

Palliative Nursing Care in Pediatric Oncology

Hannah K. Reynolds

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Deanna Britt, R.N., Ph.D.
Thesis Chair

Janet Brown, Ph.D.
Committee Member

Mary Highton, R.N., M.S.N., N.N.P.-B.C.
Committee Member

Marilyn Gadomski, Ph.D.
Assistant Honors Director

Date

Abstract

Palliative care is an integral part of providing adequate care for pediatric oncology patients. Whether the cancer is terminal or treatable, palliative care helps patients live their lives to the fullest by improving quality of life. Therefore, it is important to have a system to define and measure quality of life. Once quality of life can be quantitatively measured, nurses can use pain and symptom relief, psychosocial support, and spiritual care to improve it.

Pain management is essential to cancer recovery. Relief can be achieved through pharmacological or nonpharmacological methods; however, prophylactic pain relief is most beneficial. This means that the patient should be medicated or prepared to cope with the pain before experiencing the pain. Nonpharmacological methods are most valuable when adapted to the child's locus of control and cognitive coping skills.

A caring nurse-patient relationship can encourage psychosocial and spiritual wellbeing through trust, understanding, presence, and support. Psychosocial support can help patients with any fears that they may be experiencing, such as the fear of losing normalcy or the fear of dying. Spiritual care can greatly influence the child's hope and purpose in life as well. These combined foci of palliative care can improve quality of life for pediatric oncology patients and help them to a more successful recovery.

Palliative Nursing Care in Pediatric Oncology

When a patient has an illness, multiple health care interventions may be put into action to enable the patient to overcome the illness. Sometimes in chronic illnesses, however, this is not enough. A patient may need not only solutions to *correct* the illness, but care to help in dealing with the illness and its effects on a day to day basis. Palliative care may be used in situations such as this. The World Health Organization stated, “Palliative care improves the quality of life of patients and families who face life-threatening illnesses by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement” (Palliative care, 2009, ¶ 2).

Palliative Care vs. Hospice Care

Palliative care and hospice care are two terms that are often used interchangeably; however, there is a distinction between the two. Though a part of palliative care, hospice care supports and cares for patients in the final phases of an incurable illness. Hospice care may specifically be implemented in the last six months of life (Heitkemper & Staats, 2007). Palliative care, on the other hand, begins at the point of diagnosis. It is not focused on death and the dying process of the patient, and neither post-pones or accelerates death. Instead, palliative care involves a multi-disciplinary approach at helping the patient live life to its fullest potential. It also aims to support bereaved families so they can remain intact and functional (Jennings, 2005). It is also not limited to one type of health facility. Palliative care is flexible in that it can be provided in hospitals, community health centers, tertiary care facilities, and even in the patient’s home (Zernikow, Michel, Craig, & Anderson, 2009).

Palliative care may be necessary for four main categories of illness. First, palliative care may be appropriate for illnesses in which curative treatment or treatment to prolong life is available but may fail. Second, palliative care is beneficial for conditions needing intensive treatment for an extended period of time to prolong quality of life. Third, palliative care is used in progressive conditions that exclusively require palliative treatment from the point of diagnosis. Finally, palliative care can benefit those with conditions that involve non-progressive disability and cause the patient to be susceptible to other health complications. Therefore, oncology patients are candidates for palliative care.

Palliative Care Foci for Children

Pediatric palliative care differs slightly from adult care in that the care is child focused *and* family centered. Although adult palliative care takes family into account, family plays a more integral role in pediatric palliative care (Himmelstein, 2006). The nurse working with these children must also be knowledgeable regarding the different stages of growth and development that children go through. Nursing care should be patient specific to that child's physical growth and cognitive development. For example, a 14-year-old girl going through puberty and trying to find her identity will have different needs than a 3-year-old boy who is trying to gain autonomy (Hesselgrave, 2009). Palliative care for children also involves a very large interdisciplinary team. Along with physician, nurse, and pastoral care, the child may need input from social workers, child psychologists/psychiatrists, art and music therapists, physical therapists, speech therapists, and possibly others (Himmelstein, 2006). All of these differences must be taken into account while caring for children in a palliative care setting.

Quality of Life in Children

Since pediatric palliative care involves improving quality of life for children, it is important to have a system to define and measure quality of life. When one can properly evaluate and measure a child's quality of life, a goal can be set and interventions can be put in place to improve quality of life. Previously, an adult perspective has been used to determine a child's quality of life. In the last decade however, studies have attempted to make a quality of life assessment based on the child's perspective. This provides a more relevant assessment based on what the child values in life. In recent years, tools have also been formed for specific populations of pediatric patients with cancer. These population specific assessments focus more on the needs and values of children in particular circumstances. For example, there are now quality of life assessments specifically for those participating in bone marrow transplants, those newly diagnosed with acute lymphocytic leukemia, or those who are current survivors of childhood cancer. As extensive testing is done on a variety of new assessment tools, nurses can better understand how to improve quality of life for pediatric palliative care patients (Hinds, Burghen, Haase, & Phillips, 2006).

Recent interviews and analysis have also led to defining pediatric oncology quality of life from a child's perspective. Quality of life is defined as, "an overall sense of well-being based on being able to participate in usual activities; to interact with others and feel cared about; to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience" (Hinds et. al., 2004, p. 767). In this study, pediatric quality of life was further divided into six dimensions including: symptoms, health status, usual activities, mood, social and family interactions, and

meaning of being ill. Each of these dimensions that quality of life encompasses can allow the nurse to assess and intervene if necessary.

Once one finds the appropriate quality of life assessment tool, the nurse must use it to assess the patient at regular intervals throughout treatment. This will help give the patient a voice in the cancer experience. If used and evaluated properly, these tools can greatly improve communication between the patient, family, and healthcare staff. As scores are obtained, the nurse and healthcare team can determine which areas can be improved upon to increase quality of life. The nurse can then help the patient and family identify their strengths, and interventions can be set in place to aid them in coping with the cancer and treatment. This will ultimately improve quality of life for the patient and family (Hinds et. al., 2006).

Physical Care: Pain Management

After quality of life is able to be determined, interventions can be set in place to improve quality of life. Palliative care involves a holistic approach encompassing physical, psychosocial, and spiritual care. Physical care is one of the first things that one thinks of with regard to nursing care and cancer. One may envision a patient undergoing chemotherapy and the associated nausea, vomiting, and hair loss. Next one may think of the pain, fatigue, or other physical symptoms involved with cancer and its treatment. Pain is a primary focus of physical nursing care as children are largely concerned with pain management.

Since pain is subjective and affected by numerous factors, the nurse should never minimize the patient's pain (Himmelstein, 2006). Studies have shown that distress related to pain is inversely related to the age of the child. It was found that distress levels were

five times higher in children five years old and under. Ages six to seven years showed a dramatic decrease in distress which is carried on throughout older childhood. This is thought to be related to the age in which children can intellectually comprehend the need for these painful procedures. Children's distress decreases as they begin to understand that a short period of pain can have long term benefits (Lioffi, 1999).

Causes of Pain

Pain for pediatric oncology patients is related to one of five causes. First, the pain may be cancer related due to tumors infiltrating organs, bone, nerves, or other tissues. This type of pain occurs in about 25% of patients. However, the most common childhood cancers are malignancies such as leukemia instead of tissue-infiltrating tumors. Therefore, the patient may not have the chronic, cancer-related pain that adults usually experience. If the child's pain is not directly caused by the cancer, it could be a side effect of treatments such as chemotherapy or radiation. Third, the pain could be related to procedures such as diagnostic testing, venipuncture, lumbar punctures, bone marrow aspiration, biopsy, or surgery. Pain is 50% likely to be caused by therapy and procedures (Lioffi, 1999). Fourth, the pain could be a complication associated with the cancer, such as venous thrombosis, neuralgia, or invasive infection (Zernikow et. al., 2009). Finally, pain experienced by the child could be of another etiology.

Pain Assessment Tools

The assessment of the patient's pain should be appropriate for the child's age and development. It should include where the pain is, what it feels like, its severity, and things that make the pain feel better or worse. Pain can be assessed by the nurse through observation of behaviors. There may also be parents who do not permit communication

with the child and would rather act as a third party to discuss pain. If possible, however, the pain assessment should be self reported by the patient (Himmelstein, 2006). Children may not be outspoken with the nurse or other healthcare workers regarding their pain. Therefore, pain assessments should be performed regularly to ensure the child has adequate pain relief.

Behavioral pain assessment. There are multiple pain assessment tools that the nurse can choose from. For infants, toddlers, and other children who cannot accurately express their pain, the nurse can use behavioral measures. These tools record behaviors and physical responses to pain. Three common tools used to measure behavioral manifestations of pain in pediatric oncology include: the Procedure Behavior Checklist, the Procedural Behavior Rating Scale, and the Observational Scale of Behavioral Distress. Children in pain may display behaviors such as crying, screaming, verbal resistance, muscular rigidity, physical restraint, flailing, verbal expression of pain, requests for emotional support, nervous behavior, and seeking of information. However, some of these behaviors are not exclusive to the expression of pain and may just indicate distress or anxiety. Another disadvantage of behavioral observation is that individuals display pain differently. Therefore, individualized responses may not mean the same thing on a generalized scale.

Self-report pain assessment. Self-report measures can be used for older children who are able to express their pain. These pain assessments require children to have a certain level of linguistic and cognitive development. There are multiple types of self report measures including images, pain-adjective descriptors, and numerical scales. Younger children between three to seven years old should use scales such as the Faces

Scale. This has different faces with a series of facial expressions that reflect pain.

Children can point out the face that describes how they are feeling. Another child friendly scale is the pain thermometer scale. This is a vertical numerical scale in which children can point to the spot on the thermometer that represents how much pain they have.

Children seven years and older may use a pain adjective list which uses descriptive words to describe the different dimensions of pain. Children can use this list to pick out adjectives that describe their own pain. A zero to ten numerical scale may also be used to reflect the intensity of the pain.

These pain assessment scales can be used individually or in combination with each other. Also while assessing for pain, the nurse should observe the patient's heart rate, oxygenation status, and signs of the stress response. These can also indicate how the patient is responding to any pain that they may be having.

Importance of Prophylaxis

The stress and anxiety caused by these painful situations and procedures may become a hindrance in the child's compliance to treatments. Younger children may act out on their anxiety by kicking, screaming, or fighting. Physical restraint may be necessary to carry out the procedure (Lioffi, 1999). Therefore, it is extremely important that the nurse assess and *prophylactically* manage pain. This means that the nurse should not wait until the child is in pain before administering medication. Pain medication should be administered at regular intervals along with additional doses for breakthrough pain. If a painful procedure is expected, the nurse should administer pain medication an hour beforehand so that the medication will be in full effect when the time comes for the

procedure. If possible, topical pain medications can also be used prophylactically for certain procedures such as venous or lumbar puncture (Zernikow et. al., 2009).

Pharmacological Interventions

Pharmacological relief is extremely beneficial when children are experiencing pain or anxiety. Prophylaxis is important if procedures or other painful stimuli are expected. Pain relieving medications can be administered ahead of time to allow the patient to absorb the medication and experience full pain-relieving benefits during procedures. Local anesthetics, conscious sedation, and general anesthesia have also proven to be beneficial to reduce anticipatory anxiety and pain in young patients undergoing procedures (Lioffi, 1999). When administering medications to children, one should use the least invasive and less painful route first. Also ask the patient which medications have worked best on previous occasions. Oral and sublingual routes are usually preferred, and some children may prefer liquids if they are available. One must also keep in mind the differences in pharmacokinetics and pharmacodynamics between children and adults. For example, two to six year-old children have better clearance of opioids than that of adults, so they may need more frequent dosing. Close attention must be paid while titrating and dosing medications to prevent overdose (Himmelstein, 2006).

Opioid use. The World Health Organization suggests the use of the analgesic ladder which differentiates weak/strong opioids, nonopioids, and adjuvant medications for pain. Adjuvant medications are not classic analgesics, but they can relieve symptoms if used alongside other pain medications. Examples of these include corticosteroids, glucocorticoids, benzodiazepines, topical lidocaine, regional anesthesia, antidepressants, and anticonvulsants. The analgesic ladder suggests that for low-intensity pain, one should

receive a nonopioid with or without an adjuvant medication. Nonopioid analgesics may include acetaminophen, dipyron, ibuprofen, and diclofenac. For moderate pain or uncontrolled low intensity pain, one should be given a weak opioid with or without nonopioids and adjuvant drugs. Weak opioids may include Tramadol or Codeine. For severe pain and uncontrolled moderate pain, the patient should be given a strong opioid with or without nonopioids and adjuvant drugs. Strong opioids may include Morphine, Hydromorphone, Methadone, Fentanyl, Buprenorphine, or Oxycodone. With opioid therapy, titration and drug rotation may be necessary as one develops tolerance, uncontrolled pain, or unrelieved side effects.

PCA use. Patient controlled analgesia (PCA) may be indicated so that patients can give themselves extra medication as needed. This type of pain control is often preferred by pediatric postoperative patients and patients experiencing fluctuating pain. Some of these patients have been reported triggering up to twenty boluses a day using the PCA. Before beginning PCA treatment, good pain control should be obtained using titrated opioid therapy. Parents should be advised not to press the PCA button for the child. Nursing care should include frequent monitoring every two hours or as needed of respiratory rate, blood pressure, heart rate, sedation score, pain score, and nausea score (Zernikow et. al., 2009).

Local anesthetic use. In addition to opioid treatment, local anesthetics, conscious sedation, and general anesthesia may also be beneficial for procedure related pain. Local anesthetics may be administered through local infiltration or topically. Eutectic mixture of local anesthetics (EMLA) cream is very beneficial for prophylactic pain relief. This cream contains lidocaine and prilocaine and is applied to intact skin and covered for one

to two hours. When the cream is removed, analgesia is present in the underlying tissue for multiple hours. This is beneficial for children undergoing venous or lumbar punctures, and is preferred over intradermal anesthetic injections.

Conscious sedation use. Conscious sedation is recommended to manage pain associated with bone marrow aspiration and lumbar punctures. This combination of medications depresses consciousness, but keeps protective reflexes intact. The patient is able to maintain airway, and respond appropriately to verbal command or physical stimulation. Conscious sedation is a combination of an opioid and a benzodiazepine. Usually midazolam and morphine or fentanyl are used. These provide analgesia and sedation with a rapid onset, easy administration and titration, short duration of action, and easy reversal with antagonists. The nurse must be available for continuous monitoring and prepared with emergency drugs, oxygen, airway management intervention, suction, and other emergency supplies.

General anesthesia use. Short-acting general anesthesia may also be beneficial to some for procedures and surgery. However, more research is necessary to determine if this is a practical approach for lumbar punctures and bone marrow aspirations procedures. Although it ensures a pain free procedure, there are many disadvantages. General anesthesia is more costly, has an increased chance of complications, and requires additional scheduling with anesthesiology. Although general anesthesia ensures a pain free procedure, it does not eliminate all procedure related distress (Lioffi, 1999).

As previously mentioned, an aggressive approach with pharmacological intervention is often necessary for pediatric oncology patients. Children can develop tolerance and become physically dependent on opioids. Parents may require education

about this concern regarding the benefits outweighing the theoretical risks. Too much hesitation in this issue can cause inadequate pain relief, and aggressive pain management is necessary for these children (Goyal, Mishra, Bhatnagar, & Gupta, 2007).

Nonpharmacological Interventions

Although pharmacological pain relief is important, nonpharmacological interventions can be used synergistically to improve the patient's outcome. Psychological interventions can decrease pain-related distress and improve the child's coping skills. A coping style assessment should be performed first. After this assessment, appropriate interventions can be set in place. Useful psychological interventions for pain include preparation, distraction, and incentives.

Assessment of coping style. An assessment of the child's coping style should be performed to determine patient-specific interventions that will best aid in coping. The cognitive model states that one's individual perception of an event influences behaviors and reactions more so than the objective reality itself. One's believed influence on the event also shapes the perception of the situation. Therefore, cognitive styles play a key role in perception and coping mechanisms during stress.

Cognitive coping styles include internal versus external locus of control, minimization vs. vigilant focusing, representing repressors vs. sensitizers, and monitors vs. distracters (Lioffi, 1999). Locus of control describes how one views life events and the things that control them. One with an internal locus of control sees life events as being influenced by oneself. Those with an external locus of control may perceive life events to be controlled by fate, higher powers, chance, or luck. This plays an important part in pediatric cancer patients as children with an internal locus of control may feel that

they have more control over their healing (Harvey, Barnes, Sperry, & Harris, 1974).

People that are referred to as minimizers, distracters, or repressors are those who typically use selective inattention, avoidance of information, denial, and rationalization while coping with stressful events. Those who are referred to as vigilant focusers, monitors, and sensitizers usually cope with stress by actively seeking out information.

Preparatory interventions. Preparation is one of the most important psychological interventions for patients of all cognitive coping styles. This helps the child reduce fear and anxiety by explaining why the procedure is necessary and what will happen. Preparation is further broken down into procedural and sensory information. Procedural information describes the steps of the procedure that the child will go through. Sensory information depicts the sensations that the patient will experience during different stages of the procedure. For example, the child may be told that they will feel pressure or burning.

Preparation also includes introducing the patient to medical staff and those that will be involved in the procedure and recovery. If the child feels comfortable with the staff, there will be less distress. A tour of the hospital or other areas the child will reside in can also increase familiarity with the procedure. The nurse should then use developmentally appropriate education to explain to the child what will be done and how it will feel. Time should be given to allow the child to ask questions and voice concerns. When this is completed, the child should be able to handle and become familiar with the medical equipment that will be used. He or she can also practice the medical procedure on a doll. Once again, familiarity will decrease the child's anxiety. Allowing the child to verbalize their thoughts and feelings about the procedure is also beneficial.

Patient specific interventions. Once the child's cognitive coping style is determined, appropriate interventions can be set in place. If the patient copes by avoiding anxiety producing stimuli, then distraction techniques may be beneficial. If the child copes by seeking out control in the situation, the patient can be given some control during procedures. For example, the child can control if the procedure is performed on the count of three or the count of five. Children who focus their attention on the painful stimuli can also be shown how to refocus their attention in a more positive manner. Breathing techniques can give the child something active to focus on during the procedure. Breathing techniques may involve the child taking deep breaths, breathing out slowly, and making a hissing sound. Emotive imagery may be also be used to refocus attention. There are multiple ways that this can be done, but one example can involve the child's favorite superhero. Children may imagine that they are part of a special mission given to them by this superhero. This not only provides another distraction, but it transfers the meaning of the procedure and pain. Incentives such as trophies may be given to symbolize mastery of a procedure. The presence of parents can also be helpful if they are appropriately trained to help with these distraction, imagery, and relaxation techniques. Parental reassurance is often calming for children as well (Lioosi, 1999).

Psychosocial Care

Although physical care is a large part of palliative nursing care in pediatric oncology, psychosocial care plays a large role as well. Children and adolescents with cancer are often required to grow up quicker than other children and deal with more difficult situations. These children may need help to find trust, understanding, and support with those that are caring for them. They are often faced with fears concerning

their life, losing normalcy, living with purpose, and holding onto hope. Palliative psychosocial care can help these children handle these feelings appropriately (Ritchie, 2001).

Teamwork in Psychosocial Care

The interdisciplinary team is especially important in psychosocial care as many individuals may be needed to help these children adequately cope. The nurse can provide education to the patient, encouragement, and an opportunity for therapeutic talk therapy. A psychologist can help the child cope appropriately with fears and feelings about the diagnosis, treatment, and outcome. They may also be able to teach coping mechanisms for pain and nausea. Social workers can provide support as the patient and family deal with financial burdens. Child life specialists can help the child cope through play therapy. Patients may also be referred to massage therapists, art therapists, or music therapists.

A study on the availability of these services found that social services were *automatically* supplied within a month of the diagnosis in 80% of oncology facilities. Psychological services were mostly *made available* upon request in 60% of oncology settings, and only *automatically* offered in 26% of facilities. This indicates that psychological services are not being offered proactively, but rather only in cases for patients who are displaying difficulties with coping. Pain and anxiety management were only provided by the nurse in 32% of these cases. Therefore, there is a large opportunity for nurses to step up and participate in more holistic care, particularly with psychosocial care. Oncology facilities can also *automatically* provide more proactive psychological services in more cases. This could prove to be more cost efficient as those involved in psychological services display decreased anxiety, increasing compliance with treatment

and survival rate (Kaufman, Harbeck, Olson, & Nitschke, 1992). A more recent study further drives this point of prophylactic psychological intervention. This study by Ramini, Brown, and Buckner states, “Rather than assume that an adolescent will independently adapt to the diagnosis of cancer and the physical and emotional aspects of treatment, health care providers must be willing and able to provide the support and education needed for positive adaptation” (Ramini, Brown, & Buckner, 2008, p. 79).

Relationship with Healthcare Providers

Developing meaningful relationships with the healthcare providers can improve the patient’s support system and positive relationships which strengthen their ability to adapt to the cancer diagnosis and treatment. A qualitative study on adolescents adapting to cancer reported some participants describing some of their doctors and nurses as father and mother figures. This displays the potentially huge impact that the healthcare team can have on young patients (Ramini, Brown, & Buckner, 2008). Qualities of a healthy patient-nurse relationship include developing trust, understanding, being present and providing support. The nurse and other health care providers must establish caring provider-patient relationships to provide effective psychosocial interventions.

Developing trust. If children do not trust their nurse, they will not be receptive to care the nurse tries to provide. Trust with the patient begins with the nurse genuinely appreciating the growth and development stage that the child is in and the way cancer can threaten development. The nurse must be able to keep this in mind and interpret the child’s behavior through this developmental understanding. The nurse can build trust by being honest, following through with commitments made to the patient, and being consistent in care. Consistency of care helps children to feel secure that they are being

taken care of by competent nurses. Children also feel a sense of trust when nurses set definable boundaries and honor these limits.

Understanding the patient. Another objective of a caring nurse-patient relationship is understanding. As part of an adequate assessment, the nurse must understand the patient as a whole to provide appropriate nursing care. This includes the knowledge of the treatment experience, available resources, patient goals, and the patient's future expectations. This information can be gathered from the patients, their families, the nurse's own observations, and other members of the healthcare team. Understanding of the child's developmental stage should be known to understand how the cancer and treatment is affecting developmental tasks. The nurse should ask the patient what they perceive as normal and the meaning that illness has for them. This helps the healthcare team better meet the unique needs of the patient and what they consider to be normal. Understanding will also encourage communication and help the nurse see the child's world as he or she sees it.

Being present. Being present with the patient requires not only physical presence by the nurse, but emotional presence as well. Emotional presence requires commitment from the nurse, communication with the patient, and a genuine caring attitude that allows the child to feel safe and cared for (Ritchie, 2001). If the patient is undergoing something uncomfortable or painful, the nurse can also be with the patient to simply hold a hand. This is a simple gesture that has shown to be meaningful for patients. Physical presence and human touch have shown to help patients feel a sense of security. Physical and emotional presence with the patient helps to foster a caring nurse-patient relationship (Hockenberry-Eaton, & Minick, 1994).

Providing support. Support is another large part of psychosocial health that is greatly beneficial to the patient. The nurse should nurture the patient's previously existing social support systems as well as complement them with support from the healthcare team. These support systems may involve the patient's family, friends, and peers (Ritchie, 2001). Children with good social support have decreased psychosocial distress and higher coping abilities (Neville, 1998). Nursing care should nurture social support, especially among peers. Visits from healthy peers, phone calls, and internet communication can aid in preventing social isolation for children with cancer. Family members should be encouraged to stay during hospitalizations and other visits. They should also be encouraged to participate in care for the patient. This support furthers a caring provider-patient relationship which will encourage appropriate psychosocial development for children with cancer (Ritchie, 2001).

Common Fears Among Children with Cancer

Pediatric oncology patients often experience fear from the day of diagnosis, if not prior to being diagnosed. The previously mentioned aspects of a nurturing nurse-patient relationship can help the nurse and patient work through some of these fears together. Members of the healthcare team, such as psychologists and art/music therapists, will also participate in helping children cope with their fears.

Fear of death. One of the most common fears of those with cancer is the fear of death and the dying process. This may be the first thought on a pediatric patient's mind when diagnosed. Children with cancer may live in uncertainty to the point of being afraid to dream and plan for the future (Cantrell & Conte, 2009). One patient in a study by Cantrell and Conte stated, "I have real small goals. Like for the next week, I want to be

able to remember more things. The next five months, I hope to be walking with little to no pain” (Cantrell & Conte, 2009, pp.319). Many of these children with cancer have future goals, but they are frightened to dream or make concrete plans or steps to achieve these goals. A fear of suffering or being forgotten after death could be seen as well (Cantrell & Conte, 2009).

Most parents upon hearing the diagnosis of cancer express feelings of anger, guilt, shock, and helplessness. They may want to reassure the child that everything will work out, but this is often difficult to control. The health care team does not want to falsely reassure the child instead of addressing the issues. Honesty and providing education to the patient and family are better solutions than false hope. Together, the family and doctor can determine a plan of care and ensure the child that everything possible will be done to help them. Psychologists and other therapists in addition to parental support and guidance can help the patient with excessive fears of death. The nurse should also have a positive attitude and be available to encourage the child (McCaffrey, 2006).

Fear of losing normalcy. Along with a fear of death, children with cancer may have many other fears as well. Since these children are no longer able to follow their *normal* daily routine due to the cancer and its treatment, they may fear a loss of normalcy. For example, teenagers may fear becoming more dependent on their parents when they should be becoming more independent.

Pediatric oncology patients may also miss numerous days of school, putting them further behind and separating them from their peers. Some children may have to deal with negative attention in addition to positive attention, such as teasing, harassment, or an overload of questions that they do not want to answer. They may be embarrassed by

things that make them stick out, such as hair loss or the loss of a limb (McCaffrey, 2006). If uneducated, adults may embarrass these children further as one child in a study by McCaffrey stated, “The teacher demanded I take my hat off in class...I was so embarrassed” (McCaffrey, 2006, ¶16). The child’s parents and health care team should educate teachers and classmates to facilitate a normal transition back into schooling. Administrators and teachers can also be educated on things to do while the child is on or off of treatment. If children are falling too far behind in school, hospital schooling or other home schooled programs can also be beneficial. (Spinetta, Jankovic, Masera, et.al., 2009).

Patients may feel further separated from their peers by maturity levels. Cancer patients are usually forced into maturity before they are ready. They may feel as if they have more things to worry about than their peers or friends can understand (McCaffrey, 2006). A 14-year-old in McCaffrey’s study who had undergone treatment for lung cancer three times stated, “I think it is stupid for my friends to be smoking, drinking, or whatever. I can say, ‘No.’ My friends give in to anything” (McCaffrey, 2006, ¶18). Although these children are usually mature for their age, they often feel behind in comparison to peers. This could be due to missing time in school or missing other milestones.

The nurse can collaborate with the patient and family on how to keep things as *normal* as possible for the child. This may involve bringing in home cooked food and having a place at the hospital for families to prepare meals. This makes the setting more like home for the patient. Hats, wigs, or other head coverings can be used to help the patient feel more comfortable with body image. Proper management of medical issues

can also reduce the amount of hospitalizations that the child has to provide or more *normal* life. Encouraging socialization also helps the patient to maintain a feeling of normalcy. Adequate visitation hours should be available for healthy friends to come visit the patient. The hospital setting should also allow space for family members to stay overnight with the child for comfort and support. Other familiar items can be kept in the hospital as well (McCaffrey, 2006).

Spiritual Care

In addition to physical and psychosocial care, spiritual care is extremely important in palliative care in pediatric oncology. Spiritual care can help children recognize purpose in life and have hope for the future. Studies show that activities of a spiritual or religious nature actually improve cancer patients' quality of life (Zebrack and Chesler, 2002). These aspects are essential to a patient coping with cancer. Christian nurses have a unique role in spiritual care for these children, as one can provide encouragement with the hope of everlasting life in Heaven. This hope of eternal life within a new and healed, heavenly body can further encourage these children who are facing premature death. Through spiritual care and relationships with the patient, nurses can play a profound part in helping their patients remain positive and hopeful for the future (Hinds, 2004).

Hart and Schneider (1997) defined spirituality in children to be, "When children are able to cognitively understand dimensions that transcend self, so they can then build on their previous experiences with personal relationships and apply their experiences to relationships of a spiritual nature" (Hart & Schneider, 1997 p.263). It is important to nurture spirituality in children with cancer because these children can easily experience depression, helplessness, isolation, inadequacy, and spiritual distress. Spiritual distress is

especially present in children facing premature death and typically leads to diminished hope and lowered self worth. These things also work to negatively impact the healing process (Hart & Schneider, 1997).

Assessing Spiritual Needs

Performing an assessment of spiritual needs in a child can be difficult, but observation and questioning can provide enough information to determine the child's spiritual needs. An assessment of the family's spiritual needs will also make it easier to understand the child. If parents have strong spiritual support, children are more likely to positively handle the cancer and its treatment.

Once again, the nurse must be able to understand the concerns of each child based on developmental level. Symptoms of spiritual distress will vary depending on the age of the child. School age children may exhibit withdrawal, sleeplessness, anger, crying, nightmares, a lack of forgiveness, and a diminished sense of love. During assessment, it is best to listen to what the child has to say. The nurse should ask open ended questions and reflect questions back to the child so that the child can explain his or her perspective (Hart & Schneider, 1997).

Spiritual Care Interventions

In infancy, the nurse should primarily observe for trust and unconditional love between the infant and parents. Cognitive stimulation as well as comfort should be provided through holding, talking to, and playing with the infant. In toddlers, preschoolers, and school age children, the nurse should observe for feelings that their cancer is a punishment for some sort of bad behavior. The nurse should reassure children that they have done nothing wrong to help diminish feelings of guilt and inadequacy.

The nurse should also include religious practices that the child has at home into the nursing care. For example, if the child prays each night, the nurse should continue this in care. The nurse should encourage children to talk to God, and pray with them according to whatever concerns that they may have. Adolescents may be more argumentative regarding religious beliefs as they try to make sense out of life and find meaning in illness. The nurse should be open and not judgmental while discussing spiritual needs with adolescents. Care should also be sensitive to the practices of each family. Spiritual wellbeing in children leads to increase hope and purpose in life which can aid in the healing process. Therefore, spiritual care is essential in the palliative care of children with cancer (Hart & Schneider, 1997).

Conclusion

Palliative care for the pediatric oncology patient is complex and involves multiple disciplines to provide adequate care. Care is not only provided for the patient, but for the family as well. Palliative care is not solely focused on the child's physical problems, but all aspects of life including psychosocial and spiritual care. With pain being the predominant physical problem, aggressive treatment is necessary to manage pain. Pain management is most beneficial when using pharmacological and nonpharmacological means. Psychosocial care involves having a caring nurse-patient relationship and establishing trust, understanding, presence, and support with the patient. Multiple fears may need to be addressed by a multidisciplinary team prophylactically to ensure the child's psychological well being. Finally, spiritual care that encourages the patient to have hope and find a purpose in life is important. The nurse must treat each pediatric oncology patient on a patient-specific basis according to the each child's stage of

development. A holistic nursing approach addressing physical, psychosocial, and spiritual needs in palliative pediatric oncology will improve the patient's quality of life no matter the outcome of the disease process.

References

- Cantrell, M. A., & Conte, T. M. (2009). Between being cured and being healed: The paradox of childhood cancer survivorship. *Qualitative Health Research, 19*(3), 312-322. doi:10.1177/1049732308330467
- Goyal, G., Mishra, S., Bhatnagar, S., & Gupta, D. (2007). Aggressive approach to pain and symptom management is a key for effective palliation in terminally-ill pediatric patients. *Internet Journal of Anesthesiology, 14*(1), 15. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>
- Hart, D., & Schneider, D. (1997). Spiritual care for children with cancer. *Seminars in Oncology Nursing, 13*(4), 263-270
- Harvey, J., Barnes, R., Sperry, D., & Harris, B. (1974). Perceived choice as a function of internal-external locus of control. *Journal of Personality, 42*(3), 437-452. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>, doi:10.1111/1467-6494.ep8970095
- Heitkemper, M. M., & Staats, C. R. (2007). End-of-life and palliative care. In S. L. Lewis, M.M. Heitkemper, S. R. Dirkson, P. G. O'Brien, & L. Bucher. *Medical-Surgical Nursing: Assessment and Management of Clinical Problems*. (pp.156-163). Philadelphia, Pennsylvania: Elsevier.
- Hesselgrave, J. (2009). Developmental influences on child health promotion. In M. J. Hockenberry, & D. Wilson. *Wong's Essentials of Pediatric Nursing*. (pp. 71-96). St. Louis, Missouri: Mosby Elsevier.

Himmelstein, B. (2006, February). Palliative care for infants, children, adolescents, and their families. *Journal of Palliative Medicine*, 9(1), 163-181. doi:10.1089/jpm.2006.9.163

Hinds, P. (2004, September). The hopes and wishes of adolescents with cancer and the nursing care that helps. *Oncology Nursing Forum*, 31(5), 927-934. doi:10.1188/04.ONF.927-934

Hinds, P., Burghen, E., Haase, J., & Phillips, C. (2006, January 2). Advances in defining, conceptualizing, and measuring quality of life in pediatric patients with cancer. *Oncology Nursing Forum*, 33, 23-29. doi:10.1188/06.ONF.S1.23-29

Hinds, P., Gattuso, J. S., Fletcher, A., Baker, E., Coleman, B., & Jackson, T., et al. (2004). Quality of life as conveyed by pediatric patients with cancer. *Quality of Life Research*, 13, 761-772.

Hockenberry-Eaton, M., & Minick, P. (1994). Living with cancer: Children with extraordinary courage. *Oncology Nursing Forum*, 21, 1025-1030.

Jennings, P. (2005). Providing pediatric palliative care through a pediatric supportive care team. *Pediatric Nursing*, 31(3), 195-200. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>

Kaufman, K., Harbeck, C., Olson, R., & Nitschke, R. (1992). The availability of psychosocial interventions to children with cancer and their families. *Children's Health Care*, 21(1), 21. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>

Lioffi, C. (1999). Management of paediatric procedure-related cancer pain. *Pain Reviews*, 6(4), 279-302. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>

- McCaffrey, C.N. (2006). Major stressors and their effects on the well-being of children with cancer. *Journal of Pediatric Nursing, 21*(1), 59-66.
- Neville, K. (1998). The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing, 15*, 37-46.
- Palliative care. (2009). <http://www.who.int/en/>
- Ramini, S., Brown, R., & Buckner, E. (2008, January). Embracing changes: Adaptation by adolescents with cancer. *Pediatric Nursing, 34*(1), 72-79.
- Ritchie, M. (2001, July). Psychosocial nursing care for adolescents with cancer. *Issues in Comprehensive Pediatric Nursing, 24*(3), 165-175. doi:10.1080/014608601316942531
- Spinetta, J.J., Jankovic, M., Masera, G., Ablin, A.R., Barr, R.D., Arush, M.W.B., ... & Zeltzer, P.M. (2009). Optimal care for the child with cancer: A summary statement from the SIOP working committee on psychosocial issues in pediatric oncology. *Pediatric Blood & Cancer, 52*, 904-907. doi:10.1002/pbc.21863
- Zebrack, B., & Chesler, M. (2002). Quality of life in childhood cancer survivors. *Psycho-Oncology, 11*(2), 132-141. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>, doi:10.1002/pon.569
- Zernikow, B., Michel, E., Craig, F., & Anderson, B. (2009). Pediatric palliative care. *Pediatric Drugs, 11*(2), 129-151. <http://search.ebscohost.com.ezproxy.liberty.edu:2048>