APHON Position Paper on Pain Management During End-of-Life Care for Children and Adolescents with Cancer

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Although advances in the treatment of childhood and adolescent cancer have led to an overall survival rate of nearly 85%, cancer continues to be the leading cause of death from disease in this age group. In 2020, an estimated 1,730 children and adolescents in the United States will die of cancer-related causes (Siegel et al., 2020). Attentive nursing care that emphasizes the alleviation of symptoms (including pain) supports optimal end-of-life care for the child or adolescent, as well as the family.

The Association of Pediatric Hematology/Oncology Nurses (APHON) affirms that pain experienced by the child or adolescent who is dying of cancer can be managed effectively. Two strategies are critical to achieving this goal: (1) making prevention and alleviation of pain the key focus of an interdisciplinary team that works in partnership with the patient and parents, and (2) aggressively using pharmacologic and nonpharmacologic interventions. As a member of the team, the pediatric oncology nurse has an essential role in end-of-life pain management through making nursing assessments and planning, implementing, and evaluating interventions.

Background

Children and adolescents who are dying of cancer often experience complex pain that can be challenging to manage. Pain remains one of the most prevalent and distressing symptoms at the end of life and is associated with decreased health-related quality of life (Eche et al., 2020; Montgomery et al., 2020; Wolfe et al., 2015). Pain management needs can also rapidly escalate near the end of life, requiring expert interdisciplinary care.

As cancer progresses, pain can result from multiple sources, including these:

- distention or infiltration of tissue or bone
- inflammation from infection, necrosis, or obstruction
- side effects of treatment (e.g., chemotherapy, surgery, or radiation), including massive infection, organ failure, mucositis, typhlitis, and skin breakdown
- neuropathic pain that occurs when nerves are injured by tumor infiltration or as a side effect of chemotherapy, radiation, or other therapy.

Effective pain management at the child's or adolescent's end of life is also essential in caring for the family. Parents who perceive that their child had unrelieved pain at the end of life are likely to be affected by that experience even more than 5 years after the child's death (Kreicbergs et al., 2005). Furthermore, parents' perception of their child's quality of life at the time of death predicts the parents' own grief and depression outcomes (McCarthy et al., 2010). Likewise, siblings who perceive that their sibling's death was not peaceful are at increased risk for unresolved grief, even years after the death (Lövgren et al., 2018). The role of the pediatric oncology nurse includes providing pain interventions, comfort, and support to the child or adolescent and family (Duffy et al., 2019).

Positions and Recommendations

1. **Prevention and alleviation of pain is a primary goal of care for the child or adolescent who is dying of cancer.**

Unrelieved pain is incapacitating and has multiple deleterious effects on the child or adolescent and the family. The primary goal of pain management is consistent relief of pain that supports quality of life through the use of appropriate analgesics, adjuvant medications, and nonpharmacological interventions. This goal must be made a priority across all care settings and by all members of the healthcare team.

The World Health Organization's analgesic stepladder and updated guidelines for pain management provide a framework for clinical care (Anekar & Cascella, 2020). The guidelines promote thorough pain assessment and interventions that include the use of opioid and nonopioid analgesics, adjuvant medications, and therapeutic modalities such as radiotherapy to achieve sustained relief of pain.

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

- regular assessment of pain in both inpatient and outpatient settings, using patient-reported outcome measures (both quantitative and qualitative) when possible
- readily available access to analgesics in the hospital or clinic and at home, when the presence of pain is anticipated, assessed, or reported
- interventions that are appropriate to prevent and treat the pain being experienced
- an interdisciplinary, holistic approach to managing pain
- access to pain management specialists 24 hours a day to assist parents and caregivers if the pain increases or changes in nature while the child or adolescent is at home
- clear written guidelines as part of an individualized plan of care for pain management.

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2. Interdisciplinary healthcare teams support a family-centered approach to pain management at the end of life.

The American Academy of Pediatrics (2013) and the World Health Organization (2020, n.d.) recommend an interdisciplinary team approach to caring for children and adolescents with cancer at the end of life and an approach that includes access to palliative care. Receipt of palliative care concurrent with oncology care allows children and adolescents to experience more meaningful life events and to die at home (if that is desired) without having poorer pain outcomes (Friedrichsdorf et al., 2015; National Coalition for Hospice and Palliative Care, 2018).

The interdisciplinary team should provide a family-centered pain management plan that is individualized and responsive to the child or adolescent's needs and goals; the plan should be flexible and evidence based and should include both pharmacological and nonpharmacological interventions (National Hospice and Palliative Care Organization, 2019). As essential participants in this team-based approach, children and adolescents should be recognized as experts on their own pain. Parents should be acknowledged as experts in their child's care and as advocates for the child or adolescent. According to their desire for participation, children and adolescents, as well as parents, should be provided equal access to information and the opportunity to participate in decision making and goal setting.

Children, adolescents, and their parents need information and education regarding all aspects of pain management at the end of life so that they can participate in the plan of care. The information and education should be age appropriate and individualized, and it should be provided in the family's preferred language (or languages) in a manner that is easily comprehended. The timing, quantity, and level of the information depend on the needs and desires of the child or adolescent and the parents. This information should cover, but is not limited to, these topics:

- the basic concepts of pain management and its goals
- ways to recognize and assess pain, including subtle changes in pain
- children's perception of pain
- factors that influence the experience of pain and suffering—for example, disrupted sleep, anger, depression, feelings of helplessness, fears, anxiety, fatigue, personality, culture, age, chronicity of pain
- beliefs and values related to the child's family, culture, and society
- impact of the parents' attitudes on a child's or adolescent's pain and suffering
- safe, effective pain management options individualized to meet the needs of the child or adolescent
- common side effects of analgesics and strategies for managing side effects
- whom to contact for help and when
- common fears and misconceptions about pain management (e.g., addiction, respiratory depression).

Children, adolescents, and parents need to be assured that healthcare professionals will remain actively involved in their care and that they will have access to experts in pain management throughout the child's or adolescent's end of life. They need to know that the family's strengths will be recognized and valued and that the family will be supported by the healthcare team as they face challenges. Families need to be confident that if a conflict occurs between the healthcare professionals, the child or adolescent, and the family, it will be resolved ethically. Families should be reassured that their goals for their child's quality of life will be acknowledged, respected, and supported by the healthcare team.

3. Aggressive pharmacologic interventions and adjuvant and nonpharmacologic therapies are used when necessary to achieve adequate pain control for children and adolescents dying of cancer.

Pain occurring at the end of life is complex and difficult to manage, and those dying of cancer may require aggressive multimodal management with pharmacologic and nonpharmacologic approaches to improve pain control. Uncontrolled pain results in decreased quality of life, difficulty sleeping, restrictions in activities, increased pain sensitivity, and emotional problems (Tutelman et al., 2018). The appropriate analgesic dose is thus one that effectively relieves the child's or adolescent's pain (National Hospice and Palliative Care Organization, 2019). Rapid escalation of analgesic doses may be necessary to achieve adequate pain control or to maintain pain control when the patient's tolerance of the medication makes it less effective.

Pharmacologic Interventions

Pain is treated with analgesic drugs that include opioids, nonopioids, and adjuvant analgesics. These analgesics should be given on a scheduled basis. Opioids that bind to the mu receptors in the central nervous system are the most commonly used class of opioids in treating severe cancer pain. Medications in this class include morphine, fentanyl, codeine, hydromorphone, and methadone. These drugs have no maximum doses unless intolerable

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side effects occur (Strassels, 2014). Several factors influence the selection of pharmacologic agents: the source of the child's or adolescent's pain, the ability to take oral medications, and other toxicities that could be exacerbated by a specific medication. Pain management should be individualized according to the patient's age and previous experience with pain and analgesics (Duffy et al., 2019). For children or adolescents who have severe cancer-related pain, the use of long-acting preparations, along with short-acting medications for breakthrough pain, is recommended (Morgan & Anghelescu, 2020).

A common fear associated with escalated doses of opioids is that drug abuse or addiction will follow. Children and adolescents who are treated for terminal pain may build up a tolerance to the opioids they are receiving and require higher doses to maintain adequate pain control. This dose tolerance is a pharmacological effect of pain management (Snaman et al., 2016). Effective pain management for the child or adolescent dying of cancer may require aggressive dosing and sometimes rapid escalation of opioids. Unintended side effects, such as respiratory depression, and increasing dose tolerance should not limit the use of opioids in the effort to relieve pain. If these measures do not alleviate the pain, alternative interventional techniques such as central or peripheral nerve blocks, continuous ketamine infusions, or palliative sedation therapy should be considered (Snaman et al., 2016).

Adjuvant Therapies

Adjuvant therapies are an essential component of multimodal pain management; they enhance analgesic effects and assist in optimizing doses of opioids (White, 2017). Adjuvant therapies are typically prescribed in the setting of an interdisciplinary team composed of oncologists, palliative care providers, and advanced practice nurses. The choice of adjuvant should be guided by the underlying pathology of the pain source (Snaman et al., 2016). Examples of adjuvant therapies are steroids (dexamethasone), anticonvulsants (gabapentin, lorazepam), tricyclic antidepressants (amitriptyline), and such pharmacologic agents as ketamine and lidocaine. Some adjuvant therapies have a sedative effect and should be titrated carefully.

Nonpharmacologic Therapies

The Centers for Disease Control and Prevention recommends a holistic approach to pain management for children and adolescents with cancer, one that includes nonpharmacologic strategies (Brown et al., 2017). When used in combination with pharmacologic approaches, nonpharmacologic interventions can help children and adolescents gain a sense of control over their pain and may reduce the need for medications (Snaman et al., 2016). Common nonpharmacologic interventions are mindfulness techniques, hypnosis, yoga, and acupuncture. All members of the interdisciplinary team (including nurses) should have a basic knowledge of common interventions and delivery methods and their clinical implications, so that they can provide patients and families with a holistic pain management plan (Jong et al., 2020). Nurses should encourage open communication with families about their goals and desires for nonpharmacologic therapies.

4. **The use of aggressive pharmacologic and nonpharmacologic interventions to achieve adequate pain control for children and adolescents dying of cancer is strongly supported by established ethical principles.**

As the child or adolescent approaches the end of life, the goals of care shift from prolonging life to controlling pain and easing suffering. In these cases, the administration of necessary doses of analgesics to control pain is deemed appropriate, regardless of the possible consequence of increased respiratory depression. This principle of double effect permits the potential deleterious secondary side effect (respiratory depression) in cases where the intended result (pain control) is beneficial and is sincerely intended.

Professional, religious, and bioethical organizations support the application of this principle to pain management at the end of life. In its *Code of Ethics for Nurses,* the American Nurses Association (2015) states that "The nurse should provide interventions to relieve pain and other symptoms in the dying patient consistent with palliative care practice standards and may not act with the sole intent to end life." Both the United States Conference of Catholic Bishops (2018) and the Hastings Center (Berlinger et al., 2013) endorse the optimization of pain management through the aggressive use of medications, even though such use may shorten the patient's life.

5. **The pediatric oncology nurse's role in caring for children with pain at the end of life includes assessment, planning, implementation, and evaluation.**

This role for nurses is articulated in *Scope and Standards of Pediatric Hematology/Oncology Nursing Practice* (APHON, 2014). By virtue of their direct patient care roles and frequent contact with patients (and their families) at the end of life, registered nurses and advanced practice nurses are especially well positioned to identify pain. It is essential that the nurse collaborate with the child or

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adolescent, the family, and other members of the interdisciplinary healthcare team to develop goals of care and the pain management plan.

Assessment

Early identification of pain, worsening pain, and uncontrolled pain allows the nurse to advocate for the appropriate pain management plan that will reduce pain and suffering at the end of life. Nurses, whether in the inpatient hospital setting, the outpatient clinic, or the patient's home, should assess pain and the effectiveness of the current plan at regular intervals. Comfort or level of pain may be assessed primarily through the use of self-report scales that are age appropriate, reliable, and valid. The nurse should take into consideration the unique developmental needs of the child or adolescent. The parents or other family members may also contribute a subjective assessment of the child or adolescent's pain and provide details about pain strategies that have previously been successful. The nurse should also assess objective data, including vital signs, general appearance, and response to touch or movement. The nurse may also assess the patient's and family's understanding of pain management and the dying process and the support systems that are available in the family, the interdisciplinary healthcare team, and the community.

Planning

The nurse, in collaboration with the interdisciplinary team, the patient, and the family, works to develop a holistic pain management plan aimed at meeting the goals of care and determining the appropriate methods of symptom and pain management. The nurse should incorporate education into the plan of care, covering symptoms of uncontrolled pain, delivery of pain interventions, potential side effects of therapies, and the appropriate time to contact the healthcare team if the child's or adolescent's care is being managed at home.

Implementation

The nurse identifies and performs interventions that are based on current knowledge of pain assessment and management in children and adolescents. The interventions are congruent with the age, cognitive ability, and goals of care for the child or adolescent. Interventions may include the delivery of pain medications and the use of adjuvant therapies and nonpharmacologic approaches. The nurse will also need to educate families on the delivery of these interventions. The nurse is responsible for documenting in the medical record the intervention and the patient's response and ensuring that these are communicated to all members of the healthcare team.

Evaluation

The evaluation of all pain management interventions is crucial. The nurse should also educate the family about the importance of reevaluation following pain management interventions. The nurse should continually assess the patient's response to treatment and evaluate the need for changes in the plan of care. The pain management plan is subsequently based on the assessment and evaluation of the nurse in collaboration with the interdisciplinary healthcare team, the child or adolescent, and the family.

References

American Academy of Pediatrics. Section on Hospice and Palliative Medicine and Committee on Hospital Care. (2013). Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics, 132*, e20132731.

American Nurses Association. (2015). *Code of ethics for nurses with interpretive statements.* https://www.nursingworld.org/coe-view-only

Anekar, A. A., & Cascella, M. (2020). *WHO Analgesic Ladder*. In StatPearls [Internet]. StatPearls Publishing. Updated May 17, 2020. https://www.ncbi.nlm.nih.gov/books/NBK554435/

Association of Pediatric Hematology/Oncology Nurses. (2014). *Scope and standards of pediatric hematology/oncology nursing practice*. Chicago, IL.

Berlinger, N., Jennings, B., & Wolf, S. M. (2013). *The Hastings Center guidelines for decisions on life sustaining treatment and care near the end of life* (2nd ed.). Oxford University Press.

Brown, M. L., Rojas, E., & Gouda, S. (2017). A mind-body approach to pediatric pain management. *Children (Basel, Switzerland), 4*(6), 50. https://doi.org/10.3390/children4060050

Duffy, E. A., Dias, N., Hendricks-Ferguson, V., Hellsten, M., Skeens-Borland, M., Thornton, C., & Linder, L. A. (2019). Perspectives on cancer pain assessment and management in children. *Seminars in Oncology Nursing, 35*(3), 261–273. https://doi.org/10.1016/j.soncn.2019.04.007

Eche, I. J., Eche, I. M., & Aronowitz, T. (2020). An integrative review of factors associated with symptom burden at the end of life in children with cancer. *Journal of Pediatric Oncology Nursing, 37*(4), 284–295. https://doi.org/10.1177/1043454220909805

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Friedrichsdorf, S. J., Postier, A., Dreyfus, J., Osenga, K., Sencer, S., & Wolfe, J. (2015). Improved quality of life at end of life related to home-based palliative care in children with cancer. *Journal of Palliative Medicine, 18*(2), 143–150. https://doi.org/10.1089/jpm.2014.0285

Jong, M. C., Boers, I., van Wietmarschen, H., Busch, M., Naafs, M. C., Kaspers, G. J. L., & Tissing, W. J. E. (2020). Development of an evidence-based decision aid on complementary and alternative medicine (CAM) and pain for parents of children with cancer. *Supportive Care in Cancer, 28*(5), 2415–2429. https://doi.org/10.1007/s00520-019-05058-8

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Björk, O., Steineck, G., & Henter, J. I. (2005). Care-related distress: A nationwide study of parents who lost their child to cancer. *Journal of Clinical Oncology, 23*(36), 9162–9171. https://doi.org/10.1200/JCO.2005.08.557

Lövgren, M., Sveen, J., Nyberg, T., Wallin, A. E., Prigerson, H. G., Steineck, G., & Kreicbergs, U. (2018). Care at end of life influences grief: A nationwide long-term follow-up among young adults who lost a brother or sister to childhood cancer. *Journal of Palliative Medicine, 21*(2), 156–162. https://doi.org/10.1089/jpm.2017.0029

McCarthy, M. C., Clarke, N. E., Ting, C. L., Conroy, R., Anderson, V. A., & Heath, J. A. (2010). Prevalence and predictors of parental grief and depression after the death of a child from cancer. *Journal of Palliative Medicine, 13*(11), 1321–1326. https://doi.org/10.1089/jpm.2010.0037

Montgomery, K. E., Raybin, J. L., Ward, J., Balian, C., Gilger, E., Murray, P., & Li, Z. (2020). Using patient-reported outcomes to measure symptoms in children with advanced cancer. *Cancer Nursing, 43*(4), 281–289. https://doi.org/10.1097/NCC.0000000000000721

Morgan, K. J., & Anghelescu, D. L. (2020). Opioid therapy for pediatric cancer pain. In R. D. Shah & S. Suresh (Eds.), *Opioid therapy in infants, children, and adolescents* (pp. 251–281). Springer Nature.

National Coalition for Hospice and Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). https://www.nationalcoalitionhpc.org/ncp

National Hospice and Palliative Care Organization. (2019). Standards of practice for pediatric palliative care: Professional development and resource series. https://www.nhpco.org/wp-content/uploads/2019/07/Pediatric_Standards.pdf

Siegel, R. L., Miller, K. D., & Jemal, A. (2020). Cancer statistics, 2020. *CA: A Cancer Journal for Clinicians, 70*(1), 7–30. https://doi.org/10.3322/caac.21590

Snaman, J. M., Baker, J. N., Ehrentraut, J. H., & Anghelescu, D. L. (2016). Pediatric oncology: Managing pain at the end of life. *Paediatric Drugs, 18*(3), 161–180. https://doi.org/10.1007/s40272-016-0168-2

Strassels, S. A. (2014). Opioids in clinical practice. In P. J. McGrath, B. J. Stevens, S. Walker, & W. Zempsky (Eds.), *Oxford textbook of paediatric pain* (pp. 457–473). Oxford University Press.

Tutelman, P. R., Chambers, C. T., Stinson, J. N., Parker, J. A., Fernandez, C. V., Witteman, H. O., Nathan, P. C., Barwick, M., Campbell, F., Jibb, L. A., & Irwin, K. (2018). Pain in children with cancer: Prevalence, characteristics, and parent management. *Clinical Journal of Pain, 34*(3), 198–206. https://doi.org/10.1097/AJP.0000000000000531

United States Conference of Catholic Bishops. (2018). *Killing the pain, not the patient: Palliative care vs. assisted suicide.* https://www.usccb.org/committees/pro-life-activities/killing-pain-not-patient-palliative-care-vs-assisted-suicide-0

White, P. F. (2017). What are the advantages of non-opioid analgesic techniques in the management of acute and chronic pain? *Expert Opinion on Pharmacotherapy, 18*(4), 329–333. https://doi.org/10.1080/14656566.2017.1289176

Wolfe, J., Orellana, L., Ullrich, C., Cook, E. F., Kang, T. I., Rosenberg, A., Geyer, R., Feudtner, C., & Dussel, V. (2015). Symptoms and distress in children with advanced cancer: Prospective patient-reported outcomes from the PediQUEST study. *Journal of Clinical Oncology, 33*(17), 1928–1935. https://doi.org/10.1200/JCO.2014.59.1222

World Health Organization. (2020). WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents. https://www.who.int/ncds/management/palliative-care/cancer-pain-guidelines/en/

World Health Organization. (n.d.). *WHO definition of palliative care for children*. Retrieved August 3, 2020, from https://www.who.int/cancer/palliative/definition/en/

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