pain and got so emotional, and when we were fixing my hair that day, we had to be really careful because little pieces were starting to fall out.” Wigs, hats, and scarves are means of covering hair loss for individuals with cancer. Some individuals are more comfortable than others with hair loss, and that is part of the coping process. While in the inpatient hospital, the same individual was missing her high school prom at home, so she planned a prom with her nurses, and all the families on the floor attended. She stated:

I was so self conscious about having a scarf or a wig or a hat on all times. I didn’t want my mom seeing me, my doctors, my family, or friends. There are still very few of my friends that saw my head without anything on it. And at my prom there was this little girl I knew; I asked her if we could get a picture together, and she didn’t have a wig or
anything on and she said, “No, no, I’m not pretty like you. . . .” And I had on this human hair wig that was all curled and looked like my normal hair, and I felt semi-normal in it because it looked somewhat what I used to look like and she wouldn’t take a picture with me because she felt so ugly because I had on this hair. So for the very first time in front of people I took it off, and we took this picture, and it is my favorite because I let myself be me and not try to be who I used to be!

At a very young age she came to the conclusion, “It was a big struggle, finally realizing that I was beautiful no matter what I looked like!” Body image acceptance was a large part of the coping process for two of the participants.

One parent felt, “I would have had a much harder time, I think, if I would have had to watch his hair fall out.” Hair loss was a definitive turning point in the treatment process for another individual as well; she stated, “I had all my family with me and then we got back and it was during my fourth week I got out of the shower and I started losing my hair. That was when it really started to kick in.” Outer physical changes to the body are surprising and often drastic during treatment, and they brought about many emotions for the participants.

Seeking normalcy. Each participant wanted to maintain a sense of being normal through the treatment process. Adjusting to cancer and being taken out of her normal environment was challenging: “Getting pulled out of school was really hard for me because the one thing I really wanted was to be normal. I would go to school and it wasn’t even just to be with other kids and to have them understand what I was going through in class but it was just that routine really helped.” Another found missing school events impacted her greatly:

I think that the most difficult struggle I had was not being a normal teenager there was one day that we were at a softball game, and I was watching my teammates play, and I could only go for a minute because I had to go to Spokane for treatment. And just only watching them and not being able to be out there and not being normal and doing everything else that everyone was doing was very difficult.
Feeling alone and helpless. Along with seeking a normal life in very atypical circumstances, the participants were rendered lonely and felt helpless. They had to trust their life in the hands of others. One father stated, "That was the loneliest I have ever felt; it was just me and my thoughts and my hopes that he would get better." Treatment can wear on one's strength and mental toughness, and one participant said, "Towards the end I was really bad and I knew exactly how I was going to feel I knew exactly when I was going to get sick. And exactly how long it was going to be and after the third month is when it really started to get hard for me." The potential of death is also a difficult concept to cope with during treatment rendering one participant fearful: "There was a lot of times going to bed where I was afraid and I didn't think I was going to wake up. That's a scary thing to have to deal with." Uncertainty of the outcomes for each individual was a large obstacle to overcome in the coping process.

Traveling. Each of the participants interviewed had significant distances to travel away from home for treatment. Coping with treatment and the disease is complicated enough without having to travel, and each of the individuals endured both. They traveled to seek the best medical treatment possible for their circumstances. One individual traveled to Seattle, one to Spokane, and one commuted to a larger hospital in Salt Lake. Luckily there are supportive institutions in our society that aid in the financial aspects of families traveling for treatment. One such institution is the Ronald McDonald house.

Weight changes. Chemotherapy has detrimental effects on the intestines due to the rapidly proliferating cells. It can often be difficult for patients to maintain their weight during treatment due to the medications and the increased metabolic demands of the body. During chemo one individual stated, "My first round of chemo I got pretty sick and I lost a lot of weight; in the first month and a half I lost about twenty pounds, and I was determined not to get a feeding tube, so I lost all that weight and had to backtrack to try gain a whole bunch." Younger children may not progress developmentally to eating initially and have to have supplemental nutrition through TPN and lipids. The young child with the hemangioma did not eat for his first few
months of life and his father stated, “He was very undersized because of what his body went through and he still is but he ate like crazy. At first he didn’t know what to do with the bottle and you could see him progress; eating made him a whole new kid.” Another participant stated, “Vincristine affected my major joints and it affected my jaw joint and I had times I wouldn’t be able to open my mouth so I would be in the hospital so I could get food through my IV.”

Pain. Treatment and the cancer itself have an all-encompassing effect on the body; they can cause fatigue, fear, scarring, and emotional fatigue. Radiation in particular was a struggle for one participant. She stated, “Radiation was definitely the worst part and fatigue; they warn you, you are going to get tired but you have no idea how tired you are really going to feel.” Even though she was extremely fatigued, she pushed on through treatment and maintained her motivation through this philosophy: “There is one day that you are pissed and hate the world; you are in so much pain you don’t think that you can do it any longer, and you just have to push yourself through that day and the next day might be a little bit easier, and if it’s not then you force yourself through that day.” Fear is also a tremendous deterrent in emotional strength, but it is a stage of the coping process that must be confronted. The participant stated, “There was a lot of times going to bed where I was afraid and I didn’t think I was going to wake up.”

The treatment for cancer can have caustic effects on the body that require treatment for their side effects as well. The father of the child with the hemangioma stated, “Up until 18 months he had PT and a special seat that positioned his legs so he could move. They were worried that he would not be able to walk or walk properly. And I saw walking as one of the most important times in a kid’s life.” He eventually had appropriate progression with his physical mobility but it was a long road of recovery. The participant with Hodgkin’s also underwent physical therapy, and she stated:

I did physical therapy a couple of years ago. We tried a lot; we tried acupuncture, and everything and nobody could ever tell me what was wrong and they just said oh it’s a side effect of the chemo drug and the necrosis doesn’t show up until four or five years
after and finally we did a scan, and they could see the start of necrosis in my hips which finally gave us peace of mind that that is exactly what it was.

Side effects from treatment are inevitable, and each individual undergoes strict follow-up appointments to maintain a state of remission and to monitor for these effects.

Radiation also is very caustic to the body for an individual, and she received localized treatment to the pelvis. She stated, “It just burned everything and especially being a girl it just burned everything down there. Intestines and my colon was just fried, so that was really painful. My skin was just peeling, I could hardly move and I wouldn’t eat because then I would have to go to the bathroom which was extremely painful; I had like skin coming out.” This was a very difficult time for her to overcome, and the pain was an inevitable feat that she had to overcome.

*Support and Coping- knowing*

*Families.* Each individual with cancer recalled families as the main support system and the most important unit in aiding in coping with the disease. One individual regarded her mother as her primary support; she stated, “Having my mom with me helped a lot; she was my comfort blanket. She had to be wherever I was.” Support was also available to her through their living situation: “My mom and I and we ended up living at the Ronald McDonald house so we were around a lot of people all the time and I think it would have been a lot harder if it was just her and I. I got to know a lot of girls my age and I’m still good friends with a lot of them.” Not only was family the main mean of coping, but religion played a large part in coping for one family; he stated, “I prayed a lot; that’s what helped me cope and I just felt like he was going to get better. I had faith that he would be better. I could sense it.” He also mentioned his support system:

My family was my only peace of mind I could find. I couldn’t enjoy things, I couldn’t just sit down and watch a movie, and all I could do was think about him and analyzing the situation. I couldn’t do anything without dwelling about the situation. He was the only thing in my life at the time.
One participant had nearly her entire family involved in her care which was a great support system for her coping with her disease. She said:

My family definitely and my friends [were my support]. I had an amazing group of friends. There wasn’t one time that I went to the doctor by myself; either my mom or my dad or brother and sister came with me. My sister was at UM and we would pick her up every time on our way, and she would be there along with my parents. Even my aunts and uncles and cousins came. Someone would always be with us.

Family members were an integral part of each individual with cancer coping. Family dynamics changed, and family events were altered as well to accommodate the specific needs of the individual to promote healthy coping. One participant had a particularly difficult holiday season; she said, “I woke up on Thanksgiving and took a shower and almost all of my hair fell out that day. So for Thanksgiving dinner I tried to figure some sort of braid or something I could do and we didn’t take Thanksgiving pictures like we usually do.” Not only did the families adjust to the child being in the hospital but they had to alter their home life as well: “We had to adjust and become very sanitary, and I had to wash my hands like a hundred times a day.”

**Nurses impact.** Nurses are a large part of caring for the individuals with cancer. Sometimes nurses are the only advocate the patients have. Each participant was asked what impact their nurses had on their care and how nurses should interact with their patient’s. One individual responded, “I would say just be very personable; it’s a job that you are getting paid for, but I think especially with oncology, it hits home a lot more than just going to work and doing what you are supposed to do and going home.” Many of the individuals with cancer are in the hospital for an extended period of time and repetitively, so they get a chance to get to know their nurses; another participant stated, “Our nurses were wonderful. My nurses became part of my family and they still are. My relationship with my doctor was different because the doctor only does so much like just changing my prescriptions but really other than that it was the nurses who
took care of me. They would do the IVs and the chemo, and after seeing them week after week, you really grow a strong relationship with them.”

An individual in this study really stressed caring for patients more on a personal level; she stated, “You have to get to know people and genuinely care for your patients and get to know them as people, and it gives them a little bit of comfort when something so scary and unknown going on to your body and there are people around you that are taking very good care of you and truly care about your well being.” It was also very important for family members to be involved in the care of the child with cancer so that they can still feel connected. Privacy is also difficult in the hospital setting and a particular nurse made a great impact on one family:

She would bring us curtains so we could be in our own area so we could spend time with him. . . . None of the other nurses would let us hold him but he was in a warmer with all sorts of tubes and we thought we couldn’t touch him so we would sit there and stare at him. And this nurse was the first to ask us if we wanted to hold him. . . . and we were shocked: “we can hold him this is awesome.” She wrapped him and showed us how to wrap him. That was great and we felt very thankful.

Each individual felt that it was important to make the family and patient feel involved in his or her care. Nurses also had a great impact on patients with their words, and one individual in regard to nurses said, “I just think that being sincere, not necessarily trying to understand what they are going through but just being there. One thing that always bothered me was when people would say I know exactly how you feel. . . . No you don’t.” Support through presence and humor was holistic and met the needs of this patient without sympathy. Patients wanted a sense of normalcy and someone to communicate.

Advocacy. Nurses were not only advocates but became an extended part of the patient’s support system. One participant said, “I got to know my nurses, and nurse practitioner really really well. They got to know me. . . . A lot of them are young nurses around my age, so I kind of related to them more because I was one of the older kids on the floor. I didn’t look forward to
going in to get chemo, but I looked forward to going in and seeing my nurses that had become my good friends.” This solidifies the importance of holistic nursing and supportive care to patients. One individual advised, “I needed different things and every patient deals with it different so they need different things and if you can provide that it will be just fine.”

Humor can often be an effective means of support and one participant stated, “All of my nurses were there for me trying to make me as comfortable as possible and trying to make me laugh. They just being there and being sensitive to my needs was great.” In retrospect it is interesting to see how much of an impact nurses make on a patient’s stay, and one individual declared, “I credit my nurses and nurse practitioners with my life, and they mean so so much to me, and I want someone to feel that way about me. I definitely want to go into the medical field for that reason.” Another participant had the opportunity to choose a particular nurse as their primary patient advocate, and he stated, “His nurses were awesome but a particular nurse was his advocate and she really cared about him. . . . once we picked this nurse as his advocate she was amazing. She didn’t coddle the babies and you can’t in the NICU, but she really cared about the parents and she would tell us everything. She even shared other experiences of other families and how they coped with it.”

*Communication.* Nurses used communication as a tool for not only diagnosis and but as a holistic form of treatment as well. Nurses facilitated coping through communication, and one individual stated, “It was good to have people who would come and sit and talk to me, it was comforting to have that aspect. Especially since I was so far away from everybody and everything I was used to.” The nurses are the families’ source of information while the child is in the hospital, and a father stressed the importance of the nurse helping to maintain morale through communication. He said, “Tell them what is going on and update the family as much as possible. Even though he didn’t move that much, anything she could give us was comforting. Even he opened his eyes and screamed a few times and we were like Oh, ‘he did and we missed it.’ Take into consideration that it is someone’s kid.” Communicating did not always have to focus on
medical issues either; a particular individual just wanted to have normal conversation. She said, “Before the visit they would ask how is your day, what’s going on instead of this is what’s wrong and this is what we are going to do about it.”

Remaining hopeful. Treatment often takes an extended period of time and the outcome is unknown, so remaining hopeful and adjusting were main tasks for the patients and families. One participant’s father felt that coping was easier: “Luckily his treatment was short. I just loved him for who he was and I adjusted. . . . I kept telling myself that he was going to get better. I was hopeful the whole time, and I convinced myself that he was getting better and that he would overcome this and he did.” He had a positive outlook from the initial diagnosis, “I felt better with the diagnosis and I got a strong feeling that everything was going to be fine and that point and that feeling stayed with me.” Another participant was adjusting to her physical state, and she had a discussion with her mother that changed her outlook; she said, “My mom sat me down one night, and she said you can do this the easy way and have a good outlook on this and be positive or you can do it the hard way and be negative about it, but either way you have to do it, so you might as well make it as easy as possible.”

Community support. Community support assisted with financial burdens and provided moral support for an individual after her diagnosis. She regarded this as very beneficial feeling that everyone was behind her:

One thing, I went to a catholic high school and they held a 48-hour prayer service and the community sold angels for a dollar to help with funds, it was great the support from the community; my friends and my family got me through it. . . . The support that I had was just amazing; I don’t think I could have done it without the community that I lived in or the school, and it was so small that we were all family. From just looking at my wall, I have a blanket that the entire high school had signed for me, and it really meant a lot to me.
Isolation at a camp. Another support system that is available is camps that specifically have children who have had cancer or who have active cancer come for a week at a time. One individual had an experience and she said:

I tried to go to a cancer camp with a friend of mine. Camp Good Times. There was the cancer patient and then they could bring a friend that was normal, and my mom drove us up there, and we got there and I looked around and I was the only bald patient there; it was kind of more like a camp for cancer patients in remission. It was the worst experience of my life. Everybody that I stayed with was our age, but they had gone through cancer when they were like 4 or 5 so it really didn’t help me to talk to someone. I was really hoping to find somebody that was my age that was going through the same thing, but it just wasn’t like that. We actually ended up leaving early.

It is hard for children with cancer to relate to their peers because they are forced to grow up and cope with a disease process that people their age generally have no experience with. Another participant stated, “I grew up a lot. And sometimes that’s a good thing but at the same time it’s not very fair.” It was important for them to have normal peer interaction and someone to relate to.

Education. Once a diagnosis was reached, the next step was the treatment process, and often people want answers as soon as they can have them, and there are many educational tools available to individuals with cancer. A common theme among participants was their use of physicians and medical personnel as their primary form of education. One individual learned through environmental observation and other families in the hospital. He stated, “I got to spend a lot of time with him and I got to know a lot of the families and other kids on the floor. They had all been treated for cancer their entire lives. I didn’t do a lot of reading but I more observed the children and how they felt about their disease.” Another participant was instructed not to research her disease due to it being rare and very individual; she said, “My mom and I actually decided not to look at anything on the internet because they did a study about people with cancer and over 40% of the information that they researched on line was totally untrue. So we agreed to not look
at anything on the internet because it just scares you even more. My doctors and nurses are very open to questions.” Another participant said, “I really didn’t read any kind of books; it was more people. I tried as much as possible not to deal with it. I dealt with it but I tried to forget about it as much as I could.” Each form of cancer is unique and can be highly individualized to that person, so physicians and nurses are a great primary source for recommendations towards educational tools.

_Not the Same Person_

Through their experiences with cancer each individual was changed. Each individual had to accept the change involved with cancer and adapt and grow in the experience. Moving forward after the experience was also an integral part of the coping process. One individual referred to her transition of letting go of the past, and she said, “So for the very first time in front of people I took it off [wig] and we took this picture and it’s my favorite because I let myself be me and not try to be who I used to be. . . . I still have short hair and I hate it, and sometimes I want to wear my wig but that’s not who I am anymore. So it was a big struggle trying to realize I’m not the same person I used to be.” She found tremendous growth through her experience and adapted.

Even through this life-changing event, a sense of identity remains, but the individual’s perception on life can be altered. Once the treatment is finished with either good or bad results, one must move on in life. One participant stated, “I’m still me and I look different and I’ve experienced things and I look at things a lot differently now, and you have to find beauty in that and within yourself. . . . I have to accept the things that I’ve learned. I can’t let having cancer consume me, and I have to move on and know that I’m stronger because of it and I look at things a lot differently.”

_Taking care of oneself afterwards_. Leaving the hospital and returning home after treatment entails many lifestyle adjustments. With a compromised immune system from treatment, one participant stated, “When I get sick I get really sick. My immune system is
difficult; my white count is finally back to where it should be, and for some reason when something is going around, I always seem to catch it. There are not many times that I don’t get sick.” Another referred to the challenges of maintaining a safe environment; he stated, “Sanitizing everything and everybody who came in contact with him had to use hand sanitizer and just a balanced diet. And I was really cautious and I never really noticed how dirty people are until we had to be super clean.” Not only do the individuals have to adjust to an altered home life, but they have to adjust back into their regular daily routine. One participant felt, “It was harder being around my friends at home because I think people don’t know what to say. I felt a lot different than them; I wasn’t a seventeen-year-old invincible having fun going out every weekend kid.” Once treatment is finished children who have had cancer endure lifetime checkups to maintain their cancer-free state. Follow-up care is an integral part of preventing and diagnosing secondary malignancies, and one participant stated, “I did checkups every three months for two years; then I went every six months for a year, and then every nine months and now I’m finally going yearly.”

One step, one day at a time. Treatments are challenging and taxing on the body. It took mental strength as well as physical fortitude to make it through treatments. Often patients can lose hope or become discouraged, but one participant stated, “It was never a question of whether or not I was going to live or die. I never really thought about that or exactly how sick I was; it was more like something I have to get through. There is no way around it; it is something I have to do.” Another advised, “Going through treatment, you have to take things one day at a time. There were a lot of days that I didn’t think that I was going to get out of bed and I didn’t want to.” Relating to others with the same experiences can also be a beneficial form of support, and one individual referred to her process as “I was waking up every day, fighting for my life, and I got to know other people that were going through the same thing that were my age, and I could kinda talk to them and be normal.” Being a normal teenager during treatment was never an option for two individuals in this study. One stated, “I have to worry about where I’m going to be five years
from now and what I need to do to take care of myself in order for me to be here five ten years
from now. I grew up a lot. And sometimes that’s a good thing, but at the same time it’s not very
fair.”

_Not taking things for granted._ All of the participants discovered a new found
appreciation for life, and they felt that nothing should be taken for granted. Each moment was a
precious gift for one father, and he stated, “As hard as it is finding out that cancer is what you are
dealing with, never give up hope. Spend every minute you can with them. Don’t take anything
for granted; that is what got me through it, time is valuable.” One individual not only acquired a
realization of appreciation of the future and present, but that the past should not be dwelled on.
She said, “You know I’m not invincible and I understand that... I have to remember that now,
don’t take things for granted that are happening right now; live in the moment right now. You
can’t worry about things you’ve done in the past, good or bad and you can’t worry about getting
things done in the future; just worry about now.”

One individual felt empowered by her experiences:

I realize now that it was surreal that I went through it all, and I’m also glad that everyone
still tells me that I had a good attitude because it’s so hard if you don’t have a good
attitude for the people who are trying to care for you. I’m glad that I made it as easy as I
could on everyone else. It’s something that I will take with me, and I’m very proud of it
and I openly speak about it. Now I like to do anything that I can do whenever it changed
my aspect on life, too.

It was very important to live in the moment for all individuals in the study. One individual stated,
“When you have the opportunity to do something, don’t let it get away from you.”

_Readjusting to life in remission._ Each participant in this study was currently in remission,
and each had made significant life adjustments to meet personal physical and emotional needs.
One participant was still struggling with her transition back to school she said, “I feel like I was
shoved back in where I used to be but I’m not the person that I used to be. So it’s hard getting
used to my old lifestyle in my old setting almost as a different person.” One participant had enough physical strength to return to playing sports in high school but was still overcoming her physical side effects. She stated:

They told me that after high school I had to promise to cut back and take it easy, I can’t put the pressure on my body that I had been. When I got into college I really didn’t do anything active and my hips last summer got really bad to a point one week where I was on the ground and they just hurt so bad.

She had to seek further treatment from a rheumatoid specialist, and she overcame her pain to achieve great things. She referred to her physician saying, “She gave me some anti-inflammatory and muscle relaxers and I took them daily. She said the worst thing I could do was not move, and I’ve tried to really push myself and my hips have really gotten a lot better. This last summer I ran a half marathon and this coming summer I am going to run a marathon.” She is proof that normalcy and physical achievement are possible after treatment.

Each participant had great outlooks on the future. One father was still apprehensive about his son’s progress. He stated, “I think he has an awesome future ahead of him. I do sometimes worry if the steroids will have permanent effects on him. I have a much more positive outlook. He has been really healthy since he came home from the hospital. He was a little slow learning to walk but he is a champ now, running and jumping off of things.” One participant was excited for her future replying, “I would love to have children; I’m going to be a teacher and hopefully I can get married.” Even through overcoming the great obstacle known as cancer another individual also stated:

I just want to be successful and be healthy. I want to go to college and I know it’s going to be a struggle. I want to have a family and that’s one thing I have worried about from the beginning. Nothing that I thought I would ever have to worry about in high school like worrying about being able to have a baby. I absolutely want to have children and to get married and to be successful.
A normal life after cancer is attainable and each participant in this study was striving for just that.
Coping With Pediatric Cancer

Chapter V

Discussion

Seeking a diagnosis

The initial process of prognosis and diagnosis is taxing and an emotional process that instills fear and uncertainty in the patient and family. Once a prognosis was acquired by individuals in this study, feelings of hopefulness were present. A study about diagnostic responses to cancer stated, “Having one's child receive a cancer diagnosis is a time of crisis. Previous research has identified that parental routines are altered, additional stress is encountered, and needs are changed” (Smith-Ward, Kirk, Hetherington, & Hubble, 2005, p.320). McGrath and Philips (2008) enumerated similar results and hypothesized through their research that psychological issues need to be addressed in the evidenced emotional states and phases that children of cancer go through beginning at the diagnostic phase. The diagnostic phase is particularly daunting due to its variability of length and complexity that each disease entails. It often takes an extended period of time to correctly diagnose each individual. Each participant’s families are intricately involved in the diagnostic process. Smith-Ward, Kirk, Hetherington, & Hubble (2005) conducted a study that identified the parents requesting that everything possible be done to diagnose and treat their child. It was found in their study as well that parents were significantly overwhelmed with the initial diagnosis and agreed to follow the treatment protocol recommended by the physician (Smith-Ward et al., 2005). Despite all the difficulties encountered during the diagnosis process, families and children were able to overcome their initial emotions and moved into the treatment phase.
Exposed and Vulnerable

All individuals in this research had undergone immense physical changes, one of the greatest being a change in body image which was particularly difficult for the two teenagers. In an article by Sandie Larouche and Lily Chin-Peuckert (2006) it was stated, “Such physical changes can increase suffering and distress in the adolescent with cancer and lead to maladaptation” (p. 200). This was significant in the aspect that their emotional constraints and psychological capacity were already challenged by the disease process itself, and the side effects of treatment compounded this issue of impaired body image and self-identity. As a teenager each individual was also at a pivotal developmental state in which he or she was forming a sense of identity when cancer disrupted the intricate development (Larouche & Peuckert, 2006). Another commonality among participants was a greater awareness of the disease process once external physical changes occurred leaving him or her feeling vulnerable. Larouche and Peuckert (2006) also discovered, “It is this feeling of exposure that drives the adolescents to develop a new set of behaviors to cope with their new situations” (p.200). Body image changes were also accompanied by a shift in the emotional propensity involved with cancer for the participants.

Perceived body image changes also were found to have a significant impact on adolescents’ desire to go to public events or school. Today there are various methods for individuals with cancer to cover hair loss or to enhance appearance, and this was apparent in making individuals feel more comfortable with the unavoidable physical changes surrounding treatment (Larouche & Peuckert, 2006). It was also found that adolescents were more willing to reveal their physical changes in a more secure environment in
which they were comfortable that their appearance would not be judged (Larouche & Peuckert, 2006). This also led to a progression of acceptance of body image changes and feeling comfortable with personal identity and the experiences the individuals with cancer had gone through. Another important aspect of children’s integrating back into their normal environment was acceptance by their peers which Larouche and Peuckert (2006) referred to as a “peer-shield” (p.200). This leads to the next discussion that through their experiences and conquering cancer, there was immense growth.

*Not the Same Person- Individual Growth Through Treatment*

A common theme among family units was seeking the best form of treatment possible for their child with cancer. Prompt and aggressive treatment led to remission in all three participants. Participants also found it to be a difficult adjustment returning to everyday life activities. The experiences with cancer that they had gone through allowed them to have a new appreciation for life. Throughout their treatment process, seeking out normalcy was evident, but the two teenage girls felt torn between the life they used to have and changed their outlook on life. It was a struggle for each person to find another to relate to back in the home environment. Coping with cancer is a very individual experience that no one person can completely understand but the individual who went through it.

Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl, & Prigerson, (2008) found, “For many patients who are confronting a life-threatening illness such as advanced cancer, religion and the use of religious coping becomes an important factor influencing their quality of life” (¶ 1). This was in essential in one participant’s experience with emotional and spiritual strength. It was also discovered through studying psychospiritual
well being that “six themes were evident through which religion/spirituality influenced well-being: self-awareness, coping and adjusting effectively with stress, relationships and connectedness with others, sense of faith, sense of empowerment, and confidence and living with meaning and hope. Those living with terminal illness face multiple challenges that can impede their quality of life” (Tarakeshwar et. al., 2008, ¶ 1). Spiritual strength and feeling support from those surrounding the individual during treatment provided strength for the participants, and they made it through the overwhelming task of treatment. The treatment process challenged not only the physical capacity of the individual but the psychological aspect as well. The treatment process affected the family members as well. It was found to be a time of high stress for loved ones, and it was crucial for nurses to provide supportive care to them to ensure their well being so that they could continue to remain supportive of their loved one. Getting family members involved in the care was a pivotal task that promoted connectedness in a very scary time.

*Support and Coping- Knowing*

Each participant in this study utilized a different form of coping. Each individual also remained hopeful through the process of coping with cancer which has been proven to improve outcomes. Verna Hendricks-Ferguson (2008) claims, “Researchers have identified a positive or hopeful attitude as a coping strategy associated with the psychosocial adjustment of adolescents who are receiving treatments” (p. 388). Another important aspect in the coping process is social and familial support. Each of the participants valued family support and attributed support to being a main reason for making it through treatment. Two participants found their mothers to be their main form
of support, and the father identified his brother as his and his son’s primary support system. Lynn Woodgate (2006) found, “A strong social support system is especially important in helping them cope, considering they have the potential to experience a ‘dual crisis’ in having to deal with complex normative developmental tasks as well as cancer-related stressors” (p. 122). Woodgate also discovered that the most common source of support was mothers of the children with cancer (2006).

Not only was it crucial to receive support from family during the coping process, but health care professionals were considered an integral part of the support complex. One participant accredited her nurses with her life, and another expressed the importance of nurses being present and supportive. Being there for the patients was a reoccurring theme not only in this study but in the study conducted by Woodgate as well. The presence of individuals gave the participants positive encouragement and comfort to know that they did not have to cope with this experience on their own. Health care professionals are readily accessible forms of psychological support for the children with cancer, and it was important to the participants that the nurses got to know them. This in turn facilitated a greater holistic relationship that promoted healing and coping. Verna Hendricks-Ferguson (2008) explored the theory that “knowledge of the psychosocial resources used by adolescents during oncology treatments is of particular importance to health care professionals when planning supportive psychosocial interventions” (p. 386). This highlights that not only psychologists or social workers provide psychological support but nurses and doctors and immediate forms of support as well.
Limitations of this study entailed a small sample size pilot study. It also cannot be generalized to apply to all individuals coping with pediatric cancer. It was a sample from a small location radius as well and included three forms of cancer.

*Nursing Implications*

This can be applied to not only caring for oncology patients but for all pediatric patients. A great emphasis was placed on getting to know patients not only as someone with an illness, but as people so that we as nurses can treat them more holistically in a therapeutic manner. Nurses and doctors do not only treat the diseases but we must also treat the psychological aspects while incorporating spiritual and socio-cultural dimensions as well. Nurses are in a position to empower patients and to inspire hope and well being through communication. The families of these individuals with cancer are also necessary facilitators of healing and endless members of support and caring. It should be a priority to determine the stress and coping of the family members dealing with the disease treatment process.

Children not only need compassion and communication from nurses but need promotion to acquire appropriate developmental tasks. An effective means of supportive care is to be truly present. Nurses can aid patients in identifying their strengths and weakness and proper ways to cope. They also can aid patients to develop plans to maintain a sufficient energy level and ability to complete activities of daily living. Nurses are effective resources of education and should provide the family with means to obtain any sources of information possible. Health care professionals act as advocates and a constant source of encouragement to aid in healing or with end-of-life care to facilitate the best outcome possible.
Future Nursing Research

A potential issue for future nursing research could be developing a reliable tool to determine the effectiveness of coping of the individual throughout the stages of cancer and creating methods of acting proactively to encourage effective coping. The psychological dimension of coping with cancer and underlying emotional distress is a new realm that could be of great benefit in dealing with patients with cancer and those who are in remission as well. The psychological dimension is often overlooked in the presence of complex physical problems which take priority.

Conclusion

The diagnosis of cancer in a young child can have immense physical and psychological effects not only for the child, but the child's loved ones as well. Cancer is life altering, and every individual and family affected by it undergoes the experience differently. This thesis examined the coping, stress, and pain management of the patient and life adjustments throughout the course of pediatric cancer. Through effective promotion of coping mechanisms and avid family support and aggressive treatments, children can overcome the disease process and defeat the odds. Participants adapted to their new-found psychological strength and developed new outlooks on life and a greater appreciation for present events. They learned to not take anything for granted. Nurses also had a vast impact on their well being, involvement in treatment, and empowering patients to persevere through the process. They assisted the individuals in fighting the battle for their life, and it is an experience that each individual will take with him or her for the rest of their lives.
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