



ASSOCIATION *of* PEDIATRIC
HEMATOLOGY/ONCOLOGY NURSES

Pain Management for the Child with Cancer in End of Life Care
APHON Position Paper
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Abstract

Although there have been major advances in the treatment of childhood cancer with an overall survival rate of over 70%, cancer continues to be the leading cause of death in children due to disease. In 1998, 2500 children in the United States died of cancer-related causes. Each year cancer kills more children than asthma, diabetes, cystic fibrosis, congenital anomalies, and AIDS, combined (Murphy, 2000).

The Association of Pediatric Oncology Nurses (APON) is the leading professional organization for nurses caring for children and adolescents with cancer and their families. The highest standards of nursing practice are achieved through education, research, certification, advocacy and affiliation.

It is the position of APON that pain in the child dying of cancer can be effectively managed. This can be accomplished by making the prevention and alleviation of pain as a primary goal, partnering with the patient and parents, and aggressively using appropriate pharmacologic and non-pharmacologic interventions. The pediatric oncology nurse has an essential role in the child's pain management at the end of life through nursing assessment, identifying expected outcomes, and performing and evaluating interventions.

Background

Pain in children who are dying of cancer can be complex and challenging to manage. As cancer progresses, pain may result from:

- Distention or infiltration of tissue or bone
- Inflammation from infection, necrosis, or obstruction
- Side effects from treatment (chemotherapy, surgery, and/or radiation) including massive infection, organ(s) failure, mucositis, typhilitis, and skin breakdown.

- Neuropathic pain occurs when nerves are injured by tumor infiltration or as a side effect from some chemotherapy drugs or radiation therapy.

There can be multiple sources of pain experienced by each patient. (Hockenberry-Eaton, M., Barrera, P., Brown, M., Bottomley, S. J., and O'Neill, J. B., 1999) Managing this pain requires expert care.

In their research surrounding the impact of pediatric cancer pain on the family, Ferrell and colleagues (1994) reported that parents described the experience of having a child with cancer in pain as unbearable. They felt helpless and unprepared, yet totally committed to supporting their child. In describing their child's pain they used physical terms and often could discern pain behaviors that health care providers could not. There was an underlying concern that their child's pain was not taken seriously. Wolfe and researchers (2000) interviewed 103 parents of children who had died of cancer and found that 82% of the children suffered "a great deal" or "a lot" from pain according to their parents' report. Seventy-six percent of these patients were treated for pain but treatment was viewed as successful in only 27% of the patients. Data is clear that many children with cancer at the end of life suffer substantially.

Effective pain management is essential in the care of any child with cancer and their families. For the child who is at the end of his or her life, pain can be complicated and can rapidly escalate. Providing pain interventions, comfort, and support are important components of care that the pediatric oncology nurse provides.

Recommendations:

Prevention and alleviation of pain is a primary goal of care in the child dying of cancer.

Unrelieved pain is incapacitating, and has a number of deleterious effects on the child and family. The primary goal of pain management is consistent and complete control of pain through the use of appropriate analgesic and adjuvant medications, as well as non-pharmacological interventions. This goal must be achieved consistently for all children, across all care settings (home, hospital, hospice).

The current gold standard for pain management for children with cancer is the World Health Organization (WHO) Analgesic Stepladder (1998). This model promotes thorough assessment of pain and interventions that are appropriate for the degree of pain identified by the child and/or family. When employed as a decision-making tool, the WHO Analgesic Stepladder greatly increases the probability of successful pain management.

The pain management plan for the child with cancer should include the following:

1. Regular assessment of pain in both inpatient and outpatient settings, including both quantitative and qualitative aspects of the child's report of pain.
2. Quick access to analgesics in hospital, clinic, or home, when the presence of pain is anticipated, assessed and/or reported.

3. Interventions that are appropriate to prevent and treat the pain being experienced by the child.
4. An interdisciplinary, holistic approach to managing pain in children with cancer.
5. Access to pain management specialists 24 hours a day to assist parents (caregivers) if child's pain increases or changes in nature when at home.
6. Clear written guidelines that indicate the individual child's pain management plan of care.

Children and parents are equal partners with members of the health care team in managing the patient's pain.

Children need to be acknowledged as the experts in their own pain. Furthermore, parents cannot make plans to prepare for the future until their child's pain and suffering are controlled. Parents are the experts in their child's care. They serve as spokespersons, coaches, advocates, and primary problem-solvers.

Being a member of the health care team means that the parents and child, if they wish,:

1. Have equal access to information
2. Participate in decision – making
3. Participate in setting goals

Children and parents need a pain management plan of care that is individualized, flexible, based on the latest research and evidence about pediatric palliative care, and includes pharmacological and non-pharmacological interventions.

Children and parents need information and education regarding all aspects of pain management at the end of life. The information and education should be age appropriate, individualized, and given in language the child and parent can comprehend.. The timing, quantity and quality of the information must depend on the needs/desires of the child and parent. This information includes, but is not limited to:

1. the goals and basic concepts of pain management
2. how to recognize and assess pain, including subtle changes
3. children's perception of pain
4. the many factors that influence pain and suffering such as: sleep, anger, depression, helplessness, fears, anxiety, fatigue, personality, culture, age, chronicity of pain
5. beliefs and values related to the child's culture, family and society
6. impact of the parents' attitudes on a child's pain and suffering
7. safe, effective pain management options individualized to the needs of the child
8. what to expect (e.g., side effects and their management)
9. problem solving including anticipating and preventing problems
10. when/who to call for help
11. how parents can comfort and relieve suffering
12. dispelling fears and misconceptions about pain management (e.g. addiction, respiratory depression)

Children and parents need to be reassured that health care professionals will remain actively involved in their care and that they will have access to experts in pain management of the dying child. The individual and intra-family strengths and challenges will be recognized, valued, and supported by health care professionals. They need to be confident that if a conflict occurs between the health care professionals, child and family, it will be resolved ethically. The family's goals for quality of life will be acknowledged, respected, and supported by the health care team.

Children dying of cancer may require aggressive dosing of analgesics. Medications that do not have a dose maximum should be escalated, sometimes rapidly, to achieve adequate pain control or to maintain pain control when tolerance has occurred.

Pain is treated with analgesic drugs that include: opioids, nonopioids, and adjuvant analgesics. Opioids which bind to the Mu receptors in the central nervous system are the most commonly used class of opioids in the treatment of severe cancer pain. This group includes morphine, fentanyl, codeine, hydromorphone, and methadone. These drugs have no maximal doses. Doses can be escalated until there are intolerable side effects or until there is no increase in analgesia (Hockenberry-Eaton, Barrera, Brown, Bottomley, and O'Neill, 1999). Researchers have found that while standard dosing of opioids was adequate for the majority of children experiencing cancer pain, there was a small subset of patients who required extraordinary pain interventions (Collins, Holcombe, Kinney, and Berde, 1995). These patients often had solid tumors with metastasis to the spine and major nerves. The limiting factor in escalating dosing of opioids was the adverse effects that can occur as the result of the dose.

An undesirable side effect frequently identified by health care providers is that of respiratory depression. In the terminally ill child, the specific concern is that administering aggressive doses of opioid analgesia will have a life shortening effect. Administering aggressive doses of opioid analgesia to control terminal pain is considered appropriate under the principle of double effect (Siever, 1994). Double effect is when the intended action (pain control) is good and sincerely intended, the potential deleterious secondary side effect (respiratory depression) is permissible. The control of pain and suffering has become the primary goal of treatment for these terminally ill patients rather than prolonging life (Galloway and Yaster, 2000).

Ethical, religious, and professional organizations support this principle of appropriate pain management at the end of life. In their Code for Nurses, the American Nurses Association states that, "The nurse may provide interventions to relieve symptoms in the dying client even when the interventions entail substantial risks of hastening death" (American Nurse Association, 1985). Both the National Conference of Catholic Bishops and the Hastings Center support giving a dying person aggressive pain medications for the alleviation of pain even though it may shorten the patient's life (National Council of Catholic Bishops, 1995; Hastings Center, 1987).

Although the potential for respiratory depression concerns health care providers and can be an untoward side effect, its incidence is quite rare (Galloway and Yaster, 2000). This

risk decreases significantly when children are on opioids for prolonged periods of time. Researchers in the United Kingdom analyzed opioid use during the last week of life in 238 patients who died in a palliative care unit. Patients who received a marked increase in opioids at the end of life were compared with those who received no increase. There was no significant difference between the two groups in length of survival from admission or frequency of unexpected death (Thomas and Sykes, 2000).

Another common stigma with escalated dose opioids is the fear of drug abuse or addiction. The patient who is being treated for terminal pain may build a tolerance to the opioid they are being treated with, and require increasing doses to maintain adequate pain control. This dose tolerance is a pharmacological effect of pain management (Galloway and Yaster, 2000). Drug abuse is the use of opioid without the need for pain relief. Addiction is the loss of control or compulsive drug use with potential harm. The terms drug abuse or addiction are inappropriate and should never be used in conjunction with the treatment of a child with pain at the end of life.

Effective pain management for the child dying of cancer may require aggressive dosing, and sometimes, rapid escalation of opioids. Unintended side effects, such as respiratory depression, and dose tolerance should not limit the use of opioids in the effort to relieve pain. If these measures do not alleviate the child's pain, alternative analgesic strategies such as intraspinal analgesia, neural blockade, psychiatric and surgical techniques should be considered (Galloway and Yaster, 2000).

The nurse's role in caring for children who are in pain at the end-of-life includes assessment, identifying expected outcomes, and planning, performing, and evaluating interventions.

This role is articulated in the *Scope and Standards of Pediatric Oncology Nursing Practice* (2000). It is vital that the nurse collaborates with the child, family and other members of the health care team in developing the mutual goals of care and the treatment plan. The individualized plan must be age specific and cognitively appropriate for the child.

Assessment:

The nurse collects data that leads to the development of an appropriate plan. This is done at regular intervals. The nurse providing direct care in the hospital, clinic, or home plays a key role in this assessment. Arguably the most important data to collect is the child's level of comfort. Comfort or level of pain may primarily be assessed using self-report scales that are age appropriate, reliable, and valid. The parents or other family members may also contribute by giving a subjective report on what they perceive to be the child's level of comfort. The child and family may also disclose what has helped in the past to alleviate the pain or promote comfort. In addition, objective data may include assessing vital signs, the child's general appearance, and response to touch or movement. The nurse may also assess the child and family's understanding of pain management and the dying process and the support systems that are available within the family and the community.

Identifying Expected Outcomes:

The nurse identifies expected outcomes with the help of the child, family and health care team to formulate the goals of care. Together, the appropriate methods of symptom and pain management can be determined. Expected outcomes include the identification of appropriate methods for pain management and the child/family's ability to communicate the child's level of comfort to the health care team.

Interventions:

The nurse identifies and performs interventions that are based on current knowledge of pain assessment and management in children. The interventions are congruent with the age and cognitive ability of the child. Interventions may include the delivery of pain medications, other therapeutic approaches to relieve pain and suffering, and education of the child and family. The nurse is responsible for documenting the intervention and the child's response in the medical record and ensuring that the plan and the patient's response is communicated to all members of the health care team.

Evaluation:

It is vital that the nurse evaluates all pain management interventions. The nurse should continually assess the response to treatment and compare the findings to the expected outcomes. The plan of care is subsequently based on the data collected and the consensus of the health care team and family. The evaluation data and the revised plan of care should be documented in the medical record.

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